

Resilience in a Family of a Child with a Disability: A Family's Lived Experiences

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Abstract

Social capital theorists have contributed to inclusive practice by arguing for new paradigms to build the capacity of people with disabilities and their families to participate in community life (Chenoweth & Stehlik, 2004). The aim of the research was to shed light on what has helped members of a family to be resilient when there is a child with a disability. A narrative insider approach was adopted in the qualitative research methodology as it had the advantage of capturing a naturalistic perspective on lived experiences within trusted relationships (Denzin & Lincoln, 2005; Rabbitt, 2003). Participants for this case study were 4 adult members of a family unit, known to the researcher. The family was selected because there was a young adult with an intellectual disability who had received specialised early intervention and additional support since the time of diagnosis at 18 months of age and is now 19 years of age and actively engaged in work training and other pursuits. The story of this family's experiences was worthy of exploring as it may help others to think about their own situations and offer new possibilities in inclusive practices.

A major challenge was undertaking research which can give families of children with disabilities a voice into socially inclusive policies and practices, leading to improving family quality of life issues. In teacher education, prospective inclusive educators need to increase their awareness of the value of connection with families. Narratives of family members revealed fresh insights about personal qualities that strengthen resilience. The research identified the specific factors that differentiate what makes a family resilient. Sources of resilience portrayed within and across members of a family unit may deepen understandings about protective factors and guide richer understandings of what makes a difference to learning and life outcomes for diverse learners. These new understandings of resilience in families from real-life experiences may inform the work of teacher educators in inclusive practices.

Introduction

Mental health and resilience have become increasingly significant issues confronting many in the human service professions. Good mental health is portrayed as a holistic sense of wellbeing which allows us to enjoy a quality of life and caring relationships. Resilience is described as the ability to bounce back, recover from, or adjust to misfortune or change (McGrath & Noble, 2003). Emotional and spiritual resilience enables us to enjoy life and survive pain, disappointment and sadness. It gives an individual a positive outlook and feelings of wellbeing. Resilience is thought to involve a complex interaction between the person and the environment, and can be related to self-agency (Bandura, 2001).

A sense of connectedness to families and school is the most significant protective factor for young people. Fostering student wellbeing and resilience promotes a healthy lifestyle and improves educational outcomes. Additionally, 'a strong sense of cultural identity also helps students to be resilient and resourceful and contributes to a more accepting, inclusive community' (Tasmanian Department of Education, 2006, p.6). Whereas social isolation and family risk factors negatively influence a student's capacity to show resilience (Withers and Russell, 2001).

Issues of risks and protective factors are considered important in improving students' social-emotional development. Risk is linked with 'socio-emotional factors and disengagement from school, unacceptable behavior, and a decline in personal health and wellbeing' (Education Department of Western Australia, 2000). In contrast, if a sense of belonging is encouraged then students are more likely to persist and overcome difficulties, demonstrating 'educational resilience' (Xim Ma, 2003). For some students, school may be the one environment where they have access to reliable, trustworthy adults.

To date there is a gap in the literature in relation to family members' perspectives of real-life experiences across a range of contexts in building resilience, specifically in the disability field. Family members often have unique understandings about the individual's specific needs. While valuing the input from family members as key decision makers, previous research has shown that addressing the concerns of families requires systematic planning and regular communication for individuals with disabilities to make smooth transitions across a range of settings (Bentley-Williams & Butterfield, 1996). Collaborations may encourage greater responsiveness to the circumstances and aspirations of family members affected by a child with a disability (O'Shea et al., 2003). This research sought to expand our understanding of what protective factors contributed to feelings of resilience in a family with a youth with an intellectual disability and what home, school and community experiences had supported or hindered their sense of personal efficacy when faced with difficulties beyond school boundaries.

Theoretical framework

Positive psychology (Baumgardner, & Crothers, 2009; Seligman, 1995) and cognitive behavioural theories (Ashman & Conway, 1997) underpinned this current research. The basic premise behind these approaches is that if we change the way we think, then we can change the way we feel and act. Cognitive behavioural therapy and interventions are used by mental health and educational professionals for anger management, depression and anxiety in changing negative thought patterns and promoting optimistic thinking.

Central to this investigation was the focus on identifying what is it about these family members and their circumstances that enables them to achieve positive life outcomes despite exposure to 'risk' associated with a disability and what promotes their sense of wellbeing and resilience. Kumpfer, 1999, proposes a framework of six key constructs that contribute to resilience:

- stressors or challenges that disrupt equilibrium and the perceived degree of stress
- environmental contexts such as family, culture, community, school and peers
- person-environment transaction, including perception, reframing, changing environments, active coping
- internal resilience factors - including cognitive, emotional, spiritual, physical and behavioural
- resilience processes - stress-coping processes that allow the individual to bounce back
- positive outcome (Kumpfer, 1999).

Key attributes of resilience were explored in areas of social competence, capacity for problem solving, sense of autonomy, purpose and optimism. Environments included school, community and home contexts and situations were analysed as to whether they provided caring, support, high achievable expectations and ongoing opportunities to participate.

Methodology

The study was designed to empower the voices of family members. A narrative insider approach was adopted to create an atmosphere for capturing a naturalistic perspective on lived experiences within trusted relationships (Denzin & Lincoln, 2005; Rabbitt, 2003). The term 'insider research' is used to describe where the researcher has a direct involvement or connection with the research setting ([Robson 2002](#)). Participants for this case study were four adult members of a family unit, known to the researcher and included the mother, father and two brothers aged 21 and 19 years. The younger brother has an intellectual disability.

Semi-structured interviews of approximately 40 minutes were conducted to gain the participants' perspectives from a whole family unit approach. The three interviews with each of the brothers and the parents were facilitated by a research colleague in a relaxed dining room in the family's home using an interview protocol to elicit their unique perspectives (Refer Appendix 1: Interview

Protocol). Participants gave their permission for audio-recording of the interviews for transcription purposes.

Findings

The three interviews with the older brother, the youth with an intellectual disability and their parents provided valuable insights about notions of resilience and wellbeing. Their accounts described richly meaningful lived experiences that spanned the formative years of growing from childhood into adulthood.

Perspectives of a sibling

The older brother, (M), focussed on his role as a leader and mentor for his young brother with an intellectual disability (C), commenting:

I'm the bigger brother, 2 years older, I'm his biggest role model & we're big supporters of each other, he looks up to me a lot to know how to act, C especially with his disability, he's unsure.

In looking back over primary schooling he recalled how other children picked on C and even the teacher contributed to C's feelings of social exclusion:

C had a lot of problems in primary school and was segregated a bit from the teacher's point of view... he had anger and frustration, got into trouble, he struggled, his disability was not visually obvious, got into scuffles. Kids picked on him not just at school, locally too, kids used him and manipulated him. I didn't like it and felt I had to protect him, it wasn't a good environment...put strain on the family and it filtered down, stressed Mum and Dad having to go to school and talk and Dad would take the police line

The experience at secondary school where C was accepted was quite different:

Everyone knew he was my brother, accepted first and found friends quickly. The school hadn't seen many disabled kids and he was put in with everyone else, it was good for him socially

In sporting contexts, M raised awareness of C's disability to help build understanding:

I'd meet the coach & make people aware that he has learning disorder, he's a little slow, nothing severe just takes a longer, and gets frustrated if he doesn't understand straight away. I wouldn't say it to a stranger that I don't have anything to do with. Just let the guys in the team know he might get frustrated, C would get frustrated and drop out of things like the footy club..Give him an extra chance to learn something or do something. My friends know he's a little slow they all love him

Positive respectful relationships were evident between the brothers:

Respect the fact that he's doing it harder; achieving knowing he's special

M added his view that having a brother with C's outlook contributed to his own and the family's resilience:

Makes me want to be a better person...I think C looks at things with kindness and good nature, everyone notices his smile. Other people would be bitter if they got picked on, he never showed it, he's inspirational from my point of view... so excited to go and do things, makes you want to help him out more...Gives me a better perspective on life and makes the household happy

In considering the future, some worries M raised were functional as well as personal in nature:

Employment is a worry; he's active in finding employment. He has lots of friends but finding someone worries me more than employment. He'll be here for a while, it's important to come home; it's a safe place for him. He struggles with bills, phone and car bills

Despite an uncertain future, M was optimistic and normalised negative experiences and hardships:

It's always going to work out e.g. knowing how to read... Not going to have to babysit him his whole life. Problems, everyone's going to have them ... it's not a burden it's a normal part of life. It's a long term thing, it might be bad at the start trying to read, but it's not a train wreck. Mum and Dad put in a lot of time, he can read and write, got his licence first go

M commented on becoming resilient and the critical role C had played:

Learn to become resilient by dealing with the situation itself one on one, C went through bad things. Bad harder times had a negative influence on the family; now it wouldn't throw us. If my brother had a child with a disability it wouldn't be negative, I've learnt from C... Harden by bad things and makes you more resilient, physically and socially, can even joke about it. Doesn't get frustrated fits in socially, everyone we know socially, he could fit in with. If he doesn't understand he asks someone else, gets on the better side of people. He's been called everything under the sun and it wouldn't affect him. Helps us attack other things mum's cancer, dad's early retirement, wouldn't want C any other way. I wouldn't pick on a disabled kid, it's not easy C has made us resilient as a family, it's been very rewarding.

M appreciated having learnt to handle setbacks from dealing with negative circumstances with C. He reported that he had become more resilient having experienced these hard times. He recognized that feeling connected had helped C in overcoming frustrations. He described how C was accepted and would seek assistance, indicating C's growing sense of autonomy and ability to ignore insults. M attributed the experiences with C as affecting how as a family they had become stronger in overcoming other difficult aspects of life. In concluding, M reflected on lessons learnt and commented on the behind the scenes role his mother played in C's development:

He wants to be socially normal as everyone else.. Doing nothing is the wrong thing. There were hurdles at high school; they were open and mum and dad went to meetings and they took on their input and ideas. It's important to learn in safety, understanding environment.

Some kids see it as cruel to push, but mum said no you're going, he's lucky mum pushed

M's comments demonstrated his values of maintaining a strong sense of personal and family resilience in caring for his brother's wellbeing.

Perspectives of a youth with an intellectual disability

Similarly to his brother M, C reported negatively on his primary school experiences.

I coped trying to get through learning in the classroom, learning things, school wasn't easy... Had a really, really, hard time at school down the road, had trouble with the kids got picked on a bit and had trouble socialising and getting on with kids in the classroom and school yard.

The feelings of being excluded and segregated continued in the middle school years when C was moved to a special class:

Second school was a public high school and had the same thing, had special ed unit there and I had trouble mainly the same thing, the kids in special ed learning how to read, that's my biggest weakness and making friends was really hard. They treated me like a baby; it didn't really work for me.

C was aware of how his intellectual disability impacted on him both academically and socially and felt he was patronised rather than supported in his learning. In contrast, the private secondary catholic school showed genuine values of respect and promoted an inclusive schooling environment:

Then I went to E's, knew plenty of people there and made heaps of friends through footy. They were really good friends, respected me and knew who I was and had heaps of support there. Had some support from a teacher's aide that helped me with reading and doing the work and explained things better. I had trouble finding the classes and they helped me get around the school. I want to make it better for other people with disabilities.

C spoke about how the school staff catered for his needs and he offered some advice for teachers in getting to know a student as a person:

Understand me a little bit better; they don't really know what it's like being me, just listen to me a bit better and get to know me, with spelling, reading.

C sense of accomplishment is evident in the qualifications he achieved:

Got my Higher School Certificate and courses I've done, my green card, Health & Safety, Maritime first aid, construction course and learnt how to drive a bob cat and a cement mixer, took me a while to learn left and right for the bob cat licence and they tip very

easily... Got my car licence with RTA I kept pressing the wrong buttons for the computer test and someone had to help me and had someone there sit down and help me.

The help-seeking behaviour C had learnt was brought into play when he became a volunteer with disadvantaged people in the community and his skills were acknowledged:

A Waterford award for helping homeless people with the soup kitchen helping them out with food, it was quite interesting; a concreting course and I'm also doing a Landscaping course with Active industries.

His comments demonstrated a developing understanding of self and a growing sense of efficacy:

I'm really more confident now, getting out there socialising with people; had some friends get me out of the house, some friends at school and have a certain friend in the footy team, stuck up for me, boxing and fitness, I go to the gym and relieve some stress... some memory things, I'm getting better at remembering things, I don't write them down... I'm friendly, easy going, put up with certain things, really patient sometimes, that's me. I'm not silly I don't do stupid things to people.

Chris' positive self talk had changed his attitude towards his disability and given him a positive outlook on life and opportunities to make choices. His emotional resilience was evident:

... getting my driver's licence and boat licence so I can fish and relax. People say I can't do certain things and I prove them wrong. When I was doing the course people said you'll have trouble like doing my bobcat's licence, I did an oral test not writing, it's easier. I felt relieved cause I thought I wasn't going to get it thought everyone else was going to get it. Mum always said you can do it just believe in yourself, don't give up, that's the main thing, don't show any negatives be positive. Try to be happy, don't be stressed, take deep breaths and try not to get too nervous.

Real-life experiences had given C a keen sense of the importance of keeping people safe and building supportive relationships with friends and family:

I look after my friends, make sure they don't do things they'll regret, I don't drink as much, I return their calls and say I missed your call and sorry about that. I respect their morals and don't give them a hard time. My friends do the same thing, they respect me and I have made some good friends in the past. My brothers are really good if they want something they ask, if they want a lift I pick them up, I want to get them home safely because I care about them a lot, I love my brothers and don't want them to get hurt or anything.

Perspectives of parents

A: Mum and B: Dad

When asked what their understanding of resilience in a family was, both parents expressed their views which acknowledged the hardships yet they moved forward:

A: Coming through things and having the best, able to cope, stamina,

B: You've got a family and that's the thing, you have to wear it they're your children and you have to keep going on and try not to dwell on things, keep moving forward.

A: You stand up for what you feel is right, supporting and fighting for that sometimes it's easy sometimes it's hard it's what you feel is the best.

B: The pressure is always there

A: You can draw on each other pull each other up.

They identified the hurdles they had faced particularly in the school context from both teachers and other parents:

B: The problem is that some teachers talk down to you like you're a student like you don't have a brain.

A: The teacher didn't want disabilities in her class

B: We copped it from other parents too. Tough times was when we first found out he had intellectual disabilities. That's when you look at your child in a different way, it's not the person you thought he was.

B: Others sensed we were overprotecting him.

A: He's your brother you look out for him and care for him the normal family values you care for him ...he used to watch their sport they all played together, even though the older ones ruled. They played with families with similar values as ours.

C's mother recalled critical points when his disability was first diagnosed and provided examples of her resilience and determination to help her son achieve his potential:

A: At 18 months how can you put these labels on him? I remember the psychologist saying he'll never learn to read and write, he'll never be able to drive. I thought how can you say that? And she said 'He'll probably never get a job'.

It was probably anger and I thought I'll show you. Even with his football, I said you've got to get out there. I pushed him to read, I used to say, if just got to keep pushing. It depended on what mood he was in. If he was tired and hungry there's no point. After school he was tired. Early morning I'd sit with him at the computer, talk to him in a calm manner, if you raised your voice he'd switch off, egg him on make him feel he could do it, not to go at him and he'd respond and you'd have to pick your moments. He'd play that I'm really sick, I remember the time he got in the car and went to school and he had phenomena

Both parents gave their ideas on what skills teachers need to be successful as inclusive educators commenting:

A I think the teachers are the ones to set an example, to teach other children that they're out there.

B They need to do the extra course.

A Being adaptive, setting the classroom up for him.

B Some teachers find it too much of a challenge. They didn't follow through from Early Intervention to school, hadn't put anything in place.

A: Communication and the teachers who did were more mature, very unexpected, ex-army, very strict and he took C under his wing and looked out for him. At first he was the one who said to Ms Linda I don't think I want to do all this. He did a really big one with C on a survival assignment- he's only there for the life skills. He only had to do the work at his level.

B: Someone independent, tries to get things in place and get teachers motivated and educated. Primary Schools are closed shops, tight knit. Secondary ones really shape the personality of the child more.

Parent involvement in their child's education and having high expectations went unquestioned.

Both parents managed shift work while supporting their children's learning within a real family-centered environment:

A: Learning his phonics he did sit down and do it and didn't complain. You got speech therapy through the hospital, and then paid \$40. It was hard to fit it in. I do the 6 – 11pm at night and you'd do 6am-6pm. It was always working around the timetable.

A: I look back now and think where did we get the energy? Sometimes I remember reading to him in the bath. I didn't want the high education I wanted him to fit in. The youngest would find it great. I used to involve them all.

B: My parents sacrificed a lot with 5 boys and your parents did too with 6 kids.

A: I went to speech therapy as a child because I was dyslexic.

B: Before my mum died she told me you make sure you 5 boys stick together... You do remind them what you do for them.

Their advice to other parents was to be realistic and accepting of themselves and their child, and not to judge their own identity through other's views:

B: No perfect parenting, no perfect family, we're all dysfunctional in some way.

B: Don't aspire to the normal.

B: the rewards of developing a child to their full potential, it doesn't happen overnight. Self-esteem is very important. You have a lot of power in shaping them; their personality is there you just help bring it out. You can discuss the disability they have. C talks about it openly

A: He'd plateau then peak and go with it, notice

B: Parents shouldn't feel they're disabled by their child's disability.

Their thoughts on resilience underpinned their efforts:

A: We've had our good moments. We were both raised with the same values, we were brought up similarly, we weren't spoiled.

B: we didn't walk away or ignore it. We know some people who've said there's nothing wrong but you can't ignore it.

B: It's not a rosy road along the way and things are going to happen and you have to learn coping skills. We had to cope with a lot of things that people haven't been exposed to, life experiences, upbringing, beliefs mould you and how you respond to things.

Experiences other people take for granted had shaped their understandings of parenting roles and quality of life outcomes. Identity and mutual shared values of what they considered important had kept family members connected to their past, present and future lives together.

Discussion

Pathways to resilience emerged which highlighted 4 key areas of importance across home, school and community contexts. They include a focus on:

- **Mentoring:** having a supportive role model of his older brother and parents: knowing how to act, understanding boundaries, fitting in, making people aware, building social skills and shared family values
- **Learning to overcome difficulties:** being picked on, dealing with situations, struggling on his own, realising it's not a train wreck, developing persistence
- **Being in caring relationships:** reflecting on best memories, mutual respect and closeness, expressions such as 'he makes me want to be a better person', & concern for finding that extra someone
- **Staying optimistic:** believing things are always going to work out, engaging in positive self-talk

Relationships depicted the strong connections between all family members and there was a genuine sense of care, concern and empathy that united them through the hardships and hurdles of experiencing rejection and setbacks. Resilience was enhanced as a result of facing a range of negative situations and challenges, contributing to the family members' determination to achieve despite others' low expectations. Surprisingly, it was the youth with the intellectual disability himself who had a powerful influence on building the family members' resilience. The lived experiences of this family had shown that a person with a disability can enrich family life and make valuable contributions to home, school and the wider community. Explicit demonstration of resilience by family members underpinned by shared values of care and respect, paved the way for bouncing back and achieving goals.

Conclusion

The research identified the specific factors that differentiate what makes a family resilient. Sources of resilience portrayed within and across members of a family unit may deepen understandings about protective factors and guide richer understandings of what makes a difference to learning and life outcomes for diverse learners. These new understandings of resilience in families from



real-life experiences may inform the work of teacher educators in inclusive practices. Resilience is a helpful and useful construct and an organising device to consider the issue of student wellbeing and how it can be fostered through careful and caring parenting, teaching and mentoring.

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Appendix 1: Interview Protocol

- What is resilience like for you as a parent/brother/person with special needs?
- What do you think makes your family different to other families?
- What are some of the difficult experiences you've faced at home, school and/or in the community?
- Would you like to give an example of a difficult experience?
- Looking back what made that experience difficult for you?
- What did you do? Who did you go to help you? How did you feel?
- Can you give an example of another experience that you found difficult?
- How did you cope?
- How do you think other family members coped?
- What were some of the benefits of being different and having these experiences?
- Based on your experiences, what do teachers, principals and others need to know?
- What do you think is important for children, adolescents and family members to learn?
- Is there anything else you would like to mention?