



# Caring for the carer

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Resilienc

Advocacy



Love



- Families have been found to **adapt and thrive in the face of adversity**
- Constructing **meaningful stories** surrounding the journey with their child (e.g., Green, 2002; King et al., 2006; Rolland & Walsh, 2006).
- Discover **new pathways of happiness or spirituality** as a result of having a child with a developmental disability



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ORIGINAL PAPER

## Positive and Negative Experiences of Parenting a Pre-school Child with 22q11.2 Deletion Syndrome

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Journal of Intellectual & Developmental Disability

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## Could I, should I? Parenting aspirations and personal considerations of five young women with 22q11.2 deletion syndrome

Lisa Phillips, Jane Goodwin, Martin P. Johnson & Linda E. Campbell

### PSYCHOLOGICAL WELL-BEING OF PARENTS OF CHILDREN WITH DISABILITY: A CROSS-CULTURAL STUDY

Alam, S. & Campbell, LE (2016 Unpublished Honours thesis, UoN – in prep for submission with the help of Dr Jane Goodwin, Megan Valentine, Max Katz-Barber and A/Prof Mark Rubin)

## ‘At the end of the day, it is more important that he stays happy’: an interpretative phenomenological analysis of people who have a sibling with 22q11.2 deletion syndrome

J. Goodwin,<sup>1</sup> S. Alam<sup>2</sup> & L. E. Campbell<sup>2,3</sup>

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## “You Don’t Know Until You Get There”: The Positive and Negative “Lived” Experience of Parenting an Adult Child With 22q11.2 Deletion Syndrome

Jane Goodwin, Lynne McCormack, and Linda E. Campbell  
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*Objectives:* 22q11.2 deletion syndrome (22q11DS), a complex genetic syndrome associated with more than 180 features, presents complex challenges for parents including gaining a diagnosis. This phenomenological study sought the “lived” interpretations of parents supporting an adult child with 22q11DS. a

Fathering a child with a neurodevelopmental disability:  
The role of coping strategies on the father’s well-being and psychological growth  
Rudd, K., & Campbell LE (2015 Unpublished Honours thesis, UoN – in prep for submission)

*That's always something that I struggle with ... with the medical things ... with the feeding issues ... with the sleeping, we know that that is linked into the syndrome. But behaviour I know that they can have ASD, ADHD, anxiety. But what is normal boy, two-year old behaviour anyway? So it's very hard to pinpoint what is...normal or not. [Frances]*

*I've lost a lifestyle that I loved ... I've now gained a lifestyle that I was never going to ever have. So there are benefits. [Stephanie]*

*It was like doomsday to me when he said it... I know that if it had been picked up, I would have chosen to abort, and so life would look very different for us at this point. [Elizabeth]*

“A lens into the experiences of parents struggling to make sense of their journey with 22q11DS in the **early** parenting years. It highlights that the early days are fraught with uncertainty, challenges within health systems, stigma of uncertainty and ignorance, and positively, the metamorphosis of personal strengths that is possible.” (Goodwin et al. 2017)

*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]*

*You get tired of pushing things. You get tired of when you're walking in and see them rolling their eyes ... you think I'm a bitch because I'm trying to get my son better. [Stephanie]*

*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]*

*What sort of support will he need? Will he need to go to a special school? ... How will he cope? ... Will he develop a mental illness later in life? Will he be able to function in society, and will he be happy?! Will he...be healthy? ... What curveball am I going to get thrown? [Frances]*

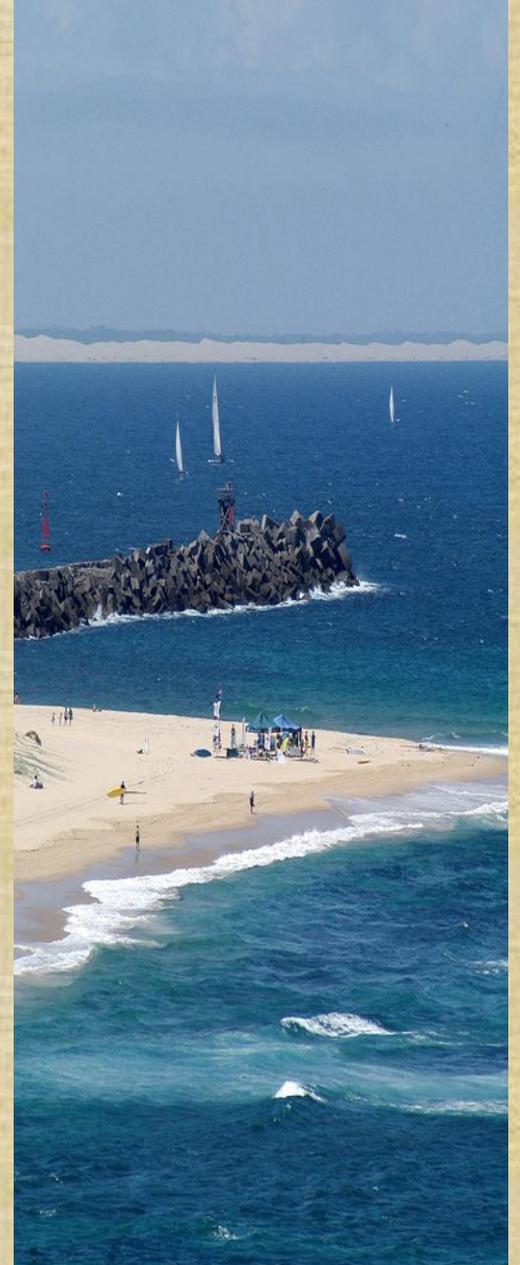
## And what about parenting ADULT children... (Goodwin et al. 2017)

Superordinate theme: Losing 'I'; Finding 'self'	
Subordinate themes	Description
<b>Stigma and a double-edged sword</b>	Stigma invades the participants' lives because the 'not knowing' leaves them the target of judgement, or victims of indifferent professionals. The diagnosis is a double-edged sword of relief and grief. <i>I don't 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]</i>
<b>Where is 'I'</b>	Participants lose themselves in the management of their child's health, behaviour, and needs. There is no respite from this role, and as such relationships change. <i>You've just got to keep on looking after your family. You don't get time out, you don't get any super answers, or anything like that. [Wendy]</i>
<b>Conflicting loss, grief, and guilt</b>	The participants cautiously reflect on the life that could have been without 22q11DS and mourn each milestone that should have passed. Although logically they know their child's deletions are de novo, they wonder if they did something to cause it. <i>I think, if you just had these few bits of chromosome, a few bits of DNA, you'd probably be something really extraordinary. And it's sad. [Max]</i>
<b>Angry advocacy</b>	Participants battle against hierarchical structures suspicious of their actions and intent. They must fight the layers of obstruction and ignorance to receive the care their child needs. <i>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]</i>
<b>Pragmatic acceptance</b>	There is an uneasy peace with the ambiguity of their child's future. Participants re-evaluate their expectations and learn to celebrate success for their child. <i>I would not stop talking about our kids ... I wouldn't cover it up; I wouldn't hide it. [Sandra]</i>
<b>Finding authenticity and purpose</b>	Psychological growth is experienced through conscious engagement with empathy, humility, gratitude and pride. <i>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. [Maria]</i>

- Increased use of **positive reappraisal** as a coping mechanism; parental perceptions of **coordinated and comprehensive health care**; and **child's age** were associated with **greater psychological growth**.
- Greater **discrepancy between ideal and actual practical social support** along with use of **escape avoidance** as a coping mechanism were associated with **less psychological growth**

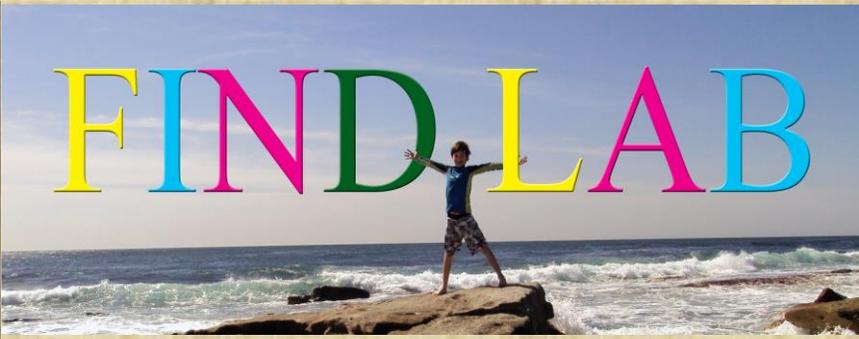
- Positive coping strategies (**self-control and planful problem-solving**) were related to **increased well-being and psychological growth**,
- while negative coping strategies (**avoidance, minimisation, distancing, selective attention**) were related to **decreased well-being and psychological growth**.

- Experiences in different families vary
- Experiences for families and individuals vary across time
- Challenges are inherent
- Uncertainty is common
- Changes are frequent
- Adaptation is necessary
- Psychological growth is possible
- Good outcomes are reported but not well explored



# HOW?

- Social support – practical and emotional.
  - Instead of asking 'What is wrong with me, why can't I handle this?' – ask yourself, what do I need right now? What kind of support can help me?
- When we are stressed we don't function well, it is important to take pauses even if just for a little while – start with a cup of tea in the shade of a tree, make sure you sleep, exercise and eat well.
- Be kind to yourself – we don't have to be perfect parents. Good enough is good enough. Practice an open, mild and non-judgemental attitude towards the problem you face.
- Be present with your full experience – the positive and negative – acknowledge and accept it.
- Importantly, looking after yourself will help your family so allow friends, family, psychologists and counsellors to help.



If you want to participate in online research on 22q11.2 deletion or learn more about what we do.

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