



COUNTERFUTURES

Left thought & practice Aotearoa

FOUR

2017

Social-model mothers: Disability, advocacy, and activism

Gretchen A. Good, Awhina Hollis-English, Ally Attwell, Anna Dickson, Anita Gibbs, Janice Gordon, and Joanna M. T. Taylor

I think the hardest part of having a child with a delay of any kind is the fight: The fight for services. The fight for people to understand who your child is and what they need. The fight for knowledge, because knowledge is power. And the quiet fight you have within yourself wondering if you've left no stone unturned.

Jessie Doyle¹

HOW DO MOTHERS of disabled children navigate the roles of advocate and activist? This paper reflects on the experiences of mothers of disabled children, exploring the impact upon families who take on responsibilities for work-

1 Jessie Doyle, "Facebook Page of the Autism Spectrum Support Group of Southern Maryland," accessed April 19 2017, <https://www.facebook.com/AutismSupportSoMD/posts/938282289573282>.

ing for disabled children's rights. It is from these experiences that, as mothers, we join other activists and academics in the growing radical disability rights movement.

We are a group of academic women who are mothers to children with disabilities. Some of the authors have had formal relationships through academia and have worked together in teaching about disability or through research. But mostly we are an informal group of women who have personal contact through our children and disability groups and/or academic connections as researchers, educators or students, and who have a child, or children, who live with disability. We gathered together to write this paper. Some of us are disabled, others are not. Some have had decades of experience of advocacy and activism, and some of us have young children and are new to the academic-disability community. Our collaborative work stems from a desire to help our children and families, but to also continue the movement to eliminate barriers that have historically marginalised disabled people economically, socially and educationally. Our common goal is to make a difference, not just for our children but for the wider community.

The purpose of this paper is to illuminate the labour of advocate mothers and to tell our stories of success. We also aim to provide recommendations to mothers, fathers, families, schools, academic communities and those invested in social justice, to work toward future positive action on behalf of disabled children. We do this work through academia and through our mothering, and in solidarity with families, academics, students and other movements to build a better, more inclusive and accessible world.

Mothers of disabled children experience discrimination and disablism. They are often propelled into contentious worlds of disability rights, complex medical and educational systems, and social justice conundrums. They often develop competence, skills and abilities in their roles as advocates and activists, yet

their contributions are often undervalued and unrecognised.² We are dismayed at the omission of disability from higher education curriculums and from social justice agendas. Even the organisers of the International Women’s March (January 2017) initially excluded disability as a women’s issue, omitting disabled women as a minority group in need of protection through policy. Already marginalised groups, such as Māori, experience inequitable provision of disability services and an inequitable voice within education curricula.³ Recent proposed changes to education systems in both Aotearoa New Zealand and the U.S. have omitted provisions for disabled children and failed to consult appropriately with families. In the face of these failures and omissions we seek to clarify the roles of mothers of disabled children in Aotearoa New Zealand, address misperceptions, celebrate our successes and lend credibility to our roles.

In this paper, we have focussed on the work of mothers as advocates, not to diminish the work of advocate fathers, grandparents, teachers or disabled persons, but in recognition that mothers of disabled children are far more likely to take on caring and advocacy roles than are other mothers.⁴ Also, for parents of disabled children, advocacy is more complex and frequent than for other parents.⁵ The advocacy work of mothers of disabled children has been defined as ‘managing the trick of engendering collective action in an institutional context uniquely designed to

- 2 Sara Ryan and Katherine Runswick-Cole, ‘Repositioning mothers: mothers, disabled children and disability studies’, *Disability & Society* 23 (2008): 199-210.
- 3 Bridget Robson and Ricci Harris (eds), *Hauora: Māori Standards of Health IV: A Study of the Years, 2000-2005* (Wellington: Te Rōpū Rangahau Hauora a Eru Pōmare, 2007).
- 4 Rannveing Traustadottir, ‘Mothers Who Care: Gender Disability and Family Life’, *Journal of Family Issues* 12 (1991): 211-228.
- 5 Sara Ryan and Katherine Runswick Cole, ‘From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum’, *Journal of Applied Research on Intellectual Disabilities* 22 (2009): 43-53; Traustadottir, ‘Mothers who care’.

forestall it'.⁶ Mothers face educational systems, health systems and communities that require our energies to negotiate, struggle with, and sometimes fight for our children's needs to be met. Activism on the part of mothers of disabled children has been described as working to affirm our children, and seeking full participation for them.⁷

The positive and negative experiences of mothers as advocates for disabled children have been absent from both disability and parenting literature.⁸ This could be because, historically, disabled children have been institutionalised and there was once a widely held belief that children in the care of the state were no longer 'mothered'.⁹ But our disabled children are no longer institutionalised. For the most part they live with us at home, are mainstreamed in school and are active in their communities. We expect that, despite disability, our children will learn, work, have loving relationships and participate in their communities. Despite our clear expectations, wider Aotearoa New Zealand society does not necessarily share them. Hence the need for strong advocacy and activism, and to create and develop a body of knowledge and literature about our journeys.

- 6 Jan Nespor and David Hicks, 'Wizards and witches: parent advocates and contention in special education in the USA', *Journal of Education Policy* 25:3 (2010): 309.
- 7 Milton Seligman and Rosalyn B. Darling, *Ordinary Families: Special Children: A Systems Approach to Childhood Disability* (New York and London: The Guildford Press 2007).
- 8 Sara Ryan & Katherine Runswick Cole, 'From advocate to activist? Mapping the experiences of mothers of children on the autism spectrum', *Journal of Applied Research on Intellectual Disabilities* 22 (2009): 43-53; Hilary Stace, 'Disability Care as Women's Work', *Women's Studies Journal* 27 (2013): 13-24.
- 9 Cynthia Lewiecki-Wilson and Jan Cello, *Disability and Mothering: Liminal Spaces of Embodied Knowledge* (Syracuse: Syracuse University Press, 2011).

The language of disability and the social model of disability

First, a word about disability language: according to social models of disability, ‘disability’ is socially imposed and created by society through attitudes, policies and environments.¹⁰ According to the UPIAS (Union of the Physically Impaired Against Segregation [UK]) and paraphrased by Oliver:

It is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.¹¹

In social models the focus is not on individualistic or medicalised views of impairment. Instead, social models of disability concentrate on equity and participation through eliminating barriers, and focusing the political struggle for equal access.¹² Therefore, the language of disability within social models rejects person-first language, such as the term ‘people with disabilities’ (people have impairments) and utilises the term ‘disabled people’ as people are disabled by the environment, attitudes and stereotypes.¹³ Some of our children, however, prefer person-first language. In light of this, we use person-first or disabled-person language where it seems most appropriate. Alternatively, within te ao Māori the

10 Justin A. Haegele and Samuel Hodge, ‘Disability Discourse: Overview and Critiques of the Medical and Social Models’, *Quest* 68 (2016): 193-206.

11 Michael Oliver, *Understanding Disability: From Theory to Practice* (Basingstoke: Macmillan, 1996), 4.

12 Union of the Physically Impaired Against Segregation <http://disability-studies.leeds.ac.uk/files/library/UPIAS-UPIAS.pdf>.

13 ‘Disability Language and Etiquette’ (Barking and Dagenham Centre for Independent, Integrated, Inclusive Living Consortium & Barking and Dagenham Council, 2001): 5.

preferred term is ‘whānau hauā’ (the paradigm for Maori disability identity), which refers to whānau (wider extended family) as opposed to the individual.

Methodology

Our paper utilises a collaborative autoethnographic approach. Autoethnography is the ethnographic and critically reflexive study of self and others with close personal connections.¹⁴ Autoethnographic research requires careful attention to the empowerment and protection of vulnerable family members. We connect these family stories to wider social, political, ethical, and cultural contexts.¹⁵ This process creates a platform for our stories, and for empowering us and other women who share the experience of parenting disabled children in a disabling society.

There are different aims for, and kinds of, autoethnographies of disability. The aims can vary from the need to illustrate the ‘lived experience’ of disability; to offer a resistance narrative to normative portrayals of some kinds of disability; to fill gaps in research; to remedy injustices to specific groups with disabilities; and to ensure change occurs at policy and strategy levels.¹⁶ Our collaborative autoethnography brings together components

14 Anita Gibbs, ‘Ethical Issues when Undertaking Autoethnographic Research with Families’ in *SAGE Handbook of Qualitative Research Ethics*, M. Tolich and R. Iphofen (in press).

15 Gibbs, ‘Ethical Issues’.

16 Sue Dumbleton ‘Goodies and Baddies: Equivocal Thoughts about Families Using an Autoethnographic Approach to Explore Some Tensions between Service Providers and Families of People with Learning Disabilities’, *Ethics and Social Welfare*, 73 (2013): 282-292; Gibbs, ‘Ethical Issues’; Sarah Wall, ‘Ethics and the Socio-Political Context of International Adoption: Speaking from the Eye of the Storm’, *Ethics and Social Welfare* 6 (2012): 318-332; Lee Murray, Debbie Pushor and Pat Renihan, ‘Reflections on the ethics approval process’, *Qualitative Inquiry*, 18 (2012): 43-54.

of evocative and analytic autoethnography.¹⁷ When using evocative autoethnography, we provide creative and emotive stories that give concrete examples of the distress families experience because of the discrimination towards their children who have impairments, both 'hidden' and 'visible'. When using analytic autoethnography, we offer analysis of the contextual influences, ideological concepts and research-based strategies that promote understanding and accommodation of families where children have a disability. It is vital that our collaborative autoethnography is able to promote understanding and changes as Donmoyer notes: 'Policymakers may value statistical data and analysis in their public discourse, in private, however if you want to convince them of something, tell them a good story'.¹⁸ Our autoethnography is not just a series of individual stories but we chose to act as a co-operative because we share a commitment to standing up to discrimination of disabled people, of advocating for their rights, and of giving voice to marginalised voices, and align this passion with our knowledge as academics and researchers.

In the following sections we provide commentary on how we have acted as advocates, how we have been activists to bring change to our neighbourhoods and beyond, how we have been allies helping others struggling with oppression, what we mean when we campaign for recognition of our children's needs and radical acceptance of their impairments, how we engage in positive action and stand up for the rights of children with disabilities.

17 Tony E. Adams, Stacy Holman-Jones and Carolyn Ellis, *Autoethnography: Understanding Qualitative Research* (Oxford: Oxford University Press, 2015).

18 Robert Donmoyer, 'Two (Very) Different Worlds: The Cultures of Policymaking and Qualitative Research', *Qualitative Inquiry* 18 (2012), p. 805.

Fusing academia, advocacy, activism and parenting

The experience of being academic mums of disabled children creates an interesting fusion of scholarship and activism with parenting. Some of us have had experiences where skills in research, writing, and speaking have been an aid to arguing successfully for resources. Paradoxically, some of us have had experiences of our families being perceived as ‘high functioning’ because we are professionals, and this has created barriers to accessing support that other families seem to access without the struggles we have encountered. For example: personal care, teacher aide hours, support and respite have been difficult or impossible to access, and have involved official complaints and endless meetings. It still can result in support being denied to the family. Our families can be fragile and on the verge of breakdown, like every family steeped in struggles related to disability. Our co-author, Awhina English, comments on the issue of being perceived as ‘high functioning’:

At times my academic role has been intimidating or distracting for practitioners, particularly those that I have taught or who are interested in my area of ‘expertise’. Sometimes when we are supposed to be talking about our need for greater support, wheelchair ramps and feeding issues, the practitioner him/herself has begun reflecting on their own studies and lack of knowledge on a particular area. It’s frustrating having to be the one who has to remind the professionals to stay focussed on my daughter and her needs—pointing out where there are gaps and real life challenges for us, while the professionals are looking for cultural supervision or professional guidance.

Despite such challenges, we also have positive opportunities to fuse our personal passions with our academic work. Our every-

day lives with our disabled children may be physically and emotionally draining, but we feel we have no choice but to use our knowledge and experience of disability and a disabling world to educate, research and advocate. Our students and colleagues are current and future educators, public health officials, social workers, parents, neighbours and citizens. They can surely benefit from gaining an understanding of social justice for disabled people in Aotearoa New Zealand and around the world.

Co-author Ally Attwell comments on this fusion of academia, advocacy, activism and parenting:

Being a mother of a child with a disability can be challenging at times, however, the benefits really do outweigh the bad. I left school without achieving School Certificate (NCEA level 1) and was told I wouldn't amount to anything! I believed these words until I became one of 'those mothers'. I found that I needed to stand up and advocate for my daughter so that she would have the same opportunities as everyone else. I am lucky to have such a supportive whānau, especially a husband that supports me as I pursue my dreams. Since T had a lot of health issues, I was unable to work, so instead I took the opportunity to study. My journey has provided me with a unique set of skills to support beginning educators, professionals and current educators in schools and early childhood centres. I did this through setting up professional development courses for the sector and by gaining a lecturer's position on the Level 3 Early Childhood Certificate. I found that as I studied, I gained much more than just skills, I learnt about who I was as a person. I found my voice and learnt how to use it! My qualifications have given me the credibility to not only support my whānau but also to pave the way for many more. With each small gain it means another family doesn't have to go through the same fight.

Recognition

Despite experiences like Ally's, of finding voice and securing credibility, disability literature tells us that 'for many mothers, advocacy and activism are a major part of the experience of mothering a disabled child yet this remains a largely unrecognised role'.¹⁹ Hilary Stace, academic and advocate mother of an adult son who is disabled, states: 'Caring for a disabled child is often a lifetime occupation for a mother (and it is usually the mother), although one with low value and status'.²⁰ Rannveing Traustadottir explains that advocacy for disabled children is frequent, complex and unlike what other parents face.²¹ Co-author Joanna Taylor, mother of six with an adult son with an Autism Spectrum Disorder (ASD) diagnosis, comments:

The time and energy I have put into this (disability related advocacy) doesn't go on my CV. It's not like I get credit for it, as I would if I was on some kind of committee. The message is so often 'It's your kid, deal with it'. Try as we might we can't make the day more than 24 hours long. So we steal hours from our sleep time. Researching medications and sorting out crises—this is middle of the night stuff. We live with dangerous levels of sleep deprivation.

Mothers of disabled children can face such difficulties, as Joanna stated, as well as difficulty with recognition when dealing with professionals. Studies show that mothers of children with disabilities often have to leave the workforce to care for their disabled child and therefore can lose a title, status, economic security, and credibility when working with medical or educa-

19 Ryan and Runswick-Cole, 'Repositioning Mothers', 199.

20 Stace, 'Disability Care as Women's Work', 14.

21 Traustadottir, 'Mothers who care'.

tional professionals.²²

Non-disabled mothers can also be left in a position to doubt whether they can have a voice within the community of disabled people. These mothers 'have occupied a complex, contradictory and marginal position within both disability studies and the disabled people's movement'.²³ As described in a personal communication by a mum of a child with Down syndrome:

As a parent of a child with DS [Down Syndrome], I do not have the right to speak as if I represent the disability community. I'm not disabled. But I listen to writers and advocates who are disabled to hear what they are saying, what they are asking for, how they wish to be spoken about. I'm an ally.

As a disabled mum, one of the authors of this paper, Gretchen Good says: 'When advocating for myself, or adult peers, I feel like I can take a breather, pick my battles and let some things go. This cannot happen, or cannot happen easily, when advocating for children'.

Recognition and acknowledgement from those people that mothers of disabled children must constantly be negotiating with, educating, and asking for services from, is hard to come by. And so it is important for us mothers to understand and value our roles as skilled negotiators, activists and spokeswomen.

22 Barbara Dobson, Sue Middleton and Alan Beardsworth, 'The Impact of Childhood Disability on Family Life', (Joseph Brownree Foundation, 2001); Ryan and Runswick-Cole, 'Repositioning mothers', 199; Traustadottir, 'Mothers who care'.

23 Ryan and Runswick-Cole, 'Repositioning mothers', 199.

Roles as advocates for our children

Advocates have been described as ‘bridging agents in generating networks, connecting parents with others, articulating their knowledge with other parents’ knowledge, and bringing additional communicative resources to encounters.’²⁴ Academic women who are mothers of disabled children can be ideally suited to this work. We often have these needed skills because of, or in spite of, how busy we can be. In the midst of all the demands of academic or professional roles and caring for disabled children, our academic skills are often called on for fundraising, facilitating collaboration amongst parents, and organising support for families amongst many other things. We often end up in leadership positions and some of our roles include: fighting for inclusion and learning to do this diplomatically, negotiating with the health system, trying to prove we are competent, while having to prove we need support, presiding over the work of disability groups, working as Trust and School Board members; and research, teaching, reading, and writing.

Co-author Awhina English reflected on a time when her academic knowledge identified something key that was missing from the processes her daughter needed:

During our many stays at the paediatric ward, I became quite familiar with the assessment forms and questions that we are asked as we are admitted. One day I asked the nurse if I could see the form and noticed there was a section that was left blank that has ‘te whare tapa whā’ on it. I asked the lovely nurse and she said that, yes, that was the model they were supposed to be using, documenting that information about whānau in that section, but that no one ever did it because they didn’t know how to. There were no instructions as to

24 Nespor and Hicks, ‘Wizards and Witches’, 309.

what to ask and basically the staff was ‘too busy’ or unfamiliar with the model implemented. I found this incredibly frustrating as this is a model that I teach my own students about and it’s been around for decades! How many whānau are missing out on the opportunity to have their cultural needs met basically because staff don’t have the cultural capabilities? Since this, I’ve undertaken workshops and seminars, given keynote talks, and attended meetings in the hope that staff can begin to gather the skills needed to do their assessment processes appropriately. I feel that often my daughter’s health needs are so complex that professionals think that she doesn’t have any other needs, but she does!

This type of advocacy is not for everybody. As one mother said (personal communication) about facing the prospect of parenting a disabled child: ‘I think I was generally feeling overwhelmed and not ever wanting to be the “pushy mom”; one of the most pervasive negative thoughts that I had when I was adjusting to my son’s diagnosis was: “Ugh, I don’t want to have to be an advocate”’.

Co-author Ally Attwell discusses some of the advocacy and activism she has undertaken as the mother of a non-verbal child:

Many professionals believe that learning sign language is too hard for them; how do we expect a child with an intellectual disability to learn it? This is one of the barriers I was faced with when we found that sign language provided my daughter T with an opportunity to fully express herself. T, who has Down syndrome, was non-verbal until the age of seven. We as a whānau were not supported in providing her with a mode of communication. Professionals told us ‘children with Down syndrome—they talk’. Well, T wasn’t just a child with Down syndrome: She was T. As whānau we chose New Zealand Sign Language (NZSL) to bridge T’s communication. We all learnt NZSL, which brought us closer. However, the choice of using NZSL was not easy and was a decision that had us encounter-

ing many barriers. T was not classed as being deaf, which meant that professionals denied her access to NZSL. I advocated for her to be assessed by Van Asch Deaf Education Centre in Christchurch. Luckily for us, the report found that she did actually have mild to moderate hearing loss, allowing her access to NZSL. Many other whānau do not have this luxury and were still fighting to have access.

At times mothers have had to advocate strongly based on their instincts and relational knowledge of their children's needs, as opposed to having practitioners', the 'experts', support in order to access services. This lack of guidance and support leads to inconsistencies in service provision, with some families unfortunately missing out. This can lead to further challenges and areas of tension for families, and the need for even more skilled advocacy work by mothers. And all of this work to gain services for our children is done while we simultaneously fight for them to be accepted just as they are.

Radical acceptance

Parenting disabled children creates a dilemma for mothers. We wish to accept our children completely for who they are yet we work tirelessly for them to change, to grow and to meet their potential. Many of us reach a point where we truly embrace a social model of disability and recognise that our fight is to advocate for changes to society and to our environments.

According to Paula Jessop, an adult who lives with autism:

Radical Acceptance begins with truly accepting that we are on the spectrum and not trying to 'cure' us and/or turn us into 'normal' people. It means basing therapies or interventions on what might

help us to thrive in the world, not what will help others find us easier to be around by forcing us to behave in less Autistic ways.²⁵

Our co-author Ally Attwell speaks of the experience of fully accepting that her child was non-verbal, and needing to change the world to accept that other modes of communication should be available to those that need it:

In 2006 New Zealand Sign Language (NZSL) became an official language of Aotearoa New Zealand.²⁶ This was a huge moment for the Aotearoa New Zealand deaf community. At this time, I stood up and explained that T, my non-verbal daughter with Down syndrome, uses NZSL not because she is deaf, but because of her difficulties with speech. As an official language, everyone should be allowed access. In 2013 they did a review of the NZSL Act and we advocated that the review was of NZSL, not the deaf community. We wanted it highlighted that there were many groups of people that would benefit from using NZSL. I was able to share with Human Rights Disability Commissioner Paul Gibson some of the research that I had found through my educational journey. This research highlighted the benefits for alternative communication modes.²⁷ I wanted radical acceptance of NZSL for all tamariki, not just for those that are deaf. It was not just about making our kids 'talk', we want them to communicate. The Human Rights Commission (2013) coined the phrase 'NZSL users'; this rightly identified all those that use NZSL.

- 25 Paula Jessop, 'Radical Acceptance of Autism', *Altogether Autism Journal*, Summer 2014: 2.
- 26 Human Rights Commission, 'A New Era in the Right to Sign: He Houhanga rongo te tika ki te reo turi' (Report of the New Zealand Sign Language Inquiry, 2003).
- 27 Anne Toth, 'Bridge of Signs: Can Sign Language Empower Non-Deaf Children to Triumph Over Their Communication Disabilities?' *American Annals of the Deaf* 154 (2009): 85-95.

In this instance, instead of trying to teach a child to ‘fit in’ by learning speech, this ‘social model mother’ works toward changing attitudes, policies and environments so many will use and understand the third official language in New Zealand, NZSL, and be more inclusive.

Another mother’s story about radical acceptance and advocacy involves learning about ourselves, our attitudes, and our children’s health and disability issues all at the same time:

A friend and I established a CMV (congenital cytomegalovirus) support network here for Aotearoa New Zealand because there just wasn’t anything for us to join to share information. I struggled at first because the international ‘catch-phrase’ was ‘Stop CMV’, which I felt was not accepting or inclusive of our children. Now I realise it’s about stopping the spread of the virus that causes these impairments; not stopping the children themselves. CMV awareness is something that I’ve been trying to spread but am really mindful that it is about being educated about the virus and being inclusive of the people.

These stories illustrate that much of our work as advocate mothers of disabled children is about promoting acceptance of our children and recognition of what society needs to be more inclusive.

Advocacy and activism for acceptance and inclusion

Social justice work ‘uses social advocacy and activism as a means to address inequitable social, political, and economic conditions that impede the academic, career, and personal/social develop-

ment of individuals, families, and communities.²⁸ But is there a difference between advocacy and activism? Some say disability activism means going beyond advocacy for your own family and working on behalf of others, even when you or your family will not benefit directly. Activism could be viewed as working collectively with others. Our collaborative research group may not like the idea of public protests or confrontational meetings, but we cannot escape that we have to advocate for our children and others who live with disability.

The actions of activist mums can be described as having a social justice rights focus that incorporates what Anne Bishop,²⁹ Priscilla A Gibson,³⁰ and Patricia O'Brien and Martin Sullivan³¹ call the ally model. Being an ally involves standing alongside others from oppressed groups and offering genuine support and power-sharing. This enables activist mums to recognise their own power and privilege when they are campaigning on behalf of other families where disability is an issue. Being an ally means becoming an agent of change, not just because of one's own family situation but because there are many such families like our own who have fewer opportunities to speak out like we academic mums do, so in being allies we choose to use our positions to help others, and to change societal attitudes towards disability. Being an ally means we offer hope, we connect to families where stigma and oppression are causing harm, and we act against oppression. We stand alongside others who struggle; we share some of the

28 Manivong Ratts, 'Social Justice Counseling: Toward the Development of a "Fifth Force" Among Counseling Paradigms', *Journal of Humanistic Counseling, Education, and Development*, 48 (2009): 160.

29 Anne Bishop, *Becoming an Ally: Breaking the Cycle of Oppression in People*, (New York, Zed Books, 2002).

30 Priscilla A. Gibson, 'Extending the Ally Model of Social Justice to Social Work Pedagogy', *Journal of Teaching in Social Work*, 34 (2014): 199-214.

31 Patricia O'Brien and Martin Sullivan, eds., *Allies in Emancipation: Shifting from Providing Service to Being of Support* (Melbourne: Thomson Dunmore, 2005).

same forms of oppression, but we also have privileges that may make our experiences different. We work hard to find the balance between multiple, often competing demands on our time and skills. All of this must be done without burning out, whilst maintaining our own quality of life and that of our families.

Successful positive action

Janice Gordon offers two stories that illustrate the success of collective action. A mother of an adult son who lives with multiple impairments, she describes advocacy work and activism she was active in involving health and education sectors that had very positive outcomes for her family and others:

In the 1980s I was part of a group of young parents who were mentored by IHC and the Beasley Institute to become advocates for disabled people. This was a time of change and new frontiers for services, breaking with the concepts of the past to empower families and people with disabilities to advocate for themselves. I have two stories to share from this time. First, my local school was not accessible or welcoming to disabled students—not uncommon in the 1980s. In my role as co-coordinator of Parent to Parent, a support organisation for those involved with disability parenting, I organised a hāngī at the school, a family event with outdoor activities. Many of the families attending had neuro-typical students at the school as well as a child with impairments who wanted to attend. I introduced them to the principal, and we discussed the school environment and the need for ramps and access as well as teacher aides. This event was a turning point for the principal who became a great advocate for his students. Some of the parents have since taken up advocacy roles in the health, education and disabilities sectors,

and at least seven returned to adult education and have qualified in various degrees and returned to paid work in this sector.

In my second story, in 1988 Palmerston North Hospital provided an incontinence service to children with disabilities and offered informal support to families. This contribution was of extreme value to families that were already stretched with the care of the child. However, all hospital managers were asked to make a 10% budget cut, and the community manager chose to delete this continence service. I was one of those families affected—my eldest son was nine and would have a lifetime of incontinence ahead of him. At that time I was also studying at Massey, and the lecturers offered to assist families to design a strategy to help our situation. Through the media we informed the hospital board that we would attend the next meeting with our child without their incontinence aids (nappies)—meetings generally lasted for at least two hours. This action would have come at a personal cost to our children's dignity and we did not carry this out. This is an illustration of the lengths to which mothers may need to go, and the risks they had to consider for the long term dignity of the children. However, as a result of our work, the service was reinstated two days before the public meeting.

At this point the group had also discussed radical action. We wanted to make clear that our losses, as unpaid carers, were equivalent to the loss of work resources to the hospital paid staff. Thus, we considered cutting off the power plugs of hospital photocopiers and seeing how long it took to find the resources to replace them. This form of subversion was not actually engaged in, but it was food for thought. Paid work is valued, visible, and resourced more than the unpaid work of caring for disabled adults and children. Unintended results from this activism were that other issues about resources from community health were identified. The manager of

these services resigned under the pressure of the issues that this group of advocate mothers had unearthed.

These stories are about power and resources and the needs of people with disabilities and their families. My experience over many years has taken me to places I would never have gone if not for my son's needs, and others for whom I have advocated. I have been supported by my lecturers at Massey, politicians, other advocates, family and friends. Advocacy requires passion and support of many to achieve best results.

This and other advocacy/activist experiences indicate that when we politely ask for help we often get turned down and are ignored. So we often only get action if we 'threaten' an unusual course of action; a manoeuvre that does not sit comfortably at all for many mothers, but again, we have to weigh up the risks, long term and short term for our children.

For example, as co-author Anita Gibbs reports:

Help for my children has only come through when I have implied to the professionals that the children are physically harming me and that I plan to physically defend myself—probably with a frying pan. I would never do that but I let it be known that I might. Then help has been provided.

Illustrating positive action when disability is 'invisible'

Those who live with invisible disabilities face unique sets of challenges. As with her work recounted above to get disability recog-

nised and responded to, Anita describes work she has undertaken so that the invisible disability of her children is understood. However, families face the dilemma of disclosing such disabilities or risk having needs go unmet:

Fetal Alcohol Spectrum Disorder (FASD) is a lifelong brain-based disability affecting up to one in 100 children in Aotearoa New Zealand.³² It is a medical disorder that has only recently been acknowledged, though it has been with us as long as alcohol abuse has. FASD results from the foetus being exposed to alcohol in the womb. Research shows that there is no safe limit for alcohol consumption during pregnancy,³³ and public health prevention campaigns are built around this message. As a disability FASD is 'hidden' in that only 4% of people with it have obvious physical features,³⁴ but it results in significant impairments socially, cognitively and behaviourally.³⁵ The economic costs to the nation are staggering,³⁶ yet these are the tip of the iceberg as the costs of secondary disabilities arising from having an FASD, like exclusion from education, involvement in the justice system, significant mental health co-mor-

32 FASD Working Group, *Taking Action on Fetal Alcohol Spectrum Disorder: 2016-2019: An Action Plan*. (Wellington, New Zealand: Ministry of Health, 2016).

33 Ministry of Health, *Taking Action on Fetal Alcohol Spectrum Disorder (FASD): A Discussion Document*, (2015). Retrieved from: <https://www.health.govt.nz/system/files/documents/publications/taking-action-fetal-alcohol-spectrum-disorder-discussion-document-dec15.pdf>.

34 Julia Brown and Mary Mather, 'Fetal Alcohol Spectrum Disorder: Parenting a Child with an Invisible Disability', (Oxford, UK: FASD Trust, 2014); Sterling Clarrén, Celeste Halliwell, Christine M. Werk, Rolf J Sebaldt, Annie Petrie, Christine Lilley and Jocelynn Cook, 'Using a Common Form for Consistent Collection and Reporting of FASD Data From Across Canada: A Feasibility Study', *Journal of Population Therapeutics and Clinical Pharmacology*, 22 (2015): 211-28.

35 Svetlana Popova, Shannon Lange, Larry Burd and Juergen Rehm, 'Burden and Social Cost of Fetal Alcohol Spectrum Disorders'. *Oxford Handbooks Online*, (2016 September).

36 Brian Easton, Larry Burd, Juergen Rehm and Svetlana Popova, 'Productivity Losses Associated with Fetal Alcohol Spectrum Disorder in New Zealand', *New Zealand Medical Journal*, 129 (2016): 72-83.

bidities, and alienation from family, cannot be quantified. Another 'hidden' cost is the stigma faced by birth mothers of children with FASD. Virtually no mother wants to harm her unborn child, and birth mothers often feel ashamed and find it hard to seek help. Many of the children with FASD are adopted or fostered but some birth mothers do face the harsh realities of unintentional harm and they will actively advocate for the needs of their children to be met.

For 20 years, parents, grandparents, foster caregivers and professionals have been campaigning to get FASD acknowledged and supported as a neuro-disability in need of action to support individuals and families.³⁷ My story, as a mother of two Russian-born children with an FASD, offers some insights into how academic mothers both advocate within existing systems, while battling to change them. In 2007, we adopted our boys from Russia and for the last 10 years we have been aware of their disabilities and challenges, most of which have got worse as discriminatory systems of education, social welfare, and societal discourse have impacted upon the whole family. Research in Aotearoa New Zealand echoes our own family story with stories of family distress, professional ignorance and wrongful convictions.³⁸

The 'daily grind' of living with children with a disability requires energy, tenacity and mindfulness; without these none of us would get through one day let alone try to change the world around us for

37 Anita Gibbs & Kesia Sherwood, 'Putting Fetal Alcohol Spectrum Disorder (FASD) on the Map in New Zealand: A Review of Health, Social, Political, Justice and Cultural Developments', *Journal of Psychiatry, Psychology and the Law* (2017): 1-18, accessed May 3, 2017.

38 Kerryn Bagley, 'Fetal Alcohol Spectrum Disorder Diagnosis and Intervention: An Investigation of Professional Practice in New Zealand' (PhD diss., University of Otago, 2013); Gibbs and Sherwood, 'Putting Fetal Alcohol Spectrum Disorder (FASD) on the Map'; Jenny Salmon, *The Experiences and Views of Individuals with Fetal Alcohol Spectrum Disorder: A New Zealand Approach*, (New York, NY: NOVA, 2014).

our children, and others with similar struggles. As an academic, registered social worker, and mother, my everyday lived experience has become fuel for research, networking, advocacy and activism. Not one day passes where I am not reaching out to the macro from my micro level reality. My colleagues at work get a daily review of what FASD was like for breakfast, and what it will be like for tea. They are well educated in this disability! My students get FASD 101 in any lecture I can throw at them—in my field this is critical, as these are the ‘wannabe’ social workers, psychologists and lawyers, who, in a few years, will be dealing with boys and girls like mine and making ignorance-based decisions, as many professionals have done before them. So, I have to teach them about FASD as no-one else will! I spend a lot of time doing public awareness raising workshops to professional groups locally, and networking nationally and internationally. All of this effort is directed towards enhancing awareness, helping other families, and reducing societal intolerance towards those with an FASD, and the stigma felt by those with an FASD. I do it because I am fired up by social injustice that blames disabled children and their families for having an impairment. I don’t see myself as having any options but to do this, as there is so little acknowledgment of FASD as a major issue in Aotearoa New Zealand but, as we estimate that up to 20% of the prison population and 50% of the care population might be affected by FASD and other neuro-disabilities, we have to get active.

At the local level, I helped set up Dunedin’s first parent support group for FASD and we have been running this since late 2013. We only have a few members, but we share our trials and tribulations and we plan how we are going to advocate for our families to get the help they need from Dunedin’s social, correctional, and health services. A number of our parents made submissions to the government on the need for FASD to be recognised and for diagnostic and

intervention services to be made available.³⁹ A number of parents have also joined FASD-CAN, a national on-line support group dedicated to supporting and advocating for families.⁴⁰ I have assisted in developing local assessment and diagnostic capacity; this has included inviting international speakers and trainers on FASD to Aotearoa New Zealand. I have travelled to other parts of Aotearoa New Zealand and overseas to promote better awareness and good policy and practice in this disability field. My children have contributed to some of the presentations I have given; this has been about helping them find their voice and promote better understanding of the need for action (now and not later).

This is radical work because it starts as a bottom-up action for individuals, but in relationships with others who suffer, it becomes collective activism where we refuse to take no for an answer. We have written to our MPs, we have made submissions to Parliament, we post and blog on social media, and we give media interviews and contribute to radio broadcasts. For me, it's all about human rights, children's rights and disabled persons' rights.⁴¹ What and where are the rights of those with FASD? The key message is that 'no child with FASD chose to be born with permanent brain damage and life-long impairment, so why do we treat them as if they did and blame them for their disability?' Part of this message appears at the end of my email signature. It wouldn't be there if I wasn't a mum to

39 FASD Working Group, *Taking Action on Fetal Alcohol Spectrum Disorder: 2016-2019: An Action Plan*, (Wellington: Ministry of Health, 2016).

40 Anita Gibbs & Kesia Sherwood, 'Putting Fetal Alcohol Spectrum Disorder (FASD) on the Map in New Zealand: A Review of Health, Social, Political, Justice and Cultural Developments', *Journal of Psychiatry, Psychology and the Law* (2017): 1-18.

41 CRPD, Convention on the Rights of Persons with Disabilities, 2006 accessed 25 July 2017, <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>; UNCROC, *United Nations Convention on the Rights of the Child*, 1990 accessed 25 July 2017, <http://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf>

two children with this disability, and it wouldn't be there if I didn't care about advocating on behalf of, and supporting, all families in Aotearoa New Zealand where FASD has impacted their lives. The fight continues.

Illustrating positive action when disability is 'visible'

While invisible disabilities present particular challenges, so do visible disabilities. Gretchen Good, mother of two children with Down syndrome, recounts a recent battle she encountered as a result of her children's visible impairments:

A few weeks ago, at an outdoor town festival, my son was denied access to play equipment because of his facial features, which clearly announce to the world that he lives with Down syndrome. The operator told us that due to new health and safety regulations, anybody with 'a mental or physical disability' could not play on the equipment. Our eight-year-old son was physically removed, by the operator, from playing, although the operator was willing to let our daughter, aged five years, climb onto the equipment, because her facial features are not so pronounced and he did not recognise that she too has Down syndrome. I was angry and told him this was illegal in Aotearoa New Zealand. He clearly felt his hands were tied by regulations. We had to try to walk away, consoling our son, who was very distraught and did not understand what had just happened.

I alerted my friends in the local disability community, through Facebook, about what had happened and I contacted the City Council, who sponsored the event, and the event organisers. Friends immediately went on a campaign to complain or question this practice

through Facebook and emails. The City Council and event organisers either did not respond at all or politely passed me on to the other party. The Human Rights Commission did, however, understand the situation to be a clear violation of rights and backed me, should I have chosen to make a formal complaint. The play equipment company is a small, family business which I did not wish to harm, and so I declined interviews with newspapers, choosing to work with the parties who could actually fix the problem. Within a few days the operators announced publicly that they had been educated, that Aotearoa New Zealand law overrides overseas manufacturer guidelines for access to their play equipment and that they would be operating more inclusively in the future. This was a victory of sorts. My children and others should not be denied access to equipment they are capable of playing on in the future. However, this all came at a cost. The distress to my children and family lasted for days. Not just the stress of the event, but the advocacy and activism took a toll on our family too. Trying to go through official channels took up precious family and work time, yet had little effect. It was the other mothers of disabled children and disabled adults who took up the cause and vocalised their opinions on social media that pushed the operators into shutting down their Facebook page dedicated to that festival and investigating and changing their policies.

It should not be this hard.

Working for positive change in relation to inclusion for our disabled children can involve advocacy, and activism, and we do see positive results from our efforts, even though such effort can come at personal and family expense.

Conclusion

The topic of mothering disabled children is an unexplored area and the strength and advocacy power of mothers is largely overlooked in disability literature. Existing literature seems to be stuck at grief, loss, adjustment, and stress related to parenting disabled children. We wish to go beyond this pathologising and medicalising of disability and parenting to embrace and acknowledge our love for our children, our acceptance of their impairments, our healthy, respectful parent/child relationships, and our struggle to change systems, policies, and structures so that our children and families can lead quality lives. We hope to improve our skills in standing up for our children's rights. As Stace states:

We don't yet have an inclusive society in which diversity is respected and celebrated. Disabled people, their families and advocates are still constantly fighting for appropriate services and supports so they can fully participate in the citizenship of Aotearoa New Zealand.⁴²

Following on from our autoethnographic accounts, we have a set of key recommendations for advocate and activist mothers and professionals working with whānau living with disability. Our first recommendations are to mothers of disabled children. We think a good place to start is to recognise yourself that advocacy and activism on behalf of your disabled child is time-consuming, difficult, requires tremendous skill, time and patience and that your work is likely to be unacknowledged. So take care of yourself. Know that you are not alone. Find communities of support from other mothers of disabled children to find support and direc-

42 Hilary Stace, 'The Long Unfinished Journey Towards Human Rights for Disabled People in Aotearoa New Zealand', *Human Rights Research Journal*, 5 (2007): 1–13.

tion. You will need support so that your work can have valuable impact for not only your child and family, but for others who will enter the same confusing education, medical and social systems. These systems need to be changed. Value your skills and your contributions and those of other advocate and activist mothers, because society may not acknowledge your contribution. But you can find your work rewarding nonetheless. The challenges of parenting and advocating can occupy the same space as joy and fulfilment in parenting—we do see results. Poorly run institutions have been closed, inclusion in schools has been attained, human rights have been defended and attitudes toward disability have been improved as a result of mothering, advocacy and activism.⁴³

For educators, medical professionals and others who work with families, we recommend recognising and supporting the skills of advocacy and activism among mothers of disabled children. We want you to help create space for our voices. Mums can make an impact and change systems in a way that benefits many and there are many barriers that need to be conquered with your help.⁴⁴

Our collaborative group has explored areas that disability literature has not; the intersections of mothering, academia, advocacy and activism. We encourage further research in this area. We also suggest further research be pursued to identify what motivates mothers to use their skills in advocacy to become activists on behalf of others living disabled lives, and how solidarity can work for mothers to ensure that their skills and knowledge translate to positive action and outcomes.

We work towards an inclusive society that recognises our children's value. Educational, workplace and social inclusion

43 Melanie Panitch, *Disability, Mothers and Organizations: Accidental Activists*. (New York: Routledge, 2008).

44 Brian Watermeyer and Judith A. McKenzie, 'Mothers of Disabled Children: In Mourning or on the March?' *Journal of Social Work Practice* 28 (2014): 412.

benefits everybody. Best practice in all of these areas involves promoting diversity, social justice and anti-discrimination. We dream of having the time, space and resources to enjoy our families and we dream of having the skills to help our children and others too.

Hütia te rito o te harakeke, kei whea te korimako e kō?
 Ka rere ki uta, ka rere ki tai.
 Kī mai koe ki au, he aha te mea nui i te ao?
 Māku e kī atu, He tāngata! He tāngata! He tāngata!

A close translation runs as follows:

If you pluck out the flax shoot, where will the bellbird sing?
 It will fly inland, it will fly seawards.
 If you ask me, what is the most important thing in the world?
 I will reply, People! People! People!

The proverb refers to the importance of nurturing the next generations in order for the whole whānau and community to survive. In order for whānau hauā to support the next generation, advocacy and activism ensures their wellbeing is sustained.

If you like what you have read, please subscribe or donate.



COUNTERFUTURES

Left thought & practice Aotearoa

© Copyright Counterfutures 2017