Chapter 10

Disabled mothers of disabled children: an activism of our children and ourselves

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Abstract

This chapter arises from a personal conversation between two UK-based disabled mothers of disabled children, in which they explore how their circumstances have informed and shaped their activism. One found her way to activism through advocating for her child; the other found the onset of impairment in her child disrupted and, then, reoriented decades of activism. In this chapter, they consider the impact of their circumstances on the form and reach of their activism and their sense of themselves as activist; what this means for their children; what their experience offers to other disabled parents of disabled children in understanding their own possibilities for activism; and what their learning might mean for the wider disabled people's movement and for activism beyond.

Introduction

We are disabled mothers based in the United Kingdom (UK), one to a disabled child, the other to a disabled teenager. We are also long-time activists and this chapter has emerged from a series of personal conversations about what our parenting circumstances have meant for our activism. What has been the impact on its form and reach and on our sense of ourselves as activist? What does this mean for our children? What might our experience offer to other disabled parents of disabled children in understanding their own possibilities for activism? And what might our learning mean for the wider disabled people's movement and for activism beyond?

The points we make are not exclusive to being a disabled mother of a disabled child, but the knowledge and practices we discuss here have come to us directly through that experience. The commonalities and insights that have emerged will be relevant to others in similar parenting situations, including non-disabled parents. Disabled fathers, too, are likely to recognise aspects of their experiences in our account and, as parenting arrangements shift, we hope that they will add their voices to the conversation. Our children are both minors, but our responsibilities and the demands made upon us are likely to extend into their adulthood, and so our experiences may strike a chord with parents of adult disabled children too. However, the relevance of what we have learned extends beyond parents alone to a much larger activist community and practice.

Our intention here is to offer ideas and observations for others to think with: to recognise themselves in our experiences, to draw upon as they work alongside disabled parents of disabled children, and to consider as part of their own broader activist practice. For ease of reading, within this chapter we mainly refer to ourselves as disabled mothers, not disabled mothers of disabled children and young adults. Mostly, we choose to refer to our disabled child and disabled teenager as our kids, as this is what they are to us: wonderfully complex, maddeningly intelligent, fiercely adored kids, who exist in a complicated world.

Our lives as disabled parents of disabled children

How do we convey our lives: the extent to which we’re dancing around, spinning plates, firefighting? Every other week, there is crisis, and perma-pressure runs throughout. Always, there is the knowledge that we’re hanging in on goodwill and fury and, at any time, it can all come crashing down. Whilst writing this chapter, we have both faced round upon round of fending off our kids’ expulsion from education; nothing is certain and the future is scary for much of the time. The responsibility feels immense: fear that a word or action out of place might bring everything - our kids’ futures - crashing down. We know other disabled parents of disabled children who live similar lives.

In this chapter, we have not specified our kids’ impairments, partly because we have steered away from anything biographical about them, but also crucially because so much of what we are grappling with lies outside them and in the society we occupy. It is for this latter reason that we have included minimal information about our own impairments. In our encounters with professionals, who occupy so much of our lives, both our children's needs and their exclusion are often interpreted as character flaws - theirs or ours - and our activism can feel more like special pleading. The demands we make on behalf of our kids become entangled in assumptions about our fitness as parents and our unfitness as disabled women. Often, there is almost nothing left for anything intentionally activist – no time and energy that is not directly related to our kids' circumstances and nothing else to give - with the result that our activism depends on happenstance, a contribution made on of the coattails of any progress we make with and for our kids. In those moments where there is time and energy left over, sometimes all that matters is to enjoy it with our kids, to ensure that our sense of them, our relationship with them, is not subsumed by the larger context.

Whilst scarcity of time and energy is routine for parents, it is the additional battling, fending off and jeopardy running through disability that makes us forgo strikes and protests that we want to support and watch at a remove marches to celebrate a hundred years of partial-suffrage. Instead, we are responding to unscheduled challenges for our kids, responsibilities both domestic and work, to trying to manage our own health. Immediacy keeps us from rally and picket line, and our absence reinforces our invisibility.

This is the space from which we write this chapter. Our conversations might have stopped at therapy or camaraderie, except that we realised how much we have learned: knowledge and skills that are a gift to activism. We have become acute observers of human behaviour and detail, translators between languages (back and forth between social and medical models), champion negotiators, and managers of stress on a grand scale. But we have also learnt to grab activist moments and to recognise activism in spaces where we had not seen it before.

Campaigner, Advocate or Activist?

Our focus in this chapter is the activism that we engage in as disabled mothers - how it has been formed or shaped by our experiences – rather than a commentary on what we have learned about being a disabled mother of a disabled child. We are referring primarily to disabled people's activism (and, as we address below, that overriding focus can sometimes be a frustration), though much of what we write about can be applied more broadly.

We want to be clear about what we mean, as disabled mothers, when we refer to activism. Various terms are used to talk about the involvement, individual and collective, of parents of disabled children in accessing services. Terms such as advocate, campaigner and activist are used, at times interchangeably, but we consider they refer to distinct roles, albeit often overlapping and merging.

Advocacy, in our usage, is the act of supporting our children by being alongside them and, as Ryan and Runswick-Cole (2009) suggest, 'interceding' on their behalf. Self-advocacy is the tools we teach our children to act on their own behalf. Advocacy can be the personal or collective pursuit of solutions and progress for our own child or group of children, by urging, persuading and arguing for the everyday inclusion of our children. It can be an all-consuming role, yet primarily focuses on, or is driven in response to, the individual child.

Campaigning, as we use it here, is an activity that intentionally extends ambitions for change beyond the immediate needs of our own child and for broader benefit, e.g. marches and a petition to lobby for access to a play-space for disabled children. Undertaken by individuals or through informal groups or member organisations, campaigns work in an organised way towards specified goals.

Activism, here, often uses many of the same tools as advocacy or campaigning (letter-writing, petitions, marches, and so on, though also extending to methods that are more confrontational), but it does so with an understanding of the wider social and political context and relations of power in both we, as disabled mothers and disabled kids, as situated. It is overtly political, involving the pursuit of substantive structural change and cultural shifts. At its heart, is a shared understanding of the machinations, from neoliberalism to disablism, which create and constrain our life worlds and those of our children.

Whilst the three roles are intrinsically connected, as an advocate, we might pursue our child's access to a local play-space; as a campaigner, we might lobby to create a more widely community-accessible play-space; as an activist, we will challenge the deeper structures and principles that determine the comprehensive and permanent inclusivity of that play-space and of facilities beyond. Repeatedly battling for the inclusion of our kids, we find our own advocating almost inevitably crosses readily into campaigning and, in turn, into activism. The lines between the three blur constantly and each can contain aspects of the others, but for us, our activism is marked by an intention to go deeper and further into change.

Before we make more detailed observations on activism as disabled mothers, we chart our contrasting personal routes into activism and how they interweave with our experiences as disabled mothers of disabled children. For one of us, activism emerged through advocating for her child; for the other, the onset of impairment in her child first disrupted, and then worked to reorient, many years of activism.

Dawning of activism: Wendy's route to activism

My activism emerged from the shock of my lived experience as a mother of a disabled child in the UK. A dawning realisation of how little value is placed on the lives of disabled children and adults by everyone who is not disabled. An emerging awareness that impairment and disability had been the 'elephant in the room' throughout my life. That the depression I had experienced since adolescence, and which had seen me admitted to mental health wards on more than one occasion, meant that I too fitted the category of 'disabled'.

Growing up in the UK in the 1970s and 1980s, the message I received was clear: disability was something 'others' had; it meant being separated from the rest of 'normal' people as that was 'best for us all' and it was to be avoided at all costs. From the boy in our street who had Down syndrome and was bused to a special school every day, to several large hospitals nearby where adults with learning disabilities lived or those with mental health conditions were 'treated', I learned that disability meant strangeness, separation and exclusion.

When I started to struggle with depression, overwhelmed by a big black cloud which both paralysed and terrified me, I knew this was not good. I tried to fight against it, using food, alcohol, work, anything, to keep it at bay. My first admission to a mental health unit, the same big hospital I had learnt to fear in my childhood, was an abusive experience. Hard-faced nurses, who regularly aggressively restrained other patients, warned me of the dire consequences of not conquering my depression: if I failed to try harder and return to my 'normal' life, a life of prescription drug-dependence and worklessness awaited me. After discharge, I limped along for several years, before the black cloud consumed me again. My second experience of a mental health unit was more positive, this time I met some nurses and doctors who cared. For several years I was enveloped in the mental health system, as an inpatient, day patient, outpatient, a resident of supported housing, as I slowly ‘recovered.’ My friends also had long-term mental health problems; sadly, three took their own lives, and the rest struggled on with daily existence, trying to overcome our challenges. My eyes were opened: these were not people who needed to be separated, just nurtured, cared for, like me, wanting others to give us a chance to fully participate in life.

I felt transformed by this experience, and eventually I was keen to resume my career as a nurse, share my newfound wisdom and care for others. However, several visits to occupational health stopped me in my tracks. Yes, I was told, you have made great progress, but our priority is the patient, you can only come back when you have stopped your medication which will ‘prove’ that you are ‘better’. I understood: depression was seen as a flaw in my character, I was a woman with a ‘history of mental health problems’, a potential ‘risk’ to others, a person to be monitored, someone ‘other’ than the norm. I learned to hide my experiences, my time as a ‘mental health patient’, since it could bring harm, call my competence into question and, perhaps, end my career.

I engaged in life, fell in love and we decided to start a family. I was a ’new’ person: a qualified nurse, with a job, a purpose and a future. If I can juggle all this, I thought, having a baby will be the icing on the cake, my badge of ‘normality.’ The pregnancy was not easy, the birth extremely difficult, and when my baby had a seizure I had to argue with health professionals in order for them to act. I was shocked that my account was viewed with scepticism, when my experience as a nurse was so different. Wearing a nurse uniform seemed to encourage my colleagues to listen to what I said but when wearing maternity pyjamas my views were almost ridiculed. Scepticism or mistrust of my account or view has been, and remains, a key part of my interactions with health professionals. Perhaps, my history of ‘mental health problems’ is explicit in my or my child’s medical records. Whatever the reason, I remain wary when meeting with professionals as a mother, and I am conscious of my demeanour, language and approach to avoid being written off as a “mother with a history of mental health problems.”

Back to activism, my engagement in activism grew out of spending time with a group of mothers who shared my experience of advocating for their child while trying to overcome humiliating interactions with ‘professionals’. Each mother had spent time and energy advocating for their child to be given a place at a “special needs” playgroup and then advocating with the education, health and social care professionals to navigate and obtain the support their child needed from them. The playgroup provided speech and language therapy, physiotherapy, occupational therapy and behaviour support, in a “safe” space and was viewed as an oasis by us all. Suddenly we were told, without consultation or involvement, that the playgroup that we had worked so hard to access and navigate was shut. We shared this experience and we were all left with a raging anger, an overwhelming sense of powerlessness, that brought us together. We wrote letters to anyone and everyone with power, we met the local Member of Parliament and Councillors, we attended meetings loudly and clearly shouting our frustration and dissent against this decision. We tried to enlist the support of the local paper, who politely declined our invitation to join our campaign, preferring to focus on the need for a slower speed limit on a road where their editor had crashed his car. The result? The playgroup remained shut but a group of mothers was formed that met and supported each other and went on to obtain the services, therapy, benefits and education that our children, and we, needed to develop and progress.

For me this was the start of my journey into the world of disability activism, a world which understands that disability is so much more than an individual impairment and explains how much suffering is caused through the ‘othering’ of those labelled as ‘disabled’. I gained an understanding of the power and control exerted by the neoliberal concept of disablism (Goodley, 2014) and its impact upon me, and my child’s, lived experiences. Activism, I realised, takes many forms but it is driven by a collective drive for change. It is powered by a sharing of abusive and discriminatory experiences out of which emerges a drive for emancipation. Out of emancipation comes liberation and I have gained a letting go of the shame I once felt of being ‘different’, wrong and a misfit. It is this that drives my activism, a desire for liberation for my child and others like her, powered by the shared experiences of mothers like Liz.

A life of activism transformed: Liz’s route through activism

My activism preceded parenthood by almost two decades. In a brief disability awareness session, I was introduced to the idea of the social model of disability and, in an instant, everything about my experience as a disabled person changed. By separating impairment and disability – where impairment was of the body/mind and disability was socially created - the social model showed me that the exclusion I was experiencing did not emerge from my physiology but from external social structures. Now, I looked back on my struggles with education, with battles to be able to take exams in a form accessible to me or even to continue my education at all, and my conflicts with the medical profession, where using a wheelchair was regarded as character failure, and I understood them for the discrimination they were. But the social model went further, because if exclusion was socially constructed then it could also be unconstructed, reconstructed. It was an instant that shifted the trajectory of my life. Then and now, it has defined how I live, who I am.

To understand my world so differently moved me from personal predicament to collective experience. I joined a burgeoning international movement of disabled people just beginning to try our hand at civil disobedience and direct action. Through chants, chains, sits-ins, blockades and more, we created a community and made ourselves visible in public spaces as powerful and resolute. We were images of disabled people as others had not known us to be and we often had not understood of ourselves. From securing the accessibility of whole bus fleets to being instrumental in the ending of the Telethon fundraiser, we discovered our power to influence and became bolder, and we made change. It was an extraordinary time to be involved, where everything felt possible, a moment in history.

The more deeply I became involved, the more apparent it became that the principles of the social model went beyond disability to be universal, an explanation of how injustice is structured into societies. As I expanded my activism to *Stop the Clause* marches (opposing the 1988 'Clause 28' legislation that banned the 'promotion' by local authorities of homosexuality) and anti-British National Party protests (in response to the dramatic rise in racist attacks following the opening of the Neo-Nazi headquarters in the town of Welling), I realised the fundamental issues were the same: that of humanity, fairness, justice, kindness, caring for our world, in the context of political and institutional structures that mitigated against them. While the specific manifestations of injustice might vary, they were fuelled by similar values and rooted in the same imbalances of power. I found myself embedded in an interconnected movement for change and my interpretation of events, from the personal to the global, inhabited that context.

In shifting my perspective and stretching my world view, I realised that I was an activist, not only through what I did but through my outlook on life; my activism resided in both activity and identity. To understand the world as socially-created means forever interpreting events differently; to live with political consciousness is itself activist. Once that outlook becomes central to who you are, then every encounter has the potential to be activist: the casual conversation, the everyday choices, simply being present as a disabled person, because each has the potential to challenge the status quo.

I became a parent in my late 30s. Life become more local and domestic, but still threaded through with activism: less time spent on the streets with blockades (though I managed occasionally, my small child on my knee), and more spent tackling parental access to the local school or challenging assumptions about my fitness to parent. For a disabled person to be a parent at all was a surprise to most people; simply to be present was to confront prevailing notions of disabled people and disabling structures. From encountering injustice to the making of everyday decisions and to the need to minimise the impact of exclusion upon my child - across maternity hospital discrimination, charity fundraisers held at nursery, and the games we played at home - the repeating refrain became 'what more can I do with this?'

When my child, aged two, was found to have some small impairment, we were propelled into the medical system that, for years, I had worked so hard to avoid for myself. I was not a model parent, instead routinely questioning the assumptions and values underlying medical advice. To question treatments and management plans and the need for surgery was motivated by protecting my child and wanting the best for her, yet also propelled by an activist outlook that did not regard impairment as tragedy or attribute exclusion to it. We would have our six-monthly forays into the medical world, but between times we worked to our own normality. In the early years, I was predominantly a disabled parent of a non-disabled child.

It wasn't until later that I became more distinctly a disabled mother of a disabled child. Where Wendy's experience became a route into activism, mine, for a long time, caused my activism, almost, to hit the buffers. And yet, despite three years of all-encompassing crisis management, of wrangling medical and education services that would not yield, of trying to keep my child safe, the activism was also always there, bubbling under the surface, and more imperative than ever.

It was being activist that fuelled my interpretation of events and became instrumental to how I responded, even as that left us, mother and child, as a tiny unit to work things out, tough things out, for ourselves. It was activism that held me steady by giving me a powerful context for what was happening and suggesting ways to approach it, and activism that, even in extremis, left me deliberating on how our responses to our circumstances might have wider relevance, how they could be of value beyond ourselves.

Even as I was able to *do* next to nothing directly activist for a long time, I realise now that those three years become a kind of meditation on activism. Circumstances interrupted the flow of my earlier activism and redefined its form; they caused me to broaden my notions and practices of activism. At the heart of those years, despite the insistence of professionals, my task was not to shoehorn my child into a system that caused harm, but to create a kind of holding space in which we could find a way forward. I have learned of activism that sometimes it warrants the same: not a forcing through of change, but a holding of space so that change can be born.

The ethics of our writing

At the core of our activism, and in the writing of this chapter, it is vital that we consider the privacy and wellbeing of our children, and of ourselves. Our stories of being mothers to our kids are not ours alone to tell and, even as our actions seek change on a broader scale, they are first driven by the imperative to protect our kids; the decisions we make in our writing are rooted in that. Whilst we were committed to publication because we realised that our observations could be of value to a wider audience, we agreed that if either of us became concerned that we were crossing our ethical line, then we would publish under pseudonyms. As our conversations continued and the chapter took shape, it became apparent that our observations focused less upon the specifics of our children and much more on our own experiences. Nonetheless, our publishing comes with their blessing, and their own versions of the story still wait in the wings to be told.

Our second consideration was our own privacy and wellbeing, though we have found sharing our experiences and using them for broader social and political change to be an essential part of that wellbeing. Throughout our writing, we have continued to support each other, sharing our experiences and practical suggestions relating to each other’s kids, and drawing on what we have learned over the years. Our lives are written into this text, and vice versa. We became advocacy, campaigning and activism in practice even in the writing of the chapter and, even though it often felt that we had little left to work with because of our everyday demands, there was sense that we must, because how could we not. Clearly, it has been our decision what to tell, and what not to tell, of our experiences, which at times have been extreme, and our aim is that this chapter might support others to know their own experiences as more shared and their activism as more possible, as we have both learned in the writing of it.

Observations of activism as disabled mothers of disabled children

Our routes into activism

Our experience is that becoming activist can appear to happen in an instant (Liz's experience), but it can also be more gradual and undefined. Wendy's process to activism began through a need to advocate for her own child, and she witnessed a similar process taking place in parents around her. As their shared personal battles extended to learning about social structures, systems and barriers, and to new skills and community, they began to understand that their personal battles had a wider relevance. But we're also aware that our route to, and through, activism is not a one-off experience or a straight line.

For Liz, years of activism were displaced by crisis. The start of focusing back outwards came through advocacy, initially and by necessity for the sake of her child and herself alone, though the knowledge of future activism lay within. Even at the greatest remove, the impulse to do something of value beyond the specific circumstances helped keep her going through the most difficult times. Despite these contrasting routes, we have both found that activism is not a single reorientation in identity or practice, but a circling back around and constant renewal. Often, it takes a different form from much of the activism around us or that we participated in before we became disabled mothers of disabled children.

The different patterns of our activism

In particular, we have observed the following:

- The focus of our activist practice is predominantly localised and domestic. When personal barriers are all-consuming, it is their urgency that defines the issues in which we become immersed. Even where we would choose to look further, even though our focus does not reflect the full breadth of our concerns, which extend beyond both our children and disability, it is the urgency of the personal – the inability to manage much else without first attending – that both drives and limits our activism.

- Sometimes our activism stops altogether, derailed by crisis, temporarily or longer term.
- Sometimes it is compromised. What was often straightforward in relation to ourselves before motherhood becomes far more complex, nuanced and risky when it is on behalf of our children. We have found a greater need to live activism and pragmatism side by side: to put ourselves at risk in the name of principle is easy, but we are not so free in relation to our children. Pragmatism means we sometimes compromise politically in ways we would not have imagined for ourselves, in order to secure our child's inclusion or wellbeing. Sometimes, we compromise personally, exposing more about our impairments than ever we usually would, in order to create alliances with professionals that might secure our children's future.
- At times, what we do for our own children contradicts what we argue for through our activism. We might argue for inclusive education and, yet, in its absence, send our child to a 'special' school because that is the nearest to suitable education that can currently be found.
- Sometimes our activism is to the fore. Sometimes we (appear to) use our child for our politics, availing our own family's experience to drive through larger change. Sometimes the only way we can fight our child's corner is to win a larger battle; without being activist, without tackling the system, the particular barrier cannot be addressed individually.
- Sometimes our activism is public and direct, such as resisting cuts to crucial services, but often it is difficult to be directly, and more conventionally, activist. Much of our activist work is behind closed doors, scarcely visible and often not recognised as activist. It exists in our encounters with professionals, our exchanges with other parents, in the way we talk to our children of their lives and of our lives together. It inhabits the work of support groups and online communities, participants in consultations and complainants, social media activists and scholar-activists. It is in telling the story, like here.

For us, parenting disabled children as disabled people ourselves has brought an additional imperative to our activism. We know that marginalisation and exclusion demand urgent action, but witnessing the exclusion of our children cannot help but shift that imperative to another level. At its extreme, we witness the horrifying urgency of the Justice for Laughing Boy campaign set up on behalf of Connor Sparrowhawk by his mother, Sara Ryan (Ryan, 2017), in the aftermath of her son's preventable death. Four months after Connor moved into an NHS-run residential unit, he was left unattended in a bath and drowned.[i] It is Sara Ryan's sustained and courageous writing, public speaking and social media work that exposed the professional arrogance and institutionalised undervaluing of disabled people, particularly with learning and developmental difficulties, that led to her child's death and which continue to hold life-threatening consequences for other disabled children and adults.

When events such as these make it apparent just how vital activism is, it is painful to have to compromise or delay our own, and yet we have realised that, even when we must, our activism remains present. It informs how we interpret, manage, negotiate and argue. We collect experience and evidence as we go, knowing that individually-experienced injustice might be used in the longer term for something larger. Knowing that our activism is still there, waiting - even that the current crisis will bring more to it when we resume - gives strength. Understanding the politics that underlie the crisis, the mechanics of social structures, brings a greater clarity to our immediate circumstances and makes them a little more manageable. Sometimes, we find our activism has been concealed at the point of doing; that, even when our energies have been locally and personally focused, we realise with hindsight that the ripples have spread beyond ourselves.

We have learnt, beyond being disabled mothers of disabled kids, that activism can become woven into identity. It defines our interpretation of our circumstances – an activist politic and consciousness means forever interpreting events differently – and it links us to others in similar situations or with a similar understanding of the world. We have found that even when we are not actively activist, our 'being in the world' as politicised disabled mothers of disabled kids is itself activist; simply being present disrupts the system and presents other ways of being and doing. In a world that very often does not see the value of our children or ourselves, even to hold onto the pleasure that is our children and the privilege of being their mothers is political.

We have come to understand that within our lives, advocacy, campaigning and activism have the potential to be all-consuming. We considered whether there should be a point at which you (let yourself) let go? Do we turn everything to activism? Do we risk turning our kids and ourselves into objects of activism? Yet, we have discovered that, even in the most difficult times, being activist is a powerful means of keeping going. To be activist is to understand ourselves as part of a community of parents and disabled people, advocating and activating on behalf of our kids both now and for the future. There is strength, out of the most difficult circumstances, in being able to contribute beyond ourselves. Commenting on Sara Ryan's blog, Ragged University (2017), described the scale of its reach and influence:

> it has over 800,000 views and nearly 400 followers; it is apparently being used in teaching health and social care students and [Sara] has an email folder of messages describing what a difference it makes to parents, carers, siblings, grandparents, people who experienced bereavement, professionals and students in their practice and learning.

Our everyday practise of activism

In our everyday practice, our activism is confounded, informed and fuelled by our circumstances.

1. *Growing up, education, and the rest*

Social structures are woven into the lives of children to a far greater degree than at other stages of life. From the moment of conception and through transition to adulthood, from in vitro monitoring to mandatory education, they are prominent in the day-to-day minutiae and the grand sweep of growing up, as well as in our lives as parents. Those structures, instituted through medics, educationalists, social services, and so on, wield enormous power over our children. When there is a mismatch between a child and the demands of a structure, or when additional resources are needed to meet personal needs, the tensions between the two are magnified.

Our role as parents is to navigate our children through these systems as safely as possible, so that they can become, or retain, themselves. As activists, our role is to challenge and subvert those same systems, to make them inclusive of our children and others. In practice, the two roles closely entwine, often, the small changes we seek for our children ripple out to others;

often, to secure our children’s future we must pursue change on a much larger scale. It is not only an enormous task, but a risky complicated one. As disabled people, and as parents of disabled kids, we are often at odds in our encounters with others, including fellow parents and the professionals we must work with to access crucial resources. As activists who base our understanding of our children’s lives and our own in the social model, we respond not only to impairment, but to its context of profound social barriers; our primary focus is to remove those barriers to our children’s participation.

We find that our negotiations with professionals and conversations with other parents of disabled children are often rooted in the medical model, with its premise that our children’s impairments are tragic and the cause of their marginalisation. Beyond the immediate needs of our children, by necessity our role is to educate those around us, translating across models, questioning the assumptions about our children and ourselves, presenting our circumstances deliberately to politicise them and, ultimately, to challenge the system that has created such barriers. Obliquely or intentionally, our negotiations become activist, paving the way for families who follow. For Wendy, it was the realisation that, to secure her child’s needs, she must necessarily address the systems in which they were based, that moved her to an activist practice.

Yet it is tiring and contentious consistently having to argue what a situation *is* before we even attempt solutions. Professionals are taught and work in a culture that typically takes a very different view from ours; they position themselves as experts on our lives (Hodge & Runswick-Cole, 2008). We find ourselves navigating a constant and complex dance between the uncompromising activist, testing their patience with what they see as our recalcitrance, and the need to win cooperation and support for the long term. Sometimes, in order to access a resource, we appear to contradict our independent stance and perform a role of the compliant parent. As disabled people and as parents of our children, we often find ourselves cast as untrusted witnesses, labelled too subjective, too emotional, too involved to see what is best for our children (Ryan and Runswick-Cole 2009). Sometimes our own impairments or the barriers we face are used to question our judgement and ability to parent, or their relevance is disregarded; at times, our impairments have been considered as presenting ‘risk’ to our children and we have found ourselves parenting precariously for fear our children might be taken from us.

The systems set up to address our children's circumstances, such as the Education and Health Care Plan, are typically entrenched in an individualistic framework. Often designed to be adversarial, it can be hard, as parents, to challenge without the fear of losing existing resources. Yet that experience of adverseness, and the shock at witnessing how it can be used to deny resources, can paradoxically create activists of us.

Occasionally, we stumble upon a professional who understands the sense in a barriers-focused approach, and that partnership is welcomed. At times when a resolution cannot be reached, or cannot be in time for the wellbeing of our children or ourselves, our response, for both survival and activism, has been to break free of statutory support. In such circumstances, we find our activism is in being brave enough to cut adrift, in seeking solutions from ourselves or our community, and in demonstrating these other ways of living. Sometimes this can be the most liberating and radically activist of all.

2. Challenging the position of parents in the world of disability activism from our own disabled childhoods

Compared to our own parents, we arrive at our circumstances with prior knowledge. As disabled mothers, we are experienced at managing discrimination in ways that (typically) our parents were not. This brings pros and cons. We revisit our own childhood experiences, including our parents' parenting, with glimmers of understanding into what they went through in advocating, and sometimes failing to advocate, for us. In contrast to our parents, we bring our history as disabled people to the raising of our children, encounters with professionals and navigation of the social world.

That history gifts us insight and skills, but also brings prior hurts from impairment, discrimination, medical abuse, and so on. Encounters with professionals on behalf of our children can be raw, requiring us not only to manage our children's situation, but to confront our own trauma and complicating our ability to respond effectively to immediate demands. Our experience means we already know too well what it is to be judged on our 'fitness'; the risks implicit in professionals' judgements about our children and ourselves as parents are palpable, but also render us better prepared to counter them.

Most disabled people will recognise how hard it is to advocate for themselves and how much easier for someone else; to advocate for your own child is the hardest of all. Yet, it is our often painful insights as disabled people that inform that advocacy and fuel our activism, in order to protect our children and others from the same. Our history as disabled people is grounded in the power of an activist movement. Shared insight, vulnerabilities, tenacity, community and the experience of successful activism mean we do not fight their corner entirely alone. In knowing their mothers as part of that collective whole, our hope for our children is that they can root their sense of themselves in that same political context and use it to navigate the complexities of their circumstances.

Historically, the disabled people's movement has judged parents of disabled kids harshly. Many of us activist in the 1980s and 1990s criticised early campaigns by parents to open up a world resistant to their disabled children, via medical treatment or access provision. There are parents whose attitudes and actions have been, and continue to be, retrograde or even hazardous to their children and to the wider community of disabled people, yet some parents' work was radical in its time, even as it is viewed with hindsight as paternalistic and retrograde. Parents of disabled children are still often met with a certain suspicion; as disabled parents of disabled children we find ourselves in a novel position: to be of the disabled people's movement and yet seen by some as a block to it. Observed more temperately, those parents laid some of the ground for us to become activist; their early work kept us alive and began our foray into the outside world. In forging new paths, they enabled us to move on to gather resources, form community and take the battle onto a larger and more radical stage. In beginning to open the world to their children – in believing we were as entitled to it as anyone else - they opened up opportunities that enabled us subsequently to criticise the limits of their aspirations and to demand more radical change. If we too have judged those earlier parents of disabled children harshly, we have now, perhaps, learnt compassion and a more nuanced view of what they achieved for, and sometimes with, us.

3. *Emotion shaping our activism*

In revisiting the role of parents of disabled children, we have found ourselves confronting the grief, anger and loss in many of their accounts, particularly by non-disabled people, of raising their disabled children. There remains a conflict between the determined focus of the disabled people’s movement on external barriers to participation and the insistence by many non-disabled parents of the tragedy of impairment. And yet, here as disabled mothers of disabled kids, we find ourselves too managing grief, anger and loss in relation to our kids. Our activism centres upon the external structures that exclude our kids, but we find, by necessity, that we must also acknowledge the impact of both discrimination and impairment on our kids; on their dreams, and our dreams for them and, indeed, upon ourselves. We grapple with making space for our sadness, not denying it as many activists would have us do. Whilst keeping the momentum of our activism, we also try to understand our loss within that context. We are learning that the two can sit side-by-side and entangle, each informing the other: our emotion brings fuel to our activism, and our activism becomes more empathic to the complexities of real life.

4. Up against the barriers: constraints and shifting contexts

Those complexities extend to our own lives. Parenting our children in a society that excludes and confounds them is hard work, both practically and emotionally; to do so as disabled people is harder still. We face both structural barriers to parenting and the constraints of our own impairments, both of which limit the personal resources we have to work with. Sometimes trying to manage the just personal barriers is too much, without also trying to change them on a wider scale. Sometimes, we are too ill or overwhelmed to be actively activist, and the everyday demands and imperative for change often takes a toll on our own impairments. We wonder how many non-disabled parents of disabled children subsequently acquire impairments themselves, not because having a disabled child is intrinsically harmful, but because navigating a hostile world is.

In the presence of impairment or illness, and in the absence of resources, advocacy and activism become much harder to practice, and yet more necessary. Advocating for our children, and being activist beyond our immediate concerns, takes place in the context of the rest of our lives, from managing work, social security and other caring and domestic responsibilities, to navigating additional inequalities such as racism or poverty. Austerity, with its onslaught on infrastructure and mounting hostility towards minority social groups, inflicts a need even more urgent to be activist. Yet, as we find ourselves fighting to secure or retain what we need, it is hard to resist becoming more inward-looking, since our own diminishing support reduces our ability to secure our children’s, and theirs in turn impacts upon our health. During the preparation of this chapter, Direct Payments, intended to pay for essential services, were removed in entirety from one of our children following an austerity-propelled, local authority policy change, with a severe impact on both child and family.

A reorientated activism

The ebb and flow of our own capacity to act means that there are times where we must select our battles carefully or even set aside being actively activist for a time. The range of our activism - how we enact it and the issues we focus upon - may be narrower than we would choose because there is nothing left to work with, or because disability *has* to be our overwhelming priority, at least for now. At times, the best we can do is make breathing space within structures; not to seek fundamental change, but to make things workable in the moment. In times such as these, we ‘hold’ our kids, ourselves and our lives, and we wait. It is a necessary retreat from activism, a time for our children and ourselves to recover from battling and from the damage sustained by navigating a society that excludes and confounds. Yet to retreat is to reflect, replenish and regroup and it becomes a part of the activist whole, enabling us to reflect on our practice and teaching us about the breadth and different forms that activism can take.

Conclusion

By circumstance, we often cannot be a part of more traditional practices of activism, those more direct, massed and often visibly confrontational events in public spaces. Instead, we have found ourselves reviewing and revising what activism is and recognising that, for us, it takes a reorientated or adaptable form, often to be found in the spaces between the larger expressions of activism. As we conclude this chapter, we summarise what this version of activism looks like, what it means for our children, and its relevance to wider activism.

- It is in our conversations with professionals about our own kids, in the way that our political positioning leads the conversation; our interpretations, our demands, and the way these shift the understanding of the professional and influences their practice beyond the immediate encounter. It is in our exchanges with other parents, ‘politicising’ them and moving them towards an activist stance in relation to their own children. It is in our being present as disabled parents of disabled children in a society that doesn't expect us.

- It is in a more compassionate and inclusive activism, towards ourselves and those we seek to influence. By necessity, our way of activism must fit with who we are and with our constraints, those competing demands, limited time and the day-by-day complexities of impairment and discrimination in our children and ourselves.
- It is in the way we raise our children and our kids' witnessing of us as activists, and as advocates on their behalf. It is in their learning a different, more powerful, interpretation of their own circumstances.

Our children have their own experience of being disabled, of being a member of both a marginalised social group and a collective, political community, and their understanding of this grows as they do. Our role as disabled mothers is to manage that emerging identity, to communicate and understand both its unfairness and its beauty, and their impact upon psyche and development. We have the task of advocating for their space in society, whilst holding a space in which they can learn a means to answer back, and our actions and activities shift as the needs, wishes and understandings of our kids develop and change.

We have taught our kids to interpret the world around them through the social model of disability and a sense of agency. We do not 'require' them to become activists, yet as we watch them grow we recognise their strong sense of themselves, which is itself to be activist. We are seeing them develop intentionally into advocates and activists, and we understand that this too is a part of our activism. It seems almost inevitable now that they will decide to become the next generation of activists, to carve out a version that is their own, and we watch in awe as they learn and teach us in return.

Our kids are becoming autonomous as they grow, developing the capability to take on more battles for themselves, to decide their priorities and take the lead. When they are small, we are the agents of their inclusion; as they grow up, part of our parenting of them, and part of our activism, is to guide them in their own agency. Yet to continue to be available to them is vital, to lighten the load of battling, of needing to be activist when so many of their peers do not.

In this chapter, we have sought to highlight what our circumstances as disabled mothers of disabled children have meant for our activism. We have found that, despite myriad obstacles, we remain activist, but our practice has shifted; often, it is more nuanced and serendipitous, entwined with the relationship between our kids and ourselves, and arising in spaces where we might not have recognised it before.

There is as great a need as ever for activism by disabled people, and that includes those of us who are parents or children. For our greatest critical mass, we need to learn to identify, practice and extend activism in its many forms. The activism that has emerged for us through being disabled mothers of disabled children holds a power and utility that we urge others to recognise and make use of and, in doing so, to acknowledge our experiences and the enduring activism that we carry out for our kids, ourselves, for other families, and for those of you beyond.

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[i] A social media campaign was started called Justice for Laughing Boy (#justiceforLB) and can be found online at: http://justiceforlb.org/who-is-lb/. Sara Ryan's blog called 'My draft life' can be found online at: https://mydaftlife.com/.