Ethical Dilemmas and Moral Conundrums

Negotiating the Unforeseen Challenges of Ethnographic Fieldwork

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ABSTRACT: Many anthropologists will be required to gain ethics approval in order to begin their research. Prior to commencing, though, it is not always possible to predict what will happen in the field, or how you as the researcher will react, much less to incorporate all possible safeguards in an ethics application. My research was conducted at a special education needs college with the aim of discovering the sense of self of students with intellectual disabilities. I underwent a lengthy and complicated ethics approval process and gained associated external approvals. As my research evolved in the field, I became interested in strands of enquiry that without care could have potentially breached my ethics guidelines. New questions could suggest to staff that I was doing something other than stipulated in their consent documents. The ethics approval process can help refine the research methodology and analysis; however, it cannot prepare us for the moral conundrums that arise in the field.

KEYWORDS: consent, ethics, ethnography, intellectual disability, morals, research

The aim of my research project was to gain a greater understanding of the self-identity of people with severe intellectual disabilities. The goal was to contribute knowledge and theory that can be drawn on to enhance the policy and practice that pervades the lives of people with an intellectual disability and to contribute to a more inclusive theoretical framework for self-determination. This has particular salience for people with intellectual disabilities in Australia, where the federal government has introduced the National Disability Insurance Scheme.¹

Self-determination was originally theorised in relation to nationalist struggles (Cobban 1970) from which it was borrowed and redefined for application to people with disabilities as 'the volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life' (Wehmeyer 2010: 857). In this context, self-determination is largely theorised as something that can be taught. People with severe intellectual disabilities

face difficulties in achieving self-determination due to their reduced capacity to communicate and to the prevalence of carers and support people in their lives (see Turnbull and Turnbull 2001). Much of the literature on self-determination focuses on the teaching of these skills to students in transition/adolescence (see Ward 1996; Wehmeyer et al. 1998; Wehmeyer and Schwartz 1997; Whitney-Thomas and Moloney 2001). This reflects the long-held belief that adolescence is a transient time of life, when children mature into adulthood, and a key stage of the life-course for identity formation (Erikson 1968). Carol Worthman (2011) points out that adolescents are also particularly vulnerable to poor or inadequate public policy and planning. Since this stage of the life-course is characterised by identity transformation and social and economic transition, my study focused on the self-identity of adolescents with severe intellectual disabilities.

Personhood, self and identity have long been characterised by consciousness, agency, intelligence and

rationality (LeDoux 2003). However, it is the perceived lack of (at least) intelligence and rationality that is characteristic of severe intellectual disability diagnoses. Joseph LeDoux's 'synaptic view of the self' (2003: 300) is a combination of perceptions, memories, emotions and experiences and the synaptic systems that integrate these processes across time and space; it is the 'totality of what an organism is physically, biologically, psychologically, socially, and culturally' (2002: 31). This definition allows for, but is not limited to, the different ontological realities experienced by people with severe intellectual disabilities (Klotz 2001), and the different social experiences that result from being labelled 'disabled' (Rapley 2004). It also informs the theoretical framework for my research.

Mark Johnson (1987) argues that our bodies are essential to who we are, to the meaning that we create, to our ability to be rational and creative, and to our selves. His compelling argument for the embodiment of human meaning refers to a body that is, at least, biological, ecological, phenomenological, social and cultural, with meaning emerging from this embodiment (2007). Following Johnson's view, people with an intellectual disability may not always be capable of high-level cognitive reasoning to interpret their life-world, but they will be capable of feeling the embodied emotional responses to their social environment, from which their world is given meaning. This view articulates the importance of all dimensions of the body not just to meaning-making but to notions of the self as well. It also suggests a methodology based on these aspects of embodiment as a pathway towards meaning and selfhood.

A special education needs (SEN) college was an ideal location in which to find a cohort of people in the 15-to-18-year age group suggested by the literature. I conducted participant observation over two semesters, and this was supplemented by guided conversations with the staff, and parent/carer interviews, with the aim of triangulating my observations of the students with those of the college staff, and parents. My own experience as the parent of a child with 'special needs' would add a degree of 'insider' knowledge and provide the opportunity for comparison and contrast (Narayan 1993). I was aware that this positionality may have implications for my perceived objectivity as a researcher. However, I hoped that it would prevent me from 'being locked into any particular one [role]' (Rosaldo 1993: 169). What I had not anticipated were the ethical dilemmas and moral conundrums that would arise in the field as a consequence of my 'shifting identities' (Abu-Lughod 1991; Narayan 1993).

One of the foremost considerations in conducting research amongst people with severe intellectual disabilities is ethics, and ethical considerations played a large part in the design and execution of my research, but they also played an analytical role. In this article, I give a reflexive overview of some dilemmas that arose during my fieldwork, and how this influenced the way I framed the analysis of my research material, with the hope that it may be fruitful for other early career researchers, for future debate regarding research amongst people with intellectual disabilities, and for anthropological research in general. It is only by speaking and writing about these matters that anthropologists will be able to navigate the ever-growing challenges faced by the discipline (see Yuill 2018).

Much of the anthropological discourse on ethics and morality conflates these two dimensions of right behaviour (Carrithers 2005; Csordas 2014; D'Andrade 1995; Desjarlais 2014; Fassin 2014; Garcia 2014; Laidlaw 2002, 2009; Mattingly 2014; Parish 2014; Scheper-Hughes 1995; Throop 2014; Willen 2014; Zigon 2014; Zigon and Throop 2014). For example, although a special edition of the journal *Ethos* is entitled 'Moral Experience', all of the authors situate ethics alongside morality in their articles. Indeed, Jarrett Zigon and C. Jason Throop make a note in their introduction that they are conflating the two terms because 'there is little agreement among those taking up an anthropological study of morality/ethics as to their respective meanings, not to mention which, if either of these terms should take priority' (2014: 12). A close reading of the literature does begin to reveal a subtle distinction whereby the ethical is imposed from without, as ethical practice, and the moral is formed from within, as embodied moral 'moods' (Throop 2014: 77). The conflation occurs because the culturally inscribed ethical dimension has a great impact on the internally formed moral dimension. For example, in Australia the ethical realm is largely informed by the Christian democratic values of our British colonial forebears. Individual morality evolves in this socio-cultural milieu but is tempered by individual circumstances and life experiences. Conversely, when enough people develop a moral 'mood' in objection to an ethical 'practice', the possibility arises to change the ethical standards in a group. In this context, the deinstitutionalisation of people with intellectual disabilities can be understood as an ethical solution to a changing moral 'mood'. It is a small distinction but may give some clarity to the ethical dilemmas and moral conundrums that I raise here.

Ethics Approval

The research project received approval from the university Ethics Review Board (ERB). Approval was also sought and gained from the Southern State Education Department (SSED) to conduct research at one of their colleges.² In addition, consent was gained from the dean of the SEN college to conduct research there. It was also necessary to apply for a permit to work with children. This is standard for anyone working with children in Southern State, and is gained by passing a review of criminal records to see if you have charges or convictions that indicate you may cause harm.

There is a rigorous process to go through in order to gain ethics approval, as there should be. My initial proposal was to conduct the research at my daughter's college, where the staff were supportive of my research goal. One of the chief concerns of the ethics committee was that my presence would cause too much disruption to the students in the campus classrooms and recreation areas. I naively thought to alleviate this by conducting the research at a college where I was well known by the staff and students, hence minimising the possible stress. Predictably, this raised the issue of being too close to my informants and my initial ethics application was rejected on the grounds that the college was attended by my daughter and that the staff, parents and students may feel pressured to participate because of their pre-existing relationship with me. This was a perfectly valid rationale and in hindsight carried more validity than concerns about possible stress that my presence in the college might create. The ERB encouraged me to resubmit the project with the design changed so that the research would be conducted at a different location. An opportunity then arose at another SEN college, which presented as a viable option. Since I had no previous association with them and there was a relatively large cohort of adolescents, I submitted a re-designed ethics application after I had made contact with the dean.

It was also necessary to gain permission from the SSED to conduct research at one of their colleges. At one stage, I found myself in the interesting position whereby ERB approval was contingent on SSED approval and vice versa. Fortunately, both parties saw the difficulty in this and each agreed to my project with the following notable stipulations: there was a condition on the SSED approval letter that stated: 'Any proposed changes to the research project will need to be submitted for Department approval prior to implementation' (SSED letter, 12 February). There

were two similar conditions in the ERB approval letter (ERB letter 14 January):

1. The application and all supporting documentation form the basis of the ethics approval and you must not depart from the research protocol that has been approved.
2. The Ethics Review Board must be approached for approval in advance for any requested amendments to the approved research protocol.

Each small amendment that was required in the process of gaining ERB and SSED approval did lead to a better research design overall. It forced me to examine closely what I was doing, the rationale behind it and the importance of thought and detail in the preparation of information and consent document packages for the participants. As a parent, I was greatly re-assured by the rigorous approvals process, but as an early career researcher I found this volleying between the various gatekeepers frustrating, mainly due to the time constraints I faced. University bureaucrats and scholarship offices increasingly insist that a doctorate can be attained in three years, and yet I had spent 14 months just obtaining the required approvals. Despite the delays, I was able to commence fieldwork one month into the college year.

Ethical Consent

The next step was gaining informed consent. The staff welcomed me to their workplace, and there were few problems gaining their consent, especially with the dean's support for the project. Just as Robert Edgerton found the trust of the staff at Pacific State Hospital 'chilling' (1993: xv), I felt a degree of concern that so many of them were prepared to accept me at face value. They did not keep their copies of my meticulously prepared documentation or my contact details, and many of them got so used to my presence that they thought of me as a staff member or volunteer, rather than as someone who had the potential to interpret their actions and motivations negatively. One reason for this easy acceptance was likely a reflection of the number of staff who come and go at the college, which brings me back to the initial concern of the ERB that my presence would cause stress to the students.

In reality, the students experience so many different staff throughout the week that it often made me smile to think of the initial concern about 'stranger stress'. To begin with the teachers, they have 'non-instructional duty' time allocated at least twice

throughout the week when they are out of the class and a substitute teacher steps into the breach. In addition to this, the teacher of the first class I was in was asked to undertake an administrative role for several months, which he agreed to do two days a week, so the students also had a regular substitute teacher to fill that gap. During this period, the students had three regular teachers throughout the week, not including substitute teachers who filled in for illness and absences. The education support people comprised the majority of staff, and they were also constantly changing. Many staff only work three or four days a week, and there are regular staff who work on these days and others who work in different rooms on different days. The number of college staff waxed and waned, but up to 25 per cent could be absent on any one day, especially in the winter months when the various head colds and influenzas were at their peak. There were also numerous volunteers in the classrooms; these were often people who were sampling the work before they applied for employment. Others were seeking volunteer opportunities to enhance their resumés and employment prospects elsewhere. In addition, there were high school, technical college and university students all getting work experience, which was often a requirement of their courses. My presence in the class never appeared to increase the stress levels of the students, despite the earlier concerns of the ERB, which I had sought to address in my initial ethics application. I asked staff several times throughout the year whether they thought my presence was causing stress to any of the students, and they always agreed that my being there made no difference to the students whatsoever. This is interesting in itself, especially considering that so many of the students were autistic – people who by definition have difficulty coping with changes to people, places and routines.

There is such a plethora of autism research across all disciplines that parents with autistic children are at best weary and at worst determined to actively avoid participating in yet more research. This both helped and hindered my project. One of the reasons the dean supported my work was that he appreciated that I would be taking the time to observe the students in their ‘natural environment’, so to speak, and his support no doubt influenced others to consent. On the other hand, parents with autistic children find themselves constantly asked to contribute to research in one way or another. No one disputes the importance of any of this research – it all contributes incrementally to our understanding of this seemingly growing problem. However, there did seem to be a

growing level of ‘research fatigue’ amongst parents. The few parents who did question me about my research were not concerned about my participant observation in the college. Rather, they did not want to sit through yet another interview. Hence, while I gained consent to work with most students individually, only a fraction of their parents consented to interviews. The parents of several students did not give consent for me to work with their children. I sent many consent packages home with the students, at the urging of the dean and the staff, who have to do the same to get documents signed for college business, so I do not believe this was an issue of oversight rather than non-consent. One student signed his own consent documents, and another 18-year-old student told me that she wanted to be included, but neither of these can be considered informed consent under current Australian guidelines. Guidelines for informed consent in the National Statement on Ethical Conduct in Human Research rest on the capacity of the participant for understanding ‘what the research is about and what participation involves’ (NHMRC 2018: 74). Given that the focus of this project was adolescents with severe intellectual disabilities, ERB approval was granted on the basis that parental consent would be sought in all cases due to the difficulty in establishing this capacity in each individual student (see also Griffin and Balandin 2004).

Ethics and Analytical Creativity

Over time, I began to question things that happened in the classrooms and in the recreation yard. My focus was drawn from the students to how the staff were shaping the socio-cultural environment of the students. The staff and their work practice became interesting in their own right, but the stipulations of the approval letters made it clear that a shift in focus from student self-identity to staff work practices would require a round of amendments to be submitted for further ethics approval. This shift in focus was no more than the usual inductive evolution of ideas experienced by ethnographers during fieldwork, as staff and work practices would inevitably have an impact on the students’ self-identity, but initially it worried me. As Heidi Armbruster asks:

If respect for others is an important moral value, what follows from this if we study others whose rights to dignity and respect have been tampered with – or if we study people who tamper with other people’s dignity? Where do we look, what do we ask, what do we write – and why? (Armbruster 2008: 4)

If I began to focus on staff practices, then it could appear to them that my focus was not on student self-identity, as stipulated in the participant information and consent documents. If they perceived themselves and their work practices to be the true object of my (sometimes critical) research, then no doubt they would have become much less co-operative. I ran the risk that they might withdraw consent, and even complain to the dean, who may in turn withdraw consent for me to continue conducting research at the college. As Bob Simpson points out though, while the chances of the ERB checking on compliance with their stipulations may be remote, the shadow cast by their 'formality and quasi-legalism' (2011: 382) is long, especially when my hosts, the SSED and the college dean have adopted the same idiom for our interactions. This situation was further complicated by the relationships I had developed with the staff. Beyond mere staff or informants, some of them had become friends and confidantes.

I spent a lot of time contemplating the vagaries of consent and the complexities of fieldwork before I came to the realisation that the dramas of the classroom and campus recreation yards were symptomatic of the same thing; the same need to prevent staff from being infected, hurt or contaminated by the students. There was no need for an ethics amendment because the focus had not shifted at all. What had shifted was my understanding of how integral the staff are in shaping the socio-cultural environment of the students, and hence their self-identity. In essence, the ethical constraints helped me to think creatively about how to incorporate all the seemingly disparate elements of my data, and once the solution occurred to me, the way forward was revealed. In my emerging analysis, I concluded that the students were being treated as though they were contagious, and then contained and managed in such a way as to reduce or prevent contamination of the staff (and sometimes other students) either through 'germs' or parasites, or anti-social behaviour (see Avery 2020). If the students were subject to these management strategies for up to 15 years of college life, then their socio-cultural development was going to be affected and hence their sense of self.³ LeDoux and Johnson were still relevant, just not in the ways I had initially imagined. The students were being shaped, at least in part, by the college environment, and while they may not have fully understood what was going on around them, there was ample evidence of embodied responses to their staff-mediated socio-cultural environment. My concept of a 'contaminated self' was conceived, and this helped me to make sense of

what I was observing, why it was happening, and, most importantly, the implications for the students. When a student was shut in a recreation courtyard because he was 'singing' loudly, I could interpret this as his aural contamination of the environment being managed via his bodily removal to the courtyard as a containment strategy. The use of restrictive practices such as this is controversial and leads me here to a discussion of the ethical and moral dilemmas that I faced whilst in the field.

Ethics in the Field

On several occasions, I was asked by a senior staff member to recount my version of events as I had witnessed them. This was informal and in response to incidents that happened during the lunch recess, whereby duty staff had interacted with students in a manner that was being questioned by managers. The events were similar, and it is not necessary to provide the details here, but one incident involved a duty staff member interacting with a student who then behaved inappropriately by throwing things and running away. This put me in an interesting ethical position because I wanted to work in the classroom of the staff member involved, so I did not want to put them 'off side'; however, if I felt that the student had been goaded into misbehaving by this person's actions, then it could be argued that I had a moral imperative to speak to the events. The event had taken place in the recreation yard, and there were any number of other witnesses, so after some reflection I gave what I considered to be a short, clear and concise rendering of events as I had observed them, and carefully avoided any speculation, judgement or conclusions.

There were other more mundane things that I witnessed daily that troubled me ethically and/or morally. These included food being picked up off the floor and given back to students, but there were more troubling things. The food from the floor was given back to a student whose parents I had interviewed and whom it would be perfectly legitimate for me to contact and meet with once more. Would it be a breach of confidentiality if I raised these issues with the parents? They may not be concerned and may trust that the staff were justified. Although it was possible that my positionality as a parent made me sensitive to these incidents, the consequences I faced as a researcher and the assurances of confidentiality that I had given had to be considered. These dilemmas also made me aware of just how problematic

the word 'confidential' can be. As agreed upon by the ERB and the SSED, the participant information form stated that 'all information collected will be completely confidential to protect the privacy of individuals and [the SEN College]', but did the parents' right to know and the health and well-being of the students override any issues of confidentiality? Were these college matters even confidential, given that any number of people may have witnessed them? What is really in the best interest of these students? Is it privacy or welfare? The notion that they have any privacy is surely an illusion. Their communication books regularly record details of menstruation and bowel actions, and this is only a fraction of the information on record about them for everything from medical and educational needs to welfare and support requirements. Granted there are families to consider, but I wondered whether privacy is an illusion for people with intellectual disability, something valued by others that they likely have little concept of or use for. Their personal welfare may have a much more immediate and ongoing importance. How was I to grapple with these seemingly competing requirements for privacy and welfare?

I am still not confident there are any correct answers to these questions, but I am certain that if I had begun to raise such welfare issues within the college, and with parents, I would have made myself unpopular, untrustworthy in view of the staff, and possibly had consent withdrawn across the board. The research would have ceased and there would have been no insights to the life-worlds of people with intellectual disabilities, and nothing with which to inform the policy and practice that pervades their lives. With the perhaps selfish goal of remaining in the field, I chose to preserve the confidentiality of the classroom and did not raise these issues with parents. In his response to Nancy Scheper-Hughes (1995), J. Tim O'Meara states that 'if the goal is to help the downtrodden of the earth, it is a pragmatic as well as a moral question whether we should become street partisans – knowing that the internal workings of the power elite will then be hidden from our view forever' (1995: 428). I cherish the hope that by remaining in the field, and writing up my research, one day enough light may be shed on these issues so as to illuminate some answers to my questions and those of Armbruster (2008), but I sacrificed a degree of self-respect each time I made one of these choices.

I was not always in opposition to the staff. They often shared my ethical/moral concerns, positioned as they were between an ethic of care for their stu-

dents and needing to get along in the workplace. One particular staff member (A) appeared to think it was funny to threaten to cut a female student's hair with scissors, and mimed this threat often. Everyone knew it was a joke, including the student, but one day another student in the class chased a staff member (B) with a pair of scissors, and was severely reprimanded for this potentially dangerous infraction. It seemed to me that the student, like the staff member (A), also thought that he was being funny when he gave chase, even though the staff member (B) was evidently frightened by his behaviour. When I broached the subject, several staff agreed that the student had probably learned the behaviour from watching the staff member (A) 'pretend' to cut the other student's hair. Whilst the other staff laughed at the hair-cutting 'joke', albeit a little nervously, to my knowledge nothing was ever done about it.

Another student appeared to be largely unsupervised at home, and was seen by staff outside college hours at various bus shelters and shopping malls around the neighbourhood on her own. She was a friendly, sociable and trusting girl but had limited verbal communication. I shared the concern of all staff that this student could be easily taken advantage of. What is more, several staff told me that they believed that she had already suffered a miscarriage at college during in the year. Her parents had not consented to an interview, so there was no way for me to confirm this, but I was assured that the appropriate people had been notified in the SSED chain of authority. We respected the student's privacy and that of her family, and trusted the SSED authorities to follow up on these issues as per their mandate.

During the year, a situation arose concerning a student who could not eat or drink due to her health condition. Twice each day, she would take herself to the nurse's station to ingest her 'meal' through a percutaneous endoscopic gastrostomy tube (see Gencosmanoglu 2004). She was a friendly and active but easily tired and slightly built 17-year-old who I estimated to weigh less than 40 kilograms. She began to bring a re-used PET soft drink soda bottle filled with a flavoured-milk-type liquid to college for 'lunch' rather than her regular fortified liquid meals. The staff made enquiries and were assured that all was well and merely an interim measure until a regular supply of the usual dietary formula could be restored, so their concern shifted to the correct storage of her 'lunch' during the warm summer days. This went on for some weeks without change until a senior staff member had the student weighed

and discovered she had lost almost seven kilograms. This young person was in grave danger of suffering from malnutrition. The staff and I were not privy to the details or outcome out of respect for the privacy of the student and her family. We had to trust in the SSED staff to act appropriately in their duty of care and concern for her. Once again, I felt very conflicted about what this student was suffering and about whether I should do something. Was it conceit on my part to think that I cared more than the staff and that I was any more capable of effecting a resolution, or was it complacency to do nothing? I followed their example and trusted in the appropriate authorities to act accordingly. This was a fine line that I had to tread, and that the staff treaded regularly, in balancing concern for student welfare, respect for privacy, and trust in the authorities to produce a satisfactory outcome.

These examples recount some dilemmas that I felt during fieldwork and that preceded any consideration of whether or how I should write about them. I carefully considered whether or not to include these ethnographic moments here, but concluded that anyone who recognised the events, and the students involved, would do so because they had been present as the events unfolded and aware of the outcome; therefore, I would not be further jeopardising anyone's privacy. It is perhaps another example of analytical creativity to write about these incidents in relation to ethics and morals, since pursuing them as a different line of research enquiry was not my main study focus and not strictly within the conditions of my research approval.

Conclusion

It has long been recognised that researchers have multiple and intersecting subjectivities that enable us to view our subjects through a variety of lenses. This positionality shapes our research interests and goals as much as the material we gather in the field. I found that my various cross-cutting subjectivities as a student, researcher, friend, parent, staff member or volunteer, and non-educator, enhanced my fieldwork experience but also resulted in challenges to my desire to adhere to ethical practice and do no harm. It also challenged me morally as unforeseen situations emerged to undermine my own sense of self and world-view.

When working with vulnerable people, and their families, it is important for all of us to be ever vigilant, but respectful, and we all need to be able to trust

that the system will work to protect them. The ethics constraints were rightly designed to protect the students, staff, parents and college from any possible harm or stress that may result from the research project, and they did help me refine my methodology. Arguably, they even provided the catalyst for my analytical creativity, in that I was pushed to analyse the research material in terms of the self when staff practice and student welfare seemed to be more obvious choices, but the constraints also prevented me from pursuing a possible emergent research agenda that included matters of direct and ongoing significance to the physical and mental well-being of students. Staff practices and student welfare were all beyond the scope of the research project as stipulated in the approval documents, and seeking further approval would have made it difficult to pursue these matters openly with staff, and they would have been costly in terms of time. Project approval conditions can be said to have obscured these welfare matters as much as they upheld the ethical emphasis on consent and privacy. Consent that was not considered informed—by the nature of the students' impairments—effectively silenced students rather than giving them a voice, and confidentiality concerns overshadowed welfare matters as much as they protected privacy. The need to protect human subjects in research is unarguable, but it 'limits both subjects and researchers by confining all to an analytical level that closes down possibilities in the relation between self and other' (Simpson 2011: 382). In effect, the concerns and stipulations of the ERB and the SSED may actually have served to obscure ethical and moral dimensions that could have been highlighted by my research, but they also led to personal discoveries and insights that must ultimately make for a better researcher.

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Notes

1. See <http://www.ndis.gov.au>.
2. Pseudonyms have been allocated for the college and all research participants.
3. The number of years that a student might attend a SEN college varies between jurisdictions, but it can

include kindergarten, pre-primary, primary and high school for a total of up to 15 years.

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