

Experiences of fathers of children with disabilities: a forgotten chapter in family research?

3rd International Disability Studies Conference

The Art of belonging

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Start of the project: some important observations

- *Historically, research on families of children with disabilities has been framed by the medical model, which views disability as a biological deficit, necessarily associated with burden and grief.*
- *We problematize the medicalization of the phenomenon of disability and resulting research inquiries.*
 - *We propose the use of narrative inquiry, theoretically grounded in sociocultural perspectives, as a critical research methodology for situating the lives of these families in cultural and sociopolitical contexts.*
 - *Narrative inquiries complicate conclusions drawn from the medical model and contribute to new insights on the ways in which interpretations of having a child with a disability are mutually negotiated between individuals and society.(Lalvani & Polvere,2013)*

Start of the project: some important observations

Following McKnight (2015, 10) - we paraphrase her analysis and call - :

- ... a wealth of literature has been conducted exploring the experiences of parents who have a child with a label/impairment.
- However, studies have been mainly quantitative in nature and have focused predominantly on mothers.
- This poses an issue because fathers can make important contributions to the development of their children.
 - Understanding their experiences may improve support organized for both children and families.
 - There is definitely a need for future research focussing and exploring the lived experiences and perspectives of fathers who have a child with a label using qualitative methods, as neglecting fathers in research and practice is worrying and potentially detrimental...

Start of the project



- Father's voices are absent both from literature and research
- The group started to collect stories from fathers



Fathers Project → an international project →

Iceland



UK



Belgium



Thank you for your time

The Netherlands



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Team Dutch students @ VU Amsterdam

Team Erasmus
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University (2016-
2017)



Overview of first sample of fathers' research

Country/source	Father and his job	Child – age	Child - Label
1. Turkey (Ailin)	clerk	12 (Efe)	autism
2. the Netherlands (Geert)	Laywer	13 (Casper)	autism
3. Greece (Sonia)	Taxi driver	Twins – 18 (George/Stratos)	Multiple impairments (physical/visual/intellectual disability)
4. Spain (Miguel)	University Professor	24 (Javier)	Intellectual disability
5. India (Damini)	cardiologist	11 (Hannah)	Intellectual disability/epilepsy
6. Spain (Mario)	retired	45 (Gabriel)	Multiples sceroses
7. Iceland (Dora)	scientist	2 daughters (20-23)	Visual impairment/hearing impairment/physical impairment
8. Spain (Jessica)	ICT-specialist	10 (Rafael)	autism
9. Iceland (Kristin)	retired	Passed away	Intellectual disability/cancer
10. Spain (Agueda)	Company owner	16 (Noelia)	Visual impairment
11. Iceland (Alice)	Manager of international company	20 (Breki)	Physical impairment (spina bifida)
----- 12. Spain (Carlota)	----- Business man	----- 12 (Arola)	----- Prader Willy

Are there videos you would choose to represent your relationship with your family? What sorts of things would they show?



- **We would like you to bring some videos of your child** that you would wish to share with others.
 - It might be how you want your child to be seen or represents how you see them or a particular aspect of them or their lives.
 - It could be something that depicts or shows your relationship with the child.

We are not seeking a full life story of your child or something that encapsulates everything about them. The video or videos can have been taken in any context or situation, it could be unedited or edited, filmed on any technology **as long as you can show it to us on a piece of technology you use**. It could have been filmed by you or anyone else. It could be a few seconds long, a longer film or part of a longer film. You could choose two or three clips (or perhaps more), but the maximum amount of time we could spend watching the videos is 15 minutes.

Interview Questions: Open-ended conversation

1. Why did you choose this video?
2. What do you see in this video? (are you interested in what I saw?) (*add Video-specific questions*)
3. Tell me about the making of this video...
4. If you could share this video to someone, who would that be?
5. Why would you share this video with a certain person?
6. Would you share it with a family member or a teacher? Why?
7. Would you be showing who your child is through your video? (do you think this video is representing your child like he/she really is ??– no acting)
8. Tell us about your child/ about your family/ about what you do together
9. Tell me about your relationship with your child. (In what way has choosing this film made you reflect on your relationship with your child?)
10. To what extent has this film made you reflect about your experience of fathering? / Tell me about your experience of fathering.
11. Has choosing this film made you think about your relationship between your child and other people?
12. How do/ To what extent do these videos accurately reflect your child's life?
13. What have I not asked you that you wanted me to ask? What have I not noticed that you wanted me to notice?

A Father's Perspective on their interview

First, I found the interview and the preparation valuable as **it was an opportunity (obligation) to sit down and think about my situation and in particular my relationship with my daughter.** Even if I've thought a lot about various issues through the days, I had not reflected deeply on some of the aspects of our relationship and in particular the importance of many seemingly ordinary and daily activities

In choosing the videos I realized that most of our videos are from "special occasions", and did not cast particularly good light on the real/normal relationships in the family (as they would typically not involve normal or daily interaction/communication between family members). This might not be a hindrance in encouraging fathers to go deeper and open up, **but for me I found the experience of thinking about the interview and making the video I wanted to make to describe the relationship between me and my daughter, a useful one.**

- A LOT OF RESEARCH MATERIAL

Theoretical perspectives

- Geert: de Certeau- tactics and strategy / Ranson+ Doucet: embodiment of care – becoming father - entanglement of bodies with gendered parenting institutions/ ideologies/discourses/social norms
- Hermina: Bauman – the stranger who does not fit in
- Kristín: Traustadóttir – caring for and caring about / Weber - intersectionality
- Alice: Narrative Inquiry / fathers as different and same / roles

Crazy collection of...

- Some fathers pick a clip
- some fathers produce a clip
- How to enlarge the sample?

Do you get the complexity??

