

# The experience of parents of Deaf-Plus children

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# Secondary analysis from an ethnography

- Understanding the unique experiences of Deaf-Plus children and their families
- Ethnography
  - 6 families
  - 18 hours of semi-structured interviews
  - 20 hours of participant observation
  - 2 hour focus group
  - 150 pages of reflexive journals

# Findings

## Study 1: Focus on school and communication

- External influences on parents' decision-making regarding language and communication,
- Language and communication varies among Deaf-Plus children and their family members
- Struggling to determine and secure an inclusive and productive learning environment for their Deaf-Plus children.

## Study 2: Focus on roles and advocacy

- The role of time in becoming a cultural advocate
- “Yes, my kid can do that!”
- Atypical gender roles, perhaps not.



# The role of time in becoming a cultural advocate

All families: Acute medical needs early in life delayed discussion of communication and community affiliation.

Connors: “Everyone just kept saying ‘let him die,’ but we didn’t. So no one really cared about who he might become. So as I sat in the hospital I just read and read about Deaf people. When the time, came, I knew what to do.”

Hills: “Our son was disposable to them and no one talked about communication. We had to learn quickly to push back and it ultimately led us to other Deaf people—culturally Deaf people, because they also had to fight.”

# “Yes, my kid can do that!”

Families internalized narratives about “can’t do,” which they shed as their children grew up.

Padillas: Sure he can’t talk, but you give him an Ipad and he will point things out, go to different sites, and so much more. No one believes all the things he can do and they never even try.”

Khans: ”He says he’s going to medical school like mom and dad. We learned not to laugh off anything he wants to do, because we learned so many times just how wrong we were. He’s going to do it or something and no one will stop him. We wonder how many times people’s opinions have stopped him?”



# Atypical gender roles, perhaps not.

4 sets of parents explicitly explained that they did not have typical gender roles, and other agreed but...

Smiths “She arranged the the appointments and told me what I needed to know...and education. I was more on-the-ground taking care of her needs. I was the fun dad that she would go to if she needed something.”

Padillas “I go to work and come home tired. I never have time to teach [son]. It’s always dad.

# Discussion and conclusion

- Remaining open to trajectories of communication/community options is important. Always question absolutes and ask “why is it this way?” The best approach” for Deaf children is a misnomer (Marschark & Spencer 2010), It should be “The best approach for *this* child.”
- Working and having a child with significant support needs changes dynamics and labor in families, but the influence of gender remains strong. The important thing was that parents acknowledged the work each did (Gerson, 2004).
- Parents, medical practitioners, and educators need to make “the least dangerous assumption” (Jorgensen 2005) about Deaf-Plus children. Systematic low-expectations teaches disabled kids not to strive for or work for their dreams.