



RESILIENCE

FATIGUE

Estelle Shields was left breathless by a NSW academic's project on resilience in families with children with disabilities ...

Abstract This project aimed to define and describe the term 'family resilience' as it relates to families. The research analysed service models in order to identify and define elements of practice that build family resilience, detract from family resiliency, and are crucial to the maintenance of resiliency during times of transition. The project identified and presented tools that can be used to measure family resiliency in families with a child with a disability.

Dear Dr.... Another learned paper on family resilience! Assessment tools for academics to weigh what does and does not make a family with a disabled member hang together! Research to discover why some families stick it out and some fall apart! Isn't this just what we need in the disability sector at the moment? Most of the families I know could write a book about resilience, if only they had the time. We don't need a dissertation on the topic - we need the means to bring it about. We all know what it is that generates resilience - we just don't know how to achieve it.

I am talking about HOPE. Parents and carers work for decades believing that they are giving their disabled charges the very best start in life. They HOPE for the best possible outcome, a person who functions to the highest of his or her ability. They HOPE for the greatest degree of independence achievable and work ceaselessly towards this goal. In doing so, they HOPE that one day their disabled son or daughter may be independent of them and will be supported to be so. They look forward to the end of their work and the same right as their fellow countrymen - retirement. They HOPE that their disabled

member will transition into adult life like non-disabled peers do. This is what makes the caring families of this country resilient. It is the idea that they, who have worked harder than all other parents, will be permitted one day to put their feet up.

We have a great social crisis in this country. I am not talking about the indigenous people or the refugees. No, the crisis involves the tens of thousands of Australian citizens with an intellectual disability for whom there exists no place at all in this rich and lucky country. When their parents die (those resilient parents) there will be still no place for them to go. This crisis is not even on the agenda, it gets no political traction and in academic discourse it gets quickly swept aside as "unmet need". This will be before the important topics are addressed: ones such as integration, inclusion, equality, rights, choice, value and my personal favourite, resilience.

I am the carer of a man in his thirties, my son, who has a severe intellectual disability. It makes me furious that the universe I inhabit never intersects with the one you and your colleagues live in. In this state, 97% of people like my son live at home with their parents and I want to tell you that the biggest decision they make about their lives is which television channel they watch. Yet the disability "industry" chugs on, lost in its own world of research, advocacy, service provision for the lucky few, conferences, round tables, discussion papers, peak bodies and the like, but never reflecting or in many cases even mentioning the issues that concern us, the families at the coal face. We have no representation, so we who do the largest share of the work do not get so much as a voice at the forums that discuss us and make decisions about us.

Let me tell you a little about the world I inhabit. I am surrounded by desperate families who have cared largely unsupported for three, four or five decades. The parents (or in many cases, parent) are exhausted, depressed and depleted of resilience - although, as I have said, these families have been tireless in the raising of their disabled offspring. The siblings are anxious and insecure about their own futures, afraid that they may be asked to continue caring for their brother or sister. The parents have reached retirement age and watch as their peers embark on the next stage in life, enjoying the "third age" in a way that is unachievable for carers. They have lost HOPE that there will ever be an offer of supported accommodation for their son or daughter as everyone they know has been assured by the department that they are "a very high priority". All new places go to those within the system - the people coming from DOCS and the prisons - and the only way to achieve a placement is to force the department's hand and abandon their beloved person.

So we have our own discourse happening out here at the coal face. It revolves around the issue of "dumping" - see the attached essay entitled "Valour". What choice do we have and what HOPE is there for our adult children? What is the more humane choice - to relinquish care while we are still around to oversee the transition or to wait until we can care no longer? And more particularly, why should people who live in a prosperous first world country be asked to make such a decision? And why do I not read of this appalling situation in any of the literature?

We have enough information to know that Australia trails the developed world in its care of its disabled people. We have given birth to the people that no-one wants. They are an embarrassment and a burden to our society. If it takes a village to raise a child, it takes a nation to raise a disabled one. Our nation has abandoned us, exploiting our love for our vulnerable children. A certain fascist regime had its own solution for people like ours in the 1930's and we regard this as immoral. But how much better is Australia's solution: leaving its disabled people at home with ageing parents and hoping they will predecease those parents?

I could go on and on. I could tell you about the decades of lobbying and the number of letters I have written. I could tell you about the efforts to get some form of grass roots representation, to no avail. Or the years of support given to the local NGO in the hope of securing an accommodation placement there, only to have all the "sweatequity" rendered null and void with the advent of DADHC's Vacancy Management System. Or the formation of our own little group, dedicated to achieving supported accommodation in our local area, and the years of garnering support, only to finally accept that no-one wants to help us.

So you see, we have given up on HOPE and that means we are no longer resilient. I am considering at this very moment dropping my son at the respite cottage and leaving him there. This is what I see as the greatest act of love that I can do for him, but my eyes fill up with tears and I get this great lump in my throat every time I think about it. So what do I do? Come on now - you are the professional and I am just a lay person, so please tell me, what do I do for the best? I cannot find any words written on this subject so please advise me - what does a parent in my situation do?