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# The Rewards & Challenges of Raising a Child with a Disability: Identifying Pathways to Growth

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# Background

- The majority of previous literature deficit focused  
(Scorgie & Sobsey, 2000; Strecker et al., 2014)



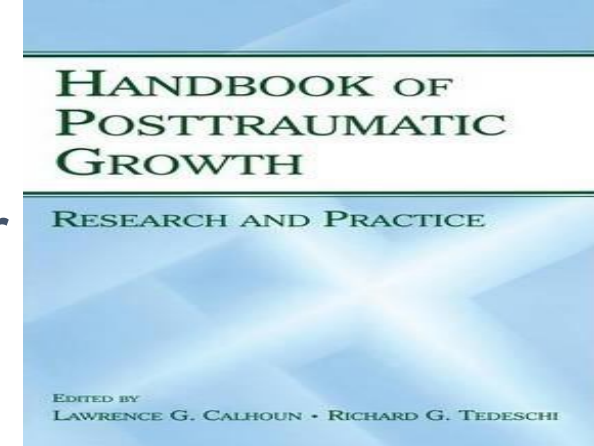
- While adding to understanding, neglects the full picture
  - Parents often adapt well
  - Parents appear to grow



# Background

- Last 15 or so years - increased effort to identify growth
  - E.g., meaning-making, benefit-finding (Larson, 2010; Samios et al., 2004, 2009)
- However:
  - Process of growth not well understood (Strecker et al., 2014)
  - Longitudinal not common (Potter, 2016)
  - Conceptual confusion RE growth models (Beighton & Wills, 2016)

# Posttraumatic Growth (PTG) (Calhoun & Tedeschi, 2006)



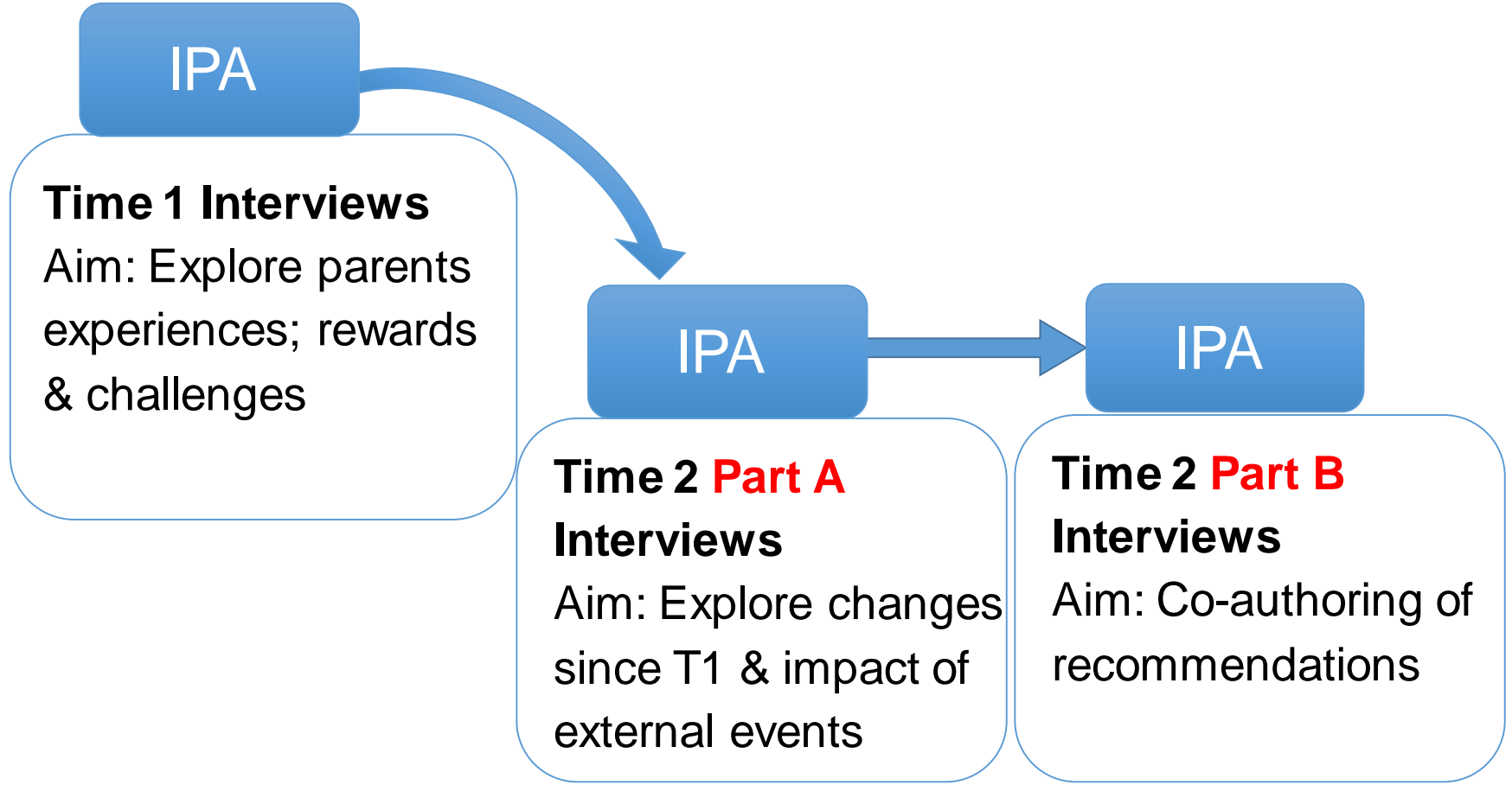
- Positive changes in some people after trauma/crises
  - PTG & distress can/often co-occur
- Process:
  - Subjective appraisal (Janoff-Bulman, 1992)
    - Core belief disruption & distress → deliberate rumination → growth
- Domains of PTG
  1. Self-perception
  2. Relating to others
  3. Philosophy of life

# Method

- Phenomenology
- Analysis – IPA (Smith, Flowers & Larkin, 2009)
- Longitudinal Qualitative (over 1 year)
  
- Setting & Sample
  - QLD
  - N= 33
  - Parents of child with ASD (n = 12), CP (n = 16) & other (n = 5)
  - Recruitment:



# Qualitative Longitudinal Design





# Results

# Results - Time 1 & 2

- 5 superordinate themes

## Superordinate Themes

Distress and Grief

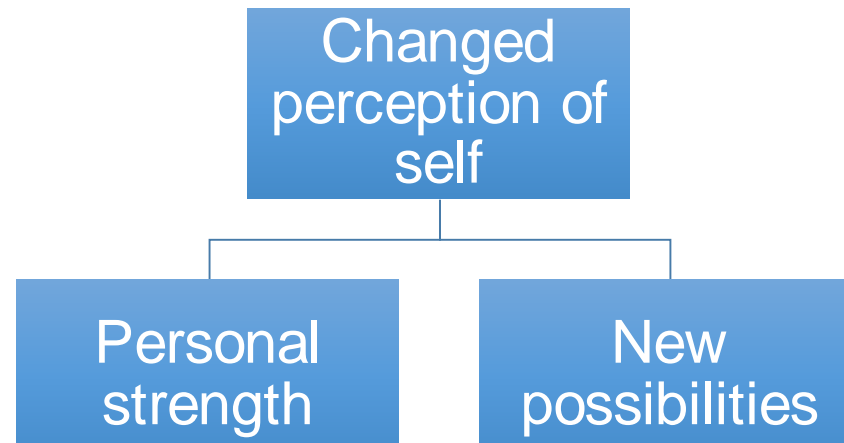
Challenges for Parents (*e.g., treatment from others*)

Coping Strategies and Resources (*e.g., shared experience*)

Rewards for Parents (*e.g., admiration for child*)

Posttraumatic Growth (PTG)

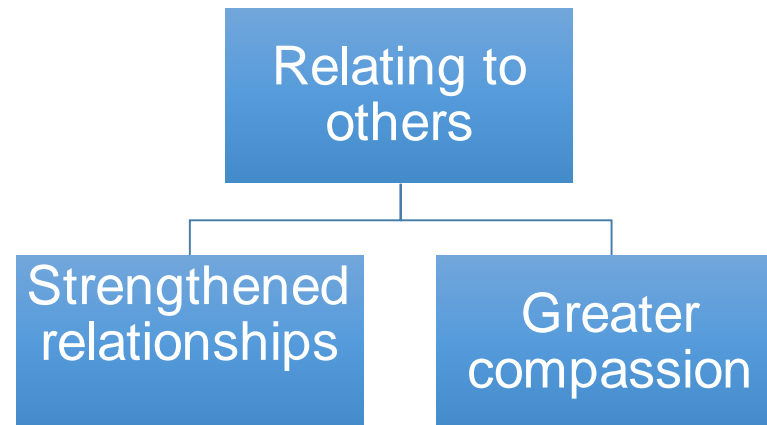
# Results – Time 1 & 2: Posttraumatic Growth



*“As much as I’ve talked about as difficult it is, you learn a strength that you never knew you had” -Julie*

*“[Before having child] I would never have thought to go into autism studies” – Louise*

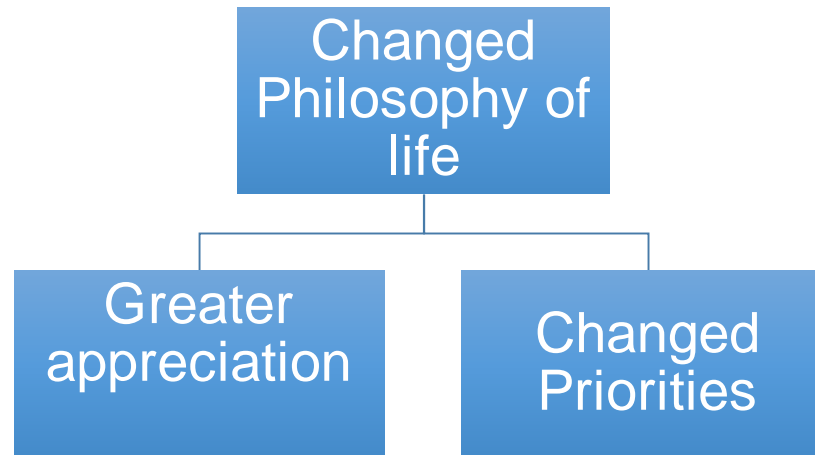
# Results – Time 1 & 2: Posttraumatic Growth



***“If she didn't have her disability we definitely would not be as close knit as we are, including our marriage - Manuela***

***“I definitely think it changes your thoughts; you're more understanding or more compassionate toward other people - you kind of do know what they're going through” - Shirley***

# Results – Time 1 & 2: Posttraumatic Growth



*“An incremental improvement may not be noticeable to other people, can mean the world to you” - James*

*“It changes your priorities and your perspectives on things, like we’re not materialistic [now]” – Julie*

# Results – Policy Recommendations

# Results: Co-authoring policy recommendations

## Key Recommendations according to parents

We want better information and support

The way we are spoken to matters

# Results: Co-authoring policy recommendations

## Better Information & Support

In the Wake of Disability: Support for Parents & the Family Unit

*“I agree about the counselling for the rest of the family, certainly our eldest daughter could've done with that” - Tom*

Greater Visibility of Information

*“How do we hear about services? There's no portal or anything you can jump on to find out these organisations” - Lucy*

We need Guidance: A Case-Manager in a new World

*“Now I feel a bit more confident. But when you're just starting out in this whole thing, it's hard to know who to go to for help” - Irene*



# Results: Co-authoring policy recommendations

The way we are spoken to matters

Communication from Medical Professionals

*“You go to the GP and you go, “my baby cries all the time”. And they go, “Oh well, babies cry.” - Ellen*

*“You've got to hear the positive sides, because what everyone sees is a deficit model” -Louise.*

Research Shows...



# Conclusion

# Important Findings & Clinical Implications

- PTG often present in parents
  - No set time frame
  - CBT, Narrative Therapy....
  - Shared experience may provide 'heavy lifting'
- Services forthcoming & visible for newly diagnosed
- Respectful communication

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Thank you