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Thinking and Doing Consent and Advocacy in Disabled Children's Childhood Studies Research

Jill C Smith

This chapter contributes to the growing body of work in disabled children's childhood studies which requires specific ethical considerations in design, methodology, procedure and perhaps most significantly, in everyday practice. I use the chapter as an example of the thinking *and* doing (i.e. the methodology *and* analysis) of disabled children's childhood studies research. The chapter explores ethical issues inherent in research, particularly in relation to advocacy and consent, which are necessary in developing, delivering and writing an ethical project.

I use this chapter to explore, in storied form, the ethical encounters from one particular research project working with disabled children and their families (Smith, 2016b). What began as an ethnographic project spawned in to something inherently auto/ethnographical due, in part, to the significant ethical dimensions within which I felt entangled as a researcher. *Being* a researcher, *doing* research, with disabled children and their families was a blurring of traditional researcher/researched relationships as I was invited into family homes, family lives and children's everyday worlds. There are ethical imperatives at the heart of any work that puts the everyday, embodied lives of disabled children at the front and centre.

My research and this chapter sit within dis/humanism, part of dis/ability studies (Goodley and Runswick-Cole, 2014; Goodley et al., 2016). The slash (/) of both dis/ability and dis/humanism brings to attention '...the meaning making of either side of the disability-ability binary and the messy stuff in the middle. Dis/ability is also a moment of contemplation: to think again what it means to be dis/abled and what it means to be human' (Goodley, 2014, x). Where dis/ability in its slashed form enters, we are invited at once to the *ability* complex of dis/*ability* and to question its form and power. Dis/humanism, as dis/ability, also takes the prefix 'dis' from dis/ability and from the colloquial verb 'to dis'

as in to dis-respect (Goodley and Runswisk-Cole, 2014). *Dis/*humanism in this sense, is ambivalent to the modernist conception of the human, independent, rational and contained, as it so often is incongruent or exclusive of those who experience dis/ability (ibid). Dis/human (Goodley and Runswick-Cole, 2014), and more recently DisHumanism (Goodley et al., 2016), act as somewhat of a heuristic of dis/ability, which invites complexity, invites relationships and invites humanity, to a commitment of dis/ability politics. This turn in Critical Disability Studies is '...ambivalent about the human because too often it represents only a minority and bypasses the empirical human world' (Goodley and Runswick-Cole, 2014, p. 10). Instead of, as Titchkosky suggests is the case, 'detaching' disability from what it means to be human, dis/ability and the dis/human allows us a way in to renegotiate humanism to consider '...how we value the human and what kinds of society are worth fighting for' (Goodley and Runswick-Cole, 2014, p.4). In bringing in the 'dis' to humanism, Goodley and Runswick-Cole (2014) ask that whenever we speak of the human, a politics of dis/ability should not be far behind. In more recent writing developing this compelling challenging of 'the human' Goodley, Runswick-Cole and Liddiard introduce us to the DisHuman child; the demand 'to think in ways that affirm the inherent humanness in [disabled children and young people's] lives but also allow us to consider their disruptive potential...' (Goodley et al., 2016, p.777). This is a call to a new ethics in our research with disabled children, a different starting point, one which in both theory and practice affirms the humanity of a claim to childhood whilst recognising and disrupting its ableist, exclusive boundaries.

The children I worked with all had labels of autism; they were living within bodies that were discursively constituted as both 'child' and 'autistic'. Traditional conceptualisations of disordered childhood, such as those labelled with autism, ruminate on a particular ghostly spectre of ableism; the child with an autism label deviates from an imagined normative developmental trajectory. Research centred around this developmental deviation does not see an ethical imperative to value the lived, embodied childhood associated with this disordered cognition. From a different starting point, one of dis/ability and more specifically dis/human, we are able to shift our ethical gaze away from the disembodied disordered mind of a child and towards a politics which disrupts, and contributes to, what it means to

be a valued child and a valued human (Goodley and Runswick-Cole, 2014; Goodley et al, 2016).

So what does this shift in our ethical gaze mean and why does it require distinct thinking and doing? Ethics here is not merely procedural, an adherence to social research or university ethical *codes*, it is a commitment to ethical *values* (Homan, 1992). Ethical here means understanding and valuing the everyday lived experiences of children and their families as valuable in and of themselves; to challenge the dominant discourses of medicalisation, pathologisation and psychologisation that stalk disabled children's childhoods. To value and speak to their childhoods and their humanity. To trouble discourses and practices that do otherwise. To be ethical is to interrogate the moral implications both implicit and explicit in the designing and doing of a project; the risks and potentialities of such issues. 'Ethics' do not exist in a vacuum and take place in the social (Bulmer, 2008), that is, the commitment to ethical research takes place *with* the participants not simply before, or around them.

It is with this commitment to ethics that I now turn to some of the most pertinent considerations embedded within this project's conception and undertaking; consent, advocacy and valuing embodiment. What follows are a number of stories and reflections upon them about some of the poignant ethical moments I encountered in the thinking, doing and writing of this project. I focus on a conversation about consent and advocacy with Kate, a mum of five children with autism diagnoses, pertinent reminders of risk from two of Kate's children, Max and Joe, and a brief example of the embodiment of consent with another child, Zac, which took place on a community allotment.

Consent and Advocacy

Billington (2006, p.8) asks us, as professionals working with children to question, 'how do we speak of children?' I extend this to the work we do in research with disabled children; how do we speak of disabled children?

It became apparent very early in meeting each of the parents in this particular project that advocating on behalf of their children was a familiar and well-worn path. I was to be one of many 'professionals' that had come before, and would come again, in to their family lives in the complex relation to dis/ability and their child. I write about the complexity of the ethical process in a formal sense of gaining informed consent from both the parents and the children, and the enmeshment of advocacy woven throughout parents' conversations with me throughout the process. Parents, in their talk of their lives, children, autism and dis/ability, narrated the stories of other lives too, their other children, their partners, teachers, professionals and more. In recognising how stories seep into one another, spreading from one life to another, let's consider some of the ethical possibilities inherent in such leakage; 'the familial relation is not a simple one; it is an embodied relation and as such it is a messy, tangled nexus of love, hope, grief, anger, disappointment, joy and, always, always more' (McGuire, 2010, p.1).

I had originally developed an extended period of consent to be undertaken with the children in my project. This was to include a period of discussion with the parents including the sharing of ideas and materials (photographs, favourite TV characters, music, hobbies) to be developed into an interactive, personalised consent form on an iPad. This was designed to explain the purpose of being introduced to the children in a way that recognised the need to make such a process personal and meaningful for the child. However, for a number of reasons, some of which I will go on to explore, this digital process of personalised consent didn't happen with any of the families. Instead parents gave written consent and the consent with children was established verbally and on a moment-by-moment basis.

I turn here to the ethnographic story I wrote after a conversation with one mum about how I should be introduced to her son and what I would or should mean to him and him to me.

> *We had an interesting conversation about how Kate should 'pitch' me to Max. She remarked that however she pitches me will effect whatever experience I am able to share with him and that I needed to know what that was manufacturing. Am I Kate's friend who is interested in stuff to do with autism? Am I a researcher? Am I from the*

university? Or am I someone that likes to play with Lego? I very much wanted Kate to take the lead on this and talked about how I was never quite sure of how comfortable how much families had to 'give' to be part of research.

We talked about consent and the assumptions and potential for 'overdoing' it. I explained my plans for the super-personalised digital consent and had to concede that, knowing Max as she does, Kate was probably right in suggesting I could just talk to him instead, negotiate a deal. She laughed as she said she didn't have a problem consenting for him, she does it all the time anyway. Perhaps it's because we as parents think we have ownership over our children - Kate reflected. Her one reservation was about how much time I spent with Max and how he might become attached and then distressed after I stopped the research. We need to talk about this more.

This story had the hallmarks of conversations I have had with the parents about consent for their child's participation in numerous projects. Each in one way or another, as Kate reflected, seemed happy to claim 'ownership' over their child that if they said something was fine, the child would accept it was fine (or have to accept it). This varied from 'oh there's no point trying to explain it to them, they won't get it anyway' or 'she'll let you know if she doesn't want you around, trust me!' These responses to the consent process aren't unique to this project or perhaps even specifically about parents referring to their child's communication or comprehension skills in particular, but more a common discourse around parent-child decision-making. Within the sociology of childhood there has been an active move to counter the discourse that reifies children as passive in an adult-led world, submitting (or being without) agency in their decision making because of their lack of adult competency. Developing research projects with children's active participation in the ethical consent process has been front and centre of such a move (James and Prout, 1997; Danby, 2002; Christensen and O'Brien, 2003; Christensen and James, 2008). This paradigm shift brought with it research aimed at increasing the participation of children in their childhood (Clark, 2005). Traditional representations of the child as '...unreliable and developmentally incomplete' (Mayall, 2008, p.110) were replaced. 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. I would suggest, as have others (Watson, 2012; Davis, 2012; Curran and Runswick-Cole, 2014), that the participatory research agenda has somewhat sidestepped or bypassed disabled children in an overly homogeneous conceptualisation of childhood agency and participation that doesn't account for differing embodiments or communicative modes. 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). Disabled children, particularly those who didn't use spoken language as their primary mode of communication remained 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 et al., 2004; Rabiee et al., 2005). In turning to a more critical conceptualisation of participation, the centring of ableist, normative markers of autonomy, agency and voice can be destabilised (Curran and Runswick-Cole 2014; Watson 2012; Davis et al., 2008).

In drawing together an ethic of disabled children's childhood studies which recognises ableist approaches to conceptualising participation, I spent time considering how best to recognise agency and value communicative intent for the potential children I envisaged taking part in my project. I felt at times that I was becoming over-reliant on narrow cognitive conceptualisations of competencies associated with autism and communication that were pushing me towards a deficit-approach reifying children's passivity in the process, for example, how to 'compensate' for children who didn't use language. In drawing back from such a slippery slope I returned to the sociology of childhood's framing of agency whilst resisting its normative stance. In de-prioritising spoken language, I turned my attention to a more visual and personalised presentation of what my project could mean to the children participating. This drew loosely on communicative strategies supported by autism theory

such as the Picture Exchange Communication System (PECS), which recognises the value of personalised, visual information. Where I would caution against the homogenisation that is latent within such assumptions about autism and communicative preferences, the adoption of techniques that at least offered creative inroads to the complex process of consent were welcomed.

It was within such move that I had gone to such lengths to develop a creative consent procedure for the children that drew on notions that recognises their ability to communicate intent and make decisions. I stand by such an intent but also recognise its limits; I needed to be mindful not to undermine parents' expertise about their children, whilst ensuring that my consent process centred around children as active in the process. In a similar quandary, Davis et al (2008) wrote of their ethnographic study with disabled children at school in which the children were homogeneously positioned as incapable of understanding the consent process, with the power to 'access' remaining firmly in the staffs' hands. It seems possible that, perhaps not knowingly on either side, I was becoming re-socialised by the parents and their constructions of their children by changing my original plans for consent. How was I to value the parents' expertise about their children (a central call of the project) whilst simultaneously remaining mindful of what/who is conceived when parents advocate for their disabled child (McGuire, 2010)?

I reminded here of the ever-pertinent words of Titchkosky (2007, p.3) who heeds us to 'read our readings and watch our watchings' of how we come to speak of disability in particular ways. Building on this, McGuire (2010) cautions that we need to be mindful of the 'we' being conceived when 'we' (parents and allies) seek to speak of 'living with' the disability of another (in this case the child). Taking Butler's (2004) notion of 'unknowingness' the distance between you and I is at once what binds and separates us (McGuire, 2010, p.5); it is not a natural space but a negotiated one that happens at once between parent and child, researcher and family. McGuire contests the 'we' of those 'living with' disability and reminds us to be ever-mindful of the seamless leaps that are often presented as natural when describing our interpretation of another's life. The temptation to gloss over the power exerted when a parent speaks of their child or *for* their child is not a site for moralising parents' knowing of their child but a site to interrogate how the 'other' is always already

being reconstituted through such a storying even within intimate family relations. 'To 'live with' the other, to speak the 'we', is always to be at risk of relation to the other violently (ibid). However, this risky space may also be an opportunity to re-enter the story that 'we' are telling and to tell it differently' (ibid, p.14).

The ethics of such a power imbalance and its complex facets, were at the heart of this project and remained a cautionary tale in my research with families, my writing of the stories and the analysis of the 'we' (the child, parents, and I) that I speak of. As I saw it, for this project to be ethically grounded, it had to be done with a commitment to not prioritise the parents over the children; to continually problematise the 'we' that was being conceived by myself, in interactions with parents, and children. Without problematising this 'we', the project risked further perpetuating the dominance of research that is carried out around disabled children's lives that is actually exclusive of their experience and focuses only on the experience of their parents.

There was tension within this; was the project becoming more about the parents at the expense of the experience of the children? I felt quite strongly that the process I had developed was conceived recognising the children's participation actively in the consent process. So, despite moments of reservation, I had to take trust in each of the parent's advocacy of their child's consent in the first instance, and work on a range of verbal and embodied sharing of my project's intentions and the children's consent as I met them. This is not by any means to suggest that once the formal consent had been handed over by the parents that I assumed the children's participation.

Consent as embodied and ongoing

As I have explained, I began by relying on relatively traditional tenets of ethical codes in a *procedural* sense, with a consent 'form' that perhaps was still overly reliant on markers of participation that favoured normative participation, spoken words, active agency demonstrated through a literal 'voice'. In *practice*, the process of consent was very much embodied and enacted in a shared moment-by-moment becoming of participation. It was undoubtedly 'assent' that I sought rather than informed consent. This was not because I

believed the children's consent to be unimportant or that I believed them to lack the agency or competency to give consent, rather that I problematise the ableism of the individualising concepts themselves. It would be problematic to suggest the children participated in something that could be called informed consent by traditional definition; (1) presentation of information, (2) understanding, followed by (3) a response where consent is either given or withheld (Morris, 1998). Significantly, this was not exclusive to the children but speaks to more general issues around informed consent in research. I spent many hours conversing with parents about my project, its everyday workings, its potential outcomes and dissemination, and would still contend that many did not give fully informed consent relating to either their understanding or my presentation of information. On one occasion long after the formal consent process and several visits with the family, one of the dads said, 'Are you still wanting to do your study? When are you going to start?' Somewhat taken aback, I realised that despite information sheets, consent forms and conversations explaining what the project would 'look' like, there was still an expectation somewhere that I would be *doing* some kind of formal *studying* of the children. There I was, digging away in their community allotment, chatting to a parent about school, the children pottering around me, *doing* my research, or so I had thought. The dad however, was seemingly still waiting for me to *do* something with his children. That my research didn't involve testing, requiring the children to do something *for* me undid much of the negotiation of informed consent. This is an important lesson for those of us interested in research with disabled children about their childhoods, the expectations that we will be *studying* their impairments is a powerful one with a long history of pathologisation and medicalisation. The distinctiveness of disabled children's childhoods studies lies within the challenge to this expectation; a valuing of research about everyday lives not impairments (Curran, 2014). Part of the role of disabled children's childhood studies is in changing these starting points and redressing expectations. Part of the challenge is the reminder that this needs to involve on-going conversations with those we research about what 'research' is and what it looks like.

So, instead of somewhat unreflexively assuming informed consent, I sought to understand children's assent to my presence. This valued embodiment as a way of knowing and a process of meaning-making (Hackett, 2014; 2015). With the children at the allotments this

was often just a 'checking in' as I arrived at the site, a wave from a distance, a crouch to say hello or a shared plot of soil to dig alongside without the need for any direct interaction. I was never the only 'stranger' at the community site and the children seemed as indifferent to my presence as to any other adult who pottered and dug around their play for the most part. The children had the space to be far removed and out of site from mine, or anyone else's 'gaze' as much as they pleased and I made a conscious effort not to spend any time with them that wasn't initiated by them. This meant that for the most part my time at the allotments was spent chatting to the parents and other adults and various siblings scattered across the site. Over time, as I became more familiar, Zac in particular began to initiate interaction with me, for the first time in the hunt for dock leaves after a he got particular distressing nettle sting.

> *I'm pottering away weeding the seamlessly endless knots of weeds around the raspberries, chatting away to one of the mums about schools and classrooms and difficulties with friends in playgrounds. Zac is brought to my attention with a sharp scream before I catch sight of him in my periphery. He yelps, whoops and sobs, dragging me by the arm through the site to an area where he'd previously found the helpful leaf. I turn back to his mum to check she doesn't want to intervene. She looks a little shocked and mouths quietly, 'let's see what happens, he always comes running to me, it's good that he's not'. I scramble for a leaf, with a vague panic that my choice wouldn't be a medicinal leaf but something poisonous and assist in the ritual rubbing of the nettle sting until his sobs subside. Subdued, red in the face and a little snotty, Zac leans in to me for a moment and then carries on his merry way.*

On a different occasion, Max brought home the slippery task of truly informed consent and the difficulty in clearly articulating exactly what involvement in the project actually meant (Smith, 2016a).

> *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, whatever 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 is a reminder of the need for clarity and an extended, negotiated process of consent. After all, mine and Max's versions of what constituted a story were of course different for a number of reasons not least that I consider myself a storytelling researcher. I love writing and Max hates writing. It would be easiest to equate these crossed wires to a child/adult binary and to suggest that an adult would have understood what I had intended by the use of a singular word, 'story'. That somehow discredits Max's knowledge and overstates my explicitness. It has been helpful food for thought when considering the legitimacy of any process of consent as every being truly achieved within the procedure rather than a shared negotiated relationship between myself and the children and families. Joe, Max's older brother challenged the legitimacy of ethics procedures, which are designed to protect and safeguard participants in research further in the following story.

Joe's reminder of risk

Coming towards the end of a visit to the Goodwin's, I come down to the kitchen after a stint of serious den-building and am greeted by a chuckling Kate and Joe who eyes me with caution and humour. 'Joe has something he wants to ask you, Jill' Kate smiles flitting her attention between me and Joe's grin. Joe returned his gaze to his computer screen seemingly presenting as nonchalant. 'He wanted to know if you were a paedophile. He asked me how I knew you weren't a paedophile and I realised couldn't say for sure, that I suppose I just assumed you weren't. I asked him why you thought you might be - why else would an adult want to play with children, he thinks it's weird. I told him you weren't a peadophile and that I trusted you. If I didn't then I wouldn't let you spend all this time with my kids would I? But then he asked if I'd be ok with you going up to my children's bedrooms and playing if you were a man and I

realised that I wouldn't be - so my son's just pointed out that I'm sexist too!' All the while Joe gives half of his attention to the conversation and to mine and Kate's lighthearted dismissal of his lighthearted accusation. We all spend some time chatting through his astute recognition of such questionable consensual ethical agreements between myself and parents. Kate conceded that my university branding had given me de facto access to her children and de facto status as trustworthy and non-threatening. She had led her children to believe they were safe with me. She admitted that her willingness to take part in my project and to continually consent to my time spent with the children being somewhat reliant on my being a woman and a small, seemingly bubbly, young one at that. That if I'd been a man she'd have been suspicious - which she recognised as equally shaky but true nevertheless. Joe had recently been in trouble for having a 'voice chat' with someone he didn't know over the internet. He'd be chastised for talking to strangers which was explicitly against the clear and defined rules of his access to computers. He'd be trading something complicated (the understanding of which fails me) and the voice transaction had made it easier and quicker. Debates around safety, predatory adults, strangers, and paedophiles was a hot-topic between Joe and his mum at the moment and he'd spotted inconsistencies in his mum's line of argument by her agreement to let a relative stranger spend time alone with her children, something he considered far more risky than a virtual conversation.

As lightheartedly as Joe and his mum negotiated a serious, and within the family context, legitimate concern, it was a pertinent reminder of the powerful discursive foundations which are brandished, often unwittingly, through mine and the parents in this project's clandestine advocacy on the behalf of their children. It is a reminder that the will of the children in this project is always somewhat subjugated by that of their parent's willingness to invite me in to their homes, schools willingness to open their classroom doors without question or hesitation. I am pleased that I am not asked if I'm a paedophile on a regular basis, that it is assumed that my intentions are legitimate rather than sinister but I am also troubled by it. Without any sinister intent, it perhaps shouldn't be so readily assumed that my status as a university researcher makes me devoid of fault or the potential to harm

(despite ethics procedures designed to formalise such a commitment). There is inherent risk in research with people and children that at some point or another, my presence or actions can cause distress. Or that in the writing of a project, a paper or a chapter, ethical integrity also becomes problematic. In storying the life of others there is the potential for violence as McGuire (2010) cautions.

Advocating Otherwise

Here I draw on the overlap between the advocacy of parents consenting on behalf of their children, talking of their children within the storying of their lives, and the advocacy I rely on in my storytelling as a researcher. Many of the critiques of auto/ethnography as an ethical form of enquiry could equally be applied to the processes that happen when parents speak about their children, or *for* their children. Parents tread a line of 'auto' whenever they speak of their children as the storying of their lives as parents and the storying of their children's everyday lives are wholly intertwined. As Tolich (2010) speaking of auto/ethnography, reminds us, even when we think we are speaking of 'ourself', we are implicating others, 'the self is porous, leaking to the others (p.1608), which he fears is often without due ethical consideration of such blurring. Such leaking, Chang (2008) would argue is the fundamental to our lives as social beings, others are always visible and invisible in our storying of it, we do not live in a vacuum which Clandinin and Connelly (2000) then ask, if we tell a story, do we own it? I ask these questions of the stories I write in this chapter and the conversations I have with parents about their children. My negotiation of the ethical rub of storying others' lives is to consider Denzin's suggestion that 'telling does not subtract from other tellings; telling is not a zero-sum game' (Denzin, 1996, p.47). This is a reminder of the ever-multiple becoming of storying as always incomplete and contingent on teller, listener, time, place, and a whole host of other factors (Davies et al., 2004). What must be remembered here is that these stories, though pinned to the page of a book chapter, forever remain unfinished. These are stories shared in a moment, on a particular day, with a particular researcher. These stories have been told before in different ways and will become re-told and re-fashioned in other contexts, on other days, informed and moulded by other experiences and the passage of time. In that sense, they forever remain complex, incoherent, changing, and moving. I draw here on Pulsford's (2014) claim to story-as-rhizomatic; they will forever

reach in multiple directions, morphing as they come in to contact with other stories, creating, disrupting and blurring assemblages.

Stories left untold

It is worth a brief aside here to acknowledge another specific ethical mire of this project in relation to the sharing of stories; the conversations I had with parents that I felt could not (or should not) be written. The reasons for such hesitancy in writing up certain conversations in to the storying of this chapter range from the blurring of the ethical integrity of telling others stories (for example of children and families not part of the project) or a much debated issue of storying aspects of lives that the participants hadn't explicitly consented to being part of the project. Ellis (2007), a much revered auto/ethnographer, discusses the criticism that she has exploited consent as the people within her work had never given actual consent to be part of research. As much as I recognise that within an ethnographic process there are unexpected moments that could never be planned and prepared for, the only solace I could find within literature justifying either side of this coin was in Medford's (2006) call to only ever include material that you would be happy for participants to read. I don't expect that my participants will read my writing, in general, but have used such a tool as my yardstick for when to take fingers to keyboards and when to leave encounters unwritten. There were conversations that I had with parents that were no doubt influential to the storying of theirs and their children's everyday experiences that nevertheless felt too intimate for the page. Stories of days spent with families in which I felt unable to write without drawing in aspects of their lives that I had never intended to be part of the project and they hadn't ever thought would be included. Such is everyday life and a project based around it. These stories, though never written, have nonetheless inevitably permeated my writing of the project as they permeated my ongoing relationships with the families; they coloured my knowing and understanding of them and framed what it was possible to know and understand beyond it. It may seem somewhat of a teaser to speak of untold stories but it is an acknowledgement of the limitations of any project in its written form, and any writing to always be bounded and to recognise that any story told is never the only story possible.

Conclusions

I am cautious and mindful to attend to the implicit discourses embedded in reductive or representational leaps of storying the experiences I shared with children and their families in this project. I cling tightly to a Critical Disability Studies imperative to expose and trouble ableism stalking the stories I told and the analyses I went on to make. McGuire's (2010) cautionary tales of the risk and violence of advocacy bled in to the experience of storying, and relating to the experience of narrating these children and families everyday lives. I used these tools along with critiques of auto/ethnography as yardsticks to evaluate the more slippery ethical dimensions of what should and shouldn't be written and how it should (or could) be analysed. The danger is always to slip into analytic practices that served no more of a productive purpose than the dominant discursive conceptualisations of children labelled with autism I seek to trouble. The potential and possibility of advocating otherwise (McGuire, 2010), is to stay with the conception and deployment of ethical procedures always as situated, problematised and taking place *with* participants. The distinctness of disabled children's childhood studies ethics is to trouble conceptualisations and methods of participation, as I have shown in the development of consent processes, that challenge normative markers of agency that would exclude disabled children as less valuable contributors or unable to contribute (Curran and Runswick-Cole, 2014). This is a dis/human turn to claim (active participation) and reject narrow definitions (normative modes of participation) of what it means to be a valuable and valued child in everyday life (Goodley and Runswick-Cole, 2014).

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