



FAMILIES, DISABILITY & FAMILY QUALITY OF LIFE



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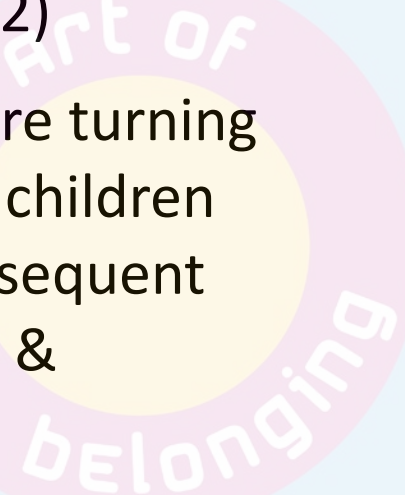
Overview of this presentation:

- ❖ Families: why, what & who
- ❖ Family Quality of Life
- ❖ What we know (so far)
- ❖ Perspectives at this conference
- ❖ This session



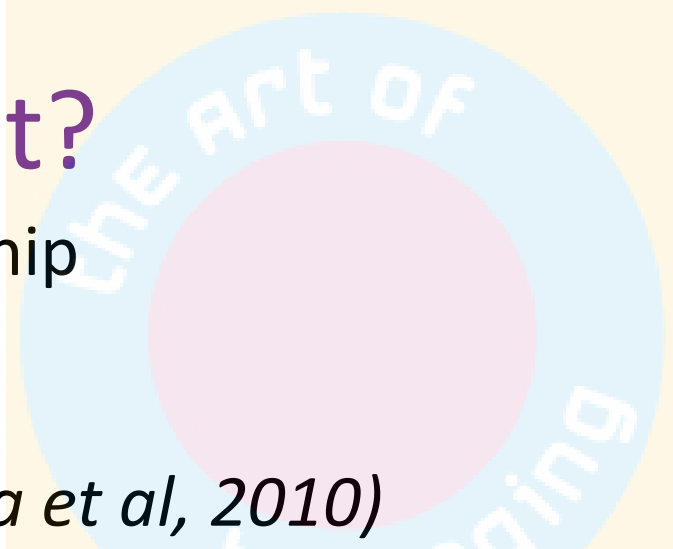
Families: why?

- ❖ People with disabilities worldwide live with their families or important others
- ❖ World Report on Disability (2011): 12-15% of world population lives with disabilities -> 25-30% close to them as well
- ❖ The family is the primary environment of most children and many adults with disabilities (Samuel et al., 2012)
- ❖ “Governments and other funding sources (...) are turning to families to provide the principal care to both children and adults of all ages with disabilities” with subsequent effects on families (Brown, Anand, Fung, Isaacs, & Baum, 2003)



Families: what?

- ❖ Family: related by blood or relationship
- ❖ Support one another regularly
- ❖ Think of themselves as a family (*Zuna et al, 2010*)



Family Quality of Life

- ❖ QOL: goal of disability policies, practices and services E.g. UN-CRPD
- ❖ FQOL: helps to understand the factors involved to explain why some families flourish in the presence of disability while others do not (Faragher & Van Ommen, 2017)



Family Quality of Life

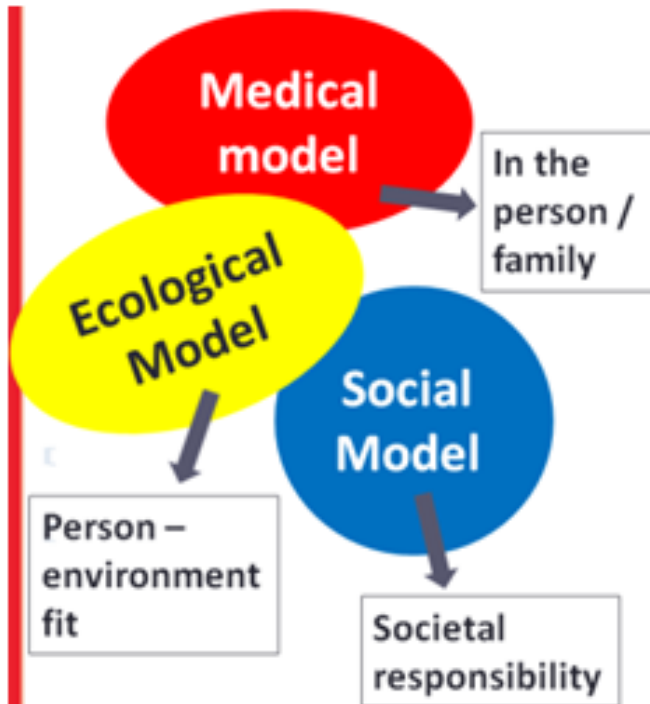
Dynamic sense of family wellbeing, encompassing the collective and subjective perspectives of the family and its members, and the interaction between their needs (*Zuna et al, 2010*)



Theoretical lenses

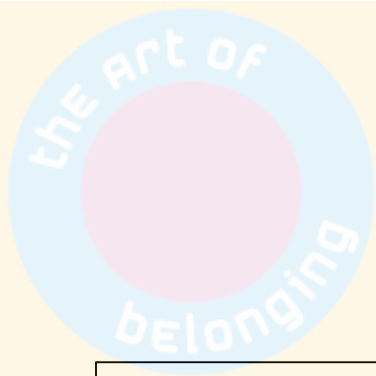


Support traditional ways of looking at quality of life



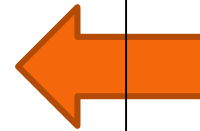
Support new ways of looking at quality of life





Who? Social perspective

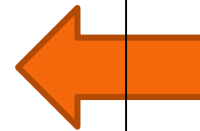
- People with disabilities and their families have been marginalized and discriminated against;
- We have assigned roles and social constructs that limit;
- This is wrong and needs to be changed;
- Positive action is needed to redress wrongs.



Who? Individual/family perspective

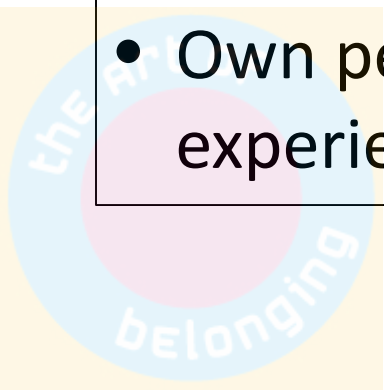
An individual's or family's –

- Internal view that is unique to the family
- Own perception of own characteristics, resources
- Positive and negative perception of acceptance, marginalization
- Own perception of lived family experience



**Internal
Model**

**Critical
Disability
Model**



Family Quality of Life

Important topics:

❖ Role of siblings

❖ Strategies for the family as a whole

❖ Inclusion of families in the community

❖ Informal and formal support

(Zuna, Brown & Brown, 2014)

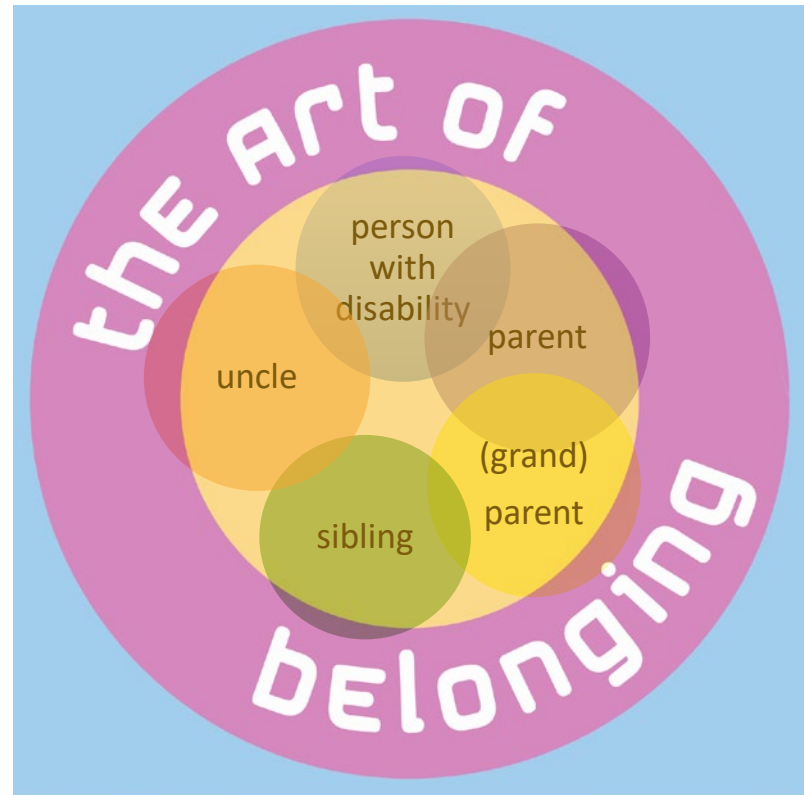
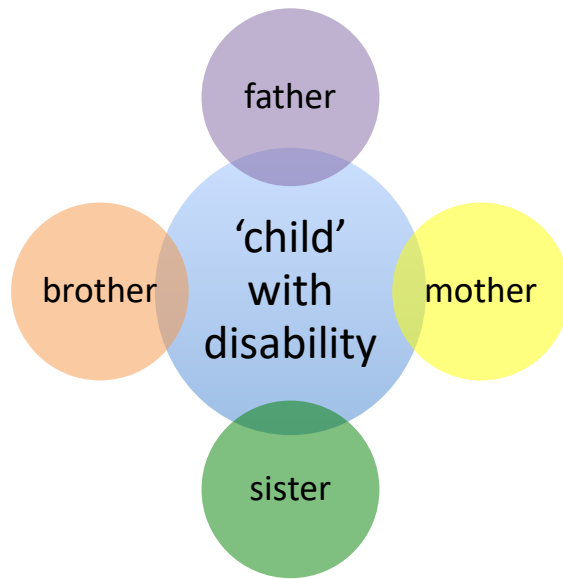


Family Quality of Life

What we know (so far):

- ❖ Families around the world are quite similar
- ❖ Opportunities are low for families around the world
- ❖ ++ Quality of Life: Family relationships, Values
- ❖ -- Quality of Life: Support from others, Support from services

This Conference's Perspectives on Families, Quality of Life & Disability



From the person with disability and 'internal perspective' -> to families, their allies and the wider community and a more 'contextual perspective'

This Session: perspectives of Mothers, Fathers & Generations

- ❖ *The Grace of Motherhood* – Belaynesh Tefera Nidaw
- ❖ *Experiences of Fathers of children with disabilities* – Geert Van Hove
- ❖ *Generational Differences in Deaf people's signing practices* – Anja Hiddinga



References

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