

# RETROSPECTIVE FRAMES OF DISABILITY



Themes derived from parents of children who  
grew up with congenital disabilities

A phenomenological study

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# INTRODUCTION

- Who am I and why does that matter?
- Why does the perception of parents of a child with a disability matter?
- My research

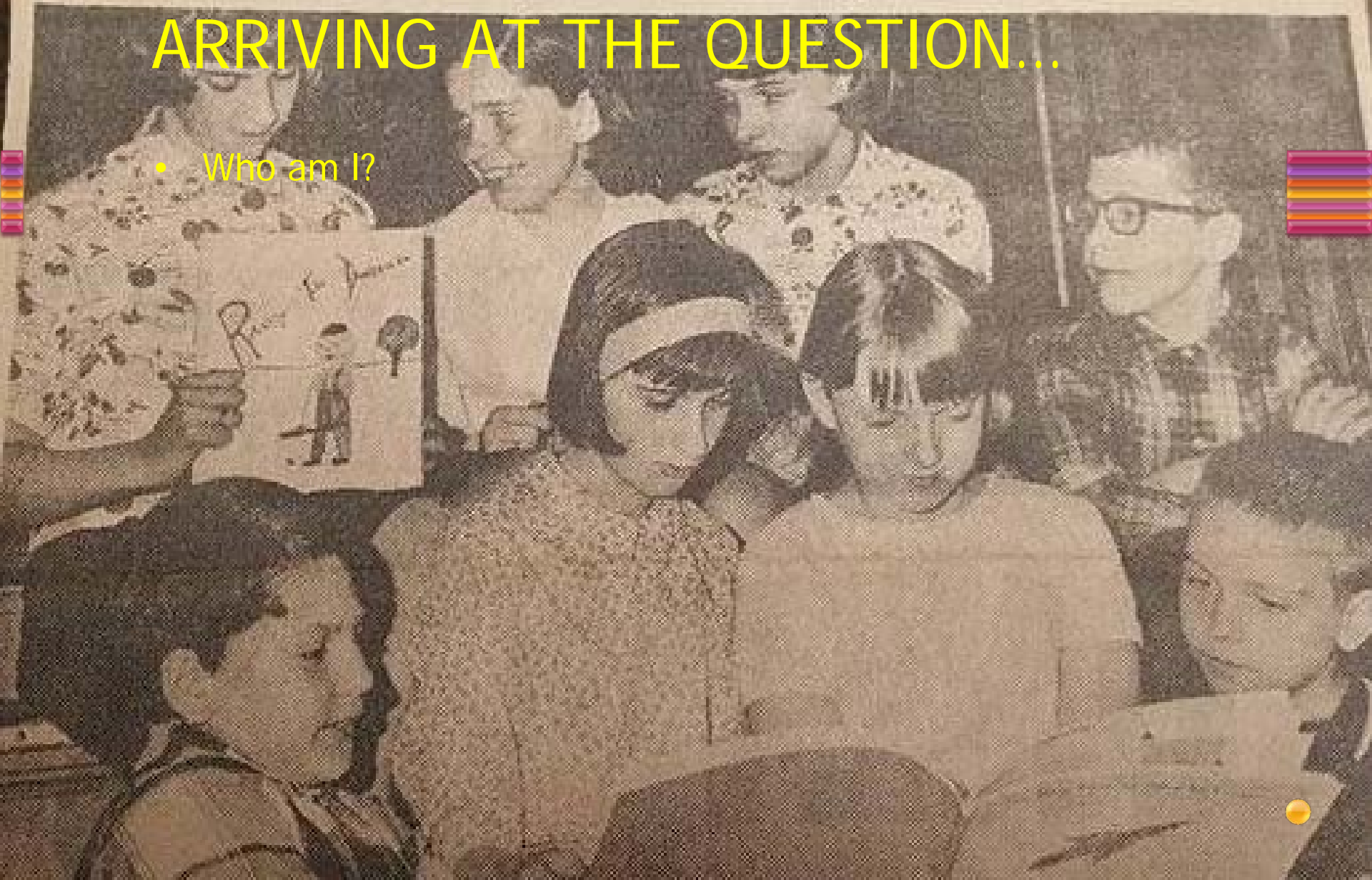
# We all have a me...

- I had a “we” ...
- For me, disability meant nothing... I just knew that normal was hard

# Creation, Imagination

ARRIVING AT THE QUESTION...

- Who am I?



The “same”... until 1999





From a Master's to mastering parenting...



My questions about mine...easy

- My questions about my mom and dad...

**UNANSWERABLE**

*Why did it matter to me?*

**Why does it matter?**





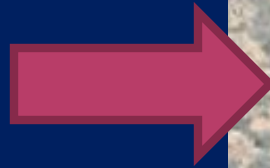


# Once upon a time

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- These parents were expectant parents (Baker, 2008)
- 

# What expectant parents most hope

- Amniocentesis
- In-depth ultrasound
- Family history
- Blood work
- Preventative Information
  - Nutrition, vitamins, smoking cessation
- Regular prenatal care





# The wait is over

- 
- 
- **Emergency procedures** (protocol)
  - **Assessments** (Burkhart, 2013)
  - **Interventions** (Trivette, Dunst & Hamby, 2010; Barnett et al., 2003)
  - **Best laid plans** (Tate & Pledger, 2003; Palisano, 2010)
  - **A change in reception** (Wendell, 1996)




Congratulations

...on your bundle of Joy







After an infant is identified with a  
disabling condition...



What will the new  
family story be?



# Cross-sectional perceptions

- Friends
- Family
- Hallmark
- The medical team
- Spiritual sources
- Parents
- Siblings



# Literature Review

- **Family systems/adaptation** (Allen et al., 2007; Arango, 1999; Carter & McGoldrick, 1989; Palisano et al., 2010; Piggot, 2002)
- **Family interventions** (Almasri, et al., 2011; Burkhart et al, 2014; Palisano et al., 2010 Rosenbaum et al., 1998; Trivette et al, 2010)
- **Access and rights** (Applequist, 2009; Charlton, 2010; Neumann, 2007; Simeonsson et al., 2010; UN, 2015)
- **Collaboration** (Barnett, 2003; Turnbull &Turnbull, 2001)
- **Living with a disability** (Barnes, 2004; Watson,2002)
- **Caregiver burden** (Roper, 2014; Reichman,2007; Taanila, 2002; Guralnick, 2004)
- **Mixed perceptions/framing** (Charlton, 2000; Tate & Pledger,2003; Smart & Smart, 2006)



# The Research Question

- How do parents describe the lived experience of rearing a child with disability from infancy to adulthood?





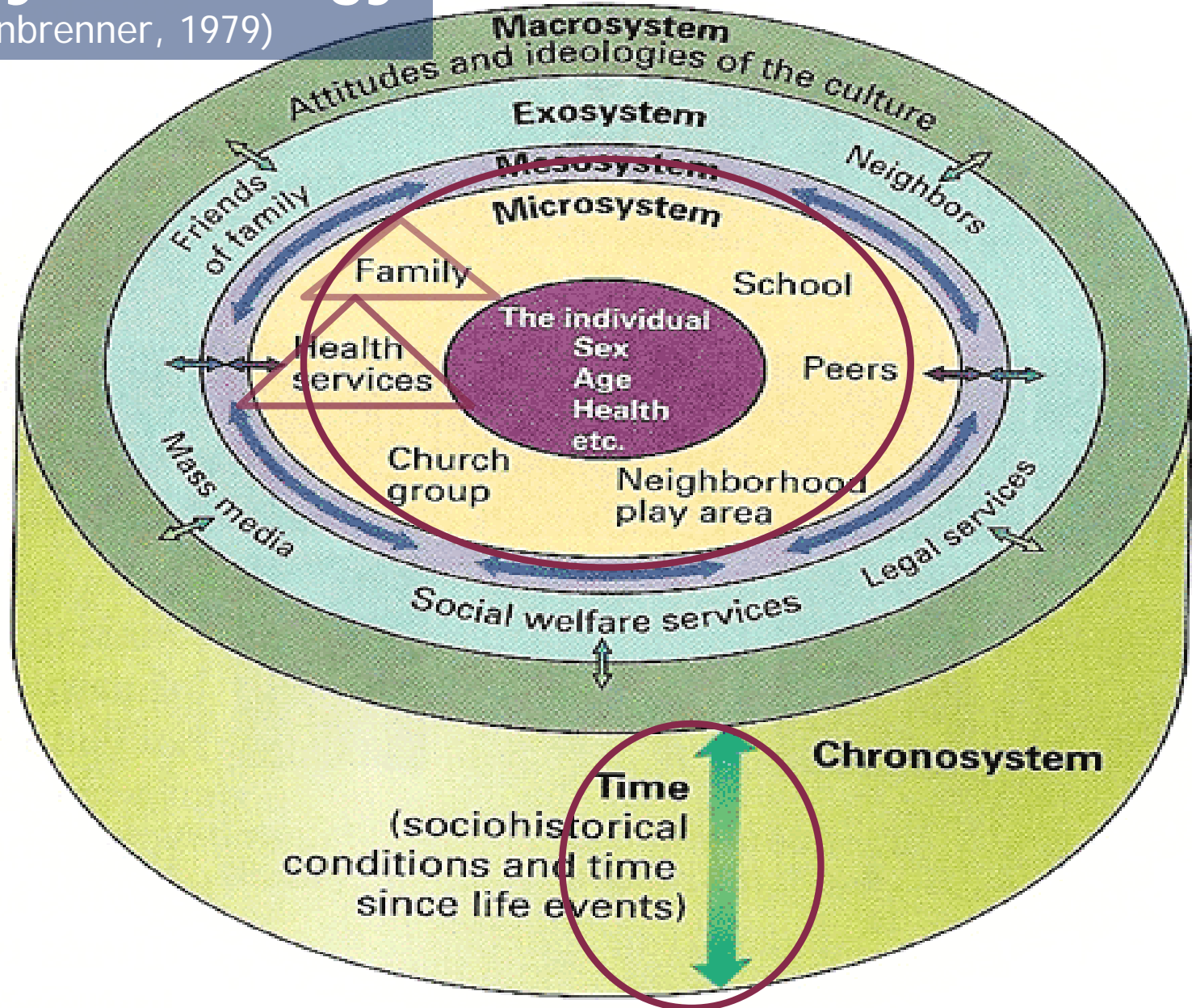
# Setting the stage

- 
- 
- Person (child) centered philosophy (Pearpoint & Forest, 1998)
  - Family systems (Allen et al, 2007)
  - Disability studies (Shakespeare, 1996)
  - Family systems intervention (Trivette et al, 2010)
  - Ecological (Bronfenbrenner, 1979)





# A Family's Ecology

(Bronfenbrenner, 1979)





# Methods: Heuristic Phenomenology

- 
- 
- Investigation of the lived experience of parents of children with disability (Field & Morse, 1985; Denzin & Lincoln, 2001; Creswell, 2009)
  - Structures, attributes, mechanisms of introspection, exploration, and discovery (Kleining & Witt, 2000; Moustakas, 1990)

# Methods

- IRB approval, informed consent



Sample: purposive		PARENT age ranges GENDER	CHILD CURRENT AGE	CHILD'S CONDITION SIBLINGS?	ANNUAL INCOME	Marital status
	1	40-49 <i>F</i>	24	Cerebral Palsy (CP) Hemiplegia <i>Y-2</i>	100,000+	M
	2	60-69 <i>F</i>	31	CP Quadriplegia <i>Y-2</i>	25-50,000	M
	3	50-59 <i>M</i>	23	Sensory Integration Disorder <i>Y-1</i>	25-50,000	M
	4	50-69* <i>F</i>	25	CP Hemiplegia <i>Y-2</i>	25-50,000	M
	5	50-59 <i>F</i>	25	Developmental coordination disorder <i>N</i>	25-50,000	D
	6	50-59 <i>F</i>	20	Rett syndrome <i>N</i>	0-25,000	S
	7	50-59 <i>F</i>	29	Rett syndrome <i>Y-1</i>	75-100,000	M
	8	40-49 <i>F</i>	22	CP Quadriplegia <i>N</i>	25-50,000	D
	9	60-69 <i>F</i>	31	Down syndrome <i>Y-2</i>	50-75,000	M

# Participant profiles





# Sample: purposive





# Methods: Instrumentation

- 
- 
1. Demographics
  2. Written questionnaire
  3. Semi-structured interview
  4. Field notes
  5. Fill-in graphic based on design of  
McGill Action Planning System  
(Adapted MAPS)

(Pearpoint & Forest, 1998)





# Validation of themes

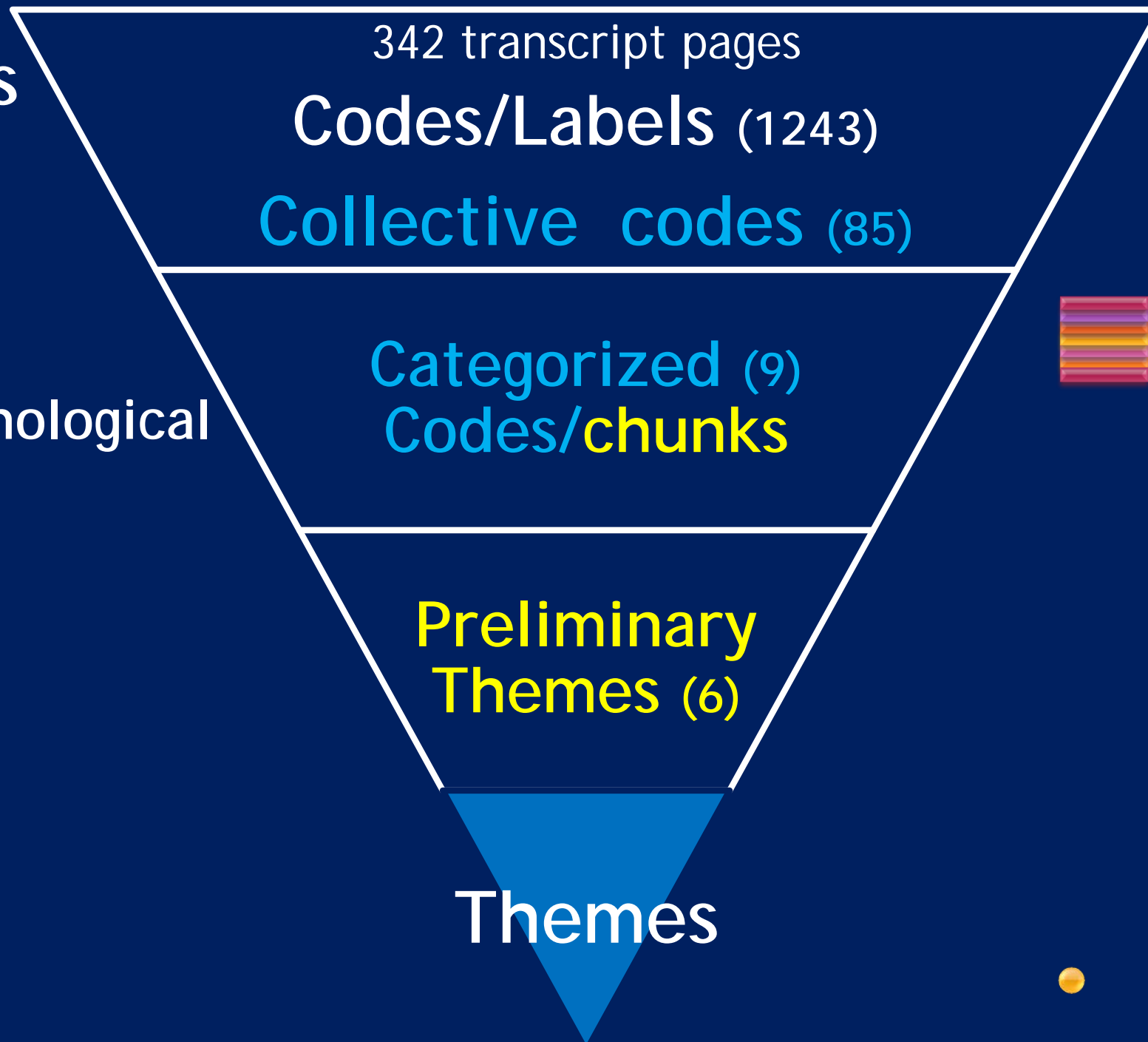
- Member checks
  - All parents agreeable
  - Randomly selected three participants
  - Confirmed themes



# Methods



## Phenomenological analysis



Themes






# Results: emergent themes



The derived framework in which parents lived their experience of disability




1. Navigating Normal for Us
  2. Pride and Joy
  3. Anything but Disability
  4. Lived Lives, Looking Back and Looking Forward
- 

# 1. Navigating normal for us


- Family/child team
- Becoming us
- Tolls
- Different paths



# Navigating normal : Family/child team



“...Our therapist was like family. And we fell in love with her... the whole time they would be working with Anna, you know I’d be right there ...talking and laughing. ...I tell them I felt like they were my therapist also because I had somebody to talk to that cared ” (Christina)




“I entrusted Josh to them” (Rebecca)






# Navigating normal: Becoming us




“I had a marriage to think of, the two other girls, church, work, all that. But no matter what, it was Steffie in the middle that pulled me back to the necessary things.” (Susie)









# Navigating normal : Tolls




“Our support systems made a huge, huge difference in terms of what is possible as a person, as a family...yeah, to achieve those bits of normalcy. It’s hard physically and emotionally, and we kept getting older.” (Nina)






# Navigating normal: Different paths




“What made us different from our friends was the way we had to prioritize- it left us out of many of their outings.” (Rebecca)




## 2. Pride and Joy


- The child we lost and the child we gained
- Membership and belonging
- Gifted
- Following their lead



# Pride and Joy: The child we lost & the child we gained



“I’d look out the kitchen window to the back yard, where is she, she’s ‘sposed to be playing...” (Carla)




“The Down Syndrome became less and less of what we saw ...more and more just Roger.” (Dee Dee)






# Pride and Joy: Membership and belonging




“I had two daughters younger than Steffie. They would just go and kiss her and say I love you between care duties. They played with her as if she were just another sibling. ” (Susie)






# Pride and Joy: Gifted




“... I’ve met your daughter and oh my gosh, no matter what the responsibilities, this is an amazing young lady.” (Nina)








# Pride and Joy: Following their lead



“I used to feel so sorry for Sari. So many scrapes and bruises. She’d come home from school that way. ...but it never stopped her from being on the playground dead center with the other kids. Honestly, she just picked herself up and carried on. So that’s what we did, too.” (Molly)



### 3. Anything but disability


- Defined by ability
- Skills and resourcefulness
- Strength in weakness
- Becoming an advocate

# Anything but disability: Defined by ability


“Disability was not a factor. I had a relationship with her. She was just my little girl. I was being her mom.”  
(Christina)



# Anything but disability: Skills and resourcefulness



“I can tell you this, getting to know him and be his dad was one of my hardest but greatest achievements and blessings. “  
(Carlos)



“We had to stay positive, not get bogged down” (Carli)





# Anything but disability: Strength in weakness

“Were we affected by disability? Yeah. Our choices were modified by Steffie’s condition. ...we experienced things differently than with our other kids...(such) deep questions we asked .” (Susie)



# Anything but disability: Becoming an advocate



“I got thick-skinned. It really has helped with vocational efforts... to be her back up. She knows how hard their rules are to follow.” (Patsy)





## 4. Lived life

### Looking back and looking forward

- Transforming perceptions
- From where I stand: lessons learned
- Being human
- What next

# Lived Life: Transforming perceptions



“We never could predict or prevent entirely Steffie’s emergencies... someone always acted like we were somehow to blame. Over time, we learned to just roll with it and not take these things personally.” (Susie)



# Lived Life: From where I stand



“...You can’t do it alone...” (Nina)

“ Trust yourself, that’s a big one...”  
(Molly)



# Lived life: Being human

“How’d we do it? We had to be like super human.” (Nina)

“Doctors so hate it when you lose it.  
(But...) we were so human...” (Carli)



# Lived life: What next



“What next? I ask myself everyday... partly about me, partly about her... ” (Susie)




“I don’t really have a career. I have hopes now on working on my master’s soon.”  
(Carli)






# What they have said about the story

- 
1. Navigating Normal for Us
  2. Pride and Joy
  3. Anything... but Disability
  4. Lived Lives, Looking Back and Looking Forward





# Discussion



- 
- The parent you see
  - A story always in process
  - A pivotal world view
  - No end to their story
  - Universal and unique



# What understanding can be gained?






## Professionals and Educators

- 
- Recognize critical roles
  - Understand/support family worldview
  - Exercise care in use of labels
    - See the child
  - Be an advocate/expert beyond scope of practice beyond childhood
  - Develop immersive understandings
  - Parents need other parents
- 



# Future Research

- 
- 
- How siblings perceived disability and impact on their lives
  - Exploration of individual themes toward grounded theory
  - The families that say “no” - what is their story
  - The what next? Tracking the story of adulthood forward
  - Critical roles in critical places
- 






# Limitations

- 
- 
- Reminiscence
  - Instrumentation
  - Perceived limitations of qualitative research





# Trustworthiness

(Creswell, 2009; Moravscik, 2014)

- 
- 
- Triangulation
  - Prolonged engagement
  - Member check
  - Audit trail
  - Peer debriefing
  - Reflexivity and transparency
- 



# Concluding thoughts

- 
- The stretch of normal
  - The certainty of pride
  - Able families
  - The push continues
- 



*RETROSPECTIVE FRAMES OF **DISABILITY***

*ANYTHING BUT DISABILITY*



## Acknowledgments

The UK Rehabilitation Science faculty, students, and staff for invaluable support over a decade

My sister, my children, and my bull terrier

My parents and how they believed in me





Thank you for being part...





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# appendix



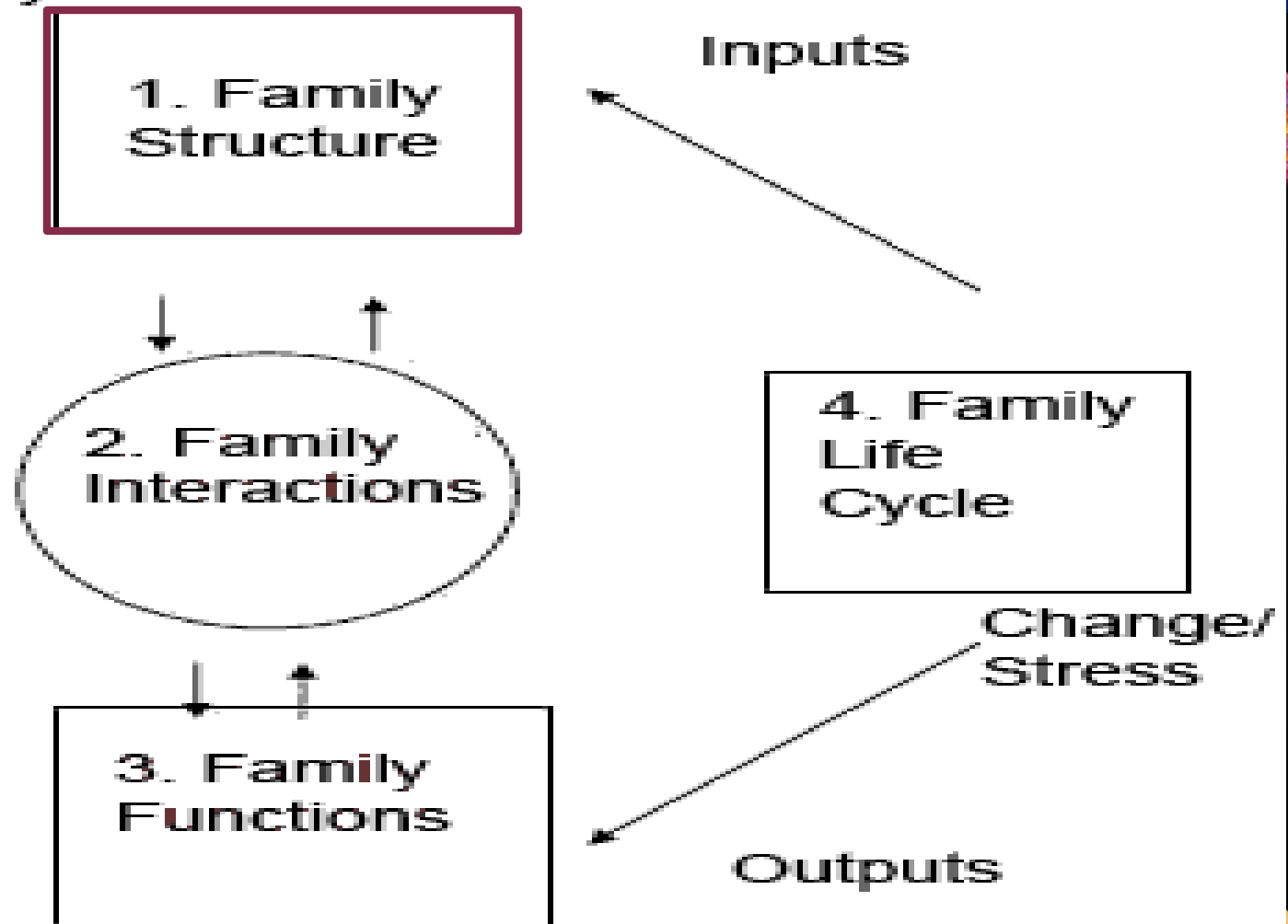
Contributing models



# Family systems

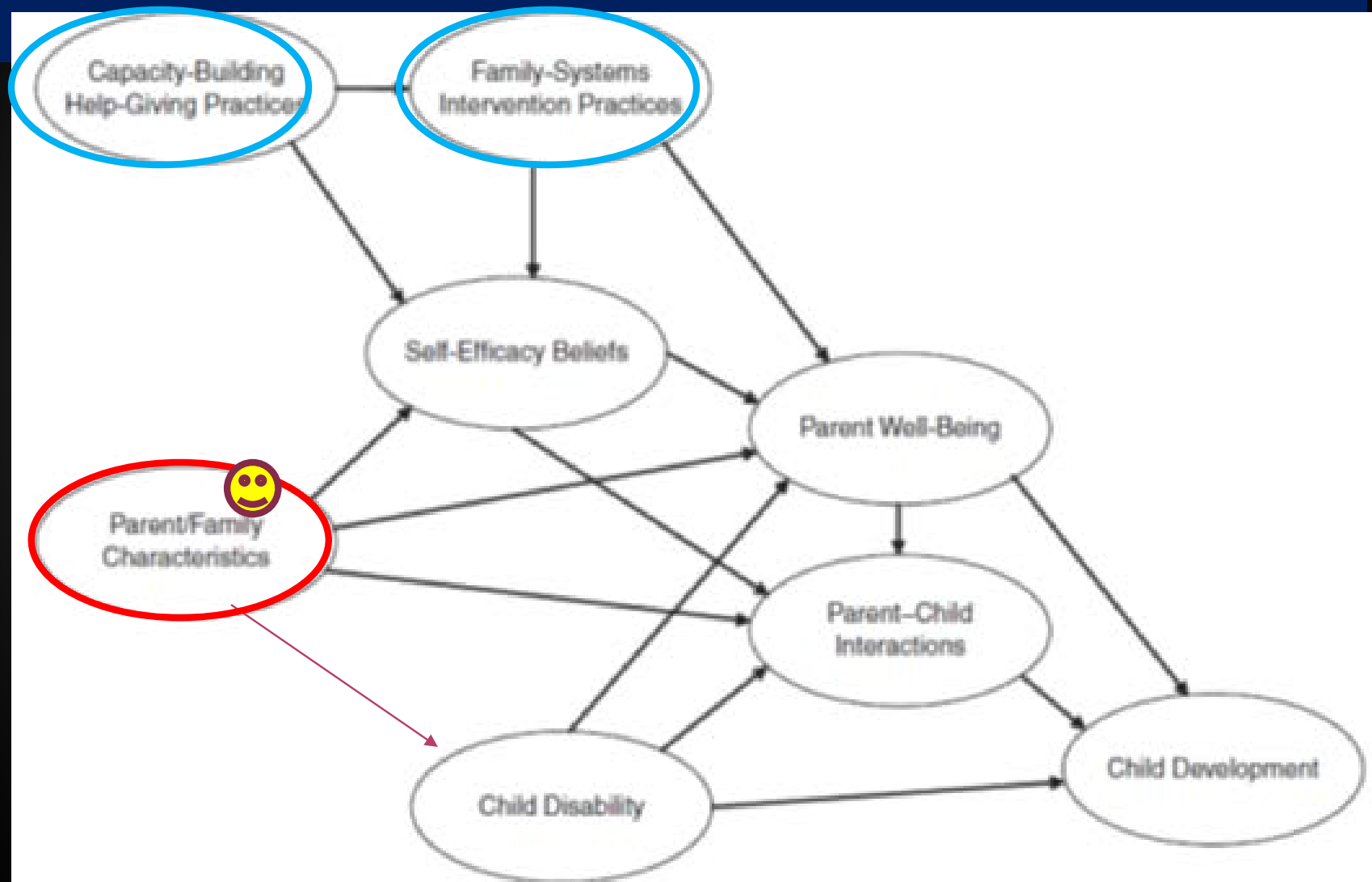
(Allen, Cornelius, & Lopez, 2007)

## Family System



# Family systems intervention model

(Trivette et al. 2010)



# Disability studies

(Gabel & Peters, 2004; Smart & Smart, 2006)


## Family

Experiential      Phenomenological  
(sociological, social, environmental)  
Ethical/Political

Experiential including:	Function =	Dysfunction =	Changes in function =
1. Difference →	Atypical	Usual	Improvement
2. Universal →	Eventual	Part of norm	Envir/personal
3. Typology →	Reactionary	Depends	Match needs
4. Embodiment (stories) →	Individual	Depends	Custom
5. Resistance →	Militant	Formative	Global

# Explanation of Maps: What works for me and what doesn't based on primary peoples and systems

- Specially designed maps, and diagrams, as tools for gathering information
- Maps are used to gather information that best describes the parent/child lived world
  - People
  - Programs
  - Activities
  - Places
- Explanation of the map
- questions to consider when completing the map
- Note: Data on the maps is a sample from an ongoing process, part of retrospective

 Data source	Collection	Analysis	Results
Demographics	Written	No analysis Descriptive	Profiles & Tables
Written questionnaire	Written	Descriptive & Qualitative	Profiles & Tables Themes
Interview- audio recorded	Audiotaped Transcripts	Qualitative	Themes
Field notes	Documented during Interview	Qualitative	Themes
MAPs	Written Transcripts	Descriptive & Qualitative	Profiles & Tables Themes