

Making Memories, Making Madness: Mad (M)others of Disabled Children Write Back Through Digital Storytelling

Créer des souvenirs, créer la folie : les mères en colère d'enfants handicapés répliquent par une narration numérique

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Abstract

This article focuses on a story of education, mothering, disability and madness, with two aims in mind:

- *To reveal and to reflect upon the ways in which (m)others of dis/abled children are labelled as, and are made to feel, mad in their encounters with the psy-professions (education, psychology and psychiatry).*
- *To explore the potential of digital storytelling as a method of writing back against dominant oppressive narratives of education, mothering and disability.*

This paper is written by mothers of adult offspring with disabilities about our experiences of raising our children. We write about our experiences of making a film about being mothers. We explain that we have all been told by professionals that our beliefs about our children and what is best for them are mad—that is, they are unreasonable or not to be trusted. In the paper, we reject this view and argue that our voices should be listened to. We hope that this story telling process can reveal the ways in which discourses of madness are used to oppress (m)others of dis/abled children in encounters in education. We also hope that we can begin to build narratives of resistance so that madness no longer becomes the discourse of choice in encounters between (m)others and practitioners.

Résumé

Cet article se concentre sur une histoire à l'intersection entre l'éducation, la maternité, le handicap, et la folie. Il a deux visées :

- Révéler et réfléchir sur la manière dont mères d'enfants ayant un handicap sont stigmatisées et amenées à se sentir folles, à travers leurs rencontres auprès des professions « psy » (éducation, psychologie et psychiatrie).
- Explorer le potentiel de la narration numérique en tant que méthode de contestation des récits oppressifs dominants sur l'éducation, la maternité et le handicap

Cet article est écrit par des mères d'enfants adultes handicapés. Nous écrivons sur nos expériences dans l'éducation de nos enfants et sur la réalisation d'un film concernant la maternité. Nous expliquons que les professionnels nous ont dit que nos perceptions concernant nos enfants et ce qui est le mieux pour eux sont de la folie – c'est-à-dire, qu'elles sont *déraisonnables* ou qu'on ne peut s'y fier. Dans cet article, nous rejetons cette vision et soutenons que nos voix doivent être entendues. Nous espérons que ce processus de narration révèle les façons dont les discours de la *folie* sont utilisés pour opprimer les mères d'enfants ayant un handicap lors des rencontres en milieu éducatif. Nous espérons aussi pouvoir commencer à construire des récits de résistance afin que la folie ne soit plus le discours dominant lors des rencontres entre les mères et les praticiens.

Mots-clés : handicap, folie, maternité, narration en tant que résistance, éducation

Introduction

This article focuses on a story of education, mothering, disability and *madness*, with two aims in mind:

- To reveal and to reflect upon the ways in which (m)others of dis/abled children are labelled as, and are made to feel, *mad* in their encounters with the psy-professions (psychology, psychiatry and education)
- To explore the potential of digital storytelling as a method of writing back against dominant oppressive narratives of education, mothering and disability (Douglas et al., 2021a; Rice & Mündel, 2018; Said, 1993)

The history of madness in the lives of (m)others¹ of dis/abled² children has its' roots in twentieth century Western *psy-disciplines* (Nadesan, 2005). *Psy-disciplines* is a term introduced by philosopher Michel Foucault (1977) to refer to fields of knowledge concerned with governing behaviour including psychology, psychotherapy and psychiatry. We use the term *psy-professions* and *psy-professionals* to refer to professions such as education and social work underpinned by the *psy-disciplines*. Over the last hundred years or so, mothers have been held responsible for their children's disability and development (Nadesan, 2005); they have been accused of causing childhood disability through their disordered relationships with their children (Bettleheim, 1967; Douglas, 2014); a mother's response to being told that their child has an impairment has been characterized as grief or denial (Lazarus & Folkman, 1984); mothers must move through the ordered stages of grief towards acceptance of their child's disability or risk being seen as disordered, like their children. The rise of genetic and neuroscientific accounts of mothering and brain development in the early 21st century renders every mother vulnerable to the charge of putting their child's development at risk because of their *poor* parenting (Lowe et al., 2015). (M)other-advocacy is frequently seen as a failure to accept a child's impairment status and can be represented as a symptom of a mother's mental distress, characterized as either disordered grief or as the consequence of post-traumatic stress disorder (PTSD) (Roberts et al., 2014), rather than as a legitimate fight for social justice (Ryan, 2017).

This paper first gives a brief overview of our disciplinary locations and the interconnections between the education systems in England and Canada, where the authors are located. We then expand upon our discussion of the multiplicity of ways in which (m)others of dis/abled children have become caught up in discourses of madness and mental health disorders in encounters with *psy-professionals*, including teachers, psychologists and psychiatrists. Next, we tell a (m)other's story of madness and describe how the narrative became a digital story. In our analysis of the story, we reflect on the aesthetic, political and theoretical influences revealed through the story making process, before offering some concluding thoughts about the significance of digital storytelling as a mechanism for producing counter narratives of resistance for mad (m)others of dis/abled children.

Disciplines and Geographical Locations of the Authors

We are a group of four mother-researchers who write from Canada and England. We situate our work in critical disability studies (CDS) (Goodley, 2013; Meekosha & Shuttleworth, 2009), Mad Studies (LeFrancois et al., 2013) and disability studies in education (DSE) (Corcoran et al., 2015). We also draw on writings from post-colonial theory (Andermahr, 2015; Said, 1993). We see the value of a CDS approach as it allows us to pay attention to the intersections of disability with other forms of marginalization including gender, (hetero)sexuality, race, ethnicity, class, poverty and imperialism (Goodley, 2013). Mad Studies also offers theoretical resources to move beyond a biomedicalized and individualist view of madness (Menzies et al., 2013). Disability

¹ In the paper, we use the term (m)others to acknowledge the multiple care-givers in the lives of disabled children, but also to pay attention to the continuing gendered nature of care. When we report the work of others where this acknowledgement has not been made, we use the term *mothers*.

² We use the term dis/abled children to pay attention to the fact that (m)others of disabled children are often also mothers of non-disabled children and that we need to pay attention to the processes of ableism and disablism in the lives of mothers and children.

studies in education, too, has turned its critical attention to the production of marginalized subjects in education, challenging discourses of deficit, lack and individualization that are pervasive in special education (Baglieri et al., 2011; Douglas & Martino, 2020). We are also drawn to writings from post-colonial writers that offer resources for us to think about the ways in which stories can become counter narratives (Said, 1993) as well as scholarship that supports us to challenge the processes of psychologization that damage the lives of minoritized people (Andermahr, 2015). In this way we might contribute to a re-storying of psychological practice in educational contexts. For us, CDS, DSE, Mad Studies and post-colonial theory provide vital theoretical resources through which we read the current contexts of dis/abled children's education in Canada and in England that produce children and their (m)others as a problem (Baglieri et al., 2011; also see Douglas et al., 2021b).

Geographically, an ocean divides the education systems in Canada and in England, and yet, in many ways the systems are closely connected through their neoliberal-ableist aspirations (Douglas et al., 2021b; Goodley et al., 2014). In education, neoliberal-ableism means it is children who demonstrate the potential to become economically productive citizens that become categorized as desirable students (Apple, 2001). Children who cannot conform to the neoliberal ableist tropes of academic achievement and appropriate social skills are marked as undesirable. This process of categorization has been driven, in England and in Canada, by the turn to neoliberal market solutions to solve the problems of education (Apple, 2001). In England, the school inspection and reporting regime requires the school's performance to be made public and, as a result, academic league tables, where one school's academic results are compared with another in the local area and nationally, drive recruitment of pupils. In Canada, individual provinces and territories are responsible for education, nonetheless, many of these engage in publishing school performance measures such as standardized testing that ranks each school, reinforcing class, race and disability inequities as parents seek to enroll their children in already well-resourced schools and programs perceived as more desirable. Hierarchies of inequity are further exacerbated in Canada through barriers to resources for Indigenous disabled students. Jordan's Principle³, for example, is a federal principle created to ensure that all First Nations children have equal access to government services and supports including health care, social programs and education. However, reliance on psy-professionals and Western-based biomedical assessments and diagnoses to legitimize a child's need for supports often creates access barriers to supports, particularly for children living in reserve-based communities where psy-professionals may not be available (Chambers & Burnett, 2017).

In Canada, and in England, dis/abled children are defined by their deficits. In England, a child of compulsory school age or a young person has a learning difficulty or disability if she or he—

(a) has a significantly greater difficulty in learning than the majority of others of the same age, or

(b) has a disability which prevents or hinders her or him from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions (Department for Education and Department of Health (DfE, DoH, 2015)

In Canada, dis/abled children also continue to be defined by their deficits:

Students with exceptional learning needs are those who require specialized services or programming when deemed necessary by the in-school team because of exceptional learning,

³ See <https://www.sac-isc.gc.ca/eng/1568396042341/1568396159824>

social/emotional, behavioural, sensory, physical, cognitive/intellectual, communication, academic or special health-care needs that affect their ability to meet learning outcomes. (Manitoba Education, Citizenship and Youth, 2006, p. 5)

Discourses such as these reduce dis/abled children to “exceptional learning needs” understood to be located within individuals. On this view, it is an individual child’s learning differences that are *in need of remedy* through “in-school teams” rather than inaccessible school cultures, practices and curriculum.

These deficit discourses (discourses that medicalize and individualize disability) matter; discourse is taken up in wider culture, which makes it possible for a contemporary newspaper headline in England to suggest that allocating resources to “special needs” diverts money away from “pupils” (Hurst, 2019, n.p.), with the implicit message that children with “special needs” are neither “children” nor “pupils.” In Canada, debates rage over the costs and benefits of inclusion, prompting one major urban school board to cut support for children with “additional learning needs” or “disabilities,” stating this course of action posed “the least disruption to our students and our classrooms” (French, 2019, n.p.). Like the UK example, this statement implies that dis/abled children are not students and that they somehow do not (or should not) appear in classrooms. In a climate of neoliberal ableism in education, children with *special needs* are positioned as a poor economic-socio-cultural return on investment, and as *not quite like* other children (Hunter et al., 2019). The global health pandemic has made this neoliberal-ableist calculus for dis/abled children even more dire, a low priority for receiving scarce resources of inclusion during a crisis (Dickenson et al., 2020).

In the current education systems in Canada and England, parents, particularly mothers, are expected to play an active part in their children’s education (DfE, DoH, 2015; Ontario Ministry of Education, 2010). The system requires that “motivated” parents of “able” students become the foot soldiers for the school in supporting their children and the school to succeed in the terms of reference demanded by the neoliberal agenda (Apple, 2001, p. 413). And yet, at the same time, motivated parents of dis/abled children are often seen as anything but *reasonable*. As an individual (m)other fights for their child’s education, they are simultaneously discursively and materially produced as a problem in a marketized system in which they and their children are positioned as a threat to and a drain on that system—they too are constructed as fighters, but parents who are “literate and vocal” are accused of fighting at the expense of “others” (Gross, 1996, p. 3).

Being Unreasonable, Becoming Mad (M)other

As we argued above, being seen as *unreasonable* by bureaucrats and psy-professionals is familiar territory for (m)others of dis/abled children. A “stress and coping” model of understanding the psychological adjustment made by mothers to parenting a disabled child has been widely applied as *the* analytical lens through which to understand the experience of mothering disabled children (Lazarus & Folkman, 1984). In this model, mothers are positioned as either grief stricken or in denial in response to the diagnosis of childhood disability. As such, there is no opportunity for a reasonable response to living with a disabled child, only a binary choice and responses framed through the discourses of madness: grief or denial. Mothers of disabled children are constructed as vulnerable to a diagnosis of PTSD as a result of their child’s diagnosis of disability (Roberts et al., 2014). This dominant narrative has proved difficult to

disrupt. Indeed, a meta-analysis of qualitative studies across a 52-year period found remarkable consistencies in the experiences of mothers of disabled children (Green, Darling & Wilbers, 2013). Despite this published literature that offers an alternative approach documenting maternal love for dis/abled children, much of it written by mothers of dis/abled children themselves, the dominant narrative of madness, denial and grief persists (Darling, 1979; Douglas, 2013, 2014; Green, 2002; Ryan & Runswick-Cole, 2008).

Being labelled unreasonable, we suggest, is often the beginning of a process that ends with being labelled, explicitly or implicitly, as a ‘mad mother’. Reasonable mothers must progress, in a timely manner, through the stages of grief and coping which are said to follow the diagnosis of childhood disability (Bruce & Schulz, 2002). They must embrace a “sick role” for their child and for themselves that justifies their exclusion from life (Parsons, 1951) to benefit from the meagre resources that the neoliberal state allocates to them (Runswick-Cole, 2014). (M)others who fail to comply with the staged model of grief and refuse to accept the stigmatized status of their child (and themselves) become implicated in professionalized discourses of madness. So, for example, fighting for resources for a child in education is often read not as a reasonable campaign for equality in education, but as evidence that the (m)other is stuck in the *anger* stage of the *grieving* process and is having trouble *coping*. Criticism of the (special) education system (Fox, 2019) is too often re-framed as “mad grief,” a grief understood as originating from the failure of a mother to successfully adjust to their child’s disability (Poole & Wood, 2013, p. 95).

As we explained above, to resist this reading of (m)others’ madness, we turn to the theory and politics of Mad Studies (LeFrancois, et al., 2013) and post-colonial theory (Andermahr, 2015; Said, 1993). Mad Studies rejects the biomedical model of mental health as “a jumble of diagnostic prognostications based on subjective opinion masquerading as science” (Menzies et al., 2013, p. 2). Mad Studies allow us to re-focus our attention on the ways in which *mad (m)otherhood* is socially constructed in and through systems like education, which are relentlessly hostile to dis/abled children and to mother-advocacy (Green, Darling & Wilbers, 2013; Ryan & Runswick-Cole, 2008). It is important that we are clear: we do not wish to deny or to minimize the very *real* affects and effects of engaging with systems that lead many (m)others of dis/abled children to experience mental distress, in Canada and in England (Cullen & Lindsay, 2019; Douglas et al., 2021b). Inevitably, there are psycho-emotional (Thomas, 1999) impacts upon (m)others who engage with education systems that view their children and their (m)other-activism as a *problem* (Ryan & Runswick-Cole, 2008). And yet, we maintain that (m)others’ madness is socially produced by systems.

Post-colonial theory (Said, 1993) invites us to write back to oppressive narratives and to engage in what Said designates as a “contrapuntal” reading (Said, 1993, p. 59). This means attention is paid to multiple storylines in a narrative, the dominant narratives and counter narratives, in order to expose and to challenge histories of oppression. We also draw on critiques of models of trauma theory that view trauma as the outcome of a single, catastrophic event (Craps, 2013, as cited in Andermahr, 2015). We follow post-colonial writers who argue that when discrimination is framed as an historical event, as something to be worked through, this obscures the damage that continues to be inflicted on people who are expected to “come to terms” (Andermahr, 2015, p. 502) with an event and *move on*. (M)others of disabled children who fail to move on from traumatic events are criticized for their disordered grief (Ryan, 2017); this reading of trauma, as linked to a particular event with a *before* and *after*, pays no attention to the continuing damage that is inflicted on (m)others and children in a relentlessly disabling world in which there is no

single “before” and “after” a traumatic event (Craps, 2013, as cited in Andermar, 2015, p. 501). We know that there are tensions for us, as white, cisgender, middle class academics, drawing on the theory and politics of post-colonial writing and the risks of appropriation. We acknowledge our privilege. And yet, through the telling of a (digital) story, we aim to draw on the traditions of Mad Studies and post-colonial theory to help us to develop and to share an approach with (m)others of dis/abled children so that they, too, can tell and share their stories of resistance.

The Project: Making *Memories*

We made our digital story as part of the *Re•Storying Autism in Education* project. *Re•Storying* is a multimedia storytelling project in Canada, New Zealand and the UK led by researcher Patty Douglas, a co-author of this paper; it brings together people who have attracted the label of autism with family members, researchers, educators and artists to make short first-person films about their/our experiences of educational inclusion and belonging. The overall aim of the project is to co-create a proliferation of understandings of autism outside the biomedical, to push beyond conventional functionalist special educational and psy approaches to autism and to intervene in deficit-oriented educational knowledge and practice (Douglas et al., 2021b). *Re•Storying Autism* was developed in affiliation with the Re•Vision Centre for Art and Social Justice, a research creation centre and collective of arts-based research projects founded by Carla Rice at the University of Guelph, Ontario, Canada. Re•Vision uses the power of the arts to transform stereotypes of embodied difference as well as to advance inclusion in health and education systems.

In October 2019, three of the authors attended a digital storytelling workshop held over three days in Toronto, Canada for the *Re•Storying* project, where visual and media artists and technical facilitators from the Re•Vision Centre supported them to turn their narrative of madness and systems into a short digital story. We were drawn to our engagement with the arts in this workshop as a vital tool to expose injustice and, ultimately, to address power imbalances (Bell & Desai, 2011; Ryan, 2017).

As part of the writing project, each of the authors agreed to write short vignettes that captured something of our experiences as mad mothers. These experiences include moments where our responses in service systems were characterized as difficult, unreasonable, irrational, angry, upset and disordered, or, simply, mad. We agreed to go away and write – quickly. In fact, we all struggled to articulate our experiences on the page. The memories we were trying to capture were painful, somehow shameful, examples of being seen as or made to feel mad. There were tales of conflict with teachers, shaming of children and (m)others, and being told our views were wrong or unreasonable and driven by grief or denial. We were anxious about sharing our stories, even with each other, despite knowing we would not be judged, where we would not be blamed—again. Eventually, we were able to write and share eight short stories between us.

We came to the storytelling workshop with one of the vignettes, *Memories*, which is presented below. We were drawn to this piece of writing because, although it was composed by one of the authors, it resonated with each of us as we recognized something of ourselves and of our experiences in the short narrative.

Memories

My memories of the early years and of primary school are punctuated by discourses of madness. When I was first worried about our son's "development," I was "over anxious;" he didn't crawl because I was "an over attentive mother who gave him everything." I was worrying unnecessarily; he was "fine." Then, suddenly, it was "very serious, you know," when he missed all his milestones for the eighteen-month check. It was as if I had never raised concerns, never asked questions. My views were always described as "mum feels" but professionals' views were never feelings, they were facts. Looking back, it was gas lighting, making me lose faith in myself and in my judgements. My advocacy for support for education was "unreasonable"; I was seen as "asking for too much" and as "exploiting my education and middle-class privilege." I was accused of "denying other children their rightful support." Years later, I think I'm still uncertain about my judgements, still questioning myself about how "reasonable" I am.

Stages

Below, we report on the stages we went through to make the digital story during the three-day workshop.

Stage 1: Setting the Scene Through the Storymaking Collective

The storytelling workshop began with a day of sharing stories both with all those present as participant storytellers, artists, facilitators and researchers and within a storytelling circle where we were supported by facilitators and other participants in script development and ideas for film visuals. We viewed stories produced in previous workshops and learned about video editing software. We were uncomfortable, nervous, at first, about sharing our story as mothers of dis/abled children. The workshop gathered stakeholder groups in education (people who had attracted, or claimed, the label of autism, mothers, educators, researchers in disability studies) that are in many other contexts, such as school meetings, systemically set up in tension with one another. Communication between these groups is often acrimonious (Runswick-Cole, 2014; Ryan & Runswick-Cole, 2008). The space generated by the workshop and facilitation, however, enabled stakeholders to come together around a common interest: we all cared deeply about disability justice, autism and people who have attracted the label of autism in our lives (Douglas et al., 2021a). The workshop both facilitated and enhanced our active desire to write back. After sharing our story script with the group, we received feedback from fellow participants who were appreciative of our story and recognized threads of the story in their own lives. Through this collective story sharing, holding space for different stories and sensitive and considered feedback, the creative, political, theoretical and aesthetic process of writing back we describe below emerged.

Stage 2: Plot Lines and Phrases

We began developing our film by paying close attention to the plot lines and phrases in our story script. This drew us to reported speech of psy professionals in the script. We extracted examples:

development
 over-anxious
 fine
 an over attentive mother who gave him everything
 it's very serious you know
 mum feels
 unreasonable
 asking for too much
 exploiting my education and middle-class privilege
 denying other children their rightful support
 reasonable

Stage 3: Textual/Visual Effects

Using the app Procreate, we hand wrote the text of our story on an iPad in black handwritten lettering. Procreate animated the letters; on the film, words appear on the page without the presence of a hand or pen. Procreate then allowed us to capture the process of writing back to the reported speech in our script as live action, capturing errors, rubbings out, and 'over writing'. Inspired by the strikethrough poetry of deaf poet and activist Raymond Antrobus (2018; also see below), we use the term *overwriting* to describe the first contrapuntal writing strategy we used to write back to discourses of madness. The strategy of overwriting involved the following: First, we used the smudge tool to obscure the reported speech. We made a conscious choice to obscure rather than erase the reported speech. We wanted to acknowledge that the process of overwriting could not erase the original words and reported speech by professions, the power of which always remains with us. Our strategy was to write over the smudged lettering and replace the language of the psy-professions. And so:

development *became* difference
 over-anxious *became* worried
 fine *became* not fine
 an over attentive mother who gave him everything *became* a loving mother
 mum feels *became* mum knows
 unreasonable *became* reasonable
 asking for too much *became* asking for an education like every other child

Figure 1

Using the Smudge Tool to Overwrite “Mum Feels” with “Mum Knows”

My views were
always described as
"mum ~~feels~~ **knows**"

Image description: The words, “My views were always described as “mum feels” are handwritten in black ink. The word “feels” is smudged out and overwritten by “knows” in pink lettering.

For some examples of reported speech, rather than smudging original words and overwriting, we scrawled across the page with questions and challenges, and so:

exploiting my education and middle-class privilege *was challenged and questioned* with
how can you hold that against me?

denying other children their rightful support *became* it is you who is denying children
resources

Figure 2

Challenging and Questioning

I was accused of
"exploiting my **HARD**
educational and middle
class privilege
**HOW CAN YOU HOLD
THAT AGAINST
ME?!!**

Image description: The words “I was accused of exploiting my education and middle-class privilege” is written in black ink. The question, “How can you hold that against me?” is written over top in pink lettering in all caps and at an angle.

We chose when overwriting, questioning and challenging text, to use pink.

Stage 4: Audio Effects

The audio effects were also carefully chosen. A woman's voice reads the short narrative, and the reported speech is voiced by a man. The first few reported speech phrases are voiced by a single male voice, however, men and women's voices are added growing louder, as the story is told. We used an audio effect that gives the multi-vocal reported speech an 'other-worldly' and disorienting feel. To view this video please visit <https://www.restoryingautism.com/memories> and scroll down (password 'Memories').

Stage 5: Screening

The workshop ended with a screening event at which workshop participants shared their films allowing us to listen to and to share our responses to the films with one another. The purpose of the screening was not to offer a critique of each other's films, rather, workshop participants and facilitators shared the ways the films affected, touched and moved them. Not surprisingly (m)others in the screening recognized our story and other viewers (practitioners and autistic adults) recognized their part in similar stories.

Reflections and Lessons From a Digital Story of Mad (M)othering

We argue that the process of making the film has enabled us to articulate the making of 'madness' in the lives of (m)others of dis/abled children in ways that would not have been possible relying only on a textual approach to storytelling and analysis. It is also an inherently theoretical, political *and* aesthetic process. We try in this section to capture some of these processes. We say *some* of these processes, as we are aware that we are not able to articulate, nor are we aware of, all the influences on our filmmaking. Much of the process is inevitably lost, despite our best efforts to note down our conversations and debates as we made the film, and so we can, of course, only offer a partial account, another story, as we reflect on aesthetic, theoretical and political decision-making and the textual, visual and auditory strands within the story. This was not, however, a linear process; as we recount the process below, we move from text to visual images to sounds and back again weaving in discussion of theory, politics and aesthetics.

The text of the story was written by one of the authors and so this story could be read as the story of an individual (m)other, and yet we want to resist this reading. We were drawn to this narrative as the subject of our digital story because we see it, not as the property of one author, but as a collective account. By naming this as *our story* we are also attending to the ethical requirements of research to respect anonymity and confidentiality. By refusing to identify the storyteller, we protect her anonymity and confidentiality and that of the young person in the story.

The text reveals the ways in which (m)others of disabled children are held to account for their children's atypical development: he didn't crawl because I was "an over attentive mother who gave him everything." While we know nothing of the role of other care givers in the child's life and whether they were also "over attentive," the accusation is clear—the mother is causing her child's delayed development. The positioning of the mother's views as "feelings" and

professionals' views as "facts" reveals a subtle undermining of her knowledge and expertise of her child and a reification of professional judgements. On reflection, she describes these encounters as gas lighting, making reference to the play *Gas Light* (Hamilton, 1938/1975) in which a husband manipulates his wife into believing that she is going mad. She still questions her judgements.

The aesthetic of the film was heavily influenced by our familiarity with two pieces of textual and visual arts-based activism. The first is Raymond Antrobus' (2018) response to Ted Hughes' poem "The Deaf School" (Hughes, 1979). Antrobus, who describes himself as a deaf poet, challenges Hughes' description of deaf children as "alert and simple." Antrobus (re)presents Hughes' typed poem scored out and offers an alternative narrative which challenges the ableism implicit in Hughes' work as Antrobus says of Hughes' poem, "I was a broken speaker, you were never a broken interpreter" (Antrobus, 2018).

We were also influenced by the work of Kerry Fox (Fox, 2019). Fox's installation "Ode to Bureaucracy" presents the paperwork generated around a child labelled as having special educational needs in the English education system. The mass of paperwork generated by the system in order to *include* her son in education, has been plastered over the walls; paint, material and words in block capitals disrupt it to challenge the "officious system of bureaucratic officialdom" (Fox, 2019, p. 1) that sucks the humanity from the bones of children labelled with special educational needs and that makes their (m)others mad. Fox's (2019) work, like Antrobus', is an example of overwriting in order to write back (Said, 1993), to challenge oppressive and dominant narratives of disability as lack and of (m)others navigating the education system as mad. An image of a still photograph of the exhibition ends our digital story and represents, for us, a visual representation of madness.

Our theoretical and political orientations also influenced our artistic choices. Familiarity with critical discourse analysis (Parker, 2013) led us to pay attention to the ways in which narratives of unreasonableness were voiced by the professional and represented through reported speech. At the same time, we recognised this mode of storytelling, which speaks back to dominant representations, from our political encounters as mothers, practitioners and researchers; we recognised that (m)others often re-tell encounters with professionals in this way, as they relive the experience in an attempt to share it with others as directly as possible. We drew on insights from post-colonial scholarship as a field that has demanded an exploration of processes of *othering* and stereotyping which position colonized people as inferior to the colonizers and in need of their assistance (Said, 1993). We do not invoke colonization as a metaphor here, rather, we learn from post-colonial theory about relations of domination and their enactment in material inequities as well as discourse (Said, 1993; Tuck & Yang, 2012). We focused on small plot lines and phrases in the context of a long history of mother-blame (Nadesan, 2005) and noted the processes of othering and stereotyping in the story that positions (m)others as cowed by *professional expertise*. We explored the ways in which the story could be read contrapuntally, focusing on the multiple stories within the narrative; by using animation we could *write back* to professional power (Said, 1993) in the knowledge that stories cannot produce global truths but that they can challenge injustices (Rivzi & Lingard, 2006).

Our decision to extract the reported speech was also influenced by our knowledge of I-poems as a qualitative method in psychology (Edwards & Weller, 2015). I-poems are created by reading interview transcripts and by extracting from the interviews moments when the participants talk about themselves in the first person. Here, rather than paying close attention to where the

storyteller talks in the first person, we focused on reported speech. This shift from first person to reported speech was a reaction to the way in which the I-poem method has the potential to psychologize and individualize experience. In Said's (1993) terms, paying attention to reported speech refocused the analytical gaze away from the oppressed (m)other to the oppressor (professional).

We came quickly to the idea of writing back through overwriting but struggled with how to overwrite. We couldn't easily find words that did not simply repeat the language of professionals. As academics, practitioners and (m)others, we have become enculturated into the language of the psy-disciplines; we feel the omnipresence of the oppressor. We struggled to turn "development" back into difference and "anxiety" back into worry. We wonder if this struggle is shared by (m)others of dis/abled children who want to honour their lived experience of their relationship with their child, while finding themselves having to adopt the language of the professions to gain access to services and resources.

As qualitative researchers, we worried about *consistency* in our newly found writing-back-methods. We did not use consistent approaches in our annotations: sometimes smudging and overwriting and sometimes challenging and questioning without smudging. We worried about whether we should adopt a single methodical approach, but then we reflected on the value of the messiness of annotation and resisted the pull to systematize our analytical process in the ways in which social science demands. It was important to embrace the complexities of our project and to lean into a post-qualitative orientation (Lather & St. Pierre, 2013). We also chose not to edit out the messiness of the writing—the viewer can see us correct errors in the writing, begin words and start words again. We resisted the temptation to produce a perfect and polished digital story. The animated messiness reveals the difficulty of both telling stories and how we continue to be held hostage by the power of the psy disciplines in our lives.

This work is part of an ongoing body of work with the aim of helping psy professionals who work with (m)others across education and care systems to better understand the impact of dominant, oppressive narratives on families, and their own implication in sustaining these (see Douglas et al., 2021b). We are also planning to scale up this research and address the gap in knowledge about (m)others'/carers' experiences of oppressive systems and to disseminate counter practices supportive of new narratives beyond madness.

The process of paying such close attention to the words in the story made us acutely aware that "words wound"—this was a theme echoed in the screening of the other digital stories created in the workshop (Hodge, 2019). The plot lines and phrases delivered through reported speech, to a mother nearly two decades ago, linger; no amount of smudging or overwriting the words can fully drain them of their power. And yet, the processes of extraction, smudging and overwriting made it somehow easier to work with a story that had been difficult to write and difficult to hear.

We chose pink as the colour in which to write over the original black handwritten text. For us, pink was a stereotypical symbol of femininity that could be used to overwrite the male-stream words of the psy professional. We noted that, although the reported speech in the story could have been said by women or men, these phrases are underpinned by white, male, psychologized privilege and that the history of psychology and psychiatry is deeply entangled with misogyny (Nadesan, 2005).

The polyphonic voicing of the reported speech was designed to increase the power of the phrases and to represent the increasing impact that the professional voice(s) have on mad (m)others of

dis/abled children. On reflection, we note the irony of using polyphonic voicing to represent the dominant narrative or monoglossia (Bakhtin, 1981) of the psy-professions. We settled on an audio effect that gives this multi-vocal reported speech an *other-worldly* and disorienting feel, moving beyond the specific story to signify the shared story that (m)others of dis/abled children tell of being subjected to the professional gaze (Ryan, 2017).

By paying attention to affect in the story, we can notice the range of feelings within the story: love, misery, shame, anger, and optimism (Goodley et al., 2018). Through the use of a digital story, affect is visualised, vocalized, animated, and felt by the viewers in the screening event. And yet, while affect is felt at the level of the body, as Goodley et al. (2018) remind us, affect is always socially and culturally produced, steeped in social value, social roles and performances. Our misery and shame is not ours alone, produced as it is through psy knowledge and systemic practices that oppress. Our love, anger and optimism, too, became something more than individual within the workshop, creating space for us collectively to re-vision and re-imagine difficult memories and feelings (Rice et al., 2020).

In the final line, we sense an attempt to offer a resolution/ending to the story— “Years later, I think I’m still uncertain about my judgements, still questioning myself about how reasonable I am.” We chose to layer reasonable by overwriting in pink in political solidarity with the reasonableness of mothers who are too often characterised as anything but. The move to a potential resolution, or ending, reflects a Western-centric narrative arc. We wonder what the potential of resisting such conventions and of sitting with an unfinished story might be.

Concluding Thoughts and Future Directions

The film making process was intensive and intense. We had three days of access to the equipment and artistic and technical support. We struggled at times with learning how to use the technology, how to create the story in Procreate, how to cut the film together with the sound, and how to add the final image and acknowledgements. The process of note taking and recording discussions about our decisions added to our labour. The film making process affected us; it was, at times, exhilarating, when we found the right visual tool or sound, that animated the story, and also exhausting. The concentrated activity of the other participants in the workshop was unexpectedly energizing and helped us to stay focused.

By writing about the process and by sharing our aesthetic, theoretical and political decision-making, we could be accused of trying to influence the reading of our film, or of trying to resuscitate the author who is always and already dead (Barthes, 1977). And yet once shared, we have no way of knowing how the film will be interpreted. There is a risk that some viewers will simply re-inscribe the counter narrative back into the dominant narrative of madness and irrationality—a monophonic story.

And yet, we hope that this story telling process has revealed the ways in which discourses of madness are used to oppress (m)others of dis/abled children in encounters in education. We also hope that (m)others who view the digital story will recognise something of their lives in the film. The digital story is finished, but our project is not. We plan to share our (digital) story making approach with other (m)others of dis/abled children so that they, too, can develop and share their

stories. We want to build narratives of resistance as a collective that mean that madness is no longer a discourse of choice in encounters with (m)others and practitioners.

Key Messages from this Article

For Carers-(M)others. (M)others who advocate for their child(ren) should not be understood as unreasonable. They have important knowledge and information about what their child needs and are fighting for social justice within unjust systems. Story telling is a powerful way to write back to hurtful stories.

For Disabled People. Disabled people have a right to go to school with the help they need. This also includes support for their carers and (m)others.

For Professionals and Policymakers. Studying how psy-disciplines influence policy and practice and how care is gendered is vital for social justice in education.

Messages clés de l'article

Pour les mères et les aidants naturels. Les mères qui plaident pour leur(s) enfant(s) ne devraient pas être considérées comme *folles*. Elles ont des connaissances et des informations essentielles concernant les besoins de leur(s) enfant(s). Elles luttent pour la justice sociale au sein de systèmes injustes. La narration est une façon puissante de répliquer contre des histoires nuisibles.

Pour les personnes ayant un handicap. Les personnes ayant un handicap ont le droit d'aller à l'école et d'y recevoir le soutien dont elles ont besoin. Cela inclut aussi un soutien pour leurs mères et pour les autres aidants naturels.

Pour les professionnels et les décideurs. Pour promouvoir la justice sociale en éducation, il est important d'étudier comment les disciplines « psy » influencent les politiques et les pratiques ainsi que la façon dont les soins sont genrés.

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