



UNIVERSITY OF ICELAND

What do we Know About the Needs of Disabled Children and their Families?

Nordic conference on
Children with Special Needs and their Families
Grand Hotel Reykjavík, Iceland
31. October, 2005

Rannveig Traustadóttir Professor



What do we Know About the Needs of Disabled Children and their Families?

Overview

- What do we know about disabled children?
- What do we know about families of disabled children?
- What do we know about services for families of disabled children?
- Conclusion

What do we Know About Disabled Children?

- What is Childhood?
 - New Sociology of Childhood
 - The tyranny of the ‘normal’ child development
 - Life course approach
- What is Disability?
 - Medical understanding
 - Nordic relational understanding
 - The British social model of disability
 - Impairment (biological) and disability (social barriers)

What do we Know About Disabled Children?

Characteristics of most research

- Preoccupation with the impairment
- Preoccupation with vulnerability and dependency
- Preoccupation with the child as a 'burden'
- Preoccupation with services
- View of disabled children as a homogeneous group and denial of complex identities

What do we Know About Disabled Children?

Characteristics of most research (cont...)

- Most research has focused on the perspectives of parents, professionals and other adults
- Disabled children are viewed through they eyes of adults
- Voices and experiences of disabled children and youth have largely been absent

What do we Know About Disabled Children?

Disabled researchers, in particular, have criticized the medical understanding of disability and

- the focus on ‘deviance’ and ‘abnormality’
- the emphasis on ‘treatment’ and ‘therapy’

Early intervention is important

- but this emphasis may have negative effects on disabled children’s self-image and identity

What do we Know About Families of Disabled Children?

- The diagnosis
 - Password, stigma or relief
- Disability and family life
 - The child's place in the family
 - Caring for and raising a disabled child
 - Positive experiences (relational and personal)
- The day-to-day work
 - Disabled child usually requires more work
 - Parents as therapists
 - Constructing a 'normal' family life

What do we Know About Families of Disabled Children?

- Family patterns and family structures – myths and realities
 - Relationship between parents (divorce rates)
 - Number of children
 - Combining family life and work outside the home
 - Leisure and social life
 - Gender differences

What do we Know About Services for Disabled Children and their Families?

- Families of disabled children have extensive contact with the public service system
- Have positive and negative experiences
- Negotiating and fighting the system
- Frustrations with services and the system
- Gap between what the parents need/want and what they get
- The 'cost' of receiving services

Family Support Services

The goals of family support services

- Empower and support families to care for the disabled child
- Prevent out-of-home placement of disabled children
- Increase the quality of life of disabled children and their families

Family Support Services

What characterizes services that meet the needs of families?

- Have a clear ideological foundation
- View parents as partners
- Use family-centered approaches
- Offer individualized and flexible supports
- Work towards empowering the families

Family Support Services

What characterizes services that meet the needs of families (cont...)?

- Base their work on the strengths of each family
- Work towards strengthening existing family relations and support networks
- Believe that all children should grow up in families
- Exercise self-reflection and self-criticism, are conscious about what could be done better and try to improve their services

Conclusion

- Families are important for all children, especially disabled children
- Influence of dominant ideas (about childhood, disability, gender, ...) on disabled children, their families and the services they are offered
- Disabled children and their families in the age of normalization and integration
 - How are we doing?

Conclusion

- Disability is to a large extent about social exclusion
- Too many disabled children and their families are still struggling against social exclusion and for social inclusion

Rannveig Traustadóttir

University of Iceland

Faculty of Social Science

rannvt@hi.is

<http://www.fotlunarfraedi.hi.is>

NNDR

Nordic Network on Disability Research

<http://www.nndr.dk>

