



ETHICAL RESEARCH INVOLVING CHILDREN

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NEW ZEALAND

INFORMED CONSENT

The challenge of ongoing consent?

Background context:

When conducting ethnographic or field-based research that involves children with disability, the notion of informed consent requires the researcher to be very thoughtful about what it means to be fully informed across the full range of participants. The school based study in this example involved researchers spending significant time over a year with the same group of students (aged 11-12) and then following some of those students from year to year as they changed classes and schools. There were four researchers in New Zealand regular schools following seven students with disability. We wanted to understand how school experiences were influencing what it meant to be a student with disability. The following example is based on one researcher's experience with one of the students.

The ethical challenge:

Much of the ethical guidance on involving children in research assumes event-based studies, (e.g., taking part in an interview or completing a survey) where the consent is obtained, and data collection follows very quickly after. On the completion of data collection the child has experienced what it is like to participate in research and can form an opinion about whether they would wish to repeat the exercise.

In ethnographic studies the relationships between the students and myself developed over time within the context of classroom participation. The student experience of the research was very much influenced by the developing relationship with myself as the researcher. The children may have wondered to themselves whether I was just another adult who was going to "boss them around". My concerns at the time were: What if a student decided they didn't want to talk with me at a particular time; did that mean they no longer wanted to be part of the research anymore?; how would I check this?

When I stated that, "I want to spend some time in your classroom", they did not necessarily realise that I meant "be there all the time". We are familiar with the idea of participants saying they can withdraw from the research at any time. How was I to check whether this was the case or a student was not having a good day and would be fine tomorrow? My approach was to negotiate what participation might look like and talk about how children can influence what that might mean on a day-to-day basis.

The research information sheets that we provided advised children that they can ask the researcher to "go away" if they are not comfortable about being observed during particular times. However, usual classroom adult-child interactions often do not give children the option of doing this. It is usually difficult for any child to ask an adult not to do something, as this contravenes the usual power relationships in schools. It may be even more difficult for children with disabilities to do this, given the number of extra

adults they may have around them.

Choices made:

What did this mean when spending time in the classroom? Here are some examples.

As the focus was on the experiences of the student with disability I spoke with Alex and his family first.ⁱ Thus I spent as much time as was required to give an initial explanation of the study. Once I had their approval to begin I then gained permission from Alex's class. I did not start data collection, that is, writing notes, as soon as I began spending time in the classroom. I wanted students to get to know me first as an adult in the classroom. Over time, many of them were comfortable about asking me to support them in their classroom activities. At the end of the first day I talked with the class about what I was hoping to get from my time in the classroom. I spoke about taking notes and talking with them about their day, but I also gave them permission to talk with me individually or say they would not want to be part of my study.

I provided information sheets about the project, which they could take home and talk about with their parents. I then gave students two more days to raise any questions while they got to know me better (it also allowed me to catch up with any students who might have been away when I spoke with the class the first time).

As I walked past Alex who was doing a writing exercise he leaned over his work and put his non-writing arm over his page making it difficult for me to see. I walked past and talked with another student.

When the class finished for lunch it was often a useful time to review the morning's events with Alex. I was mindful, however, that this meant that he was not spending time with other students. At one point I think he also preferred to spend time with me rather than go out and interact with others. I decided to vary and limit the time I would spend speaking with Alex at the lunch break, despite it being beneficial for the research or the student's preference. Instead, I looked for other opportunities to have these discussions.

Students were used to having adults in the class, but not researchers. Many students wanted to know what I was writing during those times I was in the class. I decided to show them my notes, as they were very messy and I only ever had those for the day with me. (I write my notes in expanded form later in the day.) I showed students my notes and then verbally explained what the 'scrawl' meant. This allowed me to leave out any personal details and reassured the students that my focus was on classroom activities. They did not tend to come back and ask again after the first time.

Reflexive questions/considerations:

In the context of ethnographic research, the researcher is the experience. Therefore, how children get to know the researcher determines what it means to be informed. This raises a number of questions:

- How will you introduce yourself (or allow others to do it)?
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• ⁱ Alex is a pseudonym

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- What opportunities will you give all children to get to know you and what you are doing?
- How much time will you give children before you ask for an initial commitment, and how will you check their views about ongoing participation?
- The criteria for appropriate interactions with a researcher emerge over time. How often do you check that the situation is still okay for the students? In institutions children are not used to challenging adults and they tend to comply with requests. What clues do children give you that they would like things to be different?
- How do you make sure that your relationship with one child does not compromise their relationships with others, such as their peers?
- How will you appropriately reassure children about the nature of the data you are collecting?
- How do you balance the research activities of observing/recording data with participating in classroom activities?

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