Family and Disability

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June 5th 2015
A BIG TOPIC
Parents and children - the centre of an inter-related complex system

- Service delivery policies, programs, and practices
- Family resources, values, beliefs and goals
- Systems: health, disability, social security, education, child protection
- Family friends and support network
- The child as a developing individual
- Parents and family life stage and age
- Programs for the child or young person
- Social and cultural location of family
- Attitudes towards disability, stigma and social exclusion
- Programs to support parents and siblings
- Parental feelings of loss or grief or burden
- Parents and child or children’s health, impairment, chronic illness
- Family resources, values, beliefs and goals
Overview of presentation

Three key points

- Traditional approaches to understanding families and disability
  - Parental and family psychopathology

- Newer approaches to understanding families and disability
  - Family resources, values, beliefs and goals
  - Families in population context

- The child or young person as a developing individual in their own right
  - Social participation of children and young people with disabilities
  - Children and young people’s perspectives on their own lives
Traditional perspective

- Devastating impact of a child with disability, particularly intellectual disability, on the family
- Parental and family psychopathology perspective results from considering child impairment as a tragedy
- This leads to a focus (and research) on:
  - Burden
  - Grief and ongoing sorrow
  - Depression
  - Marriage breakdown
  - Concerns about sibling neglect
  - Social isolation
Narrow focus of this traditional perspective

- Assumes that the child’s impairment is the most important influence in family life
- Dominance of psychological models focuses on
  - Proximal stressors and particularly child characteristics
  - Parental characteristics and psychological resources
- Studies typically conducted with families known to service providers
- Much less concern with the disabling consequences of impairment, the social – cultural ‘position’ of the family, the social resources available in the family’s community and society more generally AND the position of the person with disability
Continuing focus on impact

- Impact within the family on mothers, fathers, siblings and grandparents

- Impact on different ‘types’ of families
  - Determined by impairment: Down Syndrome, autism, cerebral palsy

- Impact between different ‘types’ of families
  - By impairment type
  - Families with disabled children compared to families with children without disabilities
Convention on the Rights of Persons with Disabilities

www.un.org/disabilities/
Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

Article 1, Convention on the Rights of Persons with Disabilities, 2008

People with disability have unique insights about their disability and situation but have been excluded from the decision-making process about issues that directly affect their lives.

In line with Article 4 of the Convention on the Rights of Persons with Disabilities, persons with disabilities through their representative organizations should be fully consulted and actively involved in all stages of formulating and implementing policies, laws, and services that relate to them.

WHO Global Disability Action Plan 2014–2021
Increasing interest in resilience of families

- Rights-based international instruments such as the Convention on the Rights of Persons with Disabilities informing a more inclusive approach to families.

- Recognition that disability is not inherent within the person.

- More positive and affirming language moving away from disability first to people first terminology.

- Inclusion of persons with disabilities in all decisions which affect their lives.

- Changing professional practices including strength based approaches.
Key point 2 – Newer approaches

Family resources, values, beliefs and goals

- Traditional approaches to understanding families and disability
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Families in context

- All families experience the same changing social conditions
  - Increased emphasis on women in workforce vs. women’s primary responsibility of caring for dependent children, those who are ill and the elderly
  - ‘Stressors’ in relation to finding and maintaining a work/family life balance
  - Women of working age ‘sandwiched’ between looking after dependent children and ageing parents at the same time

- Consider the lives of families with children with disabilities within the current social conditions
  - That is, turn from a primarily psychological model focusing on influence of child impairment on the family to a social model which focuses on the family in its social context
Families in social context

Eco-cultural theory

- Posits that all families strive to develop meaningful and sustainable everyday family routines (Gallimore et al., 1983)

- Everyday family routines provide a window on to how a family is doing

- What is a successful everyday family routine?

- This is a routine that:
  - ‘Fits’ with family goals, values and beliefs - meaningfulness
  - Meets the needs of everyone in the family – congruence
  - Continues in the face of changing circumstances - sustainability
Families in social context

Person-environment theory

- Posits that families strive to balance family fit and balance (Voydanoff, 2005)

- Assumes that children do well when families do well

- Families do better when they are supported to ‘juggle’ demands effectively

- Families do better when they have the resources they need to ‘juggle’ successfully
Family well-being is understood as the ability to create meaningful, congruent and sustainable family routines.

There is no one standard of family well-being as this changes over time with changing family life stages and family member ages.

Families create their own ‘family’ culture.

The task of agencies and practitioners is to understand and support family culture so that families can achieve sustainable family care over time.
Family care is more sustainable when the family routines work for all family members.

Family care is more sustainable when the family is living within their available resources.

Family care is more sustainable if routines are reasonably predictable.

Family care is more sustainable when routines are meaningful to all family members and their goals.

- Balance
- Resource Fit
- Meaning
- Predictability

Sustainable family routines
Key point 2 – Newer approaches

Families in population context

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Building the knowledge base

- Investigating the impact of the broader social context in which families with children with disabilities are living

- Utilizing representative and sufficiently large samples to have power in the studies to understand influential factors - interaction with various barriers which hinder full participation

- Taking account of other factors that are central to the lives of ALL families

- Comparing the life circumstances of families with and without children with disabilities

- Employing longitudinal designs that can address more complex relationships between family characteristics and the socio-cultural environment over time
Literature examining socio-environmental context

Characteristics of this literature

- Utilizes large population surveys and administrative data sets rather than clinical samples
- Allows examination of influences such as socio-economic position, household composition, health status, and geographic location on family life

Overall families of children with disabilities are more likely to score lower on well-being, on quality of life and individual constructs such as happiness, self-esteem and self-efficacy

HOWEVER

- Controlling for disadvantage – low socio-economic resources, unsafe neighbourhoods, unemployment – eliminates the statistical relationship between child disability and family wellbeing
Bringing the traditional and the newer approaches together:

On average, a child with a disability has an impact on family wellbeing

HOWEVER

This impact is moderated by environmental influences such as lower personal and financial resources, unsafe neighbourhoods, and other measures of disadvantage

AND

Families not being able to develop meaningful, congruent and sustainable everyday family routines
Key point 3 – The child or young person

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UN Convention on the Rights of Persons with Disabilities - Article 7

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

A regional approach

The Incheon Strategy to “Make the Right Real” for Persons with Disabilities in Asia and the Pacific

- **Goal 5**  
  Expand early intervention and education of children with disabilities

- **Target 5.A**  
  Enhance measures for early detection of, and intervention for, children with disabilities from birth to pre-school age

- **Target 5.B**  
  Halve the gap between children with disabilities and children without disabilities in enrolment rates for primary and secondary education

http://www.unescapsdd.org/publications/incheon-strategy
Measuring social inclusion

A human rights approach


- Disability is now understood to result when society excludes or discriminates against people with impairment, or creates or allows disabling environmental conditions

- Indicators of inclusion and participation
  - Material and economic resources
  - Employment
  - Health
  - Education and skills
  - Engagement with family, friends and community
  - Social resources
  - Personal safety
What is inclusion? What is participation?

- **Inclusion**
  - Staying in the family home
  - Being in school
  - Being in the community
  - Being part of the peer group

- **Participation**
  - Involvement in life situations
  - Being and feeling part of ……
  - An insider perspective

- **Exclusion**
  - Being placed outside of family home
  - Not attending school
  - Not going out
  - Not having friends and playing

- **Restrictions on Participation**
  - No involvement in everyday life
  - Not being or feeling part of ……
  - Only others speaking on your behalf
A study from the region

The wellbeing of children with disabilities in the Asia Pacific Region

- Analysis of UNICEF MICS 3 SURVEY data from Bangladesh, Lao PDR, Bangladesh, Mongolia, and Thailand
- Analysis process
  - Indicators developed from UNCRC and UNCDRP
  - Aligned with items in MICS 3
- Examples include:
  - Child has been registered with civil authorities
  - Ever breastfed, Vaccination for BCG, Polio and DPT, Measles
  - Protected or piped drinking water, flooring other than earth or dung
  - Ever attended school
  - Told stories to child, sung songs to child
  - Taken child outside home, compound, yard or enclosure
What did we find?

Stand out features

- In all four countries children with disabilities were markedly more disadvantaged than their non-disabled peers on the majority of the indicators available.

- In all four countries children with disabilities were markedly more disadvantaged than their non-disabled peers on indicators relating to the child’s right to education, health and an adequate standard of living.

- In all four countries there were notable differences between disabled children regarding the extent of disadvantage they faced.
  
  - In both Bangladesh and Lao PDR, for example, children with sensory impairments fared particularly poorly.
  
  - In Thailand, by contrast, children with cognitive delay fared particularly poorly.

Llewellyn, Emerson, Madden & Honey (2012)
Social inclusion of disabled young Australian adults

LEFT BEHIND: 2014

- Transition to adulthood is marked by educational attainment, employment, family formation and having a voice in the community.
- We use Australia’s *Indicator Framework for Social Inclusion* which provides indicators to measure progress towards social inclusion.
  - This tool contains 27 headline and 23 supplementary indicators.
- We apply this to all waves (currently 2001-2012) of the annual survey of *Household Income and Labour Dynamics in Australia (HILDA)*
- We focus on young people aged 15-29 years
- We now undertake this analysis every year to monitor the status of young people with disabilities in Australia

What did we find?

Stand out features

- In 2012 young disabled Australians were **fourteen times more likely** than their non-disabled peers to experience entrenched multiple disadvantage.

- Between 2001 and 2012 the **gap between the social exclusion of disabled and non-disabled young Australians** has **widened markedly** over time in 11 critical areas:
  - Not being employed
  - Living in a jobless household
  - Being long-term unemployed
  - Not being fully engaged in work or education
  - Not acting as a volunteer
  - Having low economic resources and financial stress
  - Having low subjective well-being
  - Not having someone to turn to in times of crisis
  - Not having a voice in the community
Widening gap between social exclusion of disabled (blue line) and non-disabled (red line) young Australians 2002-2012
Key point 3 – The child or young person

Their own perspectives

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Equality doesn’t mean Justice

Equality  

Justice
We need to acknowledge that children and young people have the right to have their voice heard

Children and young people’s perspectives are different to those of adults

Researchers are challenged to use methods that can explore the child or young person’s perspective

Qualitative research is helpful here to understand children and young people’s lived experience

A very important question is **what is wellbeing?**
Children and young people’s views on wellbeing

8 to 16 years  (Foley et al. 2012)

- ‘Having things to do’
- ‘The most important thing is good friends’
- ‘You know home is where the heart is’
- ‘Nothing seems to stick in my brain’
- ‘You need some way to cool down’
- ‘Feeling good about yourself’

- Valuing participation in meaningful activities
- Providing a sense of belonging
- Getting along with your parents and siblings
- Being anxious about performing at school
- Coping strategies in the face of bullying and negative experiences
- Personal growth and occupying a valued place in society
For the child or young adult with disability “expanding their world occurs when they participate in experiences that they did not before. This is crucial in each and every stage of their development. Enhancing human flourishing as expanding one’s world means expanding opportunities to discover who they are and what they can do” (Reinders, 2014, 212).
Disaster preparedness is a critical community priority in Indonesia, one of the most natural disaster prone nations in the world.

Including children, young people and adults with disabilities is crucial given their higher morbidity rate – around 4 times higher – in natural disasters.

How to do this?

- All school children learn disaster behaviours for earthquakes
  
  \textbf{Drop, Cover, Hold On}

- Adapted teaching for children with disabilities

\textbf{However} 90-95% children with disabilities in Indonesia are not in school!
Aha, Sekarang Aku Bisa!

Panduan Pembelajaran
Materi Pengurangan Risiko Bencana
Untuk Anak Berkebutuhan Khusus

Disertai CD Koleksi Materi ASB

Aha, Semua Pasti Bisa!

Panduan Praktis Penyajian Informasi
an Prosedur Pengurangan Risiko Bencana
untuk Anak Berkebutuhan Khusus
Non Verbal Communication for Earthquake Safety Tips

https://www.youtube.com/watch?v=bu3XgG08cL8

THE NEXT BIG STEP
Conclusion

From family and disability to young adults and the community

- The child or young person as a developing individual flourishing through expanded opportunities

- And, being included as part of the community in community prioritized activities

- Remaining within families with sustainable everyday family routines and becoming adults fulfilling inclusive and participatory lives in society

- And, supported by non-government organizations and Disabled People’s Organizations to realize their rights and responsibilities
Thank you for your attention

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