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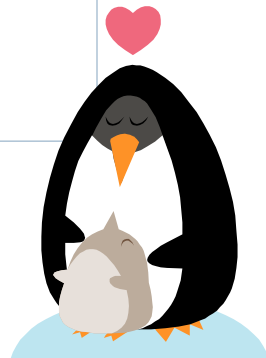
FINDLAB



22q11.2 deletion syndrome: Lived parental experiences

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# Background

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- ▶ When a child has a developmental disability the entire family unit is affected (Carroll, 2013; Rolland & Walsh, 2006)
- ▶ Parents of children with disabilities are at risk of mental health problems and stress compared to family members of healthy children (Hartling et al., 2014; Miodraga & Hodapp, 2010; Singer, 2006)
- ▶ As the child grows into adulthood, challenges continue for both parents and child.
- ▶ Ongoing care can create chronic parental stress
- ▶ Extended stress/crisis state increases vulnerability to burnout



# Positive changes

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- ▶ There is a growing body of research that highlights *positive* psychological changes as a result of a struggle with adversity (Fee & Hinton, 2011; Green, 2002; Joseph & Linley, 2008; King et al., 2006; Monaghan, Sanders, Kelly, Cogen, & Streisand, 2011; Rolland & Walsh, 2006).
- ▶ Psychological growth among parents of children with disabilities is a relatively new concept in the literature but includes:
  - ▶ Positive adaptation
  - ▶ Thriving in the face of adversity
  - ▶ Constructing meaningful stories surrounding the journey with their child
- ▶ Psychological growth: positive change in psychological functioning after trauma; e.g., developing strengths (Joseph, 2012)



# What did we do?

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- ▶ Research studies

- ▶ Survey: parents who have a child with a developmental disability

- ▶ To explore participant and child characteristics that predicted psychological growth in parents of children with developmental disabilities.

- ▶ Interviews: Parents who have a child with 22q11.2 deletion syndrome (22q11DS)

- ▶ To explore the 'lived' experience of parents on their journey with 22q11DS



# Survey – what did we do?

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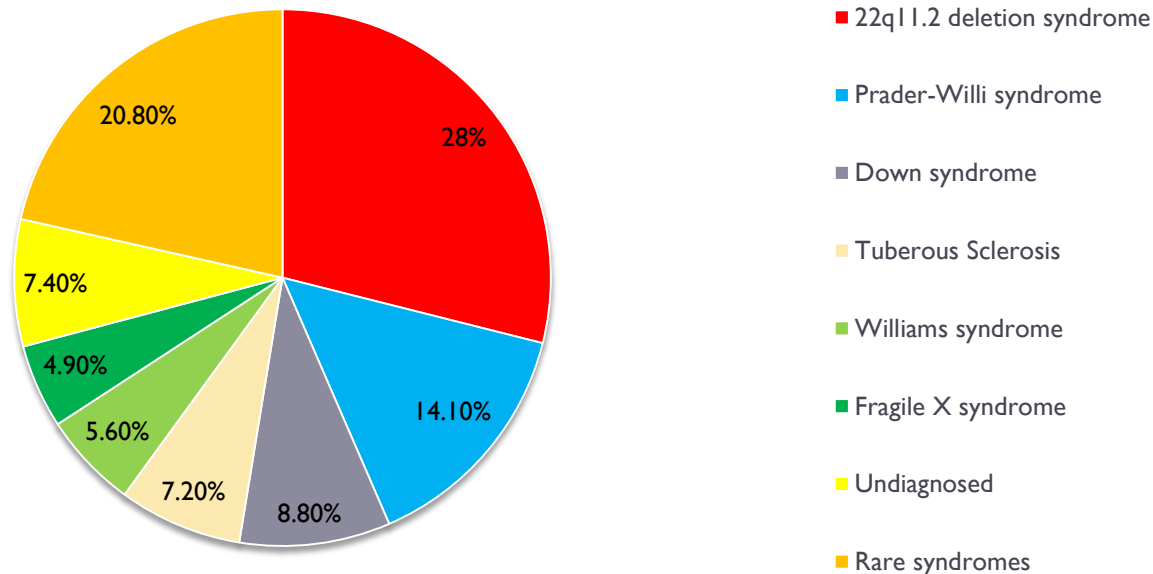
- ▶ To explore participant and child characteristics that predicted psychological growth in parents of children with developmental disabilities.
- ▶ 262-item questionnaire
  - ▶ Coping: Ways of Coping Questionnaire (WAYS; Folkman & Lazarus, 1988)
  - ▶ Social Support: Significant Other Scale (SOS; Power, Champion, & Artis, 1988)
  - ▶ Psychological Growth: Psychological Well-Being - Post-Traumatic Changes Questionnaire (PWB-PTCQ; Joseph, Maltby, Wood, Stockton, & Hunt, 2011)
  - ▶ Family-Centred Services: Measure of Processes of Care (MPOC-56; King, Rosenbaum, & King, 1995)



# Survey – who took part?

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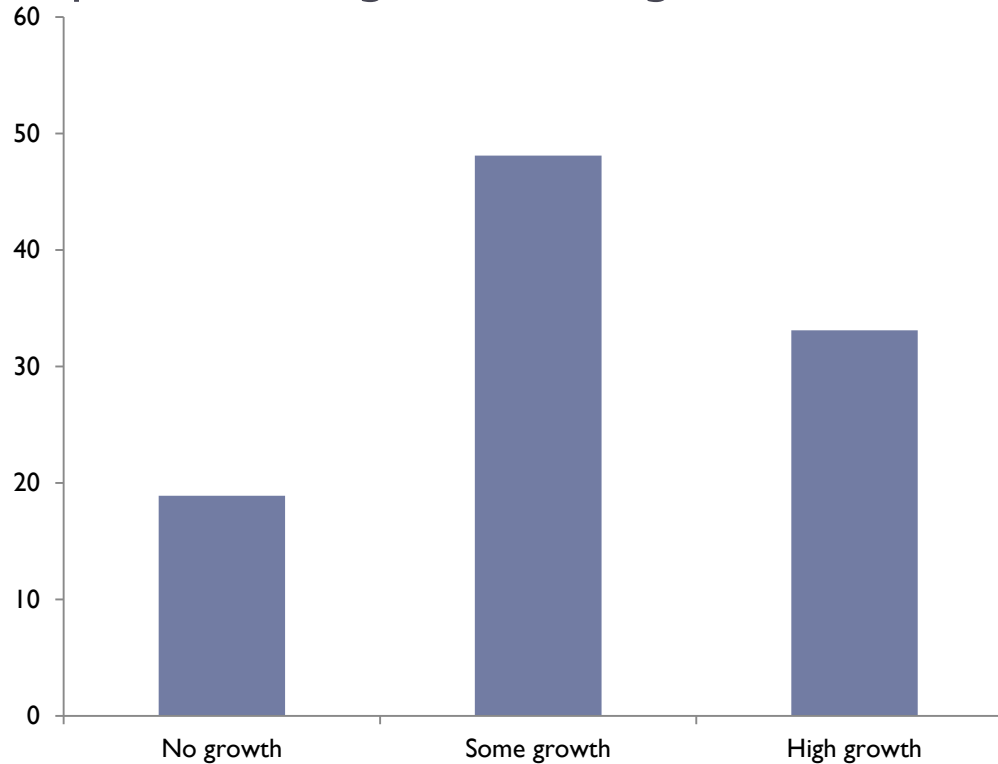
- ▶ 432 parents of children with developmental disabilities.
- ▶ North America (47.7%), Europe/United Kingdom (23.8%), and Australia/New Zealand (22%).



# Survey – what did we find?

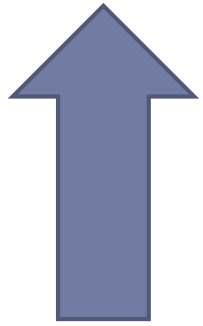
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- ▶ 19% of participants experienced no growth
- ▶ 48% had experienced some growth
- ▶ 33% had experienced high levels of growth

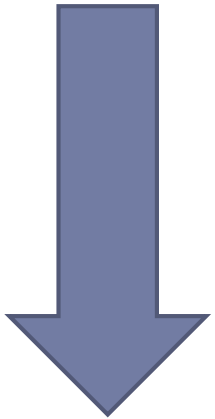


# Survey – what did we find?

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- ▶ Use of Positive Reappraisal as a coping technique
- ▶ Older child
- ▶ Better coordinated and comprehensive care



- ▶ Greater discrepancy between ideal and actual practical support
- ▶ Use of Escape Avoidance as a coping technique



# Survey - conclusions

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- ▶ Communication between professionals in healthcare services is important
- ▶ Realistic expectations for parents: positive and negative
- ▶ Need to bridge the gap between ideal and actual social support
- ▶ Psychological growth may need time to develop, or be fostered once the immediate health concerns are managed
- ▶ Interventions to promote specific adaptive coping mechanisms may be useful to promote parental psychological wellbeing



# What about 22q11.2 deletion syndrome?

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- ▶ May occur as frequently as in 1 in 992 births (Grati et al., 2015)
- ▶ Important to know about the impact on parents throughout the child's life
- ▶ Wide variability of symptoms
  - ▶ Varying degrees of psychological distress pre and post diagnosis
  - ▶ Distress can be exacerbated by the demands on family life from chronic or acute medical issues



# Interviews - what did we do?

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- ▶ Explored the 'lived' experience of parents on their journey with 22q11DS
  - ▶ Young children
  - ▶ Adults
  
- ▶ We asked about:
  - ▶ Parenting a child with 22q11DS
  - ▶ Positive and negative experiences of support
  - ▶ If and how they have changed
  - ▶ How they expect their future will be influenced by their child and related experiences.



# Interviews - who took part?

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- ▶ Parents of young children
  - ▶ N = 6 (2 male)
  - ▶ Children's ages ranged between 8 months – 3 years
- ▶ Parents of adult children
  - ▶ N = 8 (2 male)
  - ▶ Children's ages ranged between 21 – 29 years
- ▶ None of the parents had a 22q11DS



# Interviews - what did we find?

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## Grief

- ▶ That's supposed to be a really joyous time...We couldn't get the baby baptised, and our friends couldn't see her ... we had this phantom baby. [Margaret, adult]
- ▶ There's all those things that change...no wedding, no grandchildren...live with him for the rest of your life... [Sandra, adult]
- ▶ Did we do something wrong ... it's just not normal to see your child suffer. I just feel like, why couldn't it be me, why couldn't I have had all the problems and not my son. [Anna, adult]



# Interviews – what did we find?

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## Agony of Uncertainty

- ▶ What the f\*\*\* 's going to happen? I have no idea what VCFS really means... because there's so many varying factors ... So that's where I'm stuck ... I just don't know. I'm in limbo. [Stephanie, child]
- ▶ It's nice to have a diagnosis. But then you look at the list of signs and symptoms and you think what sort of diagnosis is that?! [Sandra, adult]
- ▶ There's a huge range of symptoms...so where are we? Dunno ... What's the prognosis? Dunno. What causes it? Dunno ... What do we do now? Dunno. What happens in the long term? Well, a few develop schizophrenia ... So how can we tell? You can't. You don't know until you get there. [Max, adult]



# Interviews – what did we find?

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## Systemic Stigma

- ▶ I almost felt like I had Munchausen's (laughs) in and out, in and out, in and out. The child would vomit and then they'd get there and the child wouldn't vomit anymore. [Deborah, child]
- ▶ I do not know whether they thought the syndrome could be caught like a disease . . . You're at school but you're on the perimeter . . . we were just singled out and singled out on so many occasions. [Tracy, adult]
- ▶ I look like this nasty, snarly, foul-tempered, foul-mouthed woman with a baby on her hip... [Stephanie, child]



# Interviews – what did we find?

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## Pragmatic acceptance

- ▶ If there's 1/100 births that has a heart condition, then why shouldn't it be us? Someone's got to make up those numbers, so . . . it was us! [Wendy, adult]
- ▶ The one thing you learn on this journey is trust and acceptance. You've got to trust that it's going to be ok in the end, and accept where you are now. [Margaret, adult]
- ▶ When you read some of the things about how kids are struggling and how many problems they can have... She can do so many things. [Gabriella, adult]





# Interviews – what did we find?

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## Finding authenticity

- ▶ You've really got to try to find this deep love to get through the challenging times (laughing)! And that's a positive thing, like really sort of delving deep within yourself to try to find patience and acceptance, and all these things that if he hadn't come into my life, well...I wouldn't have known on the level of depth that I feel and have gone through. [Frances, child]
- ▶ In my trial of life, it provides a great opportunity ... I get my moments when I ask why...but then I think this has been a really good opportunity to be able to love someone anyway. [David, child]
- ▶ I've had the big transformation. I'm really pleased with that because...looking back...I don't like the mother I would have been... We're a very close knit family. [Margaret, adult]



# Interviews – what did we find?

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## Finding authenticity

- ▶ I think it's because it's part of God's plan. I think that is the only simple answer...For me personally I can't see that there's been any harm come to it. I can only see good. [Deborah, child]
- ▶ God's given the hard troubles to me because he knew I wouldn't pike out. [Anna, adult]
- ▶ He was a miracle. He was meant to be. I was meant to have him on this journey, whatever this journey is going to be. [Stephanie]



# Interviews - conclusions

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- ▶ Diagnosis can be both positive and negative
- ▶ Dichotomous experience of grief and wonder
- ▶ Invalidation and stigmatisation within healthcare services that invalidated parents on their search for a diagnosis
- ▶ Simultaneous experiences of conflicting negative and positive emotions
- ▶ Purposeful rumination allowing psychological growth despite distress.



# Conclusions

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- ▶ Positive psychological outcomes are realistic for parents whose children have a developmental disability such as 22q11DS and should not be neglected in research and practice
- ▶ Medical frameworks often poorly support the biopsychosocial needs of families
- ▶ Healthcare professionals are well-placed to promote positive psychological outcomes
- ▶ \*This is not the WHOLE experience, nor EVERYONE'S experience\*



# It is ok to ask for help & you do not need to be perfect!

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## ▶ Self-care

- ▶ Exercise (mindfulness, yoga, meditation)
- ▶ Time out
- ▶ Couples time
- ▶ Respite

## ▶ Friends, family

- ▶ Off-load
- ▶ Have fun
- ▶ Connect to online communities (e.g., 22q11 Ireland Facebook/Twitter)

## ▶ Professionals

- ▶ Counsellors/psychologists
- ▶ Helplines (e.g., Scope: 0808 800 3333)



# Thank you

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# References

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1. **Goodwin, J., McCormack, L., Campbell, L. E.** (2017). Positive and Negative Experiences of Parenting a Pre-school Child with 22q11.2 Deletion Syndrome. *Journal of Advances in Neurodevelopmental Disorders*, 1(2), 63-72. doi: 10.1007/s41252-017-0010-z
2. **Goodwin, J., McCormack, L., Campbell, L. E.** (2017). “You don’t know until you get there”: The positive and negative ‘lived’ experience of parenting an adult child with 22q11.2 deletion syndrome. *Health Psychology*, 36(1), 45-54. doi: 10.1037/hea0000415

