

The Ethics of Child Assent in Research
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Ethics in Research
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For the past five summers, I've had the sometimes wonderful and other times infuriating experience of working as a camp counselor. My summers are filled with six weeks of first graders and each day on the job brings with it a new problem to solve. Some of these issues are serious, such as a missing child, and some of them are laughable, like a child who is afraid no one will recognize him with his new backpack. Every year, I look forward to the day that I accompany my campers on a field trip because it is usually a day without any problems. One year, however, one of my campers began to cry when we started to line up to get on the bus for the field trip. I was a bit taken aback. Why would going to an arcade make her upset? When I asked her this, she explained that she did not want to go on the trip. I asked her why she felt that way, but she did not respond.

I brought the child to the camp director, hoping he could make her feel better about the field trip or somehow excuse her from going. He did neither of these things and he explained that because her parents signed the permission slip for her to go on the trip, she was required to go even if it made her upset. Sitting in the main office, holding my crying camper's hand, it seemed that there was no solution to this problem. Suddenly, I realized that, having never been on a camp field trip before, the child was likely just scared because she did not understand what she was getting herself into. I decided to try a new approach with her. "So, are you sure you don't want to go to the arcade and win prizes?" I asked. She looked at me with skepticism. "Prizes?" "Yes," I answered. "There are lots of games you can play with your friends, and there's a bouncy castle too." She wiped her tears. "I think I want to go on the field trip," she said.

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This was a teaching moment for me because it made me realize that even though I had been on the camp field trip a number of times and knew what to expect, the children for whom I was responsible were experiencing it for the first time. Their parents had given their consent for them to go, but the children were left unaware of what would happen to them on the trip and for this child in particular, the prospect of the unknown was scary. My informing her of what would happen on the field trip helped to ease her mind. This relates very closely to the topic of assent in research involving child subjects because researchers often obtain parental consent and then conduct studies on children without properly explaining the research to them. If children are fearful of going on a field trip because they do not know what it entails, how can they be expected to participate in research that they do not understand?

The Belmont Report, created by the National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research, is a document which outlines a set of principles for conducting research in an ethical manner. In this report, under the principle of Respect for Persons, it is mentioned that research subjects must be informed about research and asked for their consent before participating. The report also states that special provisions need to be taken to obtain informed consent from those who have limited autonomy, such as children (The Belmont Report, 1978). Such provisions may include obtaining children's assent in addition to parents' consent. Informed consent is an adult's agreement to participate in research after being informed about the study and its potential risks and benefits, while assent refers to that of a child. Assent can not be obtained merely from a child's compliance with directions and lack of resistance. It must be demonstrated through affirmative verbalization and active willingness of the child. While this method does allow researchers to be sure that the child subjects actually

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want to participate, it does not guarantee that they understand what participation in the research entails. Researchers tend to neglect the importance of children's understanding of research, or, in some cases, they assume children know more than they do, like how I assumed my campers knew what field trips were like. It is, however, important that children are made completely aware of the purpose of research studies as well as the risks and benefits associated with them. This is because the Belmont Report asserts that informing participants of these things is necessary in order to provide due respect for them. Just as adults are informed about research prior to being asked for their consent to participate, children should also be informed, in terms that they can understand, before being asked to provide assent.

Kantian ethics supports this moral principle outlined by the Belmont Report. According to Immanuel Kant, one should always act in ways that treat the humanity of each person as an end in itself, and never merely as a means to an end. In the context of research, this means that researchers must treat both adults and children as beings with dignity who deserve to be completely informed about the study in which they are participating. Obtaining assent from children without informing them properly is treating them merely as a means to their end of gathering research participants rather than as ends in themselves. Thus, when researchers perform studies on children without making it abundantly clear to them what the research entails, they are treating them with disrespect and they are conducting research in an unethical manner.

Another reason that child comprehension of research is important is that, unfortunately, parents may not always have their child's best interest in mind. Some parents may give consent for their child to participate in a high-risk study because they desire the monetary compensation the researchers offer. Thus, it is imperative that the child, him or herself, is made

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aware of the risks and benefits of the research and is given the opportunity to decide whether or not he or she would like to participate. This process of gathering relevant information and then making a decision plays a vital role in the development of children's autonomy. Thus, in including children in the decision-making process, researchers are protecting them from being coerced into harmful research, and, at the same time, improving their ability to make judgments for themselves.

It is evident that the current methods many researchers use to explain research to children are not effective. According to a recent study, which investigated the research comprehension of children between the ages of seven and twelve, children are reasonably accurate in describing the purpose of studies, but many of them do not understand the possible risks or benefits of participating (Abramovitch, Freedman, Henry, & Brunschot, 1995). This is an ethical issue because if children are not made aware of the risks and benefits associated with certain studies, they are not receiving the respect they deserve as research subjects and they may be misled about the likelihood of harm associated with the study. As such, when obtaining assent, researchers should be especially clear in describing risk and benefit to children because evidently, this area is what children seem to have the most trouble comprehending. In order to make risk and benefit more clear to children, researchers might consider repeating the information to them multiple times or using some form of media that makes the information easier for them to understand, such as a cartoon depicting potential risks and benefits.

Another way to make research information more clear might be to personalize the manner of explanation of research to children according to their ages. This method was supported by Fordham University's Celia Fisher in a report for the Institute of Medicine

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(Dingfelder, 2004). Other authors claim that “by creating age-appropriate modules of information, children as young as six years can understand potentially difficult and complex concepts such as the risks and benefits associated with participation in biomedical research” (Burke, Abramovitch, & Zlotkin, 2005). Therefore, in order to ensure that children completely understand what they are agreeing to when they provide assent, researchers should consider modifying their explanations based on the children’s ages, using simpler terms for younger participants.

Overall, it is important that child participants are not only willing to participate, but that they fully understand the implications of their participation. This is because according to the Belmont Report’s principle of respect, researchers are obligated to provide subjects with all relevant information. As such, child research subjects should be given the same respect as adult subjects even if doing so requires researchers to take extra measures. In personalizing the explanations of research based on children’s age and by being especially clear about risk and benefit, for these seem to be the most difficult for children to comprehend, researchers can properly respect child subjects and conduct research in an ethical manner.

Works Cited

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