

# Negotiating Daily Strategies and Routines



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# Introduction

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- ❑ Families differ in their priorities, values, culture, and background
- ❑ Families with typically developing children and families of children with disabilities are characterized more by similarities than by differences
- ❑ The difficulties involved in raising a child with disability often emphasized
  - Studies have also documented many positive contributions that children with disabilities make to their families
- ❑ Family routines
  - Behaviors that are important in structuring family life and giving it order

# Study Design

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- Qualitative methodology
- Participants
  - 17 parents of children with physical disabilities, age 6-12
  - Parents selected through a purposeful sample
- Semi-structured interviews
  - Parents asked to describe a typical weekday at their homes, and about their communications and relationships with the educational, health, and social services related to their child

# Results - Main Categories

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- Although the families had several things in common they used different strategies
- Two main categories
  - Balancing family life and routines
  - Collaborating with outside services

# The Home

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- ❑ The importance of physical accessibility for family dynamics
- ❑ Organizing or redesigning the space to meet the child's needs for access and transitions
- ❑ Cost of modifications

*If children are in wheelchairs, or people, then there are certain things that are a must so that the home life can function...I bought a house and I've already ripped everything out of it. I've done up the whole floor plan, the whole garden, and all of the walkways here outside. Because the other option is that he's unable to fend for himself. Stairs in the house, that's just a danger. Stairs outside, it just doesn't work.*

# The Home, Cont.

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- ❑ Demands on space and accessibility challenging the image and meaning of a “home”
- ❑ Home location in relation to school and therapy services

*I went once to this house where there was a disabled person. And I felt like the home was based on this disabled person, and everything was disabled and everyone became disabled. So that the wheelchair could move around, there were no flowers in the window, no this, no that. And I thought to myself, I found it so cold and bare, I thought, "No, you know it's possible to overdo everything.*

# Family Behaviors

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- ❑ Different priorities in organizing of daily life and routines
- ❑ For the children with the most severe impairments
  - A large part of the family's day revolved around the child's needs
  - Careful planning in order to manage routines

*There's something that I'm going to do for myself and others to learn from and that's find out how much time it takes to brush teeth, go to the toilet, get dressed and undressed when you're going in and out. Or all those things that people just do without thinking, 5 minutes for this, 5 minutes for that, it takes Tumi a half an hour, maybe an hour.*

## Family Behaviors, Cont.

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- Less time than ideal for their other children or for their partners
- Many downplayed the challenges involved in caring for their child
  - Focusing on positive aspects

*We don't sleep like regular people and haven't for the past 11 years. But is that any worse? Maybe we get sick sooner, get old sooner. But maybe instead we'll be stronger and live longer.*

# Family Behaviors, Cont.

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- ❑ Importance of social support
- ❑ Priorities regarding types of assistance and support
- ❑ Balancing the present and the future

*Of course it's been hard work all these years teaching all of these things. But in the right conditions, by thinking about this in connection with the home, you can do it. It costs a lot of money, of course, a lot of forethought. But it's worth it to be more independent and hopefully have more self-confidence.*

# Work and Social Life

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- ❑ Compromising in career plans
- ❑ Socializing within an accessible environment
- ❑ Careful planning of family holidays and vacations

*My company just advertised an opening for the position manager and that's a position I could easily have applied for...But I decided that it wasn't possible. It would have meant more time away from home, more pressure and responsibility and that just would have been such a huge deal.*

# Family Life and Routines, Summary

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- The families of those children who were totally dependent on help emphasized their tiredness
  - Involved in numerous aspects concerning their child
  - Their daily schedule extremely tight
- Individual styles and preferences, and the availability of support mostly affected how people lead their lives
  - Rather than factors related to their child's impairment
- Many parents emphasized the positive aspects and described efficient ways in balancing their lives and routines

# Collaboration with School

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- ▣ Parents wanted meaningful and active roles in their children's education
- ▣ Discontent with the extent of leadership they had to assume in achieving and maintaining services for their child

*I write everything down. I register when he goes swimming, and when he doesn't and why, because I have to have the facts for back-up when I call to file a complaint...Of course it is rather tiresome to always be on guard and having to make your point and monitor how things are going, as if the responsibility is always yours in the end.*

# Collaboration with School, Cont.

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- Many parents educated staff on professional or practical aspects
  - Up to them to ensure that things were running smoothly
- The parent's level of satisfaction had little relation to their child's academic performance
  - Rather to the measures that had been taken to accommodate the child's educational and social needs
  - The extent to which their child was content and respected at school was most important

# Collaboration with Support Services

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- Involvement of professionals valued
  - But fragmented services put pressure on family life
- Request for practical ideas and help with present challenges and in planning ahead

*There are certain things that change with the birth of a disabled child and that means lots different work and extra work if things are going to work out. On the other hand, the parents need help bearing this responsibility.*

# Collaboration with Health and Social Services, Cont.

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- Parents needed to keep things on track
  - Fight various aspects of the system
- Lack of clear pathways on roles and regulations complicated matters

*Sometimes I have the feeling that if I had a girl for an hour a day, she'd have enough to do just calling this place or that, because if an illness comes up, like with the physical therapist, then everything goes completely to pot. You need to call the travel service and change everything. And it's not possible to change anything with them within 24 hours. So it's a huge deal.*

# Collaboration with Outside Services, Summary

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- ❑ Wish for joint decision making and collaboration with outside services.
  - Need for functional yet manageable responsibilities that did not take up too much time
- ❑ Parents tried to maintain a positive attitude
  - Avoid conflicts that might disadvantage their child or disparage their reputations
- ❑ The inability of educational and health care professionals to communicate and coordinate their activities among themselves made the lives of many families more challenging

# Main Findings

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- ❑ Different families use different strategies for organizing their lives
- ❑ Each family is unique and service needs to be tailored to their individual situations
- ❑ Most of the parents' complaints involved lack of flexibility within the service system, scarce resources, fragmented services, and difficulties in obtaining information
- ❑ Professionals must carefully attend to a family's lifestyle, culture and wishes