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## Experiences of Parents with Children with Intellectual and Developmental Disabilities

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# Experiences of Parents with Children with Intellectual and Developmental Disabilities

Amy Crawford, USM, Mataquess Phillips, USM, & Chelsea Stephens, USM, and Jennifer First, USM

## Abstract

Parents deal with a number of stressors and emotions while caring for children with intellectual and developmental disabilities (IDD). Finding accurate support and services can be challenging, and some parents do not receive services that they find helpful. While there is research around social services for children with IDD, the researchers found a gap in the literature regarding parents and their perceptions, experiences, and needs.

This grounded theory qualitative study sought to understand the experiences of parents of children with intellectual and developmental disabilities both in general and regarding services in the state of Maine. We conducted in depth interviews with three parents caring for children with IDD and analyzed transcripts of in-person interviews using coding and constant comparison of major themes. This study may help inform future social work practice with families with children with IDD. This research could also inform policies in Maine around access to services for IDD.

## Background

- Concerns of parents include: opportunities for inclusion of their children, services for future-planning, interagency collaboration, consistency of services, geographic proximity of services, support services and information specific to their child's needs/disabilities/behaviors, and access to safe childcare (Freedman & Boyer, 2000; Hewitt et al., 2010).
- Finding accurate support and services can be challenging, and service providers and programs should support a family's adaptation to their child's needs, and include parents as the most important part of their development. (Felizardo, Ribeiro, & Amante, 2016).
- The rationing of services creates access inequality (Jackson et al., 2018).
- The researchers found a gap in the literature regarding parents and their perceptions, experiences, and needs.

## Question

What are the experiences of parents of children with intellectual and developmental disabilities (IDD)?

## Methods

- Conducted in-person interviews with three parents of children with IDD
- Researchers used a semi-structured interview guide developed after reviewing the literature.
- Researchers recorded and transcribed the interviews.
- Each researcher analyzed one transcript individually using descriptive coding and memoing.
- Researchers then conducted in-person cross analysis of codes and major themes.
- Researchers cross analyzed until reaching a consensus on major themes.



Figure 1. Word cloud generated from interview transcripts with common words related to special needs families

*"Watching them develop and grow, their good might look different than someone else's but you're still celebrating moments- different moments than typically developing [children]- but there's never a dull moment. It's always interesting." -Parent*



Figure 2. Word cloud generated from interview transcripts with common words related to services

## Results

- finances
  - parents discussed funding for program participation, expense of care, and interference with the parents ability to work or maintain a regular working schedule.
- child services
  - Sub-Themes included a general lack of quality in care, communication struggles, waitlists, intrusiveness of home-based services, and high turnover rates of staff.
- empowerment, advocacy, and inclusion
  - Parents expressed feelings of obligation to advocate for their child in education, home, and community settings. All three participants expressed their disappointment with how much they had to fight to get their child the support and services they needed to be successful in public school.
- parent supports and services
  - Sub-themes related to parental supports include natural family supports, lack of professional supports, limited access to and poor quality of respite services, therapy, and peer support.
- parent feels and viewpoints
  - Parents displayed a wide variety of viewpoints and feelings ranging between hope, love, embarrassment, frustration, grief and anger.

## Discussion and Next Steps

- This study identified potential gaps in services for families and children in Maine with IDD
- Research on this topic is limited, and further is needed
- This study had a small convenience sample of participated sourced from one agency, and had limited time and resources to conduct a more expanded study.
- This study can contribute to the current limited literature to inform policy makers and agencies of potential gaps in service and support, and ways to better support families and children with IDD

## Acknowledgements

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