Informed Consent in Educational Settings and the Novice Researcher

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ABSTRACT

This article describes the informed consent process for an in-progress research masters thesis about the school experiences of senior secondary school students who have funding from Ongoing and Reviewable Resource Scheme (ORRS). It examines this in relation to the 'hierarchy of gatekeepers' (Powell & Smith, 2009, Stalker, 1998) and issues of capacity to give informed consent.

Practice paper

Key Words: Capacity, disability, ethics, gatekeepers, informed consent, school.

INTRODUCTION AND BACKGROUND

Research ethics are of fundamental importance to any research. They define and shape the research process from the very beginning as they are the code on which academics rely on as guiding practice in the field (Hopf, 2004). As a novice researcher, for my very first piece of major research - an in-progress masters thesis - I chose to examine the school experiences of senior students who have funding from the ORRS. These students have been identified by the school and Ministry of Education as having "high-very high special needs" (Ministry of Education, cited in Brown & Thomson, 2005). It is research that is based in several different and yet overlapping theoretical and philosophical assumptions. These include the sociologies of both childhood and disability as well as the use of a children's rights discourse. They are all complex and distinct and yet they all have a commonality of viewing the individual as an active citizen within society (Alderson, 2003; Balen et al., 2006; Bluebond-Langer & Korbin, 2007; Christensen & Prout, 2002; Davis, 2007; Gittins, 2004; Jans, 2004; Jenks, 2004; Kehily, 2004; Mercer, 2002; Messiou, 2006; Morris, 2003; Oliver, 1996; Powell & Smith, 2009; Priestley, 2003; Punch, 2002; Roche, 1999, Shakespeare, 2006; Smith, Lister, Middleton, & Cox, 2005; Stainton-Rodgers, 2004; Taylor & Smith, 2009; Tichkosky, 2003; Whitehurst, 2006; Wyness, 1999).

For the research design I decided to work within a qualitative multiple case study framework (Yin, 2003) which included a data collection method of observations in schools and interviews with four students. Within this framework came certain ethical issues. One of the key ethical issues of this, and any research involving human participants, is informed consent. Informed consent is an interesting concept as it is interwoven with other ethical issues that include power, privacy and anonymity (Punch, 2002). All of these are ongoing concerns for a researcher and can arise at any stage of the research process (Coad & Evans, 2008). Also interwoven with informed consent, especially in the context of this research, are ideas of capacity to give informed consent. As we will see, students with disabilities have traditionally not given informed consent (Shakespeare, 2006); in fact, to conduct my research without parental consent, much negotiation between the 'hierarchy of gatekeepers' was needed (Powell & Smith, 2009; Stalker, 1998). These included the ethics committee and teachers.

This article hopes to describe the involvement of the "hierarchy of gatekeepers" in how disabled students are viewed and involved in the research processes. It will then discuss how informed consent is constructed for disabled students, with the continued use of adult proxies and finally, how issues of capacity continue to play a role within the hierarchy.

The hierarchy of gatekeepers

In a recent research article by Powell and Smith (2009), they discuss a hierarchy of gatekeepers in an educational setting. These included the ethics committee, the school (principal and teachers) and parents. Gatekeepers are generally a group or an individual including academics that all researchers have to negotiate with in order to access their target population. For my thesis, I only negotiated with the ethics committee and the school. This will be discussed later in relation to student rights. The first in the "hierarchy" however is the ethics committee.

Ethics committees play an important role in the research process. They both protect society, the academic institution and the researcher. However, in what Iacono (2006) describes the 'slowly creeping conservatism' (p.174) of ethics committees and Hammersley (2009) sees as a system that is generally out of touch with current research practices, they can become inconsistent and over-protecting of key sections of society which has led unwittingly to these sections being silenced. Generally, it is seen as a by-product of the research process, or rather of gaining ethical approval (Hammersley, 2009; Iacono, 2006; Powell & Smith 2009). It can be seen that sections of society, like

disabled students, have been silenced continually by non-involvement in research because they have been placed in the too-hard basket for gaining ethical approval (Iacono, 2006).

This filtering process of the hierarchy means that sometimes the target populations, in this case senior secondary school ORRS-funded students, can have their rights bypassed before the research has even begun (Powell & Smith, 2009). An implication for this protectionist/paternalistic stance is that the ethics committees tend to work within a medical model perspective (Hammersley, 2009) which views impairment and disability within a deficit theory (Mercer, 2002; Priestley, 2003; Shakespeare, 2006). This perspective continues to be at odds with the foundation literature for disability research, which suggests that such research be centred in and on the social model of disability (Mercer, 2002; Priestley, 2003; Shakespeare, 2006). There is a need to be inclusive of all "voices" within research or what Davis (2007) calls the 'polyphonics' (p.123) of disability research, especially those who have not had such opportunities in research or indeed society.
In my own research, trying to break the protectionist/paternalistic barrier required a lengthy ethics approval process, especially surrounding the issues of informed consent and the capacity to give informed consent. Informed consent is so engrained in traditional research paradigms it is seemingly impossible to work within such a tradition and maintain inclusivity.

Informed consent process
The informed consent process is described as needing voluntary participation which is based on full and open information (Christians, 2000). This includes the risks/benefits and what will happen to the information given (Mishna, Antle & Regehr, 2004). Traditional methods of gaining informed consent from children and people with disabilities have differed from that of the wider society (Alderson & Goodey, 1996; Shakespeare, 2006). This has been a matter of perceived capacity, an issue that will be discussed in the following section. This is in contrast with the literature of the sociologies of both childhood and disability and that of children's rights discourses (Alderson & Goodey,1996; Bluebond-Langer & Korbin, 2007; Christensen & Prout, 2002; Gittens, 2004; Jans, 2004; Jenks, 2004; Morrow & Richards, 1996; Powell & Smith, 2009; Punch, 2002; Roche, 1999; Shakespeare, 2006; Taylor & Smith, 2009; Tichkosky, 2003; Wyness, 1999) which suggest that research with children and people with disabilities should be conducted with the party of primary concern: children and disabled people. Yet, for students/children with complex disabilities proxies are continually used (Shakespeare, 2006), therefore their consent to the research process had sought assent as a token secondary action, rather than as a primary concern for those researchers. Furthermore,

many scholars have noted that the consent process for children and youth does not genuinely address them as participants in their own right (Alderson & Goodey, 1996). Instead, it gives overriding power to parents and therefore many researchers only obtain assent with a tokenistic sense of consent from the actual participants (Bloom-Di Cicco & Crabtree, 2006; Coad & Evans, 2008; Crowe, Wiles, Heath & Charles, 2006; Grieg, Taylor & Mackay, 2007; Howe & Moses, 1999; Morrow & Richards, 1996; Williamson, Goodenough, Kent & Ascroft, 2005).

Informed consent is interwoven with other ethical concerns like issues of power. This is of concern within the educational setting and can be found in the status of the students as being vulnerable because of maturation and disability labels (Grieg et al., 2007; Mahon, Glendinning, Clarke & Craig, 1996; Stainton-Rodgers, 2004). In relation to informed consent, the power of who gives consent is important. As highlighted earlier, adult proxies have been used for disabled students and indeed, the practices of the schooling system see that parental consent is necessary for student participation, which has seen some schools stick rigidly to this practice. This immediately places the students within an unequal power relationship. As power is an ambiguous and engrained aspect of research it is impossible to eliminate fully, however it is hoped that some strategies including asking for informed consent or 'informed dissent' (Alderson & Goodey, 1996, p.107) directly from the participants will lessen the effects of the power imbalance and at the very least, acknowledge their participation as individuals.

The use of adult proxies undermines this and ignores the inherent right of the participant to decide to give informed consent or informed 'dissent' (Shakespeare, 2006). By perpetuating the myth of non-capacity, traditional research is maintaining a deficit perspective of disability and students in general. It is important that the participants are recognised by any research as having the same human rights, authority and self-determination over their lives as any peer would have as a participant (even if this is not so in their life in general). This is especially important regarding any form of (non)participation, that the participants' inherent rights and wishes will not be over-ridden by formal powers of authority including that of the researcher.

It is important to note that not asking for parental consent as a part of the research was seen as a deviation from traditional educational research that describes gaining assent from children (Alderson & Goodey 1996; Fisher, 2003; Lewis & Porter, 2004; Morrow & Richards, 1996; Punch, 2002). The idea of assent did not seem appropriate for students who are considered legally independent of their parents at the age of 16 (Ministry of Youth Affairs, 2000) and whose peers would be afforded the same autonomy/self-determination. Some scholars

like Cocks (2006) advocate for assent when involving young children (under 10) as this takes an element of power away from parental consent for those who are not legally independent. However, in my research that would have been seen as tokenistic, disempowering and it could have even been seen as coercion. In order to satisfy any parental concern, students were given an information sheet that if they chose to, they could show it to their parents/caregivers.

As mentioned, other scholars like David, Edwards & Allred (2001) describe the consent process with students as being "educated" consent. This concept allows for several factors in the research process, including the inexperience of the researcher and the participants as well as viewing the consent process as ongoing. It also recognises that capacity to give consent does not have to be fully formed but rather comes with the growth of knowledge. Traditional research processes place emphasis on capacity to give informed consent and therefore key sections of society have been excluded because of a belief that they do not have the capacity to give informed consent; this includes children and people with disabilities (Alderson & Goodey 1996; Morrow & Richards, 1996; Shakespeare, 2006; Whitehurst, 2006).

Capacity to give consent: How do you know if no one has asked?

Capacity is seen as a key component of informed consent (Mishna, Antle & Regehr, 2004). Scholars have argued that vulnerable groups like those described in this research do not have the "capacity" to know the consequences that the research will entail (Mishna et al., 2004). This includes where and when the research data and the findings will be used and the risks and/or benefits for the participants. My own research was conducted because there was little evidence of research, especially New Zealand-based, that involved students who have "multiple and complex disabilities" (Whitehurst, 2006, p.57). There was a great deal of trust and goodwill between the 'hierarchy of gatekeepers' and myself throughout the research process. The few studies that have involved students with "complex disabilities" have all described assent by the student with informed consent as coming from the parents or other proxies (Clark, 2008; Shakespeare, 2006; Whitehurst, 2006). Equally, there is an emerging body of research, although small, with youth (and adults) who are 'non-verbal' that discusses involving them within research (RITE project, 2009). It is important with this type of research, as with any other, to uphold the participants' rights as citizens (Jans, 2004; Stainton-Rodgers, 2004; Taylor & Smith, 2009) and gain informed consent directly (or via an interpreter) from the participants rather than assent or capacity assertions from others. Studies of note include the British RITE study (2009), and the work of scholars such as Kelly (2007) and Morris (2003).

Nevertheless, judging capacity – that is, who gets to? how do you? - proved a major sticking point with all of the gatekeepers (those identified previously). Throughout the research, the rationale behind asking for informed consent from the students and not the parents had to be refined and redefined many times before the ethics committee would accept my proposal. The core belief that the students involved should have the right to accept or decline participation remained the same. Indeed, Alderson and Goodey (1996) have suggested that any/all participants who are not regularly involved in the process can misinterpret the consent process. This would then suggest that capacity or judging capacity should not have the importance that it has in traditional research but rather should be seen as an ongoing construction of understanding between the researcher and participant. This idea is furthered by scholars like Hammersley (2009) who have compared this type of social research to that of journalism or a form of social history where the researcher and participant have a shared interest.

The very idea of capacity is fluid. This can be seen within disability research with certain groups, such as those who have "moderate learning disabilities". Seemingly as a direct consequence of research and the 'explosion of disability literature' (Tichkosky, 2003, p.13) this group has been removed internationally from the "too hard basket" and have become accepted participants within social sciences. There is nothing to suggest other than an ethical rigour second to none and a little goodwill, the same cannot happen for students with multiple, complex or severe disabilities.

Finally, after the lengthy ethics approval process, I asked two schools if they would like to participate in the research project. One politely declined because they, as a rule, need parental consent for all visitors to the property. The other, however, said yes. They believed that it was possible for me to conduct my research because they stood as in loco parentis for all students. Consent was only asked for physical access to the school site. It was not taken as a right or a given that I would be able to recruit any students at all. All students were asked continually for their consent for me to: a) be in the classroom; b) interview them, and c) photograph them. Students who did decline all or certain aspects had their wishes upheld and respected. I spent several weeks building relationships with the students. During this time, I went into their classes but did not take notes and instead I made myself available to them so if they wanted to talk or needed help, I was there. The time spent building relationships with the students was invaluable and eventually it gave way to exposing them more and more to research practices. Using an "educated" consent process meant that they felt they could say and did say, "no" positively and assertively. It also meant those who were interviewed could feel confident when discussing their experiences, because they knew the process and what the material was being used for.

Final word

Research in educational settings with students who are considered "vulnerable" or "too hard" requires a cautiously optimistic enthusiasm on behalf of the school, great supervisors and good deal of perseverance. Those who are within the "hierarchy of gatekeepers" have a genuine need to protect society from researchers (Snook, 2003), however this must also be tempered with an openness to new (or new orthodox) ways of researching in order not to become stagnant (Hammersley, 2009; Iacono, 2006). There should instead be every effort not to (re)produce the same inequalities within the research process by encouraging researchers to maintain an informed consent process that does not fit with current research practices; this includes the emphasis on perceived capacity and assent. Consent is a continuous process, viewing it as a singular event means that views and perspectives of "vulnerable" groups will continue to be left out and ignored.

Schools that provide their students with the opportunities to be self-determined and autonomous are bucking the trend of cloistered protection and, in fact, signal the slowly shifting perspective of students from dependants to citizens (Stainton-Rodgers, 2004; Taylor & Smith, 2009). Ultimately, it must be acknowledged that there is a great deal of trust from those schools and students that participate in any research.

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