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Doing Qualitative Research is a journey
Iceland: Small population 318,452, large island, high standard of living, Nordic type welfare society, economic vulnerability, economic crash in 2008
The study 2005/2006-2008:

The focus of the study is on parents’ perspectives of informal and formal support due to a child’s disability. The disabled children are born between 1974-2007.

1979-2008 is the time when the legal framework and relevant service systems were put in place or adapted to accommodate disabled people and their families.

This is a time of great change both in the Icelandic society and in its welfare: social, educational, health and disability policies.
The goals of the study:

– Describe and explore the experience of parents of disabled children and youth giving birth to and bringing up a disabled child – and their experience of different formal and informal supports to the child and the family.

– Compare the experiences of parents of disabled children born over a 35 year period - a period of significant changes in law and services aimed at families and disabled children.

– Explore whether and in what way there is a connection between support and decisions and choices that parents make on behalf of their disabled children (e.g. regarding their placement in segregated or inclusive settings).

– Explore positive and negative implications of increased specialisation and increases in formal services directed towards disabled children and their families, and examine how specialised and generic supports can empower disabled people and their families.
Questions

• How does Icelandic social disability policy impact the quality of life available to families with disabled children over time?

• What formal and informal supports were the parents able to engage with over time and how has that changed the social construction of disability in the families?
Theoretical perspectives

Social constructionism
I am interested in the “meaning making” in the face of change.

Social capital theories
(Bourdieu, Coleman, Putnam, Allan)

Poststructuralism
(Foucault 1975, Allan 2008)

Words: Support – formal and informal
Bonding -, bridging- , linking social capitals
Cultural capitals
Social welfare policy
Method: Qualitative Sample: Strategic sampling

75 families (75 mothers, 51 fathers/partners)

Data sources:
• interviews with one or both parents of disabled children,

• interviews with 5 couples (5 men and 5 women) that selected to abort a fetus with a diagnosis,

• interviews with 12 professionals,

• 3 focus group interviews with staff at local bureaus serving disabled people and their families,

• document analysis.
The ups and downs of the process

- Why this study?
- My bias
- Preparations, permits, research assistants.
- Sampling – finding the families
- Setting up the interviews (fathers/mothers)
- The interviews
- Transcribing
- Analysis
- Ethical issues
- Writing up
Parent in Context of Social Policy


Group 2. Children born 1984-1990 (15 families)


The big story of change in the lives of the families

• Significant improvement in the quality of lives of the families with changes in policy and services (but varies according to municipalities)

• Accessing formal support gets complex except in “experimental municipalities” that link one person to the family and coordinate formal support over time.

• From no schooling, via segregated education to integrated / inclusive education and beyond...

• From parents as architects helping build the formal support system to parents as consumers.

• From a “help” discourse to a “rights” discourse.
Smaller stories: theems across the parent narratives

- Bonding social capital typically weakens at the diagnosis of a disabled child. Little informal support – especially to fathers.

- Mothers become the captain of the family ship, fathers take on a “viscosious role”.

- Accessing the flow of bridging and linking capital is related to social status, education, place, political party membership and family connections.

- Both parents feel emotional loneliness – and that they have to fight for their child.

- A normal lif with a difference

- The problems with the label of ”autism”

- The terrible choice – to have or not to have the baby
The story behind the story

• Benedikt
• Questions and doubts
• Writing in English
• Etc.