

# Enduring Strength from a Labour of Love: Family-life with Disability

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# Purpose of the Presentation

A model that reflects parents' stories from the research ...

parents with a young adult with intellectual disability who share the family home

# What did the literature say?

## Four main themes

- Parents and family at the young adult life-stage (Turnbull et al., 2010)
- Intellectual disability as a social construct (Campbell, 2012; Goffman, 1963)
- Construction of the carer label (Hughes & Sullivan, 2017; Nolan et al, 1996)
- Varying paradigms of the family lived experience – salutogenesis (Antonovsky, 1998)

# Methodology: Phenomenology and the Narrative Approach

Together, phenomenology and the narrative approach:

- Gave parents a voice
  - experts of their lived experience, to tell the life story as it is
  - members of a silenced group
- Provided an opportunity for parents to respond

# Methods

- ▶ Collaborative Partnership, Reflexivity
- ▶ In-depth interviews
  - art, artefacts, & places as prompts
  - digital recordings, story verbatim, reflective notes
- ▶ Hermeneutic Cycle
  - Repetitive cycle of data collection and analysis moves to a richness and thickness of data
- ▶ Interpretative Phenomenological Analysis (IPA)
- ▶ Member checking (& opportunity to elaborate)
- ▶ Research Rigour
  - Credibility and trustworthiness: supervision, openness and clarity of process, auditable

# Method: Participants

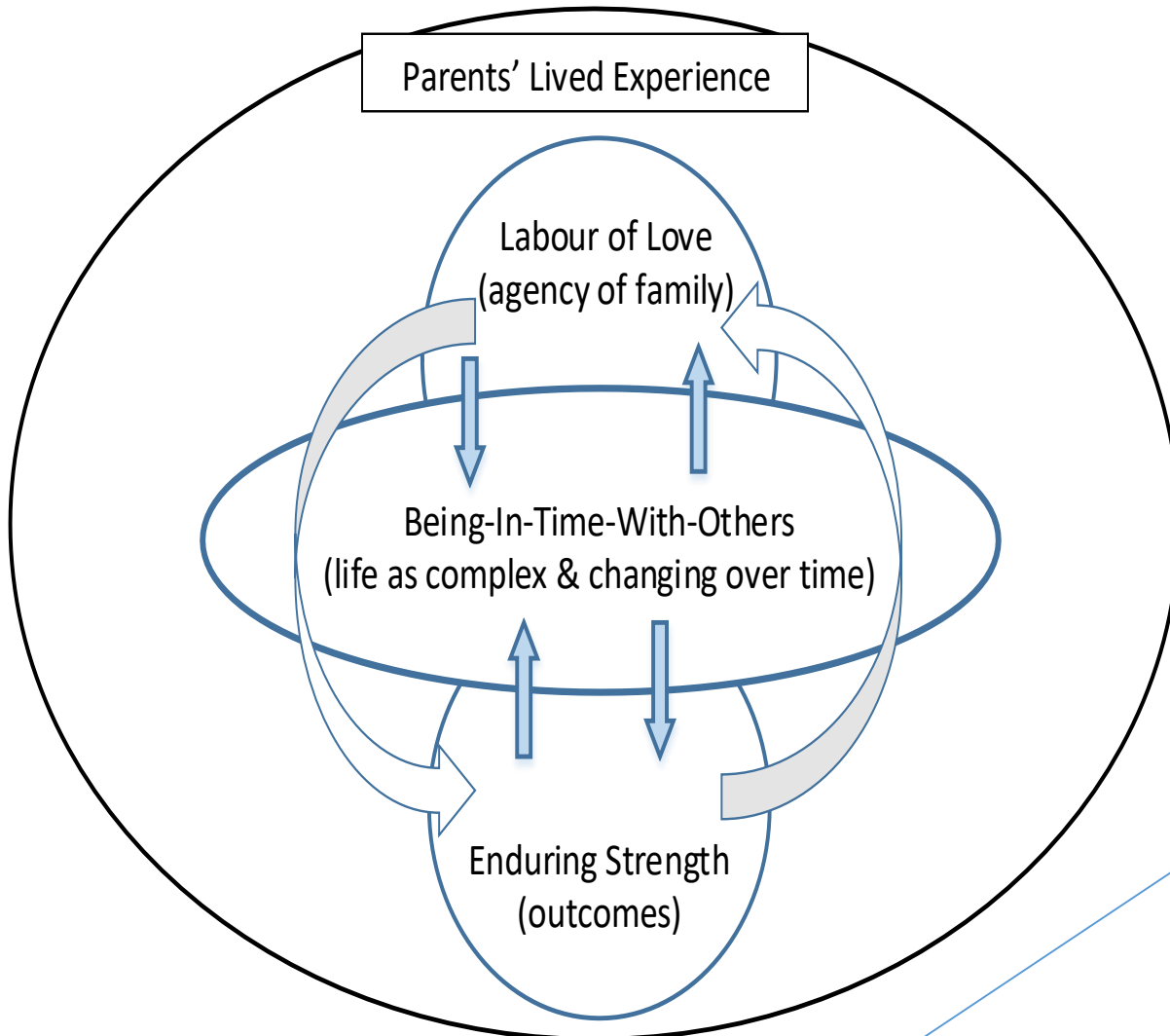
- Ethics approval
- Six parents of young adults with intellectual disability aged 18-28
- Purposive sampling
- Recruited from a disability support organisation, and contacts of families
- Case study approach ... a large and rich data set .. 40 hours of interview data

# Who were the Participants? (pseudonyms used)

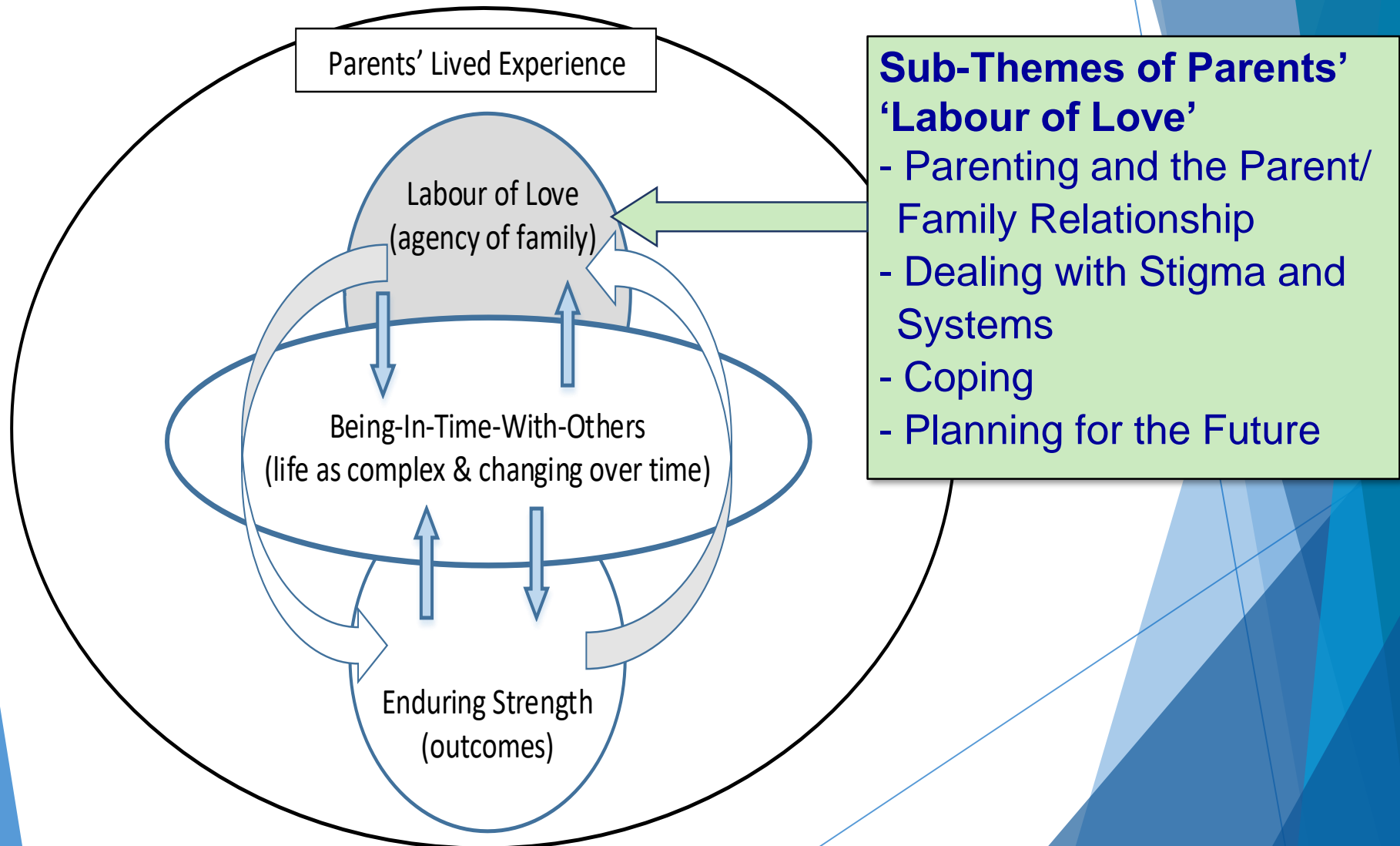
6 parents from 4 families: 2 single mothers and 2 couples (of mothers and fathers) ...

- Linda, mother of a daughter with moderate intellectual disability
- Anne, mother of two sons with intellectual disability, physical and mental health issues, and behavioural challenges
- Mr & Mrs Smith, parents of 3, one with intellectual disability and very high and complex medical and physical needs
- Mr & Mrs Jones, 4 of their 5 children with a range of disabilities and special needs

# 'Enduring Strength from a Labour of Love' theoretical model



# 'Labour of Love' sub-themes



# Linda's Labour of Love

## Parenting and Parenting Relationships

To be a parent its tricky enough. People not having respect for what is right for your child with disability. It just made 'mother life' ten times harder

## Coping

Coping and resilience for me is trying to find ways to survive. It's the comedian in my head when I'm gardening, weeding the garden ...

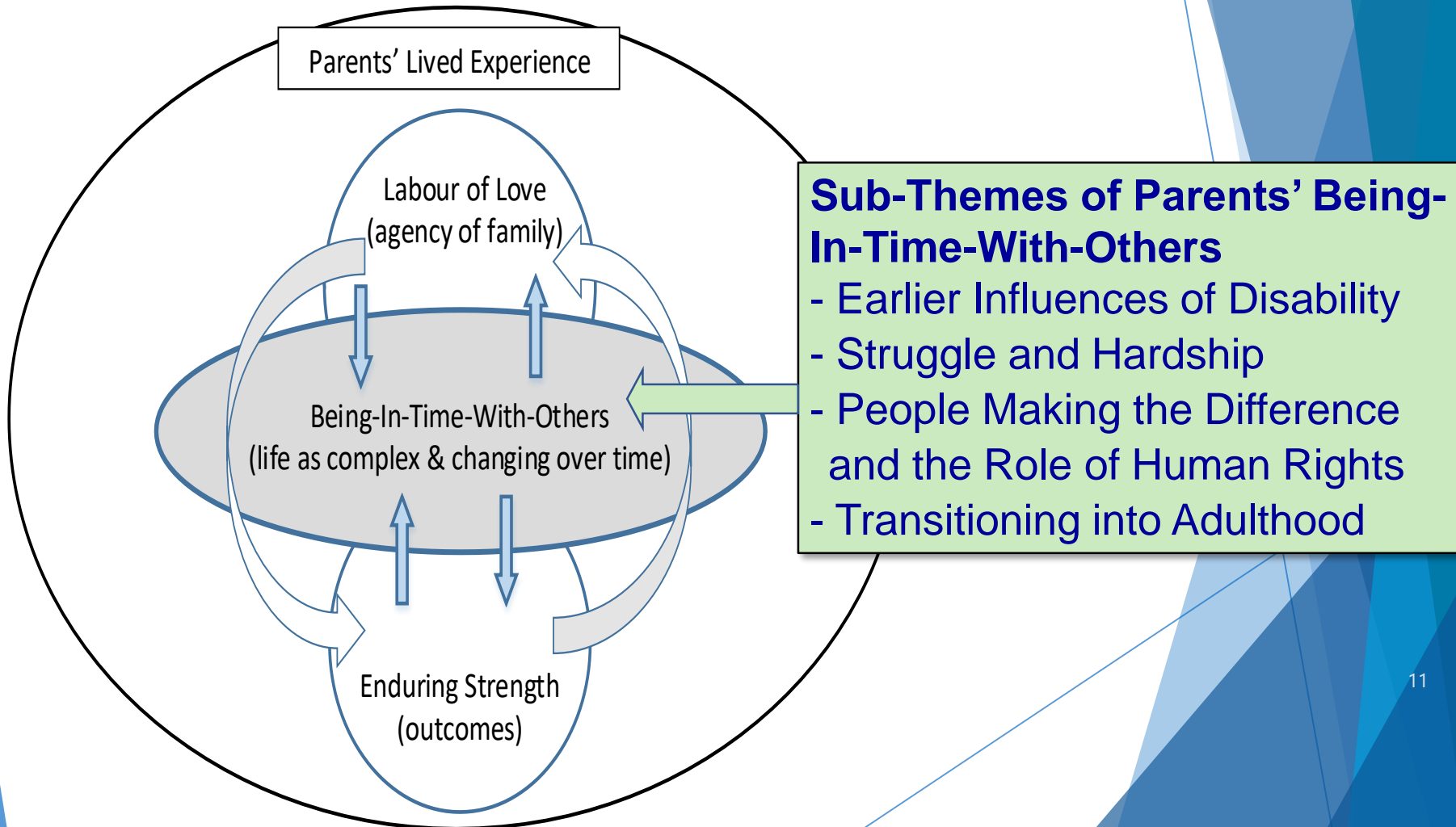
## Dealing with Stigma and Systems

It's like I've become a vigilante to keep an eye out for misunderstandings about Sarah, her needs, and the subsequent harm that they cause. That job is ongoing. School finishes, then you go on to the next system.

## Planning for the Future

People have moved so far away from what community really means. Tribes knew what community was, people knew who was in the next hut and had a genuine interdependence. If in a real-world community, someone like Sarah would not be so vulnerable, but this world does not exist.

# 'Being-In-Time-With-Others' sub-themes



# Linda's Being-In-Time-With-Others

## Earlier Influences of Disability

Before Sarah I lacked the personal infrastructure to suddenly deal with the struggle. I was living in the void.

## People Making the Difference and the Role of Human Rights

The pre-school teacher will always stay in my heart for her righteous and determined stance. Of all the horror we encountered earlier, this was wonderful, to see that our child would be respected, loved and treated as an equal at school.

## Struggle and Hardship

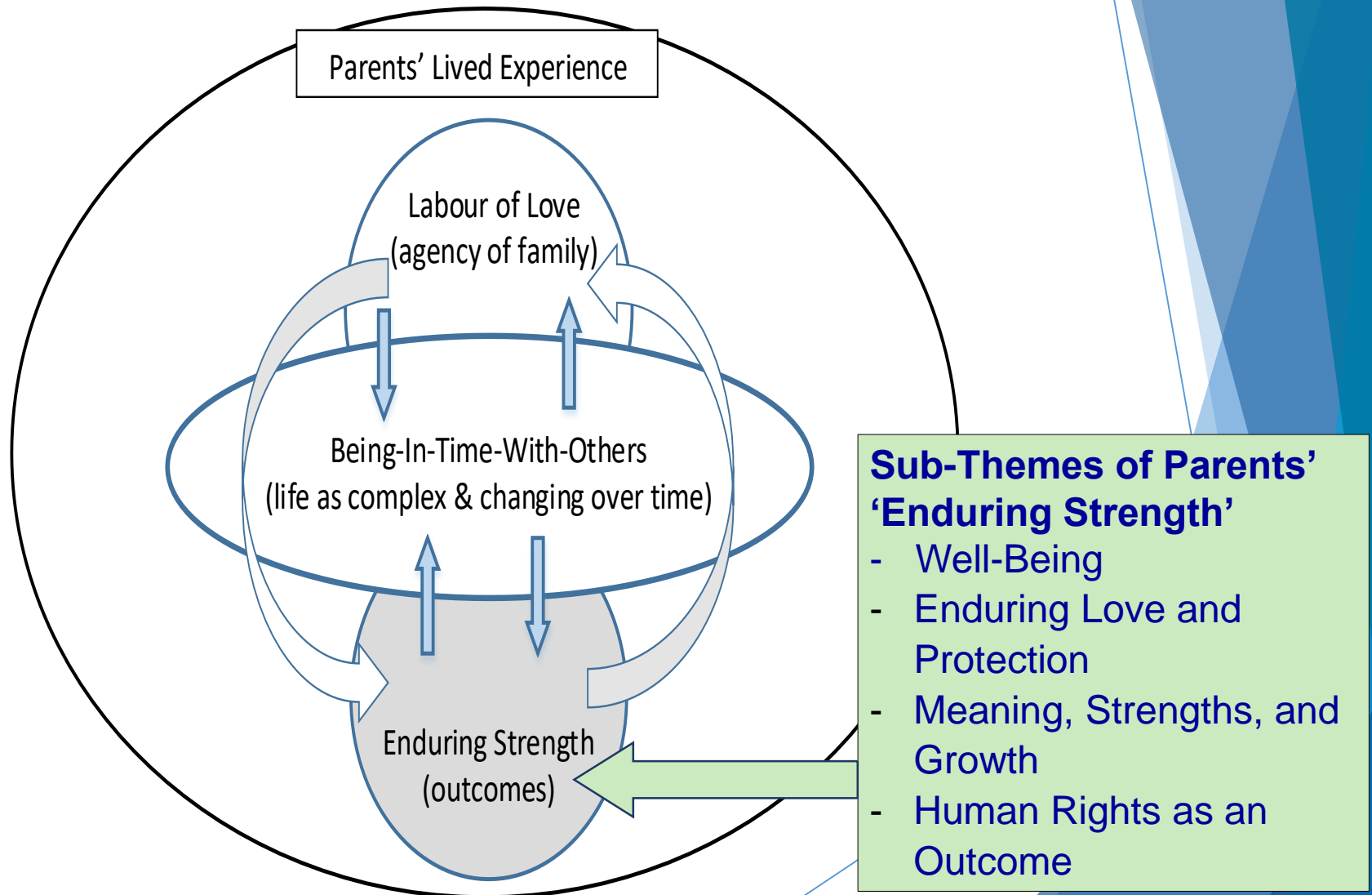
On systems ... society takes it for granted that systems work for everyone. Some systems work, some don't. Trying to move about with a young person that systems don't work for is unimaginable.

Ongoing struggle .. the future is similar to the past, just different shoes on the same feet.

## Transitioning to Adulthood

I just need to keep her safe. Sarah has no power to protect herself.

# 'Enduring Strength' sub-themes



# Linda's Enduring Strength

## Well-Being

I was just a prop in other people's lives, life was chaos, I just cocooned (i.e., withdrawn) .. Many years with the psychiatrist and counsellor

## Meaning, Strengths, and Growth

The 'me' now is so different from the 'me' then. The void has in a sense been filled by the process of getting out and walking through life with my daughter ...

## Enduring Love and Protection

I love her of course, Sarah is just a delight - very active, but a delight. I cannot protect Sarah 100% from such events [of risk] unless I provide constant care myself. I cannot guarantee this has led to success, but Sarah has not communicated anything to suggest otherwise since that [sexual abuse] incident.

## Human Rights as an Outcome

An array of experiences including some exceptional professionals ... but also experiences of oppression, discrimination, and abuse ...

# Utility of the Enduring Strength from a Labour of Love Model

- Benefits in having understanding - insider/ privileged knowledge ...
- Dynamics of family life
- Accesses knowledge at the young adult family life stage
- Inclusion and Consultation with Parents as the Experts: “We see it a bit differently”
- Using parents’ voices and the understanding within the model to inform Policy and Practice, Training/ Development
- Future Research

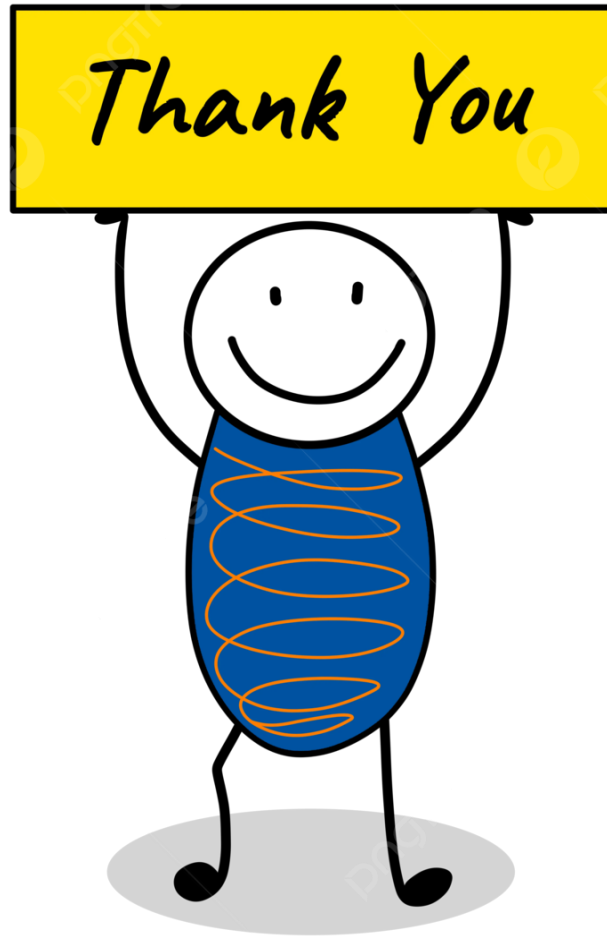
# A Final Word from Linda ...

“I am a bit older now. Enlightenment has interconnected with everything. The person that gave birth to Sarah didn't know all this, but they are well informed now.

I have a new knowing of the world, of being in the world, and of love.

I have these perspectives and opinions because of my daughter - my enlightenment”

(see Rieck et al., 2019)



[https://eprints.qut.edu.au/view/person/Rieck,\\_Murray.html](https://eprints.qut.edu.au/view/person/Rieck,_Murray.html)