

## ORIGINAL ARTICLE

# The Lived Experience of a Mother of a Young Adult with Intellectual Disability: 'My Daughter as My Enlightenment'

Murray Rieck<sup>1</sup>, Jane Shakespeare-Finch<sup>1</sup>, Mariann Märtsin<sup>1</sup> and Marie Knox<sup>2</sup>

<sup>1</sup> Queensland University of Technology, AU

<sup>2</sup> The University of Sydney, AU

Corresponding author: Murray Rieck ([murray.rieck@gmail.com](mailto:murray.rieck@gmail.com))

There is a paucity of research exploring the experiences of mothers of a young adult with intellectual disability sharing the family home. A case study using a phenomenological life story approach was conducted to gather and analyse data from 11 in-depth interviews held with a mother, Linda, about her experiences. Linda's story yielded three main themes, 1) an intense struggle and hardship of living 'in the void', 2) gathering resources and coping to counter the 'masters of the universe' and 3) developing a new 'personal infrastructure' to exit the void. Discussion underscores the value of stories of mothers and people with disability, including those of ableism, oppression, and stigma. Linda's story depicts a complex and intricate life with both challenging and enriching times and a strong need for belonging to community. Future research is suggested, such as how mothers manage and negotiate barriers and systems within their lives.

**Keywords:** parent; lived experience; young adult with intellectual disability; phenomenology; growth; meaning

## Introduction

While much research exists regarding mothers of children (e.g., Loukisas & Papoudi 2016) and older adults (e.g., Knox & Bigby 2007) with intellectual disability, there is less in-depth exploration of their lived experiences with their son or daughter at the young adult stage. This single case study explores the life experience of a mother Linda living at home with as the primary carer for her young adult daughter, Sarah, who has intellectual disability. Thus, it provides a unique opportunity to explore a mother's lived experience as understood and described by her, rather than focusing on predetermined elements of her life. Hence this paper contributes to fill a significant gap of knowledge in this area.

### *Mothers, Caring, and Young Adulthood*

The motherhood role is held as a gender-based role and thus issues for mothers are also gender based, especially for those with a child with disability (Traustadottir 1991: 211). Traustadottir (1991) identified three main meanings of caring: 'caring for', when mothers provide the caregiving itself; 'caring about' which refers to the love and affection for our children; and 'the extended carer role', when the caring role extends into addressing wider societal concerns.

Kelly (2016) explored the tensions between the disability and feminist movements about understanding 'care'. The disability stance is where the notion of care is somewhat rejected as it is understood to diminish choice and control for the person with disability, while the feminist movement focuses on valuing gender-based forms of labour. Kelly (2016) argues that if this tension is upheld, understanding and care provision should be enhanced more broadly across the dimensions of care.

Traustadottir (1991: 225) found that parents (often mothers) of a child with disability experience a level of complexity of advocating for their child that other parents do not. Ryan and Runswick-Cole (2008: 43) suggest that for many mothers this may begin with advocacy, but with such complexity often translates into a stronger activist role which becomes a significant element of the mother experience. They also suggest that mothers use several resources to support and advocate for their son or daughter with disability. More recently mothers have become activists, using internet blogs to share negative and distressing experiences of disability (e.g., Loukisas & Papoudi 2016: 128; Mydaftlife 2015).

Parents of people with disability are often referred to as 'carers'. This 'carer' labelling devalues parents' roles and responsibilities and diminishes the relationship between mothers and their adult/child with disability (Nolan, Grant & Keady 1996). Indeed, as Beckett (2015) asserts, the stigma of labelling and stereotyping of the person with disability

spreads to family members and close others. However, most parents do not identify themselves as in the carer category and argue the clear distinction between 'caring for' and 'caring about' someone (Kelly 2016: 17–24).

Young adulthood is a significant and sometimes difficult transition time, as individuals typically make major adjustments to their life and learn to cope with change and new experiences (Lenz 2001: 300). This family life-stage is the focus of this study. Importantly, this transition is also a time where change in the parent-child relationship occurs (Kim & Turnbull 2004).

### ***Disability, Ableism, and Stigma***

Problematic issues associated with intellectual disability are those of ableism and stigma. Stigma is a crucial concept in the experiences of people associated with disability (like mothers) (Goffman 1963). Goffman (1963: 45–57) coined this stigma 'courtesy stigma', where someone is degraded or disrespected by society because of their association with someone already experiencing stigma. As people with disability are often stigmatised by society, so too – in the present context – mothers of a young adult with intellectual disability may also experience courtesy stigma.

Campbell (2012: 215) described two dominating features of ableism. The first is the concept of the 'normal' or normative person; someone who is 'able' of mind and body (however that may be perceived). The second refers to a 'constitutional divide' involving a separation of the notion of the normative 'human' person from the 'aberrant' referring to 'subhuman'. While an ableist standpoint might accept that people with intellectual disability are tolerated and treated fairly, it does not necessarily propose that they are an accepted member of a diverse society or that there should be a community culture where disability should be welcomed and celebrated (Campbell 2012: 213). Thus, they and people associated with them have their identity redefined, and sometimes allocated a lower social standing with associated negative stereotypes (Beckett 2015). With these stereotypical and somewhat offensive perspectives, a person with intellectual disability is viewed as sub-human, a social nuisance, and whose delayed development inhibits progression into adulthood.

### ***Potential for Complexity***

The above brief review has demonstrated concepts and themes leading to a potentially complex life. A further complexity portrayed in the research of people without disability as a positive attribute is that of resilience. Rutter (1999: 119–121) explains resilience as a complexity of many risk and protective factors. However, the notion of someone with disability conforming to this normalised view is not helpful. There is potential for responsibility and blame to be attributed to people who are vulnerable and perceived to lack the strength to overcome challenges (Ungar 2005). As with Goffman's courtesy stigma, mothers may also be at risk of experiencing these negative consequences of association with disability. Runswick-Cole and Goodley (2013: 67) well argue that resilience should be viewed and actioned as a community relational responsibility, where attitudes, systems, and supports are integrated into community rather than as an individual concern.

Not unlike families in general, life for families with a member with intellectual disability may include many challenges (Blacher, Neece & Paczkowski 2005). Much of the earlier research has origins primarily in a paradigm of suffering, stress, and illness where one mainly 'copes' with largely negative consequences (Dykens 2005: 5) rather than including potentially transformational outcomes. Antonovsky's (1979) salutogenic paradigm offers a humanistic perspective that explains one's coping in challenging times, along with higher order survival and enrichment within the lived experience. Antonovsky (1979) suggests that an individual's sense of coherence – their capacity to find circumstances comprehensible, manageable, and bestowed with meaning – is a crucial factor in coping and survival. Salutogenesis exemplifies a theory where a mother's rich story might include both challenging times and positive, optimistic, profoundly meaningful stories of resilience, hope, enrichment, and connectedness (Calhoun & Tedeschi, 2013). Consistent with the salutogenic paradigm, life experiences may vary or co-exist, from challenging and traumatic to deeply enriching. Hence as well as exploring life's difficulties, the salutogenic paradigm explores resilience, or the capacity to respond positively to life challenges (Rutter 1999), personal growth or enriching outcomes arising from both times of difficulty and achievement (Calhoun & Tedeschi 2013). Hence, the dynamics among such concepts are complex and intricate, weaving a multi-dimensional tapestry that is mothers' life experience. The mother experience may well not remain static, with complexities challenging the simplistic and one-dimensional view of a burdensome existence of stress and strain (Cuskelly 2005).

The purpose of this study was to explore the experiences and perceptions of everyday life in the past and present and views regarding the future held by this mother of a young adult with intellectual disability sharing the family home. Thus, it is crucial to use a methodology that helps to capture and understand the complexity of this mother's lived experience as described and understood by her.

## **Method**

### ***Methodology***

The overarching methodology of this study is phenomenology, described as acquiring an in-depth understanding of the nature or meaning of one's everyday experiences (van Manen, 2016). Merleau-Ponty (1962: 476–503) explored one's consciousness and how experiences give perception meaning through thought (e.g., of life events). This study aims

to provide rich thematic descriptions giving insight into the meaning of this mother's lived experience. In qualitative research, the lived experience is about gaining first-hand personal knowledge about life, events, and interactions; it is one's self-perceptions, their subjective reality as they see it (Rice & Ezzy, 1999), rather than an attempted explanation by a theoretical or statistical approach. It is a term often used to describe an individual's own account and impressions of life as a marginalised or oppressed person, who has experienced 'the other' in their life (Yee 2013). In this study, the mother's lived experience is gathered from her telling of stories of life as she sees it, which challenges second-person understandings of people without actual lived experience of a particular phenomenon. Such stories counter the dominant discourses around disability (Fisher & Goodley 2007: 68).

### **A Case Study**

Case studies are an approach allowing the researcher to examine a single or small number of participants in great detail (Hammersley & Gomm 2000). Yin's (2009: 9) case study method provides an appropriate way of exploring the complexities and salient issues for this mother. Yin (2009: 9) describes case studies as inquiry that helps to understand complex social phenomena and real-life events in depth. As the aim of this study was to examine the lived experience of this mother, a single-person case study comprising multiple interviews (11) was used to explore life events from the past and present and her perceptions of the future. Ethical approval was granted by Queensland University of Technology, Office of Research Ethics and Integrity, approval number 1600001029.

The case study participant is a mother, Linda, who resided in her family home in an urban area in Australia with her daughter, Sarah, her only child, a young adult aged 18 with a moderate intellectual disability. Pseudonyms have been used for the given names of these two family members. Linda was recruited through a disability support organisation's newsletter.

Key to this method were the collaborative relationship and conversational interviews between participant and researcher. The semi-structured interviews used an interview guide that functioned only to facilitate in-depth discussions.

Linda was always in control of her interview and was the decision maker in ceasing the interview process when she was ready. Eleven interviews were held approximately weekly at her home over three months. Linda declined to have her interview digitally recorded; however, she agreed to comprehensive notes being taken. As the collaborative researcher-participant relationship developed, Linda suggested having a discussion about her life, then describing the key points of her story in her words as she understood her life. While the conversation was co-constructed as a trusted collaboration, Linda's life story was written by the lead researcher directly from her own words. At each session, Linda checked the quality and accuracy of her story from the previous week, often making changes to elements of the story to ensure she had conveyed her meaning.

As stories usually arose during interviews, a collaborative and trusting relationship developed over time and thus story data noticeably developed more depth and clarity. The researcher brought his own lived experiences to the relationship – experiences that would influence an empathic listener approach to gather the story. Most notable were the researcher's passion for human rights for vulnerable people, sound clinical knowledge, and many collaborative experiences with families with a member with disability.

Data analysis procedures began once each interview was converted from hand-written notes to a printed transcript. Themes and concepts emerged from the data as Linda intended them (using an inductive, bottom-up approach), rather than the researcher drawing on preconceived concepts or testing ideas or hypotheses. Some themes began to emerge with the initial reading of each transcript and with rereading, a thematic analytic procedure of open coding and axial coding was used to identify further themes and compare them (Miles, Huberman & Saldaña 2014). The researcher's reflective diary was also crucial to understanding and interpreting the data (Smith & Osborne 2010).

## **Results**

Three primary themes were identified from the analysis of Linda's life story. These are the struggle of living 'in the void'; learning, developing resources, and coping; and exiting 'out of the void', with her daughter as her enlightenment.

### ***The Struggle: Living in the Void***

Linda described her life as 'living in the void', where life was difficult, with intense hardship, isolation, and frustration, and without a personal infrastructure.

#### **Personal Infrastructure**

The first sub-theme for Linda was a lack of personal infrastructure, that is her own individual framework by which to make sense of her life and guide her through the practicalities and hardship. 'Nobody should live like this. The hardship is unimaginable ... life has been too much hardship, I tried so hard.' The data constantly reflects the courage of Linda's struggle and her inspirational tenacity and resolve to cope and care for her daughter in the face of hardship.

Life initially was about the practicalities of a life lived in isolation and a lack of needed supports. 'Life for me is nuts and bolts stuff. People don't get it. Other families take on roles to "work it out", to help out, but this is different, they don't know what it's like.' Linda described her childhood and young adulthood as highly structured, with a lack of personal framework and empowerment, and a relative paucity of foundational life experiences:

I was living in the void ... comfortable people have structure like education, family support, and economic stability. When Sarah was born, I knew nothing about kids – no cousins, no family with children; friends didn't associate with children. I didn't enter adulthood a well-constructed person; not a lot of guidance from family. Not a lot of friends or people around me.

Linda spoke about not having a good understanding or expectations of the world, 'people will tell me if I need to know or do something.' She had the view that 'other people were the experts – they know better, and so their views must be right.' Hence, Linda had a robust belief and trust in authority, doubting her own ideas. 'I must be wrong.'

#### Misfit of Systems

The second sub-theme of being 'in the void' was the misfit of various systems that are in place for a young person with high support needs. Linda described this as:

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. We are all supported by systems, and so we get a moderately good life. I don't think the rest of the world gets the depth of a person. 'It's just disabled so nothing we can do about it.'

As Sarah grew older, the gap between her requirements and appropriate or flexible systems grew wider, resulting in further challenges, as Linda explains:

The more the systems restricted her ... led to Sarah developing what the system would simply consider to be extremely challenging behaviours, but Sarah was able to communicate and exhibit to me in a more precise way than ever before what her concerns and anxieties were about.

Linda had begun to use funded respite services. However, this was a decision that she regretted, as her daughter suffered sexual abuse while in the care of an agency. 'Sarah communicated to me very clearly that during her few days away from home, she had encountered a moderate degree of sexual abuse. Sarah was more than distressed about this, not surprisingly. I'd never seen her sad like that before.'

Linda reported her concerns to the respite service manager and police to investigate allegations of abuse. She was disappointed with the lack of appropriate response and indeed rejection that the story of abuse could be true. This incident had a major impact on her life, adding another strengthening factor in her robust commitment to the protection of her vulnerable and much-loved daughter:

This crisis, in hindsight, was a major collision between all the supports that were lacking in the first part of my life, with their subsequent effect on me, and increasingly intrusive effects of others who were drawn to have opinions about my situation, because of the fact that I had a disabled daughter and the subsequent effects that had on my life's progression.

#### Professionals and the 'Masters of the Universe'

The third sub-theme was Linda's reflections of how some professionals or 'experts' from what she coined the 'institutional settings' had a different experience of being-in-the-world from the one of her understanding. These differences became a catalyst for her to consider the expert's beliefs were sometimes mistaken and not fully informed, and to recognise the clear power imbalance. Significantly, Linda's belief in authority was being tested. 'It became more complex; my "faith in authority" began to be deconstructed.'

Linda coined these professionals the 'masters of the universe' as she perceived them as 'holders of the knowledge and truth' who often provided a power-over approach rather than one of listening, collaboration, and mutual understanding:

The masters of the universe. They overstep the boundaries. They mistake their beliefs to be fact and they hang out with a gang that also believes them to be true. If people think to set themselves up to be a master of the universe ... they need to listen to hear what it's like.

Hence it was underscored that the knowledge and experience of professionals within an expert model, the 'masters of the universe', had often further marginalised Linda and Sarah, sometimes with a stark divergence from what might be useful for them. 'The "masters of the universe" related to my knowledge is the opposite. They really need to just be masters of their own universe.' Indeed, the 'masters of the universe' often provided advice and recommendations that were not in Linda's sphere of thought, contradicting her plans of commitment and protection of Sarah and were confusing and unhelpful. For example, on young adulthood she said:

In the regular family, the parent mission is now winding up. Whereas with Sarah it doesn't wind up. The master of the universe says 'you should be winding it up now'; how the world should work according to the masters.

### ***Learning, Developing Resources, and Coping***

The second theme identified was Linda's experiences with her daughter that contributed to developing a more robust personal infrastructure and understanding of both their lives. Opportunities presented for new learning, developing personal resources, and coping. Two issues stood out throughout Linda's story in terms of resources. Her commitment and protection stood firm even at times of her own vulnerability. Life was unquestionably difficult, with experiences of intense pressure and abuse. But Linda always put her daughter first, protection at all cost, rejecting pressures to relinquish her young daughter into government statutory care: '... wanted me to give it all up. I really struggled with self-esteem when it's like this.'

Linda accepts her commitment to her daughter is an ongoing responsibility, watching out for misinterpretations of behaviours and advocating for her needs to be met. '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 onto the next system, the young adulthood system.' Linda gathered information from a broad array of resources which influenced the development of a new personal infrastructure. These included listening to informative radio programs, support from school teachers, and various other trusted professionals. While Linda experienced many individuals and systems she referred to as members of the institutional model, the 'masters of the universe', she was also grateful to have very positive experiences with people whom she termed 'exceptional professionals'. Linda described the relief of working with staff who were diligent and who saw Sarah as an individual with different needs rather than a problem. She spoke of the dedication and attributes of a pre-school teacher working with Sarah:

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

Now equipped with new experiences and information, Linda was making more of her own informed choices: choices that she was comfortable with; choices founded on her own evidence rather than that of the 'masters of the universe'; especially for situations that might put Sarah at risk, '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.'

This led to Linda's views on morality and ethical issues around outsourcing human services, linking best practice to a model of community support rather than a systems approach:

There is stuff in society that's okay to outsource. Problem is once it's outsourced it loses the moral obligation to be involved and help; as it would be a responsibility in a community. In a tribe, someone cuts their toe, and someone in the community fixes the toe. But no one looks to see the cut toe in today's society.

### ***Out of the Void: My Daughter as My Enlightenment***

With Linda's struggle and shattering of basic assumptions of life (e.g., trust in authority), she developed a new knowledge structure, life norms, and expectations. It was her daughter, Sarah, who led the way to this positive change that Linda coined her 'enlightenment', her new and richer understanding of life, exemplified by significant personal growth in connectedness and a 'deeper knowing' of her daughter and of disability.

The beginning of exiting 'out of the void' culminated from experiences and making sense of the struggle and acceptance that the struggle will continue with control. Linda makes well-considered choices now – 'I might just be right after all' – however, they often include boundaries or consideration of her new knowledge, such as the protection of her daughter:

Funding for further hours directed towards another activity have not provided my freedom from the situation. Sarah's desire to continue with an activity necessitates my presence as staff don't have the knowledge of her; and not the finesse of skills to allow her to attend without her distress levels being unreasonable. There is no way in the current world that I could help to make them understand that.

Linda has a small number of coping strategies that are effective for her to deal with the day-to-day stress and struggle. For example, she writes positive quotes or events into a journal and reflects on these in difficult times:

About coping, I write down things that are encouraging (like from the radio and reading), then I underline it and read it when I'm not coping. It's not like I hear stuff and think 'Wow, I never thought of that before!' My philosophy has matured. Thank god in my understanding of the world I am not alone.

Coping and resilience for me is trying to find ways to survive.

Linda also spoke of spending much time working and pondering in the garden. She listens to the radio, writes in her diary, and uses 'self-humour', as she often jokes with herself.

Linda lives in the moment, day by day, not constantly future focused, but at the same time creating a future for her daughter as she moves forward. At the final interview, Linda recounted a vivid dream from the previous night that described the practicality of coping and creating the future:

The past was sad. Not just yesterday. Before Sarah and until yesterday. So vivid and epic, the dream stayed with me. Now is still a time of crisis, no real solution, being aware that Sarah is facing an impossible future. But that's today. There's a transition from now to the future. The future is not like the past. I constantly create or find the future. I have to create the future. A future of community.

Building a sense of community around her daughter helps Linda to cope and is a focus for the future. This is more an ideal for her own support system than a lived reality, as Linda has very little community support and believes that a sense of community, in the main, has been lost.

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. Today's community is like an organisation rather than the systems required, it's not people living together ... We need a community that cares about as well as cares for.

Despite learning to cope, surviving, and understanding herself, her life, and her daughter, Linda is clear that life remains a struggle and will continue to be a struggle. 'In that respect, now is similar to the past – just different shoes on the same feet.' While struggle is a prominent feature in Linda's past, present, and future, there are positive experiences, 'When I said "life shouldn't be like this", it's 99% good for me, but everything from "the professional and community" tends to go into "mourning mode". I love her, of course, Sarah is a delight – very active, but a delight.'

In telling her story, Linda emphasised the challenge of doing so and acknowledged the role and influence of her daughter in her lived experience. 'It's difficult for me to tell Sarah's story ... but I can't tell my story without Sarah's story.' She privileged and honoured her daughter's story as an agent of change in both good times and times of struggle. 'Being Sarah's mother has changed my world.' Linda provided poignant clarity about the significance of her journey with her daughter (e.g., multiple personal, family, and institutional events) that contributed to her own understanding and learning, in turn enabling her to challenge authority, take control, and exit out of the void. '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, experiencing authority, and learning to deal with it ... my own experience filled the void.'

Linda's story ended with the richness of a few short quotes that acknowledge and summarise her unique relationship with Sarah and the positive contribution Sarah has made to her life, and her 'enlightenment':

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.

This is Linda's story. Despite immense ongoing struggle and isolation, systems that often didn't fit needs, a lack of 'personal infrastructure' and emotional and social supports, Linda found a way through the difficulties to experience a deeply enriching life with her daughter as her strength and enlightenment.

## Discussion

This case study provides good insight into the lived experience of mother Linda as she perceives it. While these qualitative findings cannot be statistically generalised, there is much to learn from her story and her life with her daughter, including the influence Sarah had on her life with outcomes of positive change despite ongoing struggle, and the potential implications of these.

### ***Becoming the Vigilante: Learning from Stories***

The research provided an intensive picture of Linda's life; how it changed throughout from 'being in the void' to her coping, and how her relationship/s and events shaped a new future where she is more in control. For so long people with disability have been seen as passive. However, for Linda, her daughter Sarah has been the catalyst for positive change. As with Ryan and Runswick-Cole's (2008) work 'from advocate to activist', Sarah has led Linda to not only advocate but actively contribute to improving services as 'the vigilante' to understand and promote the rights of people with disability; including the presence of oppression. Sarah has played a very positive role in Linda's life. Her daughter has brought about the changes rather than professionals; the 'masters of the universe'.

The potential implication here for professionals and other support staff is about listening to the voice of people with disability and seeing them as experts, with a genuine role in advising supports, initiatives, and policy. If mothers are supported to see the value of their son and daughter with disability, the notion of burden may be contested by them.

It is not the intent to portray Sarah or Linda as a hero, and care has been taken not to do so, rather to let Linda tell her story and let themes arise from it. However, they (and potentially others) may have an educative role as teacher, as people without such experiences listen and learn from them, challenging ableist views toward acceptance of people with disability and their families as part of a diverse community needing supports and good systems to have a quality life. Hence the importance of research to include the voices of people with disability and mothers.

### ***Need for Belonging to Community***

Linda often referred to the 'need for community' to support her daughter Sarah. As this theme runs throughout, it is evident that neither Sarah nor Linda has experienced a sense of community. Linda speaks about many contexts of community; the parent community, school community, tribe community, and community in the general sense. Linda points out that society is far removed from traditional community and focuses on systems that do not fit people or families with different (or special) needs. Systems do not see the person through the same lens as a community might, exemplifying a person with a lacerated toe – systems do not see the toe to be able to fix it.

Thus far, Linda doesn't have a community, or a tribe as she describes it, to help watch out for and watch over her daughter. Linda is constantly searching for community, but to no avail. Will that community be available to rely upon to support Sarah in the future, as would be the case in a tribe or village? A close-knit community where members know each other, where individuals are interdependent and share responsibility for each member, particularly for people who might be vulnerable. Linda's wish is about trusted relationships in the community rather than the setting of community itself. There are implications here for community development, and roles of professionals for developing community, and the unblocking of systems that get in the way of building community. There would be much benefit in future research exploring these issues of community and the way belonging to community is integrated into the lives of all people, so people with disability and their families are supported as they would be in a village environment.

The body of knowledge of mothers would be further enhanced by life stories that bring out the ways and means that they use to negotiate the complex path of motherhood with a child with disability. While this mother clearly took control of her life in challenging circumstances, more work is needed to explore mothers' understanding, negotiating, and managing their lives in a world that many scholars (and indeed mothers themselves) describe as oppressive, as well as positive and transformational outcomes for them.

### ***Meaning, Resilience, and Growth as Outcomes of Struggle***

A predominant thread of ongoing struggle and hardship weaves through Linda's story, along with evidence of rich, positive outcomes. Hence, Antonovsky's (1979) theory is expanded in several ways by another theory to address specific elements of personal growth identified by Linda. First is the richness and depth of meaning in family life. Frankl (1998) describes meaning as a precursor to endurance which offers an explanation for Linda's apparent coping and resilience despite a long struggle. Frankl (1994) argues that someone (in Linda's case her daughter Sarah) or something provides people with a strong meaning in life, that the 'will to meaning' endures (or promotes resiliency) in times of adversity. This theory, albeit a contrast from the context from which it was written, provides an interesting backdrop for coping, resilience, and personal growth in terms of the family. The second relevant aspect of Frankl's theory was to emphasise meaning as a reason for happiness and enjoyment of family life. Frankl (1998) suggests that if one has true meaning in life, that is people or things of 'meaning', and therefore a reason to be happy, then happiness ensues. Together with love, these theories of meaning may explain why Linda (and other parents) not only cope, but supports Linda's notion of enlightenment and arguably that Linda's daughter might be the catalyst for positive transformational outcomes for her (Calhoun & Tedeschi 2013).

Notwithstanding earlier critical analysis of the concept of resilience and disability, the second positive consequence for Linda was the building of resilience to respond positively to the many challenges she faced (Rutter 1999). Linda further indicated that coping and resilience for her was finding ways to survive. As Linda developed new knowledge and skills from the variety of resources discussed, so too her 'personal infrastructure' became robust in which to reconstruct her own more resilient and confident self. With Linda's new-found infrastructure and resilience came more confidence to test the theory that she might be right, to make choices and develop a stronger sense of control over her own life as she became a committed advocate and protector for her daughter.

The third positive outcome is that of personal growth. The study findings indicate that Linda's daughter may be the agent of her mother's deeper personal growth, perhaps not well recognised or studied in the body of knowledge examining parents with a family member with disability, particularly at this transitional life stage. In her own words, Linda described her daughter as her strength, her enlightenment, noting how different she is now and how her daughter has changed her being-in-world in a positive way. Janoff-Bulman (1992) describes how the struggle itself may lead to a personal 'shattering of basic assumptions of life' (such as Linda's perceptions of mistaken trust in authority), which interact with feelings as a person attempts to comprehend and cope with the breached assumptions. This interaction of experiences contributes to the development of new beliefs of the self and others, higher order goals and schemas, and intensely positive changes and personal growth, including profound strength, endurance, and enhanced life philosophy (Calhoun & Tedeschi 2013).

In addition to personal growth outcomes, Sarah's traumatic experience of abuse was clearly a major event for both Linda and Sarah. The trauma event was a defining moment, as Linda described it. This was a significant catalyst for her to take control of her life and make stronger decisions with confidence in protecting her daughter and improving

her quality of life. Linda had already commenced the reconstruction of her own identity and 'personal infrastructure'. However, Linda's experience of her daughter's response to the trauma, together with her strong will and commitment to ensure her future safety, perhaps strengthened her resolve and the importance of her choice and control in managing their family life together.

### **On Ethics**

As in most research, the privacy, ethics, and consent issues of the participant were taken very seriously by the researcher, including collaborating and taking Linda's advice (e.g., to write the story rather than digitally record it). An issue for consideration and perhaps for further exploration is for the rights, privacy, and consent of the person with disability within a story. As identified, Sarah was a crucial person in Linda's life story – 'I can't tell my story without Sarah's story' – and as such it is a reflection that researchers consider these issues in terms of other people discussed in the interview such as someone with disability.

### **Conclusion**

The phenomenological methodology used is a useful and appropriate method to gather Linda's story of her lived experience and capture the themes important to her. Linda's life is complex, intricate, and dynamic; one where a duality of struggle and enriching times coexist. Linda has learned much from her daughter including the importance of connectedness to community, a new understanding of her mother activist role, and reconstruction of her life as positive changes occurred, such as her daughter as the catalyst for enlightenment: a new knowing of disability, of the world, and of love. As such professionals and other support staff can also learn from people with disability. Listening and involving them as experts of their lives remains crucial moving forward.

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### **Competing Interests**

The authors have no competing interests to declare.

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