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Liminal Still? Un-mothering disabled children

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Accessible summary

- Ten years ago we wrote a paper about being non-disabled parents of disabled children and how we felt that we didn't fit in – we weren't 'proper' mothers or 'proper' disability activists
- Here we look back on our advocacy over the last ten years
- We think that activism has brought about limited change
- We think we need to change the way we do activism
- We think we need to tell people not just what disabled people's lives are like, but exactly how we need to change them
- We talk about the Justice for LB campaign as a new form of activism that brings all sorts of people together
- We want activism and advocacy to be something we do together, rather than people doing it on their own.

Abstract

In this paper we reflect on our experiences as mothers, academics and activists over the last ten years. We explore the (limited) successes in campaigns for disabled children and young people and offer an analysis of why such campaigning seems to be stuck in a cycle of failure. We want to move away from traditional approaches to campaigning that rely on story telling and awareness raising. Instead we offer a de-

scription of a form of campaigning based on collective action and the 'disability commons'. This takes an innovative and imaginative approach based on the common humanity of all. Finally, we call for a shift away from the mother child-dyad as the primary site of activism and call for 'unmothering' as a way of challenging the individualisation discourse in order to break through silos of temporality and exclusion.

Introduction

Ten years ago, we published a paper in which we explored the experiences of being non-disabled mothers of disabled children (Ryan and Runswick-Cole, 2008a). The paper was prompted by our attendance at a Disability Studies Association Conference in the United Kingdom at which we felt a sense of disconnection, of not quite fitting. As we were then perceived to be non-disabled people, but parents of disabled children, we occupied a liminal space betwixt and between 'proper' motherhood and 'proper' disability activism. We wanted to explore the experiences of non-disabled mothers of disabled children, activists and academics and what these intersecting identities might mean for other mothers, and for understanding parenting, disability and childhood. We set out to offer what has become known as a 'corrective approach' in which we wanted to foreground the positive aspects of parenting a disabled child. While others have criticised this position as merely trying to swap one stereotypical portrayal of mothering for another (Watermayer, 2013) we wrote from a place of optimism, and, as we now perhaps see it, naivety, as relative newcomers to the worlds of parenting, disability, academia and activism. The paper became the top cited article for this Journal in 2010 and has continued to be well cited over the last ten years.

In the current paper, we return to some of the ideas that we presented in the earlier paper (Ryan and Runswick-Cole, 2007). Our focus remains on mothers because they continue to tend take responsibility for the labour of caring though much of what we write is of relevance to fathers and other carers (Watermeyer and Mackenzie 2014). Drawing on our continuing experiences as mothers, academics and activists, we offer

both reflection and posit ways forward to develop more diverse and outcome-orientated forms of activism. We describe the ways in which advocacy by parents for disabled children has been misappropriated by government and by large charities over the last ten years as a consequence of austerity and neoliberal-ableism (Goodley, 2014). We also explore the unique character of a social movement whose membership is constantly in flux and which is consistently fractured by the commitment to naive optimism by some, and bitter cynicism experienced by others, over time. As a result, we contend that maternal activism has become stuck in a cycle of failure.

In response to this failure, we offer an analysis, informed by disability studies scholarship and activism, of what has emerged as a novel and innovative approach to activism in the United Kingdom (UK). We trace the emergence of the #JusticeforLB campaign which we describe in detail below as an alternative to traditional understandings of maternal advocacy, and as a form of collective activism characterised as 'the disability commons' (Runswick-Cole and Goodley, 2017). Finally we explore the potential of a different approach - unmothering - which shifts responsibility for activism away from mothers alone to call for a community response to social injustice.

While we are writing from a national context in England, we anticipate our learning will be of relevance to mother-activists responding to the discrimination their children face in international neo-liberal ableist contexts (Goodley, 2014).

In this paper we offer a fresh analysis as we:

- i) reflect on the 'trouble' generated by the original paper.
- ii) acknowledge the changing global context of financial crisis and rise of neoliberal-ableism (Goodley, 2014) on understandings of 'good mothering'.
- iii) describe the (limited) successes and the failures of advocacy for disabled children and young people over the last ten years.
- iv) propose alternative forms of advocacy drawing on the power of the disability commons (Runswick-Cole and Goodley, 2017) and the disruptive and innovative potential of 'unmothering' as a means of breaking away

from traditional patriarchal, ableist, classed and raced notions of 'good mothering' that permeate global north contexts. We illustrate the possibilities of such an approach by offering an analysis of the #JusticeforLB campaign (Ryan, 2017) as an example of an alternative form of advocacy that blurs the lines between scholarship and activism.

We begin with a reflection on the 'trouble' the publication of the original paper caused.

i) Mother trouble

Looking back, we were naïve not to realise that our paper (Ryan and Runswick-Cole, 2008a) would generate 'trouble'. As early career researchers we were not fully immersed in the complexities of disability politics. We did not see ourselves either as 'allies' to our disabled children or as their 'carers'. We did not identify as somehow being in the same category as 'professionals allied to the community' (Finkelstein, 1999) not least because we had encountered only a few professionals who could claim that mantle. We knew from our own experience, of course, that family members can be 'agents of disablism' (Thomas, 2007) and understood that this includes mothers.

On reflection, we should have been aware that disability studies would have a problem with the voices of 'mother-academics'. After all, historically, it has had a difficult relationship with feminism. As disabled feminists (Crow, 1996; Morris, 1992) have argued, the Marxist materialist origins of social oppression theories of disability (Oliver, 1990) dominated disability studies allowing for little discussion of the personal as political. Indeed, disability studies and disability activism have continued to construct (non-disabled) mothers of disabled children as complicit in their children's oppression (Thomas, 2007). Troubling indeed.

While disability studies have trouble with feminism, feminism, in turn, has trouble with studies of the maternal. This discomfort stems from concern that any focus on mothering will reinforce maternal essentialism; the view that primary care is *naturally* a woman's role. Discomfort has led O'Reilly (2014: 3) to describe motherhood

as ‘feminism’s unfinished business’. As disabled, black and queer feminists have clearly illustrated (Garland-Thompson, 2002; Ahmed, 2009; Gibson, 2014) intersectional inquiry has sometimes been missing from both disability studies and feminist research. So far, studies of the maternal have demonstrated limited engagement with intersections of classed, raced, heteronormative and ableist aspects of mothering and the impact of poverty.

In our intersectional analysis we explore the *practices of mothering* and *institution of motherhood* and adopt a view of both gender and disability as *a social construction*. We remain mindful, nevertheless, of the absence of our consideration of the intersections of critical race and queer theory in discussion of these issues which we hope other scholars may take forward. We turn now to the impact of austerity on parenting.

ii) Austerity parenting

Little did we know at the time, but ten years ago we were in the middle of the heady days of *Aiming High for Disabled Children* (HM Treasury & DfES, 2007), a policy ambition driven by the New Labour government to end child poverty and to raise the living standards of disabled children, in particular. Since 2010, the gains made in *Aiming High* have been washed away as ring-fenced funds for disabled children were dissolved into an ‘early intervention grant’ by the Coalition government. The global financial crisis and austerity measures that followed have made increasing demands on mothers who now have the responsibility for labour and care (Puar, 2012). The demands of care, coupled with a continued lack of appropriate and affordable child-care for disabled children, means that mothers of disabled children remain excluded from the labour market and positioned as a burden on the state (Runswick-Cole and Goodley, 2017).

The adoption of the ‘good mothering’ narrative (inevitably constructed with reference to its opposite ‘the troubled family’ (Runswick-Cole et al., 2016)) has led to the vilification of working class mothers across the globe (Skeggs, 2005; Jensen, 2008; de Benedictus, 2012). At the same time, ‘good mothering’ has condemned mothers of

disabled children. In a context where those who rely on the welfare state are positioned as feckless scroungers, mothers of disabled children are constructed as having given birth to children whose bodies and minds threaten to place both a present and future burden on society (Runswick-Cole & Goodley, 2017).

Mothers in global north cultures are subjected to surveillance, intervention and blame, held responsible for their children's genetic inheritance and for fixing their children's impaired bodies and minds (Runswick-Cole and Goodley, 2017). Brain-based models of child development have not released mothers from blame. Mothers are now responsible for their children's faulty genetic inheritance *and* for engaging in effective early intervention to ameliorate the 'effects' of this inheritance (Lowe et al., 2015). There is little thought for the consequences of this early intervention narrative for the children (and mothers) who are characterised as 'failures' as they move further from the mythical norm.

Mothers are forced to meet these challenges as they try to weave, ease, negotiate or batter a path for their children to lead flourishing lives. At times it can feel like being in the trenches with strong binoculars, scanning the terrain ahead with fear and horror. Many mothers quickly learn that it is not their children that need fixing but the world around them (Ryan and Runswick-Cole, 2008b). They then take on the burden of responsibility as they (are forced to) campaign for both the recognition of the value and humanity of their children and for appropriate education, health and social care resources for them. A heavy price can be paid for campaigning as mothers are seen as troublesome and even 'toxic' to the extent that this impacts on their physical and mental health, and the care their children receive (Ryan, 2017). Despite the efforts of countless mothers of disabled children, and others, over the last ten years, the outlook remains bleak. We live in a world now where our children with learning disabilities will die on average 23-29 years before their peers (NHS England, 2017), startling evidence of the limits of advocacy for, with and by learning disabled people. We all seem to be stuck in a cycle of failure in advocacy for people with learning disabilities.

iii) A cycle of failure - (There is no) Secret Life of Us

Since writing the original paper, as mothers, activists and academics we have both witnessed and been involved in campaigns that aimed to improve the lives of disabled children and their families. There have been some small successes. *Aiming High*, for example, was in part brought about because of the impact of the Every Disabled Child Matters campaign led by a consortium of disabled children's charities. Despite this activity little has changed. There remains a persistent poverty of aspiration for disabled children and young people and adults locally and globally. We, and our children, feel liminal - still.

Generation after generation of mother-campaigners remain persistently and optimistically attached (Berlant, 2011) to the belief that 'people' (the general public and the government) *simply don't know* about the inequalities they and their children face. In 2007, we too felt like pioneers in the field of mother activism striving to generate a brave new world for our children oblivious to the work of women from previous generations. This isn't a position of ignorance on the part of newer families (though it may include a strand of not wanting to look ahead to the lives of older children and adults). Rather mothers are absorbed in trying to make immediate changes without thinking about the activism of previous generations. In a rapidly changing social context, the lessons of past campaigns may seem irrelevant but we suggest there is much to learn from the past.

Campaigns for disabled children have historically rested on a story telling approach (for example, Scope's 100 Stories in 100 Days (Scope, 2015)). Mothers have felt compelled, or encouraged, to tell stories in the hope for change. Each generation of mothers have hope. They believe in working with professionals and local and national government and that things would change *if only people knew*. Typically, they didn't 'know' before the diagnosis of their child, but once they 'know', it becomes important to let others know that their children are routinely and persistently denied entry into the category of fully human. Crucially, in England, as in many other global north contexts, parenting roles are socially constructed in ways that demand that it is *mothers* of disabled children who take *primary responsibility* for the fight for

their children. They are simultaneously valorised and vilified as ‘tiger mums’, ‘warrior mums’ or ‘angels’, with fathers or other family members erased.

The campaign for disabled children is an unusual social movement. On the one hand, it is in state of flux, as children grow, mother advocates move away from advocacy for children to the world of advocacy with reference to adult services and support. They, and their knowledge, are lost from children’s advocacy as they begin a new set of typically absorbing challenges. There is a further fundamental fracture in the campaign as ‘angry’ mothers of older disabled children can discomfort mothers of younger children – with good reason, as they fear for the future.

The involvement of large charitable organisations offers some degree of stability in the field of campaigning but this involves caveats. These professionalized-organisations, with considerable budgets, often set up decades ago by parents, feel a world away from their founders’ ambitions. Charities find themselves in the compromising position of relying on government for funding to deliver services for disabled people leaving them able to offer only muted criticism of policies that de-humanise the very people they claim to speak for. The services they offer have come under recent scrutiny and found to be poor, or worse. In some instances, charities themselves have been found responsible for perpetuating the abuse of disabled people and, rather than take responsibility, have sought to defend themselves robustly by using extensive resources to battle with families at the inquest of their disabled child.¹

The harsh truth that both parents and the big charities seem reluctant to face is that successive British governments have known about the social injustices in the lives of disabled children and families and have done little to bring about change. The limited impact of *Valuing People* (DoH, 2001), *Valuing People Now* (DoH, 2009), *Transforming Care* (NHS, 2014) is clear evidence of this. Disabled children and adults con-

¹ For details of one such troubling example visit: <http://www.learningdisabilityengland.org.uk/news/a-statement-following-the-inquest-into-dannys-death/>.

tinue to occupy the position of wasted humans (Bauman, 2004) alongside others minoritised through the workings of race, class, (hetero) sexuality, religion, colonialism, poverty and gender.

As mothers, activists and researchers, we too have optimistically put our faith in story telling as a catalyst for change (Runswick-Cole, 2007; 2008; Ryan, 2005; Ryan and Runswick-Cole, 2008a; 2008b). We now accept that telling stories is not enough to bring about change. We need to be clear about the change we want and how we are going to achieve it. We also need to learn from the successes and failures of other forms of disability advocacy. As early as 1997, Page and Aspis warned against the domination of self-advocacy by issues of service provision in England. In 2005, Goodley commented:

The nagging concern I have relates to the ways in which self-advocacy is conceived: does the policy-led agenda and businesslike structuring of forms of self-advocacy groups, since *Valuing People*, correspond with the actions and ambitions of the existing self advocacy movement? (Goodley, 2005 :336)

Goodley points to a concern that policy agendas structuring advocacy can work against the ambitions of the advocates themselves. We suggest that this concern is mirrored in the advocacy of parents of disabled children.

In 2011, Parent Carer Forums were launched under the umbrella of the Big Society policy narrative (Contact-a-Family, no date). While there was confusion about what Big Society meant in practice, it was based on three assumptions:

1. the need to tackle Britain's 'broken' families
2. the need to reduce welfare dependency
3. the need to roll back the role of the state and 'empower' communities to do more (Runswick-Cole and Goodley, 2011)

In this context Parent Carer Forums were set up to:

“work alongside local authorities, education, health and other service providers to ensure the services they plan, commission, deliver and monitor meet the needs of children and families”

(Department for Education & Department for Health and Social Care, 2015: Para 1.13).

The tensions inherent in imposing the principles of the Big Society on parent groups are clear. Families with disabled children often fall into the category of 'broken families' reliant on state support. Generations of parents have sought to challenge such negative stereotyping and have campaigned for acceptance of their families as different, not disordered, and certainly not lesser than the mythical normal family or, indeed, the cause of community breakdown as 'troubled families'. Families with disabled children living in them depend on welfare benefits and have no wish to see them reduced. This is not because they are feckless scroungers but because of seemingly immutable structural inequalities. The increased costs of raising disabled children coupled with the lack of accessible and affordable childcare mean that families of disabled children cannot meet the demand to reduce their welfare dependency and must campaign for more and better support. Families with disabled children, like all families, need the support of their communities. Any plan to end their social exclusion and isolation is welcome, but it is unlikely that this will dramatically reduce the need for the services of the state. The aims of parental advocacy seem to be diametrically opposed to the principles of Big Society that underpinned the establishment of the Parent Carer Forums.

In the past small, parent-led groups had grown up in their local communities to offer peer support; now, Parent Carer Forums are funded by the Department for Education who provide a grant for one forum in every local area to support their parent participation and activity. There are now 151 forums with 80,000 members (Smith, 2017). In their annual report, the National Network of Parent Carer Forums reveal that their 'greatest achievement' is 'raising awareness' (Smith, 2017: 22). This persistent attachment to awareness raising seems to us to be a very limited approach, particularly when the challenge our children currently face is early death (NHS Engalnd, 2017).

Despite this, Parent Carer Forums and big charities continue to pursue the goal of awareness raising. The Disabled Children's Partnership recently launched a new campaign #TheSecretLifeOfUs. The campaign, which, we are told, has been developed 'in partnership with parents', aims to improve 'the understanding of the challenges faced by families everyday' (DCP, 2018, np). Illustrated, primarily, with pictures of smiling mothers with their disabled children, the campaign is premised on the mistaken assumption that the lives of disabled children are hidden. They are not. A weighty evidence base exists demonstrating persistently poor outcomes for disabled children: school exclusions; bullying; isolation of families and poverty.

iv. An alternative approach: the disability commons and unmothering

So far, we have focused on the activism of mothers of disabled children. We know, however, that the practices of mothering are not tied to gender or biological relationships and that fathers engage in caring practices as do many others (Douglas, 2015; Runswick-Cole & Goodley, 2017). In recent times, we have seen women, men, disabled people, parents, siblings, activists and those allied to disability politics coming together to try to improve the lives of disabled people. A recent example is the formation of Learning Disability England (<http://www.learningdisabilityengland.org.uk/>) an umbrella organisation for people with learning disabilities, family members, academics and service providers. Elsewhere, this form of campaigning has been described as the 'disability commons' (Runswick-Cole and Goodley, 2015). Such campaigns are formed through recognition of common humanity and interdependence.

The collectivist, collaborative and interdependent nature of the disability commons allows us to think differently about mother-activism. This has led us to re-claiming the idea of unmothering as an alternative approach. We borrow from the term 'unschooling' developed by Holt in the 1960s (Gray & Riley, 2013). Unschooling means that children neither go to school, nor receive home schooling, rather their learning

is developed in exploration of and interaction with their environments (Gray & Riley, 2013). Unschooling does not abandon the importance of learning, it disrupts the assumptions about the ways in which it can take place. Similarly, unmothering does not seek to devalue mothering, it seeks to disrupt the idea that the mother alone is responsible for raising children. Unmothering appeals to collectivity and interdependence of the disability commons, challenging the discourse of individualisation and responsibilisation of the family that permeate current English government policy rhetoric.

We are not the first to think about 'unmothering'. We found an audio book by Pinkola-Estes (2005) called *Warming the Stone Child: myths and stories about abandonment and the unmothered child*. Here the unmothered child is described as a child whose mother is physically present but emotionally absent. As mothers, this makes us shudder as the ghost of Bettelheim's claim that refrigerator mothers cause autism, haunts us. As part of our activist/scholarship we think it's time to take back 'unmothering' and use it to transgress the dominant constructions of mothering underpinned by psychologisation and patriarchy.

v. Unmothering in action – #JusticeforLB

The preventable death of 18 year old Connor Sparrowhawk, also known as Laughing Boy or LB, in July 2013, and the subsequent campaign #JusticeforLB that developed as an outcome of his death is an example of unmothering. Connor, diagnosed with autism, learning disabilities and epilepsy was left to bathe unsupervised in an assessment and treatment unit and drowned. The NHS Trust responsible initially claimed Connor died from natural causes. His devastated family began a five-year battle to gain answers and accountability.

#JusticeforLB began with a hashtag and the actions of family, friends and followers of Connor's mother's (SR) blog, mydaftlife.wordpress.com. She had been documenting everyday family life since 2011 in an anonymised series of often-funny observations. When Connor became unwell and was admitted to the unit, the blog became a grim diary of the 107 days he spent in the unit before his death. While the Trust and

local authority focused their attention on various techniques of 'mother blame' including circulating a briefing document about the blog the day after Connor died, the responsibility for gaining answers and accountability became a collective endeavour among a diverse range of people, the majority of whom had never met Connor or his family.

In 2014, a celebration of the 107 days Connor spent in the unit before his death involved people adopting days between 19 March and 4 July to fundraise for the family's inquest legal fees or raise awareness more broadly about learning disability. The underlying principle of this activity was that contributions were positive. There developed an explosion of brilliance involving people of all ages which spread as far as Canada, the US, France, Spain and New Zealand. People adopted days to take part in sporting events in Connor's memory, to create artwork, hold cake sales, produce films and animations, perform in musical events, there were academic talks, workshops, the creation of a #JusticeforLB quilt, bus rides and so much more. Towards the end, days were adopted by two or three people or organisations as there was so much interest in becoming involved. The full activity can be seen here:

<https://107daysofaction.wordpress.com/>

This organic unmothering activity continued over the next four years as each attempt to blame SR for Connor's death was met with a collective and lively resistance. In part, this was facilitated by social media that acts as a leveling device in terms of transparency and scrutiny. Connor's inquest was the first inquest to be live-tweeted and the bespoke twitter account enabled a large audience to following the proceedings virtually and witness the attempts to mother blame. Live tweeting made visible what is typically invisible including state mechanisms of erasure and silencing.

By this stage, campaigners included self-advocates, disabled people, families, health and social care professionals, human rights lawyers, information specialists and multi-disciplinary academics. There was no structure or formality to the campaign, just a commitment to gaining accountability. The Chief Executive of NHS England agreed to commission a review into deaths in the NHS Trust's learning disability and

mental health services across a five-year period. This review (Mazars 2015) revealed scandalous dismissal and disregard of certain patients and led to an urgent debate in both Houses of parliament.

Eventually, in March 2018 a Health and Safety Executive criminal prosecution led to the biggest fine of a Trust in the history of the NHS. The judge, in his closing remarks, made a point of referring to the mother blame; “However, it is clear on the evidence that Dr Ryan, in particular, faced not merely resistance but entirely unjustified criticism as she pursued her JusticeforLB campaign”.

The events both before and after Connor’s death demonstrate how entrenched the mother blame narrative is and how those in positions of power appear to accept it without question, or actively use it. The collective responsibility for what is traditionally called mothering effectively derailed the narrative in an unprecedented way. The campaign, furthermore, produced two key documents; the LB Manifesto and a Private Members Bill, the #LBBill. The LB Manifesto clearly laid out the aims of the campaign in relation to accountability for what happened to Connor and other young people like him. It had wider aims including “Proper informed debate about the status of learning disabled adults as full citizens in the UK, involving and led by learning disabled people and their families, and what this means in terms of service provision in the widest sense and the visibility of this group as part of ‘mainstream’ society”.

The LB Bill aimed to change the law for disabled people so that they have more control over what happens in their lives. Once drafted, feedback for the bill was crowdsourced electronically via social media and through targeting self-advocacy groups. Substantial contributions and comments meant the bill was finally honed into a clear, sensible and important potential piece of legislation. While not successful in the Private Members Bill Ballot, details remain online at <https://lbbill.wordpress.com/> and Norman Lamb, then Secretary of State for Social Care, drew on sections of the bill and worked with campaigners when producing the Green Paper *No Voice Unheard, No Right Ignored*. Both the manifesto and bill offer clear direction

around what change is needed which to us is key actually to generating change.

Final thoughts

For too long now, mothers of disabled children have been positioned within a particularly toxic space by health, social care and education professionals. Having a disabled child is typically an unfamiliar experience and families start from scratch on unexpected journey. Public sector bodies meanwhile are well versed in various mother blame techniques as we have both witnessed and experienced over the twenty or so years of our motherhood. At the same time, the social movement of active, determined and ultimately loving parents is fundamentally fractured by temporal differences and compromised charity support. These factors mean that the power of the movement is diluted and parents are caught up in a repetitive cycle of failure.

Social media has offered a mechanism to enable people to come together, challenge abuses of power and better recognise and learn from the salience of past experiences. We suggest that collective activism and actively unmothering can challenge the individualization discourse, enable a shift in the power imbalance and break through the silos of temporality. In this way, we hope that we can end the cycle of failure of mother-activism and, working as a collective, set the agenda for change.

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