

Rachel Robertson

*Out of Time: Maternal time and disability*

**A moment**

He is laughing. He stands under a jet of water, arms out-stretched, hands wide, face tipped, mouth open – and he laughs. Then he runs around to do it all again – up the steps, down the water slide, through the fountain of water and finally standing under the bell-shaped spout as it gradually fills with water and laughing as it tips down and over him. It's a hot day and other children are here too, shrieking and racing up and down the slide and through the water sprays. There are toddlers, wobbling around on fat legs and stomping in the puddles, a pair of girls who look like twins, about six or seven years old, several groups of little boys chasing each other, and a very small boy with a serious face, being encouraged by his dad to try the slide. And there is my son, Ben<sup>1</sup>, fourteen years old and twice the size of every other child around him. When he gets to the top of the slide, he lets the other children go in front of him, waving them on. Some of them even go down and then race back up for a second slide while he still stands there, waiting for his turn. Then, finally, he decides the time is right, and his body is so long, he hardly has any distance to travel before he is at the bottom, splashing in the shallow pond.

I am smiling as I watch him, a coffee in my hand, my book temporarily closed. It is such pleasure to see him having fun in the sun and the water, at ease with his environment and oblivious to difference. It is like a momentary vision of equality, where chronology and cognitive ability don't count, an alternative world where developmental time no longer rules, and difference unites not divides. Here, nobody cares that Ben is a teenager playing alongside much younger children. In spite of his height, he merges into the scene because his actions are similar to all the other children's. He is a part of a moving mosaic of bodies in water, and even his stiff-armed gait as he stands and runs is unremarkable in the midst of falling toddlers and boys chasing and jumping and sliding around him.

Such moments are rare for us. It is more common for Ben to stand out. He is always either too 'old' chronologically or too 'young' cognitively, socially and emotionally. This local water park and swimming pool complex is one of the few places where time is irrelevant; it is a liminal world of possibilities unfolding and never foreclosed.

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Rachel Robertson, *Out of Time: Maternal time and disability*

*Studies in the Maternal*, 7(1), 2015, [www.mamsie.bbk.ac.uk](http://www.mamsie.bbk.ac.uk)

I note that I have written ‘such moments are rare for us’, not for him. I include myself in this experience of temporal dissonance, even though Ben is now fourteen years old and I might have expected more separation between us by now. Like everything else about my mothering experience, though, my relationship with my son is not following imagined or textbook defaults. This temporal dissonance is shared by me; indeed, it is probably noticed and experienced by me to a greater extent.

This article explores the notion of disabled maternal lived time and how might we understand this.<sup>2</sup> I examine how we think about the temporal structures that complicate disabled maternal subjectivity and agency. I take a feminist disability studies approach to the notion of time and maternal subjectivity and build in particular on the work of Alison Kafer (2013), Lisa Baraitser (2009, 2012) and Rosemarie Garland-Thomson (2011, 2012, 2014). I start by exploring the way notions of time are central to discourses about disability before summarising some key discussions on women’s time and caring, including Baraitser’s work on interrupted time and mothering. I suggest there may be a parallel between maternal subjectivity and disabled subjectivity in the way both problematise temporality. My discussion then draws on Kafer’s and Garland-Thomson’s discussions about futurity to explore the relationship between futurity, maternal subjectivity and disability.

In speaking of disabled maternal time, I am not suggesting that I claim the identity ‘disabled’ myself, an issue that is much debated but which I don’t want to address directly here. My claim is to share some of the experiences of disability through my role of mothering a disabled son, what Alison Kafer describes as feeling a ‘collective affinity’ with disabled people (Kafer 2013). My son Ben doesn’t identify as disabled either at present, though he does identify as autistic (which is his official diagnosis) or sometimes as Aspie (which I would describe as a disability rights term but Ben may not understand as such).<sup>3</sup>

As always, it is questionable to use the single term ‘disabled’ to refer to the very diverse lives of people experiencing disablement. I recognise that the experience of disability varies greatly. I am starting from my own lived experience of mothering an autistic child<sup>4</sup> (one who is verbal, was not diagnosed with an intellectual impairment but does have cognitive differences), not to suggest that my experiences are generalisable but rather as a form of anecdotal theorising, using ‘the fertility of the specific as the site of productive thinking’, as Jane Gallop describes it (2002, p.138). I am following the model offered by Lisa Baraitser (2009) in her work on maternal encounters because she has shown how fruitful and apposite anecdotal theory is for thinking about and around maternal subjectivity. This approach is

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**Rachel Robertson, Out of Time: Maternal time and disability**

**Studies in the Maternal**, 7(1), 2015, [www.mamsie.bbk.ac.uk](http://www.mamsie.bbk.ac.uk)

similar to what Garland-Thomson names as ‘the feminist disability studies practice of putting story in the service of theory’ (2014, np). I am writing as the mother of a disabled child, using the insights of this role, in a manner that has been deployed by scholars such as Cynthia Lewiecki-Wilson, Eva Feder Kittay, Katherine Runswick-Cole and Sara Ryan. While my own particular experience relates to autism (and I have contributed to critical autism studies elsewhere), my interest here is to use personal experience via anecdote to enable a more general consideration of the way mothering a disabled child may result in a range of complex relationships to temporality.

### **Time and Disability**

Notions of time are central to the discourse around disability, both in terms of medical discourse and definitions but also the cultural discourses that surround disability. In fact, living with disability often opens up a temporal focus that wasn’t there previously. There is diagnosis time, prognosis time (what or how long a future is imagined), curative time (what treatments or interventions are offered), relapse or remission, and there is developmental time, that imaginary ideal trajectory of human development based on finding the mean of able-bodied/minded people’s experiences. Most noticeable to me when my son was diagnosed with autism was the way his future suddenly became both present and unimaginable to many people. I was asked: (how) will he go to school, learn to drive, get a job, have friends, get married, become independent? It is easy to see that economic and physical independence, and marriage and reproduction have become the markers of adulthood in our culture. I don’t think other mothers of three-year-olds are asked if their child is likely to be able to drive. The very name of a developmental disorder like autism encodes time doubly: the condition is life-long and it delays, disorders or disrupts the ‘normal’ development of a child. It therefore creates the sense of an unpredictable future, something that western cultures tend to fear. As Rosemarie Garland-Thomson says,

A world and life trajectory that is unpredictable or uncontrollable is anathema to our liberal modern ethic of self-determination, design, and freedom. One reason we do not expect people with disabilities to appear in our world is because we do not have predictable narratives of their future; we do not imagine them as having tractable futures or life trajectories (Garland-Thomson 2012, p.351).

Kafer (2013) describes how Judith Halberstam (2005) claims that ‘normative narratives of time’ underpin ‘definitions of the human in almost all our modes of understanding’ (Halberstam quoted in Kafer 2013, p.34). Elizabeth Freeman uses the term

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**Rachel Robertson, Out of Time: Maternal time and disability**

**Studies in the Maternal**, 7(1), 2015, [www.mamsie.bbk.ac.uk](http://www.mamsie.bbk.ac.uk)

‘chrononormativity’ to describe the use of time ‘to organise human bodies into maximum productivity’ (2010, p.3) through the use of clocks, schedules, calendars and time zones which inculcate particular temporal experiences and privilege powerful groups. As Karen Davies (1990), building on the work of E.P Thompson and others, points out, clock time may appear natural to us but it is in fact socially constructed. Linear time, then, is linked to productivity and is the time of history or teleology. The past is useful to us as a form of prediction for the future. Davies also notes that we test people’s cognitive functioning by asking them about time: asking what day or year it is and about temporal order and cause and effect. In other words, as Bruner (1987), Eakin (1992, 1999, 2004) and others have demonstrated, our notion of ‘personhood’ is closely linked to the ability of an individual to understand and recount a temporal narrative about her or his self.<sup>5</sup>

Kafer argues that Halberstam’s ‘normative narratives of time’ all presume a ‘linear development from a dependent childhood to an independent adulthood defined by marriage and reproduction’ (Kafer 2013, p.34). When this linear development is disrupted or contested, the most common response is to have recourse to what Kafer describes as ‘curative time’. If an individual cannot be cured as such (as with developmental conditions), then the focus falls on normalising treatments, in order to assimilate difference. Autistic children, for example, are taught to behave more like others by making eye contact even though they may not wish to or to avoid public vocalisations and actions (‘stimming’) that are deemed inappropriate.

I was struck by the fact that it was the apparatus of chrononormativity that was used to help my son manage his life in a non-autistic (neurotypical) world: visual schedules and timetables were among the most common tools used by schools and therapists, for example, in helping him transition from one activity to the next. There are also autistic adults and children who require adherence to timetables in order to provide a form of predictability or security to their lives, removing some of the unpredictability of daily life. My son’s limited ability to formulate cause and effect required an external reference point, so that socially constructed clock time became essential to understanding how to live with others in the world. Ben, his embodiment appearing to rupture linear developmental time, is tied back to it via external apparatuses of control.

I recognise that my anecdote about Ben playing in the water park might be read as an ableist framing of disability. I identify my usual experiences with Ben as a disruption in the temporal field, and describe his embodiment as a form of asynchronology where body and mind are not aligned. By saying he is always either too young or too old, I may seem to

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**Rachel Robertson, Out of Time: Maternal time and disability**

**Studies in the Maternal**, 7(1), 2015, [www.mamsie.bbk.ac.uk](http://www.mamsie.bbk.ac.uk)

support a normative ideology where difference is excess or deficit and not valid, where the linear developmental norm is given value over people's individual differences. I don't support this ideology but I think my anecdote reflects the way we are all subject to, and contributors to, this kind of ableist framing and that it can be a complex thing to unravel these frames. The fact that my lived experience is out of sync with the norm and that I read critical disability studies scholarship doesn't make me immune from the dominant discourses of my culture. I still find myself saying to Ben, 'stop making those weird gestures', when we are out in public, whether because they discomfort me or others I don't entirely know.

That moment in the water park stands out for me as a desired future, what I describe as a 'vision of equality' (for me, not necessarily for Ben or other children or parents). It is not a vision of Ben before, after or without his disability but rather a changed world, where this seeming misalignment of mind and body is no longer a problem, but simply accepted as a possible way to be.<sup>6</sup> This imaginary future would be a place where Ben can make 'weird gestures', where the teenage body is not seen as grotesque or threatening or shameful in non-teenage spaces. It is a place where chronological age would no longer be the main structural marker for education, recreation and communal life. In this future, too, my own experience of mothering would not be marginal. As a mother I would not experience what Rozanna Lilley (2013) names as 'attachment stigma', a stigma resulting from the prolonging of the child's dependency on the mother.

### **Maternal care, time and interruption**

Just as linear time has been associated with men and the world of work, cyclical time has been associated with women (see Davies 1990, Felski 2002, Kristeva 1981). In 'Women's Time', Julia Kristeva argues that monumental (or eternal) time and cyclical time are linked with female subjectivity, based on the association of women and maternity. Christine Battersby has explained the association of women and maternity through the 'shared position *vis a vis* the founding metaphysical categories that inform our notion of individuality', arguing that 'whether or not a woman is a lesbian, infertile, post-menopausal, or childless, in modern western cultures she will be assigned a subject-position linked to a body that has perceived potentialities for birth' (Battersby 1998, p.16). For Kristeva, monumental time cuts across linear time and creates cyclical time. Davies notes that in the pre-industrial west, cyclical time was associated with everyday life, as well as being associated with mythological consciousness. Cyclical time, she argues, reproduces the past. The daily activities of care for others require

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**Rachel Robertson, Out of Time: Maternal time and disability**

**Studies in the Maternal**, 7(1), 2015, [www.mamsie.bbk.ac.uk](http://www.mamsie.bbk.ac.uk)

short repeated cycles of work. These everyday activities are reproduced within larger seasonal and communal cycles.

Rita Felski (2002) writes that ‘Repetition is linked to the everyday, and the everyday to woman. For feminists, this connection can be a problem or a source of strength’. (2002, p.25) Davies suggests that women’s time can be seen as continuous because of the on-going nature of caring. However, thinking specifically about maternal caring, Baraitser (2009) makes the point that the repetitive and continuous nature of caring for young children is also subject to interruption. Indeed, she argues that the interruption itself ‘forms the ground of maternal experience against which all other maternal experiences are understood’ (2009, p.74). In what follows, I try to think through this idea of interruption as a primary maternal experience and how this links with the everyday repetition of maternal caring in the context of disability.

Baraitser articulates the maternal subject is ‘both she who is subjected to relentless interruption, and she whom interruption enunciates’ (2009, p.67). She describes the ‘breaches, tears or puncturing to the mother’s durational experiences bringing her back “again and again” into the realm of the immediate’ (2009, p.68) and how those interruptions reveal the background of experience through rupturing it. She suggests that the mother is often in the not-thinking immediacy of responding to her child, that interruption is the rule rather than the exception.

Baraitser builds on Steven Connor and Jacques Lacan to argue that these interruptions have a generative as well as a depleting force. She uses the work of philosopher David Appelbaum on ‘the stop’ to explore ‘an articulation of maternal subjectivity that does not necessarily devalue or seek to eliminate such experiences, but seeks to foreground them as providing access to new subjective experiences’ (2009, p.76). Baraitser’s reading of Appelbaum traces how the interruption gives rise to conscience and an ethical imperative. Through these experiences, Baraitser argues, the mother accesses a new sensory or somatic mode of self-experience (2009, p.80).

Baraitser’s thinking on interruption is particularly relevant for the mother with a disabled child, especially a child with a developmental condition. If mothering a baby is indeed ‘the pitilessness of the present tense’ (2009, p.66), what about mothering a child who may remain dependent for far longer than the usual span of years? Both the intensity of the child’s demands on the mother and the extent of them are expanded. In this case, the mother’s ‘new mode of self-experiencing’ (2009, p.80) is likely to be much more radical.

Accepting interruption and the rupturing of flow as the basic fact of one's life as the mother of an infant is one thing; accepting this for an indefinite period is something else.

For the mother of a disabled child, then, I would argue that interruption needs to be read in conjunction with repetition. The mother is repeatedly interrupted but also this dynamic may be played out in repetitive form for the rest of the mother's life. I am not suggesting here that disabled children fail to develop and change or that they necessarily continue to make on their mothers the kind of interruptive demands that Baraitser describes babies and young children making. But the fact of disability, as our culture perceives it, means that mothers of disabled children may imagine or fear such an experience, and many women do directly experience this. When a friend asked me how I would provide for my son (then still in primary school) if he couldn't gain a paying job, she was unwittingly reflecting this notion that developmentally disabled people will always be dependent on private care and that it is the mother's role to provide or organise such care. These views both reflect the status quo for many families, in Australia at any rate,<sup>7</sup> and are easily internalised or actively adopted by mothers of disabled children (see Landsman 2009).

Baraitser describes the mother of a young child as encumbered by all the equipment she needs to take with her to successfully care for that child. By the end of her book, the mother emerges as a 'dis-abled figure', and the child is conceived of as an 'extra unpredictable limb' (2009, p.153). Baraitser's 'dis-abled' mother is 'dis-abled' by physical matter – by the baby, the baby's stuff, by the physical landscape or streetscape, by the lack of access that is characteristic of the places most of us live. Once again, this state of encumbrance will be magnified for the mother of a disabled child, as she is likely to need specific equipment and be more constrained in her ability to navigate place (as will be a disabled mother). Baraitser's mother is an encumbered self, newly aware of the material elements of her environment. This is reminiscent of the physical world as experienced by people with physical or sensory disabilities or those experiencing chronic pain. It may even be similar to the experiences of those with psychiatric or cognitive impairments, as the noise of traffic confuses, the road rules obscure and other people become difficult and unpredictable objects in one's path.

Baraitser's 'dis-abled' mother sees another kind of world as a result of her 'dis-ablement'. Again, this may be likened to discussion in disability studies about how disabled people may, by virtue of their non-normative embodiment and experiences, contribute specific ways of knowing to the world, what Jackie Leach Scully describes as 'experiential gestalts' (2008, p.91) and Garland-Thomson describes as an 'epistemic resource' (2012,

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**Rachel Robertson, *Out of Time: Maternal time and disability***

**Studies in the Maternal**, 7(1), 2015, [www.mamsie.bbk.ac.uk](http://www.mamsie.bbk.ac.uk)

p.346). Baraitser says: ‘In a not completely serious manner, I suggested that an answer to the question what/who comes after the Subject might be informed by taking the maternal subject, glimpsed as a bizarre dis-abled figure, as if she were “normal”’ (2009, p.153). Is this in part a recognition that what we call disability is ‘the essential characteristic of being human’, as Garland-Thomson (2011, p.603) has argued? As many disability scholars have claimed, disability is really the ‘normal’ of being human, and perhaps particularly so of being a mother. It is a ‘normal’ still repressed, denied and fought against of course because disability also holds its status as ‘the master trope of human disqualification’ (Mitchell and Synder 2003, p.3). In this way, the disabled subject is surely similar to Baraitser’s take on the maternal subject. Disabled subjectivity – if we accept there may be such a thing – is like maternal subjectivity in the sense that it is, as Baraitser notes, ‘excessive to’ (2009, p.22) disabled identities. As Garland-Thomson notes, ‘Disability is, then, a conceptual category that represents something going beyond actual people with disability’ (2012, p.352).

I’m suggesting here a parallel between maternal and disabled subjectivities because of the way both problematise temporality. The maternal subject is continually pulled into the present by the interruptions of the child. Continually interrupted and encumbered in her attempts to move through space, she encounters a new and generative mode of self-experience. The disabled subject, too, has a different relationship to space and time. She (or he) presents a challenge to chrononormativity, disrupting ideal linear development and exhibiting a failure to ‘fit’ within normative time and space. This, too, can be generative, as disabled people develop and share new resources for managing this ‘misfit’ (Garland-Thomson 2011).

### **Maternal time, disability and the future**

In her discussion of ‘crip time’, Kafer demonstrates how the notion of ‘the future’ has been deployed in the services of compulsory able-bodiedness and able-mindedness. She argues that disability all too often serves as ‘the agreed-upon limit of our projected futures’ (Kafer 2013, p.25). Utopian visions of the future are always disability-free, as if it is self-evident that this is better than a world with disability. Kafer describes curative time as ‘a *curative imaginary*, an understanding of disability that not only *expects* and *assumes* intervention but also cannot imagine or comprehend anything other than intervention’ (2013, p.27, emphasis in original). The future for disabled people, then, is always described as either a diminished future (a poor



quality of life with impairment) or a curative future (where impairment no longer exists or is normalised).

Kafer, building on the work of Lee Edelman, suggests that futurity is always figured in reproductive terms and that the figure of the Child is the imaginary beneficiary of every intervention (2013, p.28). Focusing on creating a better future for our children leads to ‘an ethics of endless deferral’, as we work towards a future cure rather than assisting disabled people to live more fully in the present (2013, p.29).<sup>8</sup> According to Kafer, ‘the only culturally acceptable – culturally recognisable – future [for disabled people] in this context is a curative one, one that positions a medicalised cure as just around the corner, as arriving any minute now’ (2013, p.43). This positions disabled people in a temporality that cannot exist fully in the present; life is always on hold.

For the mother of a disabled child, this curative futurity demands that the present is always in service to the future. The mother’s caring role is amplified to include a kind of future-fear, whereby the mother must balance every decision she makes not just against the present but also against an imaginary curative future and/or a seemingly unimaginable non-curative future. Of course, all mothering involves planning for a child’s future but because the future of a non-disabled child is assumed to be predictable, it does not cast the same shadow over the present. For mothers of disabled children, the child’s diagnosis creates a future that dominates the present by virtue of its known unknowability. This double-time living creates a marginality of its own, one that is exaggerated by experiences of asynchronology due to a specific impairment or difference. In noting down my anecdote about my son playing at the water park with children half his age, I could have also noted the feeling I often get that I should not encourage him to have this sort of harmless fun because his time would be better spent learning skills like crossing the road safely or trying yet again to play a team sport. I could also have added that it crossed my mind to wonder how much longer he might be able to play in this place, how soon his body will make him too distinctive and cause problems for us. In thinking about my son’s future, I am aware that disabled people are continually being written out of the future, that researchers have explored the possible genetic bases of autism, perhaps with a long term aim to create a pre-natal test for autism so that autistic people are no longer brought into this world.<sup>9</sup> I may yet witness my son ‘rendered the sign of the future no one wants’ (Kafer 2013, p.46).

Garland-Thomson reads the dilemma of disabled futurity in a more hopeful fashion. Noting that ‘Disability represents a problem with temporality as it is formulated in

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**Rachel Robertson, Out of Time: Maternal time and disability**

**Studies in the Maternal**, 7(1), 2015, [www.mamsie.bbk.ac.uk](http://www.mamsie.bbk.ac.uk)

modernity', she suggests that disability frustrates 'modernity's investment in controlling the future' (2012, p.352). She is suggesting that we can read disability as severing the present from the future, rather than deferring the present for a pre-determined imagined future. She argues that,

disability can be a narrative resource that does not trade the present in on the future. More than simply an antidote to modernity's overreaching, disability contributes a narrative of a genuinely open future, one not controlled by the objectives, expectations, and understandings of the present. Perhaps counter-intuitively, rather than dictating a diminished future, disability opens a truly unpredictable, even unimaginable, one and, in doing so, confounds Promethean prognosis—that narrative of the future upon which we premise so much of our present (2012, p.352).

By suggesting that disability demands that we imagine a subject whose life trajectory is not managed or determined by the present, Garland-Thomson argues that one of the gifts of disability is that it rescripts our temporal practices and understandings (2012, p.353). This may provide the space for Kafer's non-curative approaches to futurity. Breaking the notion of a mapped linear development from dependent child to independent autonomous adult, of a future controlled by past and present, we may find ourselves able both to live in the present without the shadow of the future and imagine a future inclusive of disability and all other forms of human variation.

Returning to Baraitser's encumbered mother and my parallel between the temporalities of the maternal and disabled subjects, we can see the possibility that mothering may also be read as 'a narrative resource that does not trade the present in on the future' (Garland-Thomson 2012, p.352). Baraitser argues that the mother's experience of continual interruption brings her into the present whilst also causing her to encounter the open future of her child. It is not a trade of present for future, but rather a reinforcing of the present over past and future, a change in the mother's experience of her temporal being. Baraitser describes an ethical subjectivity arising out of the maternal engagement with the child's interruption and suggests that the mother's experience of the present may include 'a kind of impossible waiting that is the time the child's futurity requires of her' (2012, p.22). Framing 'the time of maternal waiting as a certain kind of ethical labour' (2012, p.22) is a powerful idea for all mothers, but particularly for those with a disabled child. The marginal spaces and temporal dislocations we experience may help us to work towards 'a narrative of a genuinely open future' for our children (Garland-Thomson 2012, p.352).

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**Rachel Robertson, *Out of Time: Maternal time and disability***

**Studies in the Maternal**, 7(1), 2015, [www.mamsie.bbk.ac.uk](http://www.mamsie.bbk.ac.uk)

## Postscript

I am driving my son Ben home from school. He is telling me about a class discussion about what the students want to do in the future, after they leave school. First, they were asked what they liked about school.

‘What did you say?’ I ask.

‘I said I like school because it is interesting. My school is very bio-diverse,’ he explains.

Then they were asked what sort of job they wanted and what sort of workplace they would like to work in.

‘Of course,’ said Ben, ‘I want to work near a train station so that I can travel to work by train. That’s my number one want for the future.’

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My thanks to colleagues Anna Sabadini and Rosemary Stevens for comments on an earlier draft of this paper and to the two anonymous reviewers for their detailed and constructive feedback.

<sup>1</sup> Not his real name.

<sup>2</sup> In this article, I use the terms *mothering* and *maternal* to refer to the relation of care between a female adult and a person who that adult describes as their child, thus including fostering or step mothering and so on. I use the phrase ‘disabled person/child’ rather than person/child with disabilities to signal that individuals with impairments are disabled by society and in recognition that disabled has become a positive identity term.

<sup>3</sup> *Aspie* is a term used by some people on the autistic spectrum, especially those who identify as Asperger Syndrome, to describe themselves. It may be used as a positive term of self-determination and autistic pride as part of the neurodiversity movement. For information about neurodiversity, see Savarese and Savarese (2010) and Runswick-Cole (2014).

<sup>4</sup> I use the phrase ‘autistic child’ rather than child with autism in acknowledgement that being autistic may be an integral part of a person, not an add-on or something that might be removed or cured. It may also be embraced as an identity term. I use the term *autism* rather than *autism spectrum disorder* for shorthand.

<sup>5</sup> There are people who are not able to construct a self-identity narrative like this, because of cognitive or neurological differences. While autistic people have often been cited as a ‘limit case’ for self-narrative (see Smith 1996, Eakin 1999), I join other autism studies scholars in disagreeing with this interpretation (Robertson 2012). Clearly many autistic people can and do create temporal self-narratives. (See, for example, Temple Grandin, Wendy Lawson, Kamran Nazeer and Daniel Tammet, to name just a few of the many autistic writers now published commercially).

<sup>6</sup> There is plenty of literature, of course, from the neurodiversity movement about how environments can be made more appropriate for autistic people (and form the basis of events like *Autreat*) and how autistic preferences for ‘stimming’, repetition or other activities should be acknowledged and may be the basis of autistic

culture (see Clark and Nelson). In this particular anecdote I am focusing on the issue of chronological age, an issue that arises for other mothers and children, not just autistic ones.

<sup>7</sup> According to the Australian Bureau of Statistics' 2012 *Survey of Disability, Ageing and Carers*, 'females made up the majority of carers, representing 70% of primary carers and 56% of carers overall', while 'female primary carers were four times more likely than their male counterparts to be the parent of their main recipient of care' (ABS 2013, np).

<sup>8</sup> One might argue with Kafer that working towards future cure also results in an improvement in the lives of disabled people in the present, as some of this work has produced interventions that develop new skills and outcomes. This still positions disabled people as on route to a better future, however.

<sup>9</sup> The consensus at present amongst researchers is that there is no single causal pathway and that it may be more accurate to speak of 'autisms' in the plural. Whitehouse and Stanley (2013) say, 'It has been estimated that autism has a known genetic aetiology in 10%–15% of diagnosed individuals' and that 'after seven decades of intense investigation, the research community is yet to identify proximal (neurobiological) or distal (genetic and environmental) causes that lead to the full constellation of behaviours seen in all individuals with an autism diagnosis' (Whitehouse and Stanley 2013, p.302).

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**Rachel Robertson, Out of Time: Maternal time and disability**

**Studies in the Maternal**, 7(1), 2015, [www.mamsie.bbk.ac.uk](http://www.mamsie.bbk.ac.uk)

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