

# Juggling the demands of Early Intervention in the daily routine of family life

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**Background:** Striking a balance between work and family care is a very real challenge for families today. More than 80,000 families in Canada have the additional demands that come with caring for a child with disability. These demands may include complex medical needs, managing challenging behaviours, keeping appointments with health care professionals, and implementing therapist-recommended goals and home programs. Little is known about how parent carers juggle such demands in the context of their daily routines. **Aim:** Employing ecocultural theory, this study investigated 1) how parent-carers juggle demands of work, family life and early intervention, including the accommodations parents make to 'slot' Early Interventions into their daily routines, and 2) the resources and constraints that influence family 'compliance' with professional recommendations for intervention and home programs. **Method:** This study used Narrative Inquiry. Data was collected in two waves of in-depth narrative interviews with 12 families. A thematic analysis of family narratives, informed by ecocultural theory, was completed. **Results :** Parent- carers described accommodative strategies, and the trade-offs they made to 'fit' intervention into their daily routines and to maneuver through the health care and educational systems. **Conclusion:** Preliminary findings suggest that families develop innovative strategies in order to juggle the demands of work, family and early intervention. However, 'compliance' with professional recommendations can have significant personal and family costs.

**Miriam Parakkal**

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The central adaptive challenge for every family, whether they have a child with disability or not, is to create and sustain a routine.



## The central adaptive challenge for every family is creating and sustaining a routine

(Weisner, T.S., Matheson, C., Coots, J., Bernheimer, L.P., 2005)

Here are two excerpts from mothers of young preschool going children describing a portion of their early morning routine.

## The demands of routine



*“Mornings, I’m getting my kids dressed, the dog fed, the lunches made, the shopping list done”*

Mother of 3 year old and 5 year old

*“I get them out of bed, get breakfast ready, put the finishing touches on lunches... Bathroom, brush teeth, dress ... The bus shows up and he’s off to school”*

Mother of a 3 year old and 7 year old

*(Hochschild,1989;Parakkal,2011)*

The first excerpt is from the mother of a typically developing child and the second is from the mother of a child who’s been diagnosed with autism, yet, both moms demonstrate that they’re in the business of juggling a number of demands in the morning and keeping a routine going that works for them.



## Striking a balance

- Juggling work and family life is a challenge
- 200,000 plus Canadian families face an additional challenge:

Work + family demands + the demands of caring for a child with disabilities

(Duxbury and Higgins, 2001;PALS,2006)

Striking a balance between work and family life is a challenge for all families, whether or not they have a child with disabilities. More than 200,000 families in Canada have to balance work and family and the additional demands that come with caring for a child with disability (PALS, 2006). These demands may include but are not limited to managing a child's complex medical needs and/or challenging behaviours, keeping appointments with health care professionals, and implementing Early Intervention and other therapist recommendations.



The other extra demand that many of these families have is dealing with the services specifically rehabilitative services.

In the case of a family with a young child this would be Early Intervention services. This could involve various responsibilities from trying to access information about services for their child, to transporting children to therapy and or trying to implement therapist recommendations and home programs.



How families juggle this particular additional demand in their daily routine with respect to Early Intervention is what I was interested to understand.

## Additional demands

- Self care, behavioural difficulties
- Medical challenges ,doctor’s appointments, surgeries
- Dealing with services
  - therapy, home programs, recommendations

(Diamond and Kontos,2004;Freedman, Litchfield, Warfield,1995;Porterfield,2002 )



Now for a very brief background on Parental Involvement and Early Intervention: Though parenting involvement has been documented widely in literature, it focuses largely on child outcomes and intervention efficacy. Closely related with this research is the topic of compliance. Researchers have developed a keen interest in how ‘adherent’ parents are to an effective intervention and therefore have also tried to look at various strategies to increase ‘adherence’.

## Parental involvement in Early Intervention



(Hanzlik,1989;Stein and Jones Jessop, 1984)

(Mayo,1981;Law and King, 1993;Molineux,1993;Schreiber et al.1995)

(Hinojosa,1990;Hinojosa and Anderson, 1991;Tetreault et al.,2003)

There is a growing body of research on parental perceptions and wellbeing when carrying out EI for their children. However even this literature describes parental wellbeing or their perceptions with regard to child outcomes. There are a few authors who

have addressed the parental perception of home programs and therapy on family life, notably Hinojosa and Anderson. However an understanding of the process of implementation of these programs by parents is a dimension of this research that has not been explored in detail.

## The research questions

- *How do families juggle the demands of daily life and Early Intervention?*
- *What influences how families implement Early Intervention?*



So the questions I asked were

- How do families juggle the demands of daily life and Early Intervention?
- What influences how families implement Early Intervention?
- What goes into the process?

# The Theoretical lens



The Ecocultural Theory

=

Ecological  
factors

+

Cultural activities  
and practices and  
the meanings  
behind them

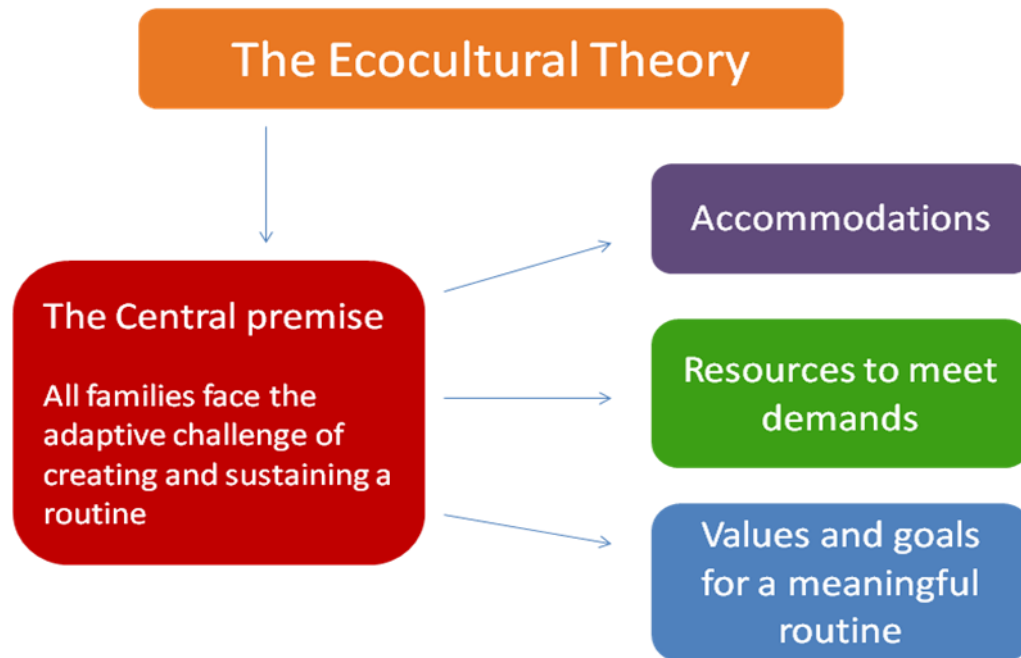
(Whiting and Colleagues)

I looked through the theoretical lens of the ecocultural theory to answer my question

The ecocultural theory combines:

- 🌿 The physical and social ecology that surrounds the family and
- 🌿 The Cultural context the family lives in and is a part of as well as the meanings ascribed to the cultural activities that they take part in.

The central premise of the Ecocultural theory is that all families create and sustain a routine



(Weisner, T.S., Matheson, C., Coots, J., Bernheimer, L.P., 2005)

The tenets that I used from the ecocultural theory to analyse my data were

- 🌿 Accommodations- the intentional adjustments families make in their daily routine to sustain their routine
- 🌿 The resources that they draw on from their ecocultural context to meet the demands of their routine
- 🌿 And finally the values and goals of the family that make that routine meaningful

## THE METHOD

The method that was used for this study was Narrative Inquiry which fits well with Ecocultural theory because it seeks to understand an individual not as an individual alone but as part of his social context.

# Methodology

## The Method – Narrative Inquiry

- Understanding an individual in his social context (Clandinin and Connelly, 2006)
- To gain insights and understand the experiences of families from their storied accounts (Sandelowski, 1994)

## The Participants

- 12 families (14 parents) from the Family Life project (McConnell, 2008) who agreed to participate in in-depth interviews

## Data Collection

- In-depth interviews conducted in two waves

### THE PARTICIPANTS

My study that is part of the larger Family Life project conducted over a period of 3 years. Out of over 500 families that responded, 40 parents of young children were contacted who responded to the Family Life Survey (McConnell, 2008) who indicated that:

- 1) they had a child under the age of 6 with a long term physical or cognitive disability
- 2) were involved in Early Intervention and tried to follow therapist recommendations and integrate them in their daily routine some or all of the time but had difficulties doing so.
- 3) 12 families 14 parents responded affirmatively to participating in the interviews

### DATA COLLECTION

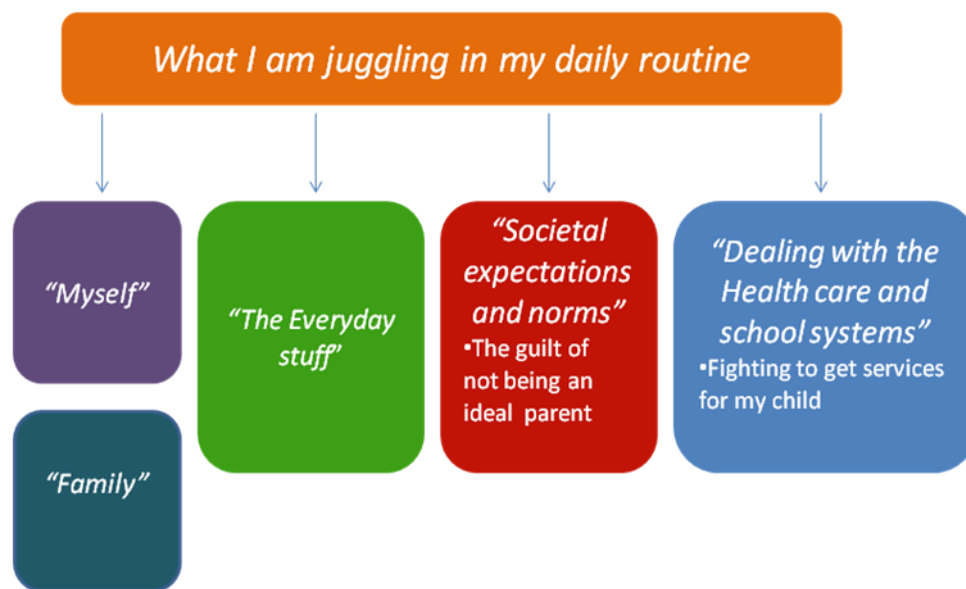
In depth interviews in 2 waves conducted with all the participants at their homes after obtaining signed consent.

- Interviews lasted anywhere between 45 minutes and 2 hours
- All the interviews were audio-taped and later transcribed

I analysed the data in 3 parts:

Firstly I looked at what exactly these families are juggling in their daily routine. The 3 themes on the left, 'Myself, Family and the everyday stuff' are aspects that are part of juggling work and family life. The two themes on the right, spoke to a whole separate set of demands that came with being the parent of a child with disability. This was almost like an extra set of juggling balls that they had to keep up in the air along with the others.

## Analysis



From the theme 'Societal expectations' I chose to share with you, the sub theme 'The guilt of not being an ideal parent'. Parents often felt guilty that they weren't doing enough for their child with disability and that they were not living up to being ideal parents to their other children as well. So they juggle both. An example of this comes from one of the moms in my study whom I call, Leigh.

Leigh has a 6 year old daughter who has been diagnosed with autism and a 13 year old son. This is what she told me

***"I keep thinking we should always be working on her and getting in her face, but it is a struggle and it is a balance but I know I am not alone and this is a common theme with all the***

***parents that we talked to with special needs kids, it is, are you doing enough? Do you feel this is doing enough? “***

She went on to talk about not being there to make breakfast for her son or see him off to school every morning:

***“And a part of me feels bad because I know that there are moms out there who see their children off to school, but this is the way it is. And it works for him the way it is and it works for us.(Leigh I1, pg,14).Sometimes I feel very guilty that he gets some self out of bed, and gets his own breakfast.(Leigh,I2,pg 65)”***

You also do see an element of ‘accommodation and strategy’ in Leigh’s story.

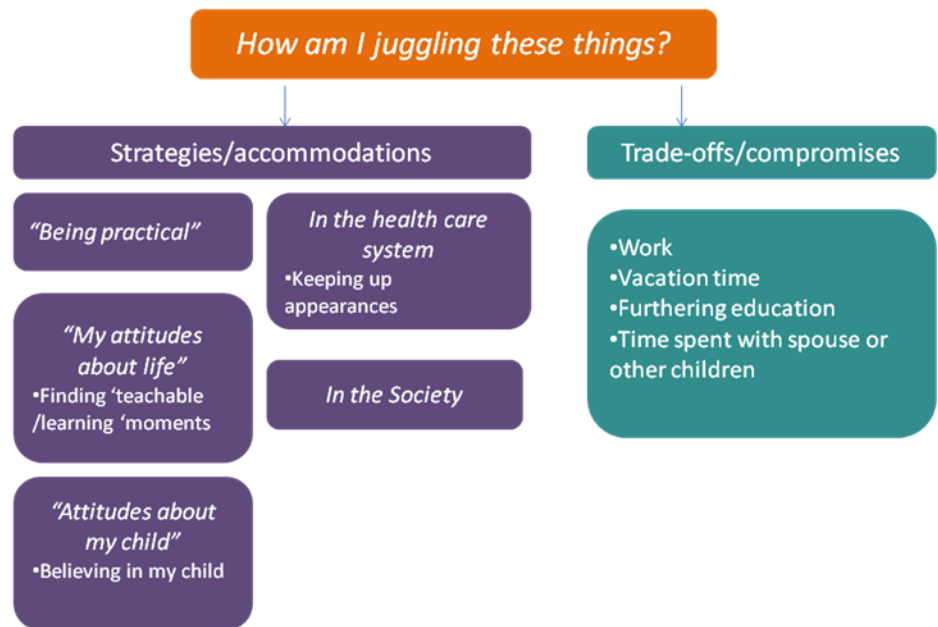
The second part of my analysis and to answer my first question was the question” How do families juggle these responsibilities?

I looked at various accommodations and strategies parents came up with specifically to fit demands of EI into their routine. This is on the left. In order to make those accommodations there I found that there were tradeoffs that families made.

Among strategies there were practical ones that families mentioned such as preparing lunches the night before, internet shopping to save on time, making use of free city programs to save on money etc.

Here what I found unique was not just the practical

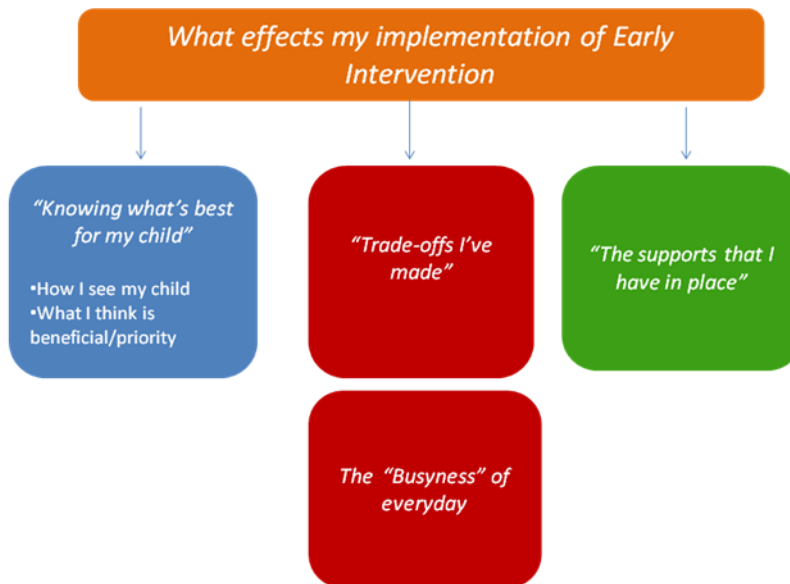
strategies that helped keep families going but their positive attitudes toward life and their child. They found potential in their child and did not entertain allowing their children to be victims of disability.



Lydia made sure to remind the school staff and the aides working with her child of this fact. She says:

***“He needs to get into the battles and he needs to learn how to speak for himself and so that’s kind of an important thing.”***

***“He is very capable of doing these things. And expect more out of him than the less because he’s going to live up to your expectations. People see his physical disability and naturally assume that there is more to it or you know they feel sorry for him. Don’t feel sorry for him because that’s the worst thing you can do for him, right?”***



And finally to answer my second question. Using the tenets of the ecocultural theory, and under the three main categories of Meaningfulness, constraints and supports, I found four major themes that influenced how and whether parents implemented EI in their daily routine.

For example, under the theme of ‘Knowing what’s best for my child’, I found that parents implemented EI based on

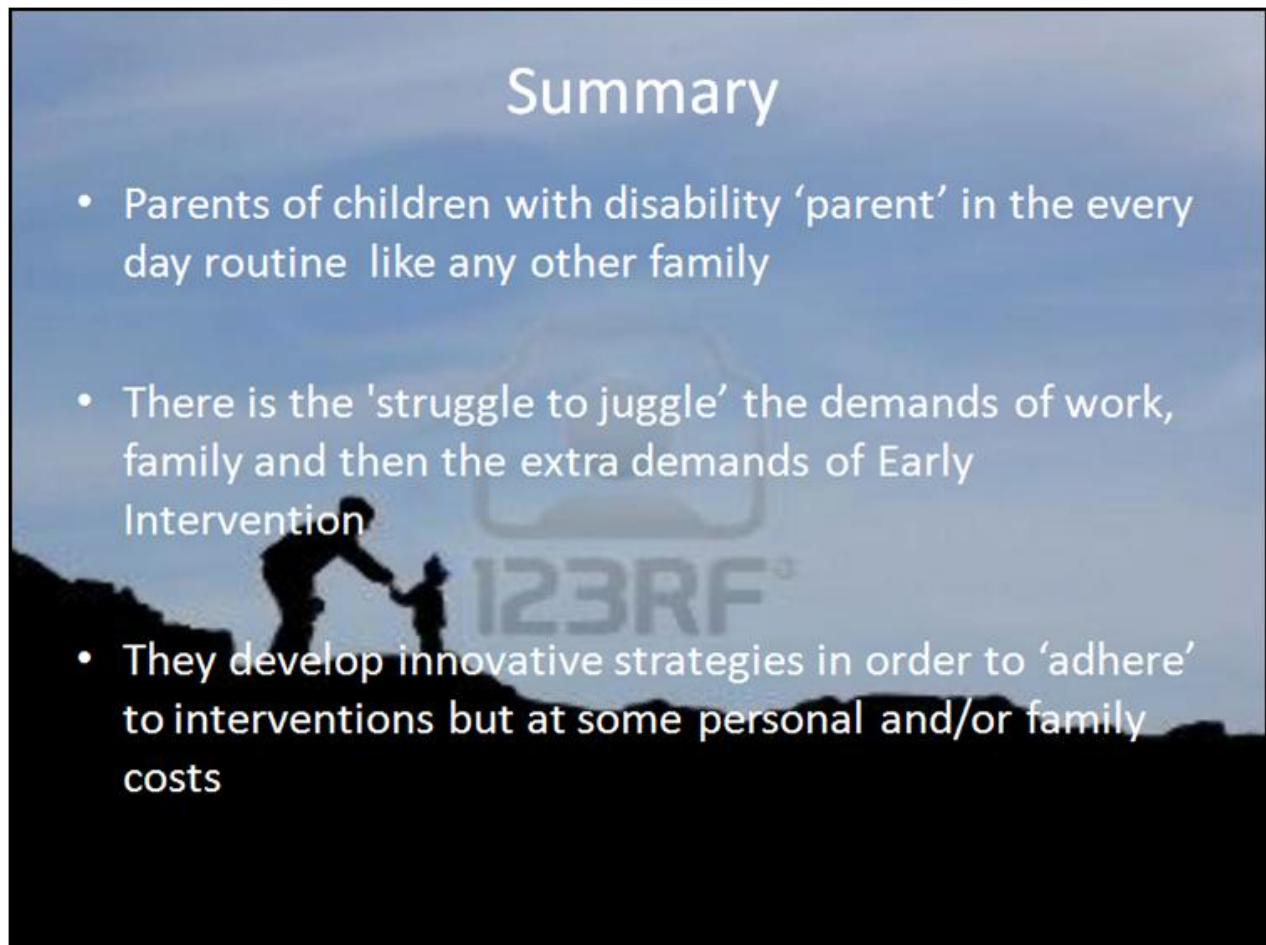
- 1) How they saw their child personally and culturally, and based on what their goal was for their child. Eg:Normalcy vs. Going with the flow.
- 2) They also tried to manage the tension between what they saw as beneficial and priority for their child, and getting as many resources for their child as possible.

Other factors were constraints like difficulties with implementing goals and resources like an understanding aide/therapist.

Asha is an example of such a mom. This is what she said:

***It's too much work. Like, it's not easy. It's very very tough. That's not the way to communicate right? He needs to understand gestures."But still we cannot stop also. That's the problem. Because we'll think, "My god! My son should get whatever help he can, we will accept it." (11,pg 27)"***

Asha felt that the therapist strategies for communication were not meaningful for her culturally yet she did implement them because she was afraid if she didn't then her son would get no help at all.



## Summary

- Parents of children with disability 'parent' in the every day routine like any other family
- There is the 'struggle to juggle' the demands of work, family and then the extra demands of Early Intervention
- They develop innovative strategies in order to 'adhere' to interventions but at some personal and/or family costs

## Conclusion

- Resources, demands, values ,goals and strategies are interrelated
- There's more to it than practical strategies and tasks of routine.
- The 'process' is just as important as the outcome

- 1) Resources, demands, values , goals and accommodation strategies are interrelated, which leads us to the next point ....
- 2) that is that parents do not only juggle just the practical task of sustaining a routine but have this... I don't want to call it a burden ... But they carry too, the weight of their culture, values, beliefs and related meanings and are constantly thinking and negotiating this in their minds when they make accommodations to fit in various aspects of EI in their routine. So 'slotting-in' EI is a whole new set of juggling balls that include the meanings, resources and constraints that go with it.
- 3) The process is just as important as the outcome.

Families are no doubt interested in the outcomes of their child just as are the professionals who work with them. However as we just saw implementing EI is part of a complex process of juggling demands for these families. Through their stories, families are telling us that this process is just as important as the final outcome.



What does this mean?

***A change in attitude and practice.***

In attitude-The knowledge of what it takes for parents to implement EI should make us as professionals think of the 'weight' we perhaps place on these families in trying to do quite the opposite which is to be family centred and to help them.

In practice-All the families in my study were trying to implement therapist recommended strategies. While this is important, perhaps we should start thinking of ways in which to 'enfold' EI into routine life and ways to draw on innovative parental strategies

Finally being mindful of and carefully assessing personal values, goals, culture and community, will help families and professionals to carry out meaningful and successful EI strategies, and move towards truly 'family-centred' practice



Thank you

Miriam Parakkal, University of Alberta  
parakkal@ualberta.ca