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### **Citation:**

BARRETT, Elizabeth (2017). Tied to the worldly work of writing: parent as ethnographer. Journal of Intellectual Disabilities. [Article]

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## ***Tied to the worldly work of writing: Parent as ethnographer***

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### **Abstract**

*Parent narratives have contributed to ethnographic accounts of the lives of autistic children but there are fewer examples of parents producing their own autoethnographies. This article explores the affordances of an online blog for enabling a parent of an autistic child to produce a written record of practice which may be considered 'autoethnographic'. Richardson's framework for ethnography as Creative Analytic Process (CAP) is applied to extracts from a blog post in order to consider its contribution; reflexivity; aesthetic merit; and impact. The article addresses the methodological and ethical implications of reconceptualising parents as researchers and the potential contribution of new writing platforms to the development of auto/ethnography.*

### **Keywords**

*autism, Auto/ethnography, blog, disability, mother*

## 1. Introduction

*On a visit to Tate Contemporary in Margate last summer I bought Dylan a badge in the Gallery shop. Reproduced from a Tracey Emin piece, the “I said No” slogan appeared custom made for Dylan. That holiday Dylan’s constant no-saying was beginning to wear me down. I fastened it to Dylan’s t-shirt that day hoping it would help me to a better humour.*

The above extract is from a blog post written in my role as Dylan's mother (Living with Autism, 2013a). Dylan and I are subjects in and co-narrators of the blog *Living with Autism* which documents Dylan's transition from school to adult services. Although the blog was originally conceived as a means of sharing experiences with other families, in due course it developed into more than a virtual diary or information exchange; *Living with Autism*, I argue in this article, acquired features of auto/ethnography.

Ethnography aims to build an understanding of the lived experience of culture-sharing groups through participant observation (Erikson, 1973). Although people with an autism diagnosis are not a distinct socio-cultural group, being autistic can be considered a shared identity and the lives of autistic children and adults have been the focus of ethnographic enquiry (Barrett, 2016). The term *autoethnography* describes a reflexive approach to ethnography in which researchers study their own culture (Clifford, 1986). In *Living with Autism* I give voice to my own preoccupations, as a caregiver, as well as interpreting the life world of my son; this focus on the parent-child dyad, I argue, makes the blog not only ethnographic but autoethnographic.

Clifford claims that contemporary ethnography presents an epistemological challenge due to a conflation of style in which ethnographies become ‘artisanal, tied to the worldly work of writing’ (1986, p. 6). This article considers whether the 'artisanal' aesthetic of online blogging may democratise ethnographic research through the facilitation of parent auto/ethnographies.

## 2. Methodological and ethical framework

In this article I analyse extracts from the blog post cited above in order to consider the ways in which a parental blog may draw on auto/ethnographic practices. The epistemological

contribution of the blog post is evaluated against the four criteria identified by Richardson (2005, p. 964) in her framework for ethnography as creative analytical process:

- substantive contribution
- reflexivity
- aesthetic merit
- impact

Creative analytic process (CAP) ethnography was selected due to its focus on work involving 'researchers writing in different formats for a variety of audiences' (Richardson, 2005, p. 962). This was judged to be particularly appropriate for an evaluation of material produced via an online writing platform. Evaluating the blog post against the CAP ethnography criteria was also appropriate in relation to discourse and genre. The term 'creative analytic process', Richardson suggests, applies to ethnographies which blur disciplinary boundaries by drawing from a range of genres, including literary, artistic and scientific traditions. This offered a relevant framework for a case study of parent-as-ethnographer where it could be said that 'the author has moved outside conventional social scientific writing' (p. 962).

Key factors in the selection of a blog post for analysis included length, focus, format and author expertise. The blog post 'I said No: re-thinking Dylan's speech' was published soon after *Living with Autism* was established and is thus a novice rather than expert text (Living with Autism, 2013a). This was considered important when evaluating the affordance of blogging in terms of accessibility to parents. The mixed format (prose, poetry, diary notes, hyperlinks and visual images) and length (2000 words) of the post offered sufficient data for purposes of analysis against each of Richardson's CAP criteria while the single focus of the post (on communication) provided a clear unit of analysis.

While the focus of the selected blog post is the communication style of a non-verbal autistic adult with intellectual disability it should be noted that this is not the substantive focus of this article. As noted above, the focus of this article is the extent to which blogging may offer parents a vehicle for undertaking ethnographic research with autistic children and adults. The article's claims to knowledge, and implications for practice, are thus concerned with the potential affordance of an online blog for ethnographic enquiry rather than the ways in which a non-verbal person with intellectual disability may be supported by a caregiver.

In writing this article I have been conscious of the narrative and ethical issues in relation to Dylan's 'voice'. Dylan, who was 19 at the time of the blog post discussed in this article, has a diagnosis of intellectual impairment as well as autism and doesn't use speech to communicate. Dylan's contribution to the narrative account of his life with me (as represented through the *Living with Autism* blog) is therefore visual and embodied rather than verbal. Thus while I am responsible for the written (verbal) accounts in the blog posts, the visual (photographic and behavioural) narrative is Dylan's. I claim my son as co-author of the blog posts because, although the narrative format is different, our accounts are equally valuable representations of the mother-child dyad. The written text in the blog posts, however, adopts the first person perspective of the mother while Dylan's point of view is imagined through (as I argue below) the blog's ethnographic practices. The 'I' in the 'I said No' slogan on Dylan's badge is thus a projected rather than voiced first person.

As noted above, the focus of this article is methodological; it draws on material from the *Living with Autism* blog in order to illustrate the claims I make about auto/ethnographic practice. As the issues raised by the blog are not my primary concern here, the voice in this article is mine rather than Dylan's. In analysing a blog post for purposes of this article, however, I have been mindful of the ethical framework I developed and applied to the posts published on the blog (Living with Autism, 2013b). Thus although this article does not claim to incorporate Dylan's voice, I have considered his interests when citing data from the blog.

The following sections of the article consider the case study blog post in relation to each of Richardson's four criteria for CAP ethnography.

### ***3. Parent as privileged other: The contribution of an insider***

In this section I argue that a parent may make a 'substantive contribution' to knowledge (Richardson, 2005, p. 964) as ethnographer of their child's life. Parents of autistic children, I suggest, acquire skills as caregivers which enable them to act as ethnographic researchers. Furthermore, I contend, they occupy a physical and socio-emotional space which gives them privileged access to 'hard-to-reach' research participants.

Ethnographic research is traditionally based on participant observation in natural settings. The parenting strategies adopted by parents of autistic children in the 'natural setting' of the home could be said to share features of the participant observation methods used by ethnographic researchers. Intensive Interaction for example, a popular approach to working with autistic children and adults, 'uses our partner's [i.e. the autistic person's] own non-verbal

body language to get in touch with them' by echoing back their actions (Caldwell, 2005, p. 13). It is through this mirroring process that a caregiver comes to inhabit the autistic person's world sufficiently to make meaning of it and thus to enter into participatory dialogue. This approach to parenting suggests a strong link with ethnographic practice. 'Observation is critical', Caldwell notes:

We have to really look not only at the sum total of what a person is doing but also at what is happening in the most minute detail. We need to know everything they are doing, because each person's body speaks their particular language. (p. 107).

While participant observation is 'still the best method for learning about the meanings of things to the people we hope to understand' (Eisenhart, 2001, p. 23), gaining access to research participants raises practical and ethical challenges. In the context of changes to social and academic practices, researchers have found it increasingly challenging to devote the time to fieldwork which ethnography requires and to negotiate access to research participants who are inarticulate or whose life worlds are configured in digital or intimate environments (Owens, 2007, p. 311). Wolcott, for example, suggests that although ethnography requires the researcher to spend two years in a research setting, most ethnographies are conducted through brief visits rather than immersion (1995, p. 77).

Jeffrey and Troman argue the need to re-conceptualise ethnographic research time (2004, p. 536). They identify three alternative modes of ethnographic access - compressed, selective intermittent and recurrent - but note that changes to time spent in the field may result in the dilution of key principles of ethnography (p. 545). This has significant implications for research with people with an intellectual disability. Research subjects who are 'inarticulate and unresponsive', Booth and Booth argue, are frequently excluded from conventional research studies, with their emphasis on 'quick results', because 'it does not generate good text' (1996, p. 67). Against this background, they note, 'it is important to remember the virtues of an older, anthropological tradition which recognised that the task of learning to communicate with subjects takes a long time.' (p. 67).

As primary caregivers, parents have privileged vertical (life course) and horizontal (contemporary) access to their children, providing rich contextual data as the following blog extract demonstrates.

*“No” isn’t the only word Dylan says. From around eight years old he has been attempting to verbalise and has developed a system of words and sounds which people who know him can recognise. However quite a lot of his speech is indistinct. As well as the difficulty with communication resulting from his autism Dylan appears to have difficulty with the mechanics of speech. He often omits one of the syllables in a two syllable word (‘dinosaur’ is ‘saur’ for example) and certain consonants seem to be difficult for him.*

The practice of caring for a non-verbal autistic child frequently reflects key stages in a research cycle. In the extract below, for example, I set out questions for enquiry as part of my everyday practice.

*Dylan doesn’t have many words but “No” is a word he uses with confidence... What might Dylan be exploring with “No”? ... he doesn’t use it in a punitive way to indicate reprimand, nor is he repeating language that he hears (I probably have to say “No” to Dylan less than I would to a ‘regular’ teenager). But why does he say it so often?*

In establishing the question I am able to draw on intimate knowledge of my son's life history as well as his current behaviour. This contextual data helps to shape the planned observations of my son which are facilitated by my open and immersed access.

*So last Sunday I wrote down everything Dylan said from 9am when he got up until around 1.30pm. I didn’t include vocalisations (his noises and babbles) but only what I considered to be attempts to communicate using language. I tried not to change my behaviour at all; I spoke to Dylan and tried to initiate verbal responses from him in the same way as I normally would...*

In addition to having privileged access to their autistic children, parents could be said to enable their participation in research through their role as interlocutor. Rogers (1980) refers to the role of empathic awareness and transference in the research relationship, something which is of particular relevance to inarticulate subjects. Autistic children and adults can experience anxiety in social situations, impacting on behaviour and communication. Parents are able to establish an environment in which their autistic child feels safe because they

understand the affective dimensions of experience; their embodied knowledge of impairment means they have socio-emotional as well as physical access to their child.

As well as unlocking the narratives of their non-verbal autistic children, parents may be considered to make meaning of them. While outsider perspectives are generally desirable in research, in the context of an ethnographic study of a non-verbal autistic child with an intellectual disability they are problematic. In such a situation, the primary caregiver is required as 'translator' of a text. In the blog extract below, for example, I provide explanatory information about my son's communication.

**Log of Dylan's speech, Sunday 15th September 2013: 9.00-11.00**

- morn [morning] prompted response to my greeting
- shtum [soap] unprompted comment
- loo [loo] repeating overheard speech
- dra-he [dressing gown] commenting on what I am wearing
- ca-he [candle] showing me a picture in his book
- ow [ow] touching the candle flame in his book (copying an action I've modelled previously)
- hair [hair] asking for this to be washed
- d-y-l-a-n [ n-a-l-y-d ] pointing to letters on his door but not matching sound to letter correctly (reversed)
- de-ya [ Dylan] saying his own name after touching letters
- cin [cinema] checking that we will still be doing this (pointing to bag as object of reference)

*Figure 1: Blog Extract: 'I Said No: Re-thinking Dylan's Speech'*

In some instances, my explanations of my son's communication could be considered interpretation rather than translation; in this situation the insider-researcher 'becomes speaker, listener and interpreter at the same time' (Owens, 2007, p. 306). Concerns have been expressed about the inclusion of such facilitated voices in research. The Norah Fry Research Centre (2004), for example, recognises that caregivers play an important role in supporting



communication but recommends their use as intermediaries only. Kelly, meanwhile, notes that narratives of 'intimate and caring others' may be a useful methodological lens but they 'may also be open to charges of oppression' (2005, p. 202). Such ethical and methodological concerns about the parent-child dyad are understandable. The inclusion of non-verbal informants in research studies, however, is dependent upon such facilitation; as Booth and Booth note, 'lives are available to us only in words' (1996, p. 66). If we are to include the perspectives of those with intellectual disabilities we must therefore accept the voice of an interlocutor; the alternative is for those who do not use speech to be absent from research accounts. The difficulties involved in vocalising such perspectives 'should not therefore be an eliminating factor when attempting to obtain the stories of informants' (Owens, 2007, p. 306).

Rather than conceptualising the choice as between oppression (by the parent) or suppression (by the research community) it may be useful to re-evaluate the contribution of the 'epistemology of insiderness' (Reinharz, 1992, p. 260) to auto/ethnography. As Bath argues, an insider perspective 'overlaps with a position that prioritises participation' and offers a valuable epistemology for conducting research with hard to reach groups (2009, p. 219). In relation to Richardson's (2005) CAP criteria, parent autoethnographies could thus be considered to make a 'substantial contribution' to knowledge.

#### ***4. Parent as uncomfortable other: Reflexivity through writing***

Reflexivity is the second of the four CAP criteria identified by Richardson as part of a practical ethnography (2005, p. 964). A key vehicle for reflexivity within an ethnographic study, however, is writing, a process with which parents have not typically been involved. While parents may instinctively engage in ethnographic practices as caregivers, they do not routinely reflect on this practice through writing. Thus there are studies of autistic children which involve narrative accounts from parents but it is less common for parents of disabled children to be participant authors in ethnography (Kelly, 2005).

Tedlock observes that 'ethnography can allow self and other to appear together with a single narrative that carries a multiplicity of dialoguing voices' (2000, p. 471). From this perspective, claims to knowledge rest on how knowledge is 'acquired, organized and interpreted' (Pillow, 2003, p. 176). In such circumstances, it is suggested, there is a need to practice a 'reflexivity of discomfort' (p. 192). This involves acknowledging that language, as well as research truths, can fail us and require a sense of disruption in our writing of the data. The accountability for people's struggles for self-representation and self-determination

crucially includes our own selves (Pillow, 2003, p. 193). It is through such reflexivity on practice, Stanley and Wise suggest, that 'a symbiotic relationship between ontology and epistemology' is created (1983, p. 166).

There may therefore be multiple benefits for parents of autistic children of engaging in regular writing. Writing is transformative in that 'we are changed not just by what we have written but through the process of writing itself' (Barrett, 2016, p. 39). Parents develop their knowledge and understanding of autism through the act of writing which should be undertaken 'without knowing where we will arrive...open to branch lines and sidings, to cul-de-sacs, cliff tops and open country' (p. 39). Writing is thus a dialogue with self; while an insider perspective produces a single text, the writing process can stimulate 'messiness' and reflexivity within the text.

Reflexivity thus becomes a response to insiderness. Kelly points out that the dialogic self which expresses itself in this way can give us 'insight into processes through which dichotomies of self and other are negotiated through systems of meaning' (2005, p. 184). The narrative reconstruction of a written account is therefore also an ontological reconstruction (Thomas, 1999). In the blog extract below, for example, I voice the possibility that I was already aware of Dylan's use of the word 'No'. However, I acknowledge that undertaking the speech collection exercise has given me a fresh perspective on Dylan's communication skills. The blog post thus allows me to 'sow the seeds of critical perspective' in order to reach a new understanding (Kemmis & McTaggart, 2000, p. 590).

*I think I was aware that [No] was an issue – what the speech collection exercise has done has confirmed this for me. It has also challenged some assumptions I had about Dylan's communication. For example, I now think he makes more attempts to speak than I realised; that he tries two syllable words more often than I thought; and that his difficulty with some consonants and sounds is more significant than I imagined. I can also see that some of his most verbal times are when he's out and about...*

Owens (2007) argues that being reflexive is especially important when using inclusive research methods because it allows us to examine our motivations and tools. Furthermore, 'reflexivity considers the notion of power and the unequal relationship between the researcher and the researched' (p. 311). In the following extract, for example, my observations of Dylan

encourage me to re-examine some of my assumptions about the nature of interaction within the mother-child dyad.

*From the speech record it seems that Dylan doesn't say "No" as much as I thought he did. When he does say it, it's nearly always in order to clarify which route we are taking or what we are doing... For Dylan, "No" seems to be more of a question: "No?"... So, all this time he has been asking me a question -*

The blog post goes on to identify the various ways in which Dylan's vocalisations represent attempts to interact and I conclude that: 'The exercise has illustrated to me what Dylan is already achieving, and is capable of, rather than any deficit.' (Living with Autism, 2013a). Such a fundamental realisation of difference is a plausible trigger for the reconstruction of a relationship between researcher and researched and, as such, reflexivity on practice through writing becomes a powerful epistemology from which new ontological frameworks emerge.

The realisation of this process could be understood through the lens of 'defamiliarisation' (Schlovskij, 1917). In order to develop fresh perspectives on everyday phenomena, writers adopt ways of seeing which shake the ordinary into new shape. Similarly, the insider-researcher engages with observational data in order to make the familiar strange (Clifford, 1986). This is an experience which a parent may find uncomfortable but one which could be considered a necessary 'reflexivity of discomfort' if the 'research truth' of an inarticulate subject is to be made explicit. Parental accounts of practice could therefore be said to incorporate the reflexivity which Richardson (2005) considers a key criterion in practical ethnography.

Richardson's third CAP criterion is 'aesthetic merit' (2005, p. 964) and in the next section I evaluate the extent to which a blog post can be considered to demonstrate this.

### ***5. Parent as artisan: The aesthetic of worldly writing***

Ethnographic representation demands that the ethnographer communicate the lived experience of the research subject in such a way that it becomes tangible to the reader. Marcus (1994), however, warns that as we write about a subject through the language and form of ethnographic writing, we become more distant from it. No matter how much a researcher tries to illuminate or explain, he argues, a sense of difference cannot be overcome; ethnography, he claims, should be seen as 'cultural translation...that never fully assimilates

difference' (p. 566). Such a situation leads us to continually reconsider not only the function of researcher reflexivity but authorial decisions of style and form.

The style and form of contemporary ethnography, Clifford argues, has become increasingly artisanal and 'tied to the worldly work of writing' (1986, p. 6). Ethnography is, he suggests, no longer a literary form but 'hybrid textual activity' (p. 26). The online blog could be considered an example of such 'hybrid activity'. The use of information technologies as an ethnographic tool, Shumar and Madison (2013) note, involves new modes of the production, sharing and analysis of text. In the networked global community, they point out, we work in spaces which are 'fluid, dynamic, virtual, face-to-face and multisited' (p.268). This makes field notes difficult to separate from moments of ethnographic writing.

Blog posts are thus able to emulate what Markham (2015) calls 'fabrication' or 'remixing', reflecting the 'layered account' of different parts of the ethnographic process (p. 1). This has implications for the differentiation between home and field in an ethnographic study which collapses in a world where on- and off line ethnography overlap. When parents of autistic children become ethnographers, their reflections may be less likely to be hidebound by theory and more open to 'objets trouves' (Okely, 1992, p. 23). As well as being free from theoretical frameworks for thinking, however, parents are not limited by the constraints of academic writing. Richardson (2005) argues for a poststructuralist understanding of language as producing meaning and creating social reality; her view of ethnography foregrounds language as a social and subjective medium where we are freed from producing a definitive text and can embrace our contribution to research as deeply situated. Such an approach to the role of writing accommodates aesthetic principles ranging from the demotic and artisanal through to the representational and literary.

Clifford notes that the use of literary techniques such as metaphor and narrative 'affect the ways cultural phenomena are registered' (1986, p. 4). Frankham and Smears, for example, utilise Emily Dickinson's work to explore approaches to ethnography which engage with the power of poetry's refusal to be either 'direct' or 'stand still' (2012, p. 363). They argue that Dickinson's use of the dash at the end of a poem 'suggests an unwillingness to signal boundedness to meaning' (p. 363). Indeed, they claim, 'silences, refusal, indirections [and] contradictions' may tell the story of a life more accurately (p. 367). Such uses of language, they argue, can unsettle a reader and ultimately be essential to learning (p. 370).

Although blogs emphasise an artisanal aesthetic, their flexible format accommodates hybrid textual activity, including literary techniques of representation. The incorporation of

literary text within a blog post can offer an alternative framework for reflection and learning. In the case study blog post, for example, I reflect on my pre-diagnosis expectations for Dylan's speech through a poem written soon after he was born:

*... my mum reminded me of the baby books in which she and my dad had recorded my developmental milestones. Was I planning to keep such a book for Dylan she asked? With my new-kindled interest in baby behaviour I asked if I could see my own baby book. I was so surprised by what I found there I wrote the following poem...*

My poem muses on my own first word [*Gone*] before ending: 'I pull you to me, hold you tight, chant these words in your ear: *Here, Now, Yes.*' (Barrett, 1998, p. 39). In the blog post I observe: 'It's ironic, I think, that the poem ends with a wish that one of my son's first words is 'Yes', given Dylan's later use of the word 'No'. (Living with Autism, 2013a). The 'messiness' of the competing storylines in the blog post (a poem, a speech log, a diary entry and a narrative) could be considered to prevent closure and encourage an openness to new understandings.

As well as offering an alternative framework for reflection, the combination of literary and artisanal writing practices within a blog could be seen to enhance the subjective authority of a narrative. A key goal of ethnographies which have literary practices at their heart, Anderson suggests, is the production of a 'compelling description of subjective emotional experiences [which creates] emotional resonance with the reader' (Anderson, 2006, p. 377). In drawing on poetic practices in my blog post, for example, I draw attention to an affective experience of mothering which might not be available through other research accounts. Such poetic conceptions of ethnographic knowledge, Fabian notes, 'touch the heart of othering' and can lend authority to an ethnography (1990, p. 766).

Tsao (2011) argues that research texts should adapt their use of literary techniques so as to be intelligible to 'actors on the front line' of social justice movements rather than primarily serving the careers of individual researchers (p. 184). To achieve this intelligibility, she puts the case for dramatic narrative as 'the rhetorical mode in which storytelling is traditionally undertaken' rather than exposition, argumentation and description (p. 189). Following Rabinow (1996), Tsao demonstrates that a journalistic storyline can embody a scholarly argument: 'we do not have to write like academics to be academics' she claims (p. 187). Tsao thus makes a case for demotic narration as a legitimate anthropological tool that

can also directly inform a sense of activism. It is in the capacity it creates for direct communication and direct action that the 'worldly writing' of the parent could be said to carry its own merit and aesthetic.

In the next section, I consider my post as a vehicle for advocacy, thus evaluating blogging in relation to 'impact', the last of Richardson's CAP criteria for practical ethnography (2005, p.964 ).

### ***6. Parent as advocate: Blogging as emancipatory ethnography***

One of the key features of ethnography is that having spent time alongside the cultural group which is the focus of the study, the researcher 'reports back' to their own culture-sharing group. The account which the ethnographer brings back to the wider community is considered to have authenticity in that it offers a glimpse into the life world of an alternative culture-sharing group based upon the researcher's long-term, intensive contact with the group. Parents of autistic children and adults engage in such 'reporting back' to the community as part of our everyday practice as caregivers; we are frequently required to explain the impact of autism on our children to members of the public, for example. As previously noted, parents are well positioned for insight into their autistic child's perspective on the world and these everyday accounts can be considered small, but nonetheless significant, acts of advocacy.

Blogging may offer parents a more effective vehicle for 'reporting back', however, through the reflexivity incurred in and prompted by the written account. Furthermore, the artisanal and demotic aesthetic of blogging may mean that parent blogs are more successful in communicating with the wider community of parents of disabled children than ethnographic accounts produced by the academic community. The potential impact of auto/ethnographic blogs such as *Living with Autism* is thus significant: not only can such blogs increase awareness of autism in the community, they impact directly on the practice of parents and professionals and therefore upon the lives of autistic children and adults. In my case study blog post, for example, I reflect on what I have learned about Dylan's speech through my observation exercise and identify the implications of this for my practice.

*Collecting this limited record of Dylan's speech has given me a lot to think about. If I had a background in language development then presumably it could help me identify some targets for developing Dylan's communication and plan some interventions.*

The reflexivity demonstrated in the account means that I can now pass evidence about Dylan's capability onto others.

*I have always known that Dylan has a rich interior life with thoughts, memories and imaginings, and the speech record confirms for me that he spends a lot of time, even when he is in company, thinking about his books, favourite characters from his films, and objects and memories he enjoys...There is also evidence of imaginative play (pretend burning of his fingers on the candle flame in his book) and socially-appropriate behaviour (returning my greeting and showing awareness of appropriate behaviour in the cinema).*

As well as impacting at an individual level, however, my blog post reflects on the implications of my study for supporting non-verbal autistic adults more generally.

*Surely it isn't too much to ask that some resource is directed to support the communication of autistic adults beyond school? That resource does not have to be intensive but it does need to be specialised. Parents, carers and support workers can take on development work but we need professional advice so that our interventions are not just sensible but informed...*

Davis argues that 'problems of essentialism and universalism can be overcome by balancing explanations of people's everyday experiences with accounts of how those experiences are linked to wider societal influences' (2000, p. 198). Parents, it is suggested, are well-equipped to undertake such a task if they are wholly situated in a research study and involved in the process of writing. Such 'insider' research has great potential impact, Coles argues, because 'it can offer a better understanding of how the clash between lived reality and policy rhetoric affects people's lives' (2015, p. 140). Multi-level approaches to research replace the polarisation between structural and experiential accounts of disabled people's lives with complex accounts and afford the ethnographer the possibility of adopting a number of different roles post-fieldwork (Davis, 2000, p. 199). Parental involvement in this process, Davis notes, is both empowering and emancipating (p. 194).

This reconstruction of parental identity affects the child's experience of impairment because parents carry their child's impairment as part of their own lived experience (Ferguson, 2001). The embodied act of care-giving is intimately connected to the experience

of disability. Parents are agents 'not only of a child's personhood to the larger world, but they also act as experiencers, interpreters and agents of the materiality of impairment.' (Kelly, 2005, p. 202). Parents' stories of disability, Kelly writes: 'provide an opportunity to examine spaces of social interaction that are both intimate and public in which impairment is produced and made meaningful' (p. 184). Parents' embodied experience is not 'second-hand knowledge of the phenomenon but partial knowledge gained in the participation of its construction' (p. 201). Through their intimate social relations with the person affected by disability, therefore, parents share some of their experience and meaning-making. Ferguson (2001) argues that this intercorporeal and intersubjective approach creates the possibility for a change in the parent's experience of disability to impact on the child's experience of their impairment. Ferguson thus urges parents to claim the space as autoethnographers in order to advocate for their disabled children and bring about positive change in their lives.

The 'excluded voice thesis' suggests that narrative methods provide access to the perspectives of oppressed groups who lack power (Booth & Booth, 1996, p. 55). Unless we think more sensitively about the researcher-researched nexus in relation to inarticulate groups such as autistic children and adults with intellectual disability, however, their voices will not be heard, even through ethnography. Twenty years ago, Booth and Booth argued that 'researchers should put more emphasis on overcoming the barriers that impede the involvement of inarticulate subjects in narrative research instead of dwelling on their limitations as informants' (1996, p. 55). Perhaps online writing platforms allow parents to claim a space for their children's voices to be heard. In this respect, blogging could be considered 'emancipatory ethnography'.

## **7. Conclusion**

This article has drawn on extracts from a blog post to make the case for blogging as 'creative analytical writing practice' (Richardson, 2005). Blogging, I have argued, offers parents a vehicle for participating in key stages of an ethnography such as observation, reflection, representation and advocacy. Ethnographic accounts of practice via online writing platforms may make a particular contribution to knowledge, I have suggested, in relation to children and adults with intellectual disability whose lives may otherwise be absent from accounts.

In 'Parent as privileged other: The contribution of an insider' section of the article, I argued that blogging offers an accessible and liberating tool for research-based practice. Although I presented my argument through an example from one blog, I suggested that the



narrative method it demonstrates has the potential to reconfigure parents as researchers more generally. I therefore contend that new writing platforms, such as online blogs, may make a significant contribution to ethnographic enquiry.

In 'Parent as uncomfortable other: Reflexivity through writing' section of the article, I argued that the practice of regular writing through blogging enables a parent to test out ideas by voicing them to self and audience simultaneously; whether parents are authors or readers, I suggested, such ethnographic accounts serve to illuminate and support parent/child relationships. I therefore claim that blogging promotes the reflexivity through writing which is an essential part of practical ethnography.

In 'Parent as artisan: the aesthetic of worldly writing' section of the article I argued that the concept and format of a blog is well suited to the type and frequency of writing associated with ethnographic CAP. Although the 'artisanal' and 'worldly' writing of parental blogs may, as Clifford (1986) suggests, present an epistemological challenge for ethnography, when viewed through the lens of the CAP criteria, they allow parents of autistic children to be investigative and creative, as well as communicative and contentious. I therefore claim that the development of accessible writing platforms affords parents the opportunity to participate fully in the research process and thus 'democratises' auto/ethnography.

In 'Parent as advocate: Blogging as emancipatory ethnography' section of the article, I argued that blogs provide space for parents who do not want to be on the receiving end of expertise but who want, instead, to practice and develop their own community of practice and gain recognition for their multiple social roles. I therefore contend that blogging may be constructed as 'emancipatory ethnography'.

This analysis has implications for those working as practitioners and researchers within the autism community as well as for parents. I have argued elsewhere that an ethnographic approach to parenting may be particularly beneficial to families in the immediate aftermath of an autism diagnosis (Barrett, 2016). Practitioners working with such families could encourage and support an ethnographic approach to parenting. This process could be facilitated through virtual and/or face-to-face networks and via resources designed to support narrative and therapeutic writing (Clough, 2002; Bolton, 2010 Barrett, 2016;). The wider research community, meanwhile, could build on the observations made by parents through engagement with blog posts as ethnographic texts and by utilising online writing platforms to involve parents more fully in the research process.

My aim in offering this analysis has been to provide a different articulation of ethnography and disability in order to enrich both of these fields of research and practice. The reconceptualisation of parents as researchers, supported by the development of new writing platforms, has methodological as well as ethical implications for ethnography. As well as enriching the lives of individual families, online blogs have the potential to make a significant contribution to our knowledge of children and adults with intellectual disability.

## References

- Anderson, L. (2006). Analytic Autoethnography. *Journal of Contemporary Ethnography*, 35, (4), 373-395.
- Barrett, E. (2016). An Ethnographic Approach To Autism: Learning Through Writing. In D. Milton & N. Martin (Eds.), *Autism and Intellectual Disability in Adults* (pp. 39-44). Hove: Pavilion.
- Barrett, E. (1998). *Gone. Walking on Tiptoe*. Matlock: Staple First Editions.
- Bath, C. (2009). When Does The Action Start and Finish? Making the case for an ethnographic action research in early years education. *Educational Action Research*, 17, (2) 213-224.
- Bolton, G. (2010). *Reflective Practice: Writing and Professional Development*. London: Sage
- Booth, T. & Booth, W. (1996). Sounds of Silence: narrative research with inarticulate subjects. *Disability & Society*, 11, (1) 55-69.
- Caldwell, P. (2005). *Finding Me, Finding You*. London: Jessica Kingsley
- Clifford, J. (1986) Introduction: Partial Truths. In: Clifford, J. & Marcus, G.E. (Eds.). *Writing Culture: The Poetics and Politics of Ethnography*. Berkeley: University of California Press, pp. 1-26
- Clough, P. (2002) *Narratives and Fictions in Educational Research*. Buckingham: Open University Press
- Coles, B. (2015). A 'Suitable Person': an 'insider' perspective. *British Journal Of Learning Disabilities*, 43, 135-141.

Davis, J. M. (2000). Disability Studies as Ethnographic Research and Text: Research strategies and roles for promoting social change? *Disability & Society*, 15, (2) 191-206.

Eisenhart, M. (2001). Educational Ethnography Past, Present, and Future: Ideas to Think With. *Educational Researcher*, 30, (8) 16-27.

Erikson, F. (1973). What Makes School Ethnography 'Ethnographic'? *Anthropology and Education Quarterly*, 4, (2) 10-19.

Fabian, J. (1990). Presence and Representation: The Other and Anthropological Writing. *Critical Inquiry*, 16, (4) 753-772.

Ferguson, P.M. (2001). Mapping the Family: Disability studies and the exploration of parental response to disability. In G.L. Albrecht, K.D. Seelman & M. Bury (Eds.), *Handbook of Disability Studies* (pp. 373-395). Thousand Oaks, CA: Sage.

Frankham, J. & Smears, E. (2012). Choosing not choosing: the indirections of ethnography and educational research. *Discourse: Studies in Cultural Politics of Education*, 33 (3) 361-375.

Jeffrey, B. & Troman, G. (2004). Time for Ethnography. *British Educational Research Journal*, 30, (4) 535-547.

Kelly, S.E. (2005). 'A Different Light': Examining Impairment through Parent Narratives of Childhood Disability. *Journal of Contemporary Ethnography*, 34, (2) 180-205.

Kemmis, W. & McTaggart, K. (2000). Participatory Action Research. In N. Denzin & Y. Lincoln (Eds.), *The Handbook of Qualitative Research*, 2<sup>nd</sup> Edition. Thousand Oaks, CA: Sage, pp. 567-605

Living With Autism. (2013a, September 1). Ethical Issues. [Web log post]. Retrieved from <https://dylanandliz.wordpress.com/ethical-issues/>

Living with Autism. (2013b, September 21). I Said No: re-thinking Dylan's speech. [Web log post]. Retrieved from <https://dylanandliz.wordpress.com/2013/09/21/i-said-no-questioning-the-meaning/>

Marcus, G. (1994). What comes (Just) After "Post"? In N.K. Denzin & Y.S. Lincoln (Eds.), *The Handbook of Qualitative Research* (pp. 563-574). Thousand Oaks, CA: Sage.

Markham, A. (2015, February). briefly: writing for process vs. writing for product. [Web log post]. Retrieved from <http://annetmarkham.com/2015/02/briefly-writing-for-process-vs-writing-for-product/> (accessed 24 February 2015)

Norah Fry Research Centre. (2004). *Information for All: Guidance*. Bristol: Norah Fry Research Centre.

Okely, J. (1992). Anthropology and Autobiography: Participatory Experience and Embodied Knowledge. In J. Okely & H. Callaway *Anthropology and Autobiography* (pp. 1-28). New York: Routledge.

Owens, J. (2007). Liberating Voices Through Narrative Methods: the case for an interpretive research approach. *Disability & Society*, 22, (33) 229-313.

Pillow, W.S. (2003). Confession, catharsis or cure? Rethinking the uses of reflexivity as methodological power in qualitative research. *International Journal of Qualitative Studies in Education*, 16, (2) 175-196.

Rabinow, P. (1996). *Making PCR: A Story of Biotechnology*. Chicago: University of Chicago Press.

Reinharz, S. (1992). *Feminist Methods in Social Research*. Milton Keynes: OUP.

Richardson, L. (2005). Part 1: Qualitative Writing. In L. Richardson & E.A. St Pierre, Writing: A Method of Inquiry. In N.K. Denzin & Y.S. Lincoln (Eds), *The Handbook of Qualitative Research* (pp. 959-978). Thousand Oaks, CA: Sage.

Rogers, C.R. (1980). *A Way of Being*. London: Houghton Mifflin.

Shklovskij, V. (1917/1998). Art as Technique. In J. Rivkin & M. Ryan (Eds.) *Literary Theory: An Anthology*. Malden: Blackwell Publishing Ltd., pp. 8-14

Shumar, W. & Madison, N. (2013). Ethnography in a virtual world. *Ethnography and Education*, 8, (2) 255-272.

Stanley, L. & Wise, S. (1983). *Breaking Out Again*. London: Routledge.

Tedlock, B. (2000). Ethnography and Ethnographic Representation. In N.K. Denzin & Y.S. Lincoln (Eds.), *The Handbook of Qualitative Research* (pp. 455-486). Thousand Oaks, CA: Sage.

Tsao, E. (2011). Walking the Walk: On the Epistemological Merits of Literary Ethnography. *Anthropology and Humanism*, 36, (2) 178-192.

Thomas, C. (1999). Narrative Identity and the Disabled Self. In M. Corker & S. French (Eds.), *Disability Discourse* (pp. 47-56). Buckingham: Open University Press.

Wolcott, H.E. (1995). *The Art of Fieldwork 2<sup>nd</sup> edn*. Oxford: AltaMira Press.