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The embodied becoming of autism and childhood: a storytelling methodology

Abstract:

In this paper I explore a methodology of storytelling as a means of bringing together research around autism and childhood in a new way, as a site of the embodied becoming of autism and childhood. Through reflection on an ethnographic story of embodiment, the body is explored as a site of knowledge production that contests its dominantly storied subjectivation as a 'disordered' child. Storytelling is used to experiment with a line of flight from the autistic-child-research assemblage in to new spaces of potential and possibility where the becomings of bodies within the collision of autism and childhood can be celebrated.

In this paper I explore a methodology of storytelling as a means of bringing together research around autism and childhood in a new way, as a site of the embodied becoming of autism and childhood. It is situated within critical disability studies (McRuer, 2006; Davis, 2006b), an interdisciplinary field with aims of exposing and disrupting dominant a-political representations of disability (and disabled bodies) as inherently individual, fixed and problematic ways of being in the world. In a move away from the deterministic view of disabled bodies as problematic, doors are opened to 'thinking about bodies' (Goodley, 2011, 14) in which the '(impaired) body has a history and is as much a cultural phenomenon as it is a biological entity' (Paterson & Hughes, 1999, 600). I share a story of a morning spent at a ballet class with Sophie, who lives in a space that is labelled with both childhood and autism. Sophie is five, she has a diagnosis of autism. She does not use language but is verbal. She goes to a special school where her mum says she is happy, and she used to attend an inclusive nursery where her mum says she was not

as happy. The nursery staff had a lot of problems with Sophie. She was described in a whole host of fixed and reductive ways; challenging, difficult, autistic. Sophie's mum suggested that I visit Sophie's ballet class, a class in a village on a Saturday morning in a dance school.

Within dominant discourses of autism studies, Sophie may be part of research as disembodied subject, as a participant with a cognitive impairment. Curran (2013) reminds us that studies of disabled children's impairments or development are not studies of their childhood. Within dominant discourses of childhood studies however, Sophie would perhaps remain absent due to the normative demands for participation which she could not enact. Even within dominant disability studies, Sophie would be marginal in research interest due to her status as child (Connors and Stalker, 2007). Disabled children it seems enter a disembodied void in research somewhere between disability theory, because of their child status, and childhood because of their status as disabled (Kelly, 2010).

Within this paper neither autism nor childhood are considered as fixed states or neutral objects but as biopolitical categories which are produced and re-produced by the discourses that circulate around their name (Goodley, 2014). As I will show, the dominant representations of autism and childhood (both materially and theoretically) collide and pull at each other in research methodologies that leaves little room for one another's existence. '...modern childhood', Rose (1990) suggested, '...is the most intensively governed sector of personal existence' (p.10). Autism is most commonly narrated in the present day, global north, as a neurodevelopmental disorder with an individual demonstrating impairments in social

interaction, communication and flexibility of thought (American Psychiatric Association, 2013). The dominant discourse occupied by autism diagnosis is one of intervention, disorder and development towards an elusive gold-standard of normalcy (Davis, 1995); the 'autistic child' is measured against (and continually fails to meet), narrow, normative developmental standards of appropriate social, communicative, age-appropriate behaviour. The governance of childhood that Rose (1990) speaks of is magnified when it is met with autism where pervasive notions of the disordered child in need of adult, expert, developmental intervention are perpetuated.

The Study of Childhood

The emergence of the new sociology of childhood in the 1990s brought about a paradigm shift in the study of children. This shift was monumental in its turn away from the positivist, natural sciences and towards the recognition of childhood as socially constructed and a worthy site for the exploration of identity, culture and agency (James and Prout, 1997). With its focus on the rights of the autonomous and agentive child there was a call for participation and coproduction of knowledge by children in research (Christensen, 2004); children were considered experts in their world. Research here was no longer carried out *on* the child but was produced in collaboration *with* the child (Alderson and Morrow, 2004; Clark and Moss, 2001). This progressive research agenda strove for the recognition of the diversity and non-universal experience of childhood and was undoubtedly hugely successful in redressing the positivist imbalance. However, as participatory methods with children developed, it became apparent that disabled children (in their diversity), who may enact their agency and autonomy in ways

that were not normatively visible, remained at the margins of such research (Watson, 2012). The beginnings of participatory methods were often framed around ableist conceptualisations of 'participation'; the autonomous child's 'voice' being predetermined by a literal voice or observable social competencies (Davis et al, 2008). Sophie in not demonstrating her 'voice' through such means would remain marginal to, or excluded from, research which aimed recognise and value the diversity of childhood experience. Those critical of such exclusion of disabled children challenged researchers to recognise that enacting 'voice' in non-normative ways did not equate to not having anything to say (Beresford, 1997). In turning to a more critical conceptualisation of participation, the centring of ableist, normative markers of autonomy, agency and voice can be destabilised (Runswick-Cole and Curran, 2014; Watson, 2012; Davis et al, 2008).

Even Prout (2005), himself one of the founders of the new sociology of childhood suggests perhaps the study of childhood needs to move towards a more critical era. No longer, he suggests, is it necessary to present the study of childhood as dependent on a set of narrow dichotomies (for example biological determinism versus social constructionism). His argument is that these claims, whilst necessary to carve the niche to emancipate the study of childhood from biological determinism now serve to divert attention from the complex spaces between such dichotomies (68). The future of childhood studies perhaps then, requires the recognition of the complex spaces of childhood and as such, methodologies which themselves allow for complexity and emergence to be central.

The Study of Autism

The vast majority of methodologies still dominating the field of autism sit firmly within positivist, empirical paradigms and are owned and operated by those with legitimate autism knowledge; the scientists and medics, the studies of brains and biology. A review of the autism research landscape in the UK showed that of the £20.8 million of funding between 2007 and 2011, £11.6 million (56%) was spent on research within 'Biology, Brain and Cognition', a further £3.8 million on 'Treatments and Interventions' and £3.1 million on 'Causes' (Pellicano et al., 2013). Autism in the present day, global north, is most commonly described as a neurodevelopmental disorder affecting an individual's social communication, flexibility of thought and imaginative capacities (American Psychiatric Association, 2013). It is perhaps no wonder then that a body that is considered both child and autistic is notably absent in research methodology interest. There is an inherent tension between the two dominant research paradigms; the child in childhood studies is now an active, expert participant in research about their lives (James and Prout, 1997), whereas the autistic is a passive, disordered object who owes the expertise in their lives to the domain of biomedicine (Milton, 2014; Milton and Bracher, 2013). Where research of both autism and childhood does exist, it is most often within medical, developmental and psychological research literature, still firmly positioned as the disembodied objects of study and intervention and as passive and silent within the research process. Forging a path for considering a research agenda for the everyday lives of disabled children, Curran and Runswick-Cole (2013; 2014) invite us to consider how a disabled children's childhood studies provides a different starting point away from the passive, disabled child as

the object of study, towards an ethics that centres the child's experience at its heart and seeks out change and challenge to the pervasive norm cast over disabled children's lives.

Methodology: ethnography and storytelling

The methodology adopted in this paper is taken from a period of ethnographic fieldwork as part of my doctorate project which explores the everyday lives of children with a label of autism. I considered methodologies and practices that would create, produce and afford a counter-narrative to the dominant discourses discussed above. Over recent years narrative methodologies have been embraced within disability studies (Smith and Sparkes, 2007) following a variety of approaches; life stories (Goodley et al., 2004), auto-ethnography (Neville, 2004), oral histories (French and Swain, 2006) to name a few. The re-presentation of my ethnographic fieldwork takes the form of a collection of stories of everyday lives. I use storytelling as a means of countering the dominant disembodied research paradigms of studies about children with a label of autism. I consider the storying of the body to be central to the disruption and contribution to these paradigms in an attempt to understand autism and childhood beyond narrow biopolitical framings.

Whilst striving towards a storytelling methodology which acknowledged the prolific field of narrative inquiry, Max, who is eight and part of my project, brought home the slippery ethical task at hand.

When I asked Max to write a story with me, about whatever he wanted, something that told me about himself, he was at first reluctant, then nervous, and eventually refused.

Once he felt comfortable enough to share his objections it was clear that his unwillingness to participate was a caution that I should heed. His understanding of a story was something made-up. If the story was going to be about him then it wasn't made-up, because he was real, and ergo, what ever we did together wasn't a story.

Perhaps, he suggested, what I was actually asking him to do was write an article, like in a newspaper. That told people real things about him. To Max, if he were to share with me his 'truth' then why dress it up as a 'story'?

Max's caution remains with me in the theorising and writing of these research 'stories'. He provides a subtle reminder of the underpinning epistemological position of this project. The postmodern turn draws us to problematising both the collecting and reporting of 'data' (Richardson, 2000) in a way that the study of autism (particularly in relation to childhood) does not traditionally afford. The postmodern crisis of representation has provided those driving what has become known as 'alternative ethnographies' with much in the way of food for thought. The authority of realist ideology pulls hard towards a need to be 'true' to the original story or experience of the individuals we study with (Clough, 1992). I indeed felt that authoritative and tempting pull before, and during my fieldwork and had much anxiety about appearing as a 'real researcher' (Wolcott, 1999) writing about what was 'true' and 'real' for children like Max. The stories that I tell after my time spent with children are crafted within the sharing of the embodied worlds we enter in to in spaces of family homes, of school classrooms and of digging in allotments. I spend time with children and families in their homes, schools, allotments and parks. We talk or don't talk. We play or don't play. We eat, we think, we make things, we share things, we build dens, dig gardens and craft meanings. Or we don't. In some

senses, the stories are written in collaboration with the families, they would never have been written without them. In a practical sense, they are written by me. It is my fingers that tap at the keyboard and re-tell, re-cast and re-present whatever it is that we happened to do together that day. I do not tell stories in the 'voices' of children or their families because I cannot disguise my hand and ethically do not wish to do so. I narrate collective stories of my ethnographic work; what Roets and Goedgeluck (2007) define as 'tagging along with each other' (85). Schwandt (2004) considers this to be the 'taking ourselves along' (36) in effort to make sense of the ethnographic experience. This is far removed from a disinterested, realist methodological application but something that Walker (2001) feels should be celebrated by storytelling approaches; subjectivity and experience are recognised as powerful and compelling; there is room to experiment with creativity and fiction within academic research (Youdell and Armstrong, 2011; Banks and Banks, 1998). The stories are written as a form of inquiry and enact a creative analytics practice (Richardson, 2000) which aim to narrate due attention to the body as a site of lived, everyday experience.

Criteria for ethnographic storytelling

Bochner (2000) asks that those working within ethnographic approaches avoid a preoccupation with rigor, with a neglect of imagination. 'I wonder....', he asks, 'what it is we are not talking about when we are talking about criteria? Instead of asking, how can this be true? we could ask, what if this were true? What then?' (p.267). Allowing the storying of everyday lives to be measured by new criteria, in which writing itself becomes inquiry (Richardson, 1994), story-

becomes-scholarship (Sparkes, 2000) and analysis happens within the story (Ellis, 2000) is the means by which my ethnography is brought to analytical life. My writing has become less about recording the data I had collected and more about creating a sense of place (Sikes, 2005) to invite my reader in to. The criteria of alternative ethnographies is my yardstick. Do my reflections, materialised through the stories, promote dialogue (Ellis and Bochner, 2000)? Do they express a reality - enacting a fleshed out, embodied sense of lived-experience (Richardson, 2000)? Do they seek to nurture the imagination not kill it (Bochner, 2000)? Do I provide a view that complexifies the phenomenon (of autism and childhood) that has enough literary substance to provide a readable balance of chaos (Ellis, 2000)? I write against these new criteria and use my writing as inquiry, as an analytic tool to think with not just about the stories I tell (Ellis and Bochner, 2000). Situating my fieldwork within the frames of alternative ethnographies based on 'movement, complexity, knowing and not knowing, and being and not being exposed (Wall, 2008, 41) takes my subsequent writing from being a 'record' of fieldwork towards a continuation of fieldwork (Tedlock, 2000).

In finding space to resist realist standards by applying new alternative ethnographic framings, I am reminded of Bochner's (2000) caution of the allure of 'criteria' in general. Even 'alternative' criteria have an inherent subtext, masked as somehow 'natural' and not socially produced and always a means by which to measure certain representations of knowledge as somehow more or less legitimate or authoritative (p.269). The conclusion Bochner (2000) draws is taken forward within my subsequent story and analysis; not to get distracted by the desire to conform to re-written criteria but rather to maintain dialogue so that we can imagine better

ways of living together. Situating this approach within a phenomenological framing of lived experience allows for this dialogue to be storied through the everyday embodiment of the children and families within my project.

Situating methodology in phenomenology

A phenomenological framing of these shared, bodily, lived experiences allows for the recognition capacity of the body itself to be a 'source of self and society' (Goodley, 2011, 56). By moving away from Cartesian dualism in modernism in which the body is a passive, pre-cultural object, phenomenology allows us to talk about 'being and becoming'; the 'experienced and experiencing body', of lived experience (Paterson and Hughes, 1999, 600). Deleuze and Guattari's (1987) concepts of smooth and striated spaces can be helpful to move this argument forward as can Butler's (2004) writing on subjectivation. Butler suggests that in order for the subject to be performatively formed (in this case, the 'autistic child'), discourses need to be produced in recognisable ways (2004, 5); the knowable autistic child who appears as both autistic and child. Deleuzoguattarian smooth and striated spaces however, take this subject beyond the individual and a singular space and in to an assemblage (Deleuze and Guattari, 1987). If striated spaces are the disciplined spaces of hierarchy, binaries and normative meanings (Youdell and Armstrong, 2011) in which a body can be known and subjectivated as both child and autistic, smooth spaces then, are the spaces in between such biopolitical governance. Lines of flight are the means by which these striations are disrupted, they '...allow us to trip out of the striations in which we are caught and skate on the smooth plateaus between, even if in doing so we slip in to or begin to grind out yet another striation' (Youdell

and Armstrong, 2011 p.145). These smooth spaces are spaces of becoming because they go beyond the knowable and appearing subjectivated autistic child and in to spaces of exploring the potential of what a body can do (Deleuze and Guattari, 1987). A methodology which allows the body to be invoked in smooth and striated spaces offers the potential to explore what the body *can* do in such spaces beyond the governed, performatively formed subject. It allows us to recognise the ways in which children use their bodies to subvert despite the limits of the biopolitical descriptions of their everyday lives. It is the means for Max to share his 'truths' of everyday life beyond his labels.

German has more than one word for the body; the 'leib' describes a body of feeling, sensing and bodily experience (Crossley, 1995), and 'korper' the exterior, objective body (Bendelow & Williams, 1995). When the body (in spaces of autism and childhood) is constituted as the 'leib' as oppose to the dominantly storied 'korper', it becomes possible to think about these bodies as sites of embodiment which if considered as a body 'worth living in' can give us the opportunity to revise how bodies *can* be lived in (Deleuze and Guattari, 1987). In a phenomenological consideration of embodiment, this body is a worthy site of knowledge because it speaks of lived experience, which in phenomenological premise, *is* knowledge (Schutz, 1972). This gives us the arena to explore the stories I tell with parents and the lived, sensorial experience of children and ask what they can contribute to our knowledge of autism and childhoods. Through a focus on the body I aim to consider new possibilities for our analysis of such embodied everyday lives; to consider what they can offer to our potential to understand things otherwise outside of framings of cognition and disorder. I would suggest that

the stories themselves are the experimentation of lines of flight from the dominant disembodied autistic-child-research assemblage. These stories themselves are an act of becoming in smooth spaces.

A story of becoming, autism and childhood

The becoming of this story affords attention to the body as a line of flight from the dominant disembodied autistic-child-research assemblage.

It's early on a Saturday morning with crisp, bright sunshine and a thick layer of ice on my windscreen. I'm going to be late. I scrape at the ice furiously. The bitter air whips under my scarf as I get in to the car and my frozen hands stick to the steering wheel. Sat nav at the ready I set off out of the lazy, deserted roads of Sheffield and it to the wilderness of unknown Derbyshire villages. In 150 yards, I bare left.

I arrive at the dance school in the nick of time and tentatively introduce myself to the first smiling face I see, in the hope that they have remembered I'm coming.

I'm in luck, it's Anna, the Dance School owner. I'm quickly ferryed in to a vast dance studio that has such a chill I see my breath. I'm offered the seat next to the burning hot electric heater which I need to enjoy while it lasts; it's switched off once the children arrive to stop prying fingers meeting a blistered fate.

In the distance of the changing rooms I hear the hum and giggles of small voices and parents wrestling with tutus. I play with my notebook and realise I have no idea what's coming next. How exciting. I wonder if Sophie is already here, if her mum was having a fight with a tutu and if Sophie is going to be having a 'good day or a bad day, we never know' like the dance teacher foretold. She tells me the new music hasn't been going down too well with Sophie and that the prop teddy bear had been drop-kicked across the room in recent weeks.

Quite out of the blue I'm pulled back in to the room by a hush and a stilling of the distant scurrying feet. From a nostalgic ghettoblaster, a Disney classic (Aladdin!) rises from the depths. The room of the studio door is opened and three teenage girls corral and direct each girl, no older than four, a vision of pink, lycra and bounce, to their assigned seat on the floor in front of Anna. Seamless. They're reminded of 'tidy toes and big smiles' and follow instructions keenly and adeptly.

I sing along (word for word) in my head.

Sophie is brought in last, guided by one of the older girls and led with enthusiasm and gusto to her spot on the floor. She watches Anna cautiously, through sideways glances whilst seeming thoroughly enthralled in the experience. The music is loud. It's consuming, filling the large space with its boom and invitation to get lost in the Disneyfication of it all and Sophie's bought in to it as much as I have. The music continues to crescendo and Sophie gets to her feet and whoops

and shouts. This isn't the instructions she should be following but the teenage helper, acting as her shadow, and Anna too, seamlessly reorganise her space and she finds a new way to express her engagement with the experience, waving her hands and shaking her head, all the time whooping.

A new girl, thinner and even smaller than the others arrives late and scurries to sit herself down next to Sophie. A sideways glance from Anna is all it takes for her to know this might makes Sophie uncomfortable. 'We're a bit squashed here', Anna casually ushers, 'let's move to here' gesturing to the other side of the room. This feels thoughtful, and easy and allows Sophie and the new girl their space to be in the way they need to be. It's seamless.

As the music continues, the helper becomes occasionally overwhelmed by Sophie's body as it bolts across the room or spins quickly and unsteadily, flopping to the floor. Again, without fuss, Anna casually steps in, sweeping with the music across to Sophie's space. She seems to be at ease with Anna's presence, her body, and allows Anna to dance along with her supporting and twirling her floppy body in a mutually acceptable way.

Somewhere amongst this musical whirlwind, plastic wands have appeared and are used to direct the next phase of the girls performance. They're each given the opportunity to solo in front of the mirror, 'sway, sway, sway and tuuuuuuuurn', tiny feet teetering and stumbling with a vague resemblance to

360 degrees; Sophie accepts the direction of her body and the regulation of her movement happily.

The rest of the class passes in a blur of Disney and a haze of pink. Adults (or teenagers) are always at hand for Sophie, for the other girls, to make sure she can join where she wants and roam free when she choses

Conclusions: methodologies to contest a knowable body

I draw here on the corpus of autism theory to demonstrate how this story can contest the descriptions of a body that is knowable as disordered. Within understandings of sensory processing complexities commonly associated with autism, is the notion of proprioception; the sense of where one's body is in relation to other bodies and objects. There is a nod towards the importance of the body in relation to research around autism but it seems to stop there, at a vague acknowledgement of sensorial abnormality or deficiency. The body as a sensory being can be a tricky one if you live in spaces labelled with autism because through the discourses that provide legitimate knowledge of what it means to be autistic - biomedicine - that sensory being becomes knowable. Most significantly, that being becomes knowable as sensorily abnormal and in turn, governable. The experiences of the body in relation to autism within the dominant discourse are accounted for by brain function, regulating, or failing to regulate sensory experiences. The body is tied up by the brain and is *owned* by it. This is a sticking point because it dictates that that the embodiment of autism is bound up in the realm of all things cognitive. These domains leave little room for anything very 'experienced' at all and are far

more concerned with the process of brain function and its consequences of subservient bodily function.

We are haunted here by what the body is and is not, and what the mind is and is not, by the Cartesian call of disembodiment. If we draw boundaries around and between the body and mind whilst insisting on a body that is ultimately dictated by the mind then an 'autistic body', labelled by an 'autistic mind', leaves little room for manoeuvre. Hickey-Moody (2009) speaks of this marginalisation of the body as a product of Descartes' pushing of corporeality as 'exterior to the realm of pure thought' (3). As such the body is not a site of knowledge, it is without thought and is limited and undervalued by virtue of its mind's 'intellectual disability'. Braidotti (1996, 55 in Hickey-Moody, 2009) imagines the body, its flesh, as the 'silent other' which Spinoza (2001) would argue is in silence or deliberate silencing, not less powerful, but less well understood. Spinoza has us believe that our 'minds are the idea of our bodies' (Hickey-Moody, 2009, 5). This alternative leads us towards the 'thinking body' (6); a body is neither able or disabled but is a process of becoming. When the limitations of Cartesian ideas are interrogated and the myth of the natural body uncovered (Butler, 1993), it becomes equally feasible to 'denaturalise impairment' (Donaldson, 2002, p.112). No longer is Sophie's body a knowable entity of sensory abnormality, of cognitive disorder, but a being which produces and pushes at Cartesian ideas of what it means to know and live at the collision of autism and childhood. Within this becoming we are offered potential from the story of the Saturday morning ballet class and from the knowledge that Sophie and her body were producing in that smooth space. Sophie and her body subverted the limitations of the descriptions by which she was bound.

Let's return to the ballet class to consider the sites in between the body and mind dualism that allows us the space to explore this potential.

From a layperson's perspective, ballet could perhaps be understood as a *discipline* by which I mean a regulated, controlled form in which one learns techniques, movements and processes for and with the body. It is very much a realm (again, understood as a layperson) of something which one can be 'good' or 'bad'. I think back to the harking 'tidy toes' that were spattered throughout that Saturday morning. Ballet requires disciplining in order to produce freedom; the body regulated as a means to an ends, the body's formalisation and precision allowing eventual expression, I would theorise. In this sense then, Sophie could have been very easily bound up within the unruly¹ realms of not being very *good* at ballet; her body did not conform to the discipline set out for it.

I had previously listened to practitioners from her inclusive nursery setting describing Sophie and her body, their descriptions encapsulating her being as 'challenging'. Narratives of professional expertise spoke of a child with 'challenging behaviour' (Emerson, 2001). Those echoes rang dim on this Saturday morning. Should not her unruly body be invoked in much the same way by the ballet teacher here? Her body could surely be considered far more 'challenging' in this space due to its disregard for the discipline that is ballet. But for some reason it was not. For some reason within a space that *should,* in theory, place much greater

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¹ I take 'unruly' from Erevelles (2000) as the body that does not adhere to, or meet humanist standards of the rational, contained, non-disabled body. I choose it for its theoretical associations and equally for what I feel the word and its sound connotates - movement, freedom, arms and legs everywhere - Sophie's body in that morning embodied unruliness.

value on bodily conformity compared to an inclusive nursery promoting free-flow-play, Sophie and her body existed with far less regulation and discipline. This space without an 'inclusive' branding or 'autism specialist'. Here, Sophie and her body were less well known (through a lens of autism and childhood) and instead were producing knowledge, of becoming. Hickey-Moody (2009) considers, 'how does one create a space with an atmosphere that positively transforms the way in which bodies can be thought?' One might be more inclined to believe that an inclusive nursery would be more likely to achieve such an atmosphere than a Saturday morning dance class. However, it would seem that this dance class was a space that far more readily embodied transformative understandings of the body. This methodological approach with a focus on embodiment as a place of knowledge production and experience offers us a means of going beyond the traditional limits and boundaries of empirical methodologies which know and measure Sophie not by her bodies production, but through her mind's disorder. In this dance class, the mind was not privileged over the body, neither autism nor child were privileged over the embodied experience of space; this was a space of becoming, of autism and child.

By introducing notions of embodiment it becomes possible to get in between the divide; the body becomes both the source and the site of agency and not an entity in need of rationalising by the mind, and in turn, society (Csordas, 1993). Through engaging in ethnographic practices such as this, the stories that we tell of bodies, of autism and childhood, can maintain a phenomenological gaze through affording attention to descriptions of collective, sensorial, embodied encounters. By bringing together embodiment through ethnography and storytelling there is the possibility to create a spaces of becoming and potential; a becoming beyond the

subjectivation of autism and childhood. I have explored the beginnings of these possibilities within this paper and reflected on the potential for our understandings of the collision of autism and childhood through a methodology of storytelling. That storytelling has been used to experiment with a line of flight from the disembodied autistic-child-research assemblage in to new spaces where the becomings of bodies within the collision of autism and childhood can be celebrated.

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