

# Everyday activism: Parental places and emotions of disability activism in Wellington, Aotearoa New Zealand

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**Abstract:** This article considers the everyday spaces and places of disability activism for parents of disabled children in Wellington, Aotearoa New Zealand. Geographers and disability scholars are yet to consider disability activism in a range of everyday child-parent spaces. Parents resist, rework, and subvert

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ableist structures and spaces in ways that may seem unremarkable, but are indeed, significant acts. We question the meaning of activism by examining the relationship between 'activism' and 'everyday family lives'. Sara Ahmed's concept of 'affinity of hammers' is adopted to understand how parental disability activism is enacted in health, educational, and disability spaces and places. Interviews and written responses from seven parents (five mothers and two fathers) of disabled children are analysed. Findings are divided into three themes: first, quiet, implicit forms of activism; second, fighting for rights and equitable access; and third, using personal experience to educate people about disability rights. We conclude that family disability activism - in its myriad forms – can provide leadership to other people, challenge ableism, and help geographers and others to rethink common understandings of activism.

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## 1 INTRODUCTION

Traditional accounts of activism are often characterised by staged acts of public resistance that are “grandiose”, “iconic”, and “unquestionably meaning-ful” (Horton & Kraftl, 2009, p. 14). Constructing activism in this way means the experience is out-of-reach to ‘ordinary’ people and the issues, politics and spaces that inform their daily lives. To understand more about the everyday embodied and emotional geographies of activism, this article focuses on the disability activism of seven parents in Wellington, Aotearoa New Zealand.

Everyday ableism creates the sociocultural conditions for disability activism. Ableism refers to “ideas, practices, institutions, and social relations that presume able-bodiedness, and by so doing, construct persons with disabilities as marginalized, oppressed, and largely invisible ‘others’” (Chouinard, 1997, 380). Ableism is part of structural sociocultural power relations that creates spaces fit for supposedly autonomous people with ‘able’ bodies and minds (Goodley and Lawthom 2019; Gahman 2017), and it is felt as a profoundly personal and embodied experience (Morrison et al., 2020). Non-disabled parents who have a disabled child are placed within, and intimately connected to, ableist socio-spatialities, such as within home, health, and education spaces. These embodied socio-spatialities can fuel a desire to act for positive social change.

Through everyday informal and formal acts of resistance parents challenge ableism. Everyday family disability activism is often “small-scale, personal, quotidian” (Horton & Kraftl, 2009, p. 14), that is, acts that take place in and around the everyday spaces of family including the home, school, and wider community. These acts can be everyday embodied

practices of resistance that make modest contributions to tackling social and spatial injustices experienced by disabled people (Pottinger, 2017). While geographers have begun to focus their attention on a much wider range of activism, this has not yet included a focus on the different ways that parents resist, rework, and subvert ableist structures and spaces. There is little known about the everyday embodied and emotional activist geographies of parents who have a disabled child.

Drawing on findings from a collaborative project between Disabled Person's Assembly (DPA),<sup>1</sup> Imagine Better<sup>2</sup> and the University of Waikato,<sup>3</sup> this article questions the boundaries of activism by looking at the relationship between activism, emotions and everyday parental places and spaces. By focusing on parents' everyday disability activism, we show that these everyday acts of resistance, while seemingly banal and trivial, are politicised, affirmative, and potentially transformative. Parents can be powerful forces for positive social change against discrimination (Luzia, 2010; Valentine, 2008), but geographers have yet to consider parents' responses to ableism. At different times and in different places, some family members may initiate, take up, or refuse opportunities for resistance and activism (Pain, 2014). Emotions are key to whether family members, in this case parents, choose to engage, or not, in disability activism (Askins, 2019).

This article builds on previous research in social and cultural geography that examines local, quiet, implicit and embodied activism (Horton & Kfaftl, 2009; Maynard, 2018; Pain, 2014; Pottinger, 2017) by focusing on the everyday embodied spaces, places and emotions of parental disability activism. In particular, this article invokes Sara Ahmed's (2016) notion of 'affinity of hammers' to understand how parental disability activism affects social change. Ahmed (2016, p. 22) contends that when our embodied places in the world are questioned by others we experience "a chip, chip, chip, a hammering away at our being". But, as she explains, to experience a hammering is also "to be given a hammer, a tool through which we, too, can chip away at the surfaces of what is, or who is, including the very categories through which personhood is made meaningful" (Ahmed, 2016, p. 22). Ahmed views this 'reciprocal hammering' as an affinity that considers how embodied position(s) afford privilege. This means that it is possible to have no direct experience of hammering – because of embodied privilege – whilst still being able to participate in chipping away at oppressive systems. While Ahmed uses this idea to discuss transphobia within feminism, we think the idea has relevance for thinking about parents' everyday disability activism. While not experiencing

first-hand the impacts of living with disability, parents experience ableism through the relationship with their disabled child/children and can use disability activism to chip away at it.

This article begins with a review of literature on activism, focusing on disability, families, parents, and emotions. It then moves to provide detail on activist research methodologies used to carry out this research. The remainder of the article explores the everyday disability activism of seven parents of disabled children from Wellington, Aotearoa New Zealand. Families can be powerful forces for prompting positive social change and challenging ableism. They can provide leadership to other families, challenge ableism, and help geographers and others to rethink common understandings of activism.

## **2 ACTIVISM AS EVERYDAY, EMBEDDED AND EMOTIONAL**

While traditional framings often define activism and activists in masculinist terms, feminist, social and cultural geographers have identified the significance of ‘quiet politics’ of activism (Askins, 2015; Johnston, 2017; Martin et al., 2007; Pain, 2014; Pottinger, 2017). Underlying this work is the notion that the collective impact of small acts of resistance are embedded within everyday lives and spaces. These accounts draw out the partial and emergent aspects of formal and informal activism, which do not depend on a linear, intentional progression from everyday lives to political movement in order to ‘count as activism’ (Chatterton & Pickerill, 2010; Horton & Kfaftl, 2009). Key to this work is the importance of interpersonal connections and social networks in everyday activism (Martin et al., 2007). Everyday affective bonds and acts constitute activism and commitment to social change. How people experience and feel about the world and their places within it is often an important catalyst to strive for change. Geographers have demonstrated the importance of the felt, affective, experiential, and interpersonal dimensions of ‘doing activism’ (Brown & Pickerill, 2009a, 2009b). It is not simply a case that emotion matters, but there is a politics of emotion when thinking about activism (Wilkinson 2009). Emotions are embodied, collective and political, and therefore central to the construction of socio-spatial relations that lead to community activism. Emotions are “bound up with the securing of social hierarchy” (Ahmed, 2014, p. 4) and they are also enmeshed in destabilizing social hierarchies (Wilkinson, 2009).

There has been scant attention paid to the geographies of disability activism. The work that has focused on disability activism has often focused on spatial scales of the nation, state, and globe. Drawing upon case studies in Canada and Ireland, Kitchin and Wilton (2003) analyse how disabled people, organise and attempt to scale up their activism to effect broader change and create new scales for political action. Also in Canada, Chouinard (2005) examines how disabled women contest barriers to engaging in activism both in the women's and disability rights movements at national and international scales. Using data from mental health activists working in Manchester, UK and Auckland, Aotearoa New Zealand, Milligan et al., (2011) illustrate how autobiographical narratives enable insights into participants' activism, and how these are shaped and shaped by, particular places both inside and outside 'the system'. We build upon this work by focusing on family disability activism that happens at the sites of the body, home, neighbourhood, and community.

Since the 1970s there has been considerable growth of disability politics and activism. Through a mix of activism, advocacy, research, and policy, disabled people have revised traditional medicalised understandings of disability as individual pathology to a system of social oppression and exclusion. Disability activists have achieved important gains in education, legal protection against discrimination, and modification of the built environment and transportation. Practices of self-advocacy enacted by disabled people across a range of spaces and places, as individuals and as part of self-advocacy groups, and in both formal and informal ways, have challenged ableism and disability discrimination (Anesi, 2019; Fudge Schormans et al., 2019; Goodley, 2005). Disabled Person's Organisations (DPOs) play a crucial role in challenging the discrimination disabled people experience. In Aotearoa New Zealand, DPOs work with government, disability support services, the media, and the general public in an attempt to ensure that disabled people are actively involved and contributing to decision-making processes on issues that affect them.

Families and family organisations often hold a contentious position within disability activism. Family members' - including but perhaps especially parents - (often) non-disabled status propels them into debates about the role of non-disabled people within the lives of disabled people and disability rights. At times, families are constructed and experienced as an ally to disability rights, while at other times, they are constructed and experienced as perpetuating paternalistic and medicalised models of disability (Carey et al., 2020). Mothers, in particular, often hold a troublesome position within disability activism with research

showing they can both challenge and reinforce ableism (Runswick-Cole & Ryan, 2019; Ryan & Runswick Cole, 2008). Some activist mothers contribute to the disability rights movement through academia, activism, and advocacy (Good et al., 2017); forming national organisations (Panitch, 2008); and, working in disability-related public service/government (Traustadottir, 1991). There is limited research on father's experiences of having a disabled child, and in particular on father's disability activism. While parents are the focus of this article, siblings, and other family members, as well as friends and carers, also play important, but not well-understood roles, in disability activism. We build on this body of work through considering the lived, felt, and everyday acts of resistance that parents use to chip away at ableism and normative notions of disability (Ahmed, 2016).

### 3 METHODOLOGY

The material in this article is drawn from a wider project on the embodied and emotional geographies of disability and (not)belonging (Morrison et al., 2020). Two of us – Carey-Ann and Esther – work at disability rights and advocacy organisations and two of us – Lynda and Robyn – work at a university. All four of us are engaged in activist research and/or research activism. We came together around our shared interest in conducting research that leads to equitable places and spaces, and that demonstrates the personal is always political (Worth, 2008).

Critical reflexivity is important to activist geographers and activist geographies. We are aware of our positions and the ways they impact our activism and research. Carey-Ann is a parent to a young disabled son and Esther is disabled. Neither Lynda nor Robyn identify as disabled. As a child and young adult, Lynda was involved in the care of her mother who lived with many physical impairments. Lynda and Robyn have, for over two decades, conducted research with individuals and groups who experience identity-based discrimination or inequality. All of us have, in different ways, experienced discrimination based on different aspects of our embodied subjectivity. Our activism is therefore personal, embodied, and emotional (Askins, 2019).

The project is co-produced and reflective of disabled people's lives and community needs (Fudge Schormans, et al., 2019; Holt, et al., 2019). Ethical approval was granted from the Human Research Ethics Committee at the University of Waikato and empirical data gathering took place between August 2018 and June 2019. We worked with disabled people

throughout all stages of the research. Data were collected through a combination of four individual and three focus group interviews, and two written responses from 12 disabled people and three families of disabled people in Aotearoa New Zealand. Some people chose to use pseudonyms and other people chose to use their names.

Of the family members involved, five are mums, and two are dads. One mum and one dad identified as disabled, while the other parents did not identify as disabled. All parents are cisgender, and all but one is married and/or in heterosexual relationships. Individual and small focus group interviews were co-facilitated by Carey-Ann and Esther. Shared experiences of disability and ableism meant that Carey-Ann and Esther were able to contribute their experiences of (not)belonging to the research. Interviews were audio-recorded and transcribed, resulting in more than 130 pages of interview transcripts. Thematic analysis was used to scrutinise data (Braun & Clarke, 2006). The lived realities of seven parents who participated in the research, including autoethnographic accounts, provide the basis for this article, and it is to these experiences that we now turn.

## **4 EVERYDAY EMBODIED AND EMOTIONAL ACTS OF RESISTANCE**

### **4.1 Parents' daily hammering against normative notions of disability**

Across a range of everyday spaces, including schools and healthcare settings, parents negotiate ableist attitudes and built environments. On a daily basis, parents deal with inadequate supports, negotiate complex bureaucratic government, health and education systems, and face a raft of ableist obstacles that discriminate against their disabled child (Goodley & Lawthom, 2019; Green, 2007). As Bernadette, 55–64 year old mum and Tony, 55-64 year old dad to an adult daughter who has learning disabilities demonstrate, the embodied and emotional effects of hammering on families are significant:

**Bernadette:** I often feel as a [non-disabled] parent, like I feel disabled by society.

I'm not a disabled person so I don't feel disabled in the same way, but having to witness and then advocate and try and make things better and all that, I feel it is an experience of being discriminated against, even though it is actually Maggie-Rose [daughter] that is more being discriminated against. I've been really mentally unwell over the years because of that, because of feeling that isolation and wanting things to be better and they're not.

**Tony:** And, beating your head against a brick wall. You said to me the other day something like, “The forces that disable Maggie-Rose also disable our family in lots of different ways.” (Focus group 10 November 2018)

Bernadette and Tony highlight the hammering families of disabled children can experience by having to engage constantly with ableist socio-spatial relations and normative categories of disability (Ahmed, 2016). Bernadette experiences a relentless chipping away at her being through having to ‘witness’, ‘advocate’, and ‘try make things better’ for Maggie-Rose and their family. The emotional impacts of ableism (Ryan and Runswick Cole, 2008) and the emotional labour of activism are deeply felt (Bosco, 2007; Brown & Pickerill, 2009b). At the same time, Bernadette’s everyday acts of family disability activism chip away at ableist norms, structures, and spaces. Bernadette is involved in a range of acts across different spaces and places to help bring about positive social change, including supporting other families with disabled children to transition out of school, sharing her experiences through academic writing, and supporting Maggie-Rose to participate in her community.

When asked about her participation in disability activism, Janiqua, 25-34 year old mum to a child with Down syndrome explained that she doesn’t engage in ‘big’ acts of resistance – she notes: “I don’t have the fucking time and energy for that.” Instead Janiqua focuses her attention on “the constant slow battle of small things”. Some of the everyday informal acts of resistance Janiqua engages in include sitting on the board for a family community group, providing one-on-one support to parents of new babies with Down syndrome, and ‘speaking out’ about ableist representations of disabled people:

There was this Health & Disability Commission poster [displayed at a public hospital], it had an awful picture of a lady with Down syndrome and she was wearing thick-as glasses and had a really bad haircut. I emailed them [the Health and Disability Commission], and I was like, ‘please can you update this photo?’ ... and like I know a lot of people with Down syndrome that don’t look like that, you know? You wouldn’t put an unattractive picture of a [non-disabled] person on a regular poster, so like why would you do that on a disability one? But, yeah, they didn’t email me back. (Janiqua, Focus group, 15 October 2018)

Often parents' disability activisms are small repetitive acts that happen through the ordinariness of encounters with others. Encounters between disabled and non-disabled people often create the socio-spatial context in which family disability activism occurs. It is during encounters that normative notions of disability are reproduced, challenged, and felt (Calder-Dawe et al., 2020). Carey-Ann has a tee-shirt with a print of accessibility symbols and the statement 'Access Matters' that she often wears out in public community spaces where ableism is acutely felt, such as the supermarket and school. During encounters, people often ask questions about the tee-shirt providing her with the opportunity to problematise normative notions of disability and subtly chip away at ableist encounters and spaces. Bernadette reflects on the ways she subtly challenges medicalised and pathologised discourses of disability that people sometimes inscribe upon her daughter during encounters in public spaces, like on the street:

Sometimes people say to me, "What's wrong with Maggie-Rose," [referring to her disability] and I go, "nothing." Sometimes I just say nothing. But other times, I'll say, "She's had a cold recently, but she's fine now." (Bernadette, Focus group 10 November 2018)

This small act of resistance - refusing to engage over and over again in encounters that pathologise her daughter - performed by Bernadette is an example of an informal and implicit activism that proceeds with 'not too much fuss' (Horton & Kfaftl, 2009). That she makes a choice about whether she offers a challenge to their assumptions about disability, highlights the relational nature of family disability activism. Socio-spatial contexts, such as the ways people respond to or react towards disability in public spaces like the street (Butler and Bowlby, 1997; Hall, 2019; Ryan, 2005), shape the decisions parents make to initiate, take up, or refuse opportunities for resistance and activism.

#### **4.2 Fighting for rights and equitable access**

Sometimes parental disability activism happens because parents feel their disabled child's needs are not being met or rights upheld. Stories of needing to fight for adequate support across education, social and health spaces and services dominate families' accounts of their lives (Panitch, 2008; Traustadottir, 1991). An ableist logic constructs disabled bodies as less deserving of appropriate and adequately funded government and social support (Goodley & Lawthom, 2019). Reflecting on an instance of parental disability activism within a healthcare

space, Anna, 25-34 year old mum to a young daughter who has Down syndrome, explains that she had to fight to have her daughter's medical condition (unrelated to Down syndrome) recognised and treated:

We knew something was wrong but had to fight them [doctors] to properly check because the doctor was saying that it [undiagnosed seizures] was just part of her, and that it was just how she moves because she has Down syndrome. I was like, "I've known this girl for six months and this is not her, this is not just related to Down syndrome." So, I had to really fight that. (Anna, Focus group, 15 October 2018)

These formal institutionalised healthcare spaces, which tend to locate 'expert' knowledge within healthcare professionals (Fisher, 2007; Ryan & Runswick Cole, 2008), chip away at Anna's being. Anna's embodied knowledge of her daughter's health is disregarded, and her daughter's physical ill-health is dismissed as disability-related. In this instance, Anna's disability activism involves a struggle for rights and equitable access to healthcare. By exercising her expert knowledge about her daughter and her daughter's impairment, Anna resists some of the unequal power relations and ableist underpinnings of this healthcare space.

Bernadette also talks about having to fight for rights, particularly in education spaces. She recounts how she had to fight to have Maggie-Rose's contribution as a 'peer-supporter' recognised as of equal importance as the contributions of non-disabled students. Maggie-Rose and the other disabled students were given certificates for being an 'assistant peer-supporter', which Bernadette feels is devaluing and discriminatory:

I challenged them [the school] about it and after a couple of years they recognised that those kids were contributing just as much as any other student, but they were stuck in that idea of it's this particular role and you do it in this particular way and you have to be able to meet these criteria in order to be a 'proper' one [peer supporter]. (Bernadette, Focus group, 10 November 2018)

It is well documented that school spaces can be disabling for students with mind and body 'differences' (Holt, 2003, 2004, 2010). Within school spaces, disabled children are routinely

measured against an able-bodied norm that locates disability within their ‘abnormal’ bodies and minds. Recognising the ways in which such discourses are inscribed upon Maggie-Rose, Bernadette challenges the idea that to be a ‘proper’ peer-supporter, students must perform – act, look, move, and sound – in specific non-disabled ways (Goodley & Lawthom, 2019). Later-on in the interview, Tony talks about how parents face problems engaging with schools when they challenge normative ways of doing things:

We very quickly labelled a ‘stropky parent’ and that immediately means you are definitely ‘other’; and there was ‘good parents’ and ‘bad parents’ ... as soon as you started complaining or to assert, or even to be emotional in actual fact. There were times particularly Bernadette when you got emotional in those ridiculous IEP [Individual Education Plan] meetings ... just even a display of emotion ... immediately you get this push and how can you belong? (Tony, Focus group, 10 November 2018)

Tony and Bernadette’s expertise, embodied knowledge and emotions as parents are considered out-of-place at school. Their attempts to chip away at the discriminatory systems within educational spaces were seemingly outside the boundaries of what is deemed to be ‘good parent’ behaviour (Vincent, 2017). This highlights some of the social and emotional risks associated with family disability activism across different spaces.

### **4.3 Everyday education**

Educating people about the needs, rights and contributions of disabled people is an important way that parents challenge ableism. Carey-Ann, for example, shares different parts of her story of parenting a young son with Down syndrome across a range of educational spaces to contribute to progressing the disability rights agenda. She uses academic writing to reflect upon the personal geographies of disability and care (Morrison, 2021), participated in a television doco-series to raise awareness about parenting a child with Down syndrome, and uses personal experience to inform teaching and conference presentations.

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Janiqua talks about creating a resource about Down syndrome and gifting her daughter's school a book to help educate the children and staff about Down syndrome and what it means for her daughter:

On International Down syndrome Day, we showed a PowerPoint about Down syndrome at school to explain that stuff ... It was really good, and they [teachers] showed it to all the junior syndicate, and then I had some of [name's] friend's older siblings come up to me at the [school] disco, and she was like, "Does [name] have Down syndrome?" and I was like, "Yeah." She was like, "Okay." And it was a cool thing, they showed things that were cool about it, and some of the not so cool things, like it's cool she can do the splits; she was super famous because she could do the splits and she had Down syndrome, and all the girls at that gym were all envious [laughter]. (Janiqua, Focus group, 15 October 2018).

Anna also talks about educating others about Down syndrome. She reflects on another time when her daughter was admitted to hospital and the doctor asked her if she was happy for trainee doctors to observe her examination:

We wanted them [student doctors] to learn about Down syndrome, but also seizures because it's so rare, just so that they knew it if they came across it ... but then [the doctor] was just sort of like, "Look at her flat face." Like, the way that [the doctor] just started talking about her was just like, oh my ... and did it in front of us. It was like this was a chance for the doctor to do it in a real positive way but they didn't. But then we got to have our say. We got to do some of that positive stuff. (Anna, Focus group, 15 October 2018).

Anna describes a moment of reciprocal hammering that takes place within a healthcare space that objectifies and pathologises her daughter. By taking the opportunity to talk about the experience of having a baby with Down syndrome beyond medicalised and deficit-based understandings, Anna chips away at ableist discriminatory systems and attitudes in the healthcare system (Ahmed, 2016).

## 5 CONCLUSION

The everyday ways parents challenge ableism may seem at odds with typical understandings of activism. Yet these everyday acts of resistance are a particular type of quiet and embodied activism (Martin et al., 2007). Drawing upon the lived experiences of seven parents of disabled children, and autoethnographic accounts, this article contributes to a body of geographical work that expands the notion of “activism” beyond public, large-scale and purposefully demonstrative protest.

Ahmed’s (2016) notion of ‘affinity of hammers’ is used to think about parents’ everyday embodied and emotional acts of resistance as informal and formal disability activism. Non-disabled parents do not directly experience the discriminatory impacts of living with disability, but they experience the impacts of ableism through their relationship with their disabled child. Families’ everyday disability activism represent a ‘chipping away’ at ableist relations and structures (Ahmed, 2016).

While the parents in this research didn’t tend to call themselves “activists” or refer to their actions as activism, our research illustrates they are engaging in actions that contribute to positive social change around disability issues. Parental disability activism is often about parents working to carve out spaces and places that are more inclusive of their disabled child, and this type of resistance is routinely part of daily life. Sometimes their acts of resistance may be in response to inequitable treatment in educational or health spaces and parents feel forced to fight for their disabled child’s rights. At other times, parents share their personal stories or undermine discriminatory attitudes to educate people about disability and disability rights during everyday encounters.

We hope that academics and activists reading this article are inspired to consider the everyday ways they can engage in a reciprocal hammering against ableism. Challenging ableist structures, spaces and social relations is part of a broader commitment to social change around bodies, difference, and inclusion that can positively impact everyone. Families and allies of other people that experience marginalisation and discrimination because their minds and bodies don’t fit ableist spaces and places, such as older people and people living with dementia, might usefully think about how they can hammer away at ableism through everyday acts of activism. While the voices of disabled children are not present in this article, they are central to driving the direction of disability activism. Parent activism happens with

and alongside disabled people's self-advocacy and activism, and any study of disability activism must prioritise the lived experiences of disabled people. It is our hope that the lived realities of participants in our research can provide leadership to other people, challenge ableism, and help geographers and others to rethink common understandings of activism.

## ENDNOTES

1 DPA is a Disabled Persons' Organisation (DPO). It provides an active, independent voice of disabled people that reflects the aspirations, concerns, and rights of all New Zealanders who identify as having a disability.

2 Imagine Better is a collective of disability activists, advocates and allies working to be a nationally influential thought leader, trainer, research, and advocacy organisation supporting the growth and effectiveness of the disability rights, visibility and justice movements. Imagine Better is a partner in the Family and Whānau Leadership Alliance.

3 The University of Waikato's aims to contribute towards the benefit of society through the creation and dissemination of research, scholarship, and creative works. Creating inclusive spaces and an inclusive society that values disabled people as active, full, and equal participants is a focus for much research at the University.

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