

Capacity and competence in children as research participants

Researchers have been reluctant to include children in health research on the basis of potentially naive assumptions

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During the past few decades, there has been an explosion in the development and use of neurogenetic technologies that promise to improve and even to enhance the lives and minds of children. These technologies offer cognitive and behavioural improvements, risk assessments for mental or personality disorders in later life, and interventions to counteract traumatic memories. Alongside the growth in neuro-interventions is a burgeoning list of mental disorders, fuelled by a growing understanding of the biological and genetic roots of disease, as well as by the need to justify the expanding use of an ever-increasing number of medical interventions.

Children present a healthy market both for mental disorder diagnoses and for neuro-interventions. In many Western countries, childhood psychiatric diagnoses and paediatric use of psychotropic drugs has grown substantially during the past decade. The use of psychostimulants has been an area of particular concern. A Canadian survey observed a tenfold increase in stimulant prescriptions for children between 1990 and 1996 (Miller *et al*, 2001); a similar study found a 3.5-fold increase in such prescriptions for Israeli schoolchildren between 1998 and 2004 (Vinker *et al*, 2006).

Existing and emerging neurogenetic technologies are dramatically shaping crucial dimensions of early childhood and adolescent experience, and will continue to do so for the foreseeable future. Many social critics and ethics observers have remarked on the implications of these technologies for children, including their identity, autonomy, individuality, free will, sense of personal responsibility, future health outcomes, and peer and familial relationships. It is most surprising, therefore, that the ethical and social debates that follow from these developments in medical technologies so rarely include the voices of children themselves. Children tend not to be consulted on their views on these technologies—not as close observers of the impact of these technologies, nor as users or members of the community.

This article is a preliminary venture into an effort to understand the broader question of why children are so often excluded in research; the narrower focus is on children's participation in social science research into the impacts of neurotechnologies. I suggest that concerns about children as research subjects can be seen as analogous to concerns about children as patients, insofar as there are similar questions about children's capacities and competencies in particular areas. I question the assumptions about children's vulnerabilities and incapacities as research participants, focusing on the familiar and contested territory of informed consent. Drawing on research into children's experiences with diagnosis of attention deficit/hyperactivity disorder (ADHD) and stimulant drug treatment, I show their largely adept understanding of, and attention to, key dimensions of informed consent. Related to this, I discuss children's ability to act as autonomous and reliable research participants. I also suggest that when it is possible to view capacities and incapacities around aspects of informed consent as context-specific rather than global, researchers can resolve their concerns in ways that respect a child's status as a competent research participant.

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In the biomedical ethics literature on patients, relevant bioethical capacities usually centre around the question of whether a person is able to make a decision about his or her treatment. Key aspects of capacity are: does the person understand his/her diagnosis; does the person understand the relevance of the diagnosis to him/herself; is the person able to understand a variety of treatment options; and is the person able to decide on one of these options. Although many bioethical discussions tend to use capacity and competence interchangeably, Martin (2007) has argued that “capacity and competence come apart”, in that a person might have capacities in some areas, such as understanding the medical facts of a case, but this might not mean that the person is competent to be granted the social status of deciding on a medical outcome and/or on treatment.

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This distinction is a useful way to understand the small amount of available research on children as patients. For many years, children and childhood have generally been painted as a time and state of great vulnerability, characterized by innocence, naivete and cognitive immaturity. Such characterizations of children’s global incapacities have given rise to a great many legal, medical and parental protections for children. More recently, however, sociologists of childhood have complicated this picture, arguing that children do not necessarily lack agency, autonomy, capacity and competence. Although children might not be granted social status as competent decision-makers, they should be viewed as social individuals with task-specific capacities, who are simultaneously shaped by and shaping their environment (Prout, 2005). Some legal scholars have agreed with this revised view of children; however, they also advise caution. As the legal scholar Barbara Woodhouse suggested to me, acknowledging children’s capacity and competence does not mean that children do not also need protection. The question is, under what conditions and in what circumstances do they need protection?

Surprisingly, some of the medical circumstances in which children have been assumed to need protection turn out to be circumstances in which they display remarkable capacities. For example, there is convincing evidence that young children with severe illness, such as diabetes or terminal cancer, are able to understand the complexities of their condition, to give informed consent to invasive treatments, to contribute to deliberations over treatment strategies, and, in the case of diabetic children, to take responsibility for administering their own treatment (Alderson *et al*, 2006; Bluebond-Langner *et al*, 2005). Children’s task-specific capacities defy their characterization as vulnerable, incapacitated patients who are fully dependent on surrogate decision-makers. In cases of mental illness, children’s capacity and competence have been shown to be markedly more complex than previously assumed, particularly in relation to treatment decisions in anorexia nervosa (Tan & Fegert, 2004). Taken together, the literature on children as patients strongly suggests that children present a unique category of ill people, whose capacities, competence and autonomy must be considered using a developmental perspective. Consideration must also be given to the particularities of the disorder or disease that the children have, and the ways in which this might shape capacity and competence.

Some of the difficulties of involving children as health research participants are analogous to those that arise in cases in which children are patients. In the social science research context, children must have the capacity to discuss their understanding of diagnosis and treatment. This understanding need not be correct to be interesting and informative; therefore the capacity is specific to the task of communication, as opposed to understanding. However, the capacity to understand correctly is crucial to a child’s ability to provide informed consent to participate in research. Despite the legal requirement of additional parental or carer consent, children should have the capacity to give informed consent to their participation in research, and they must be able to comprehend and to answer questions. Children need to be offered confidentiality, but their legal status as minors can make it difficult or even illegal to uphold confidentiality.

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Assumptions about a lack of cognitive capacity can be a barrier to children’s participation in health research in that the reliability of information provided by a child might be questioned. A reluctance to believe children’s reports and their representations of experience can be traced back to developmental psychological theory, which viewed children’s cognitive capacities as developing in rigid age-related stages (Piaget, 1977). Developmental capacities, particularly in relation to the understanding of oneself and others, must certainly be taken into account in research with children; however, children’s relatively underdeveloped cognitive capacities should not inhibit their active participation in research. Instead, these challenges could motivate innovative research methods. Unfortunately, qualitative instruments for research with children are not sufficiently well developed, with the result that interviews with children can seem to be neither rigorous nor systematic. The great majority of research that involves children uses standardized measures to ensure that the data is reliable. Moreover, too often, research purportedly on children’s experiences of health, illness and/or treatment actually relies on parents’ reports.

Children with cognitive and behavioural disabilities that characterize several childhood psychiatric conditions might offer challenges to the criteria of a competent, reliable research participant. These challenges might not only make such children less desirable research participants, but also mean that child users of neurotechnologies might be particularly difficult to enrol as research participants. According to research ethics committees, such children are vulnerable for two reasons: because they are children, and because they have a mental disorder.

It is hardly surprising that these assumed challenges to research with children who use neurotechnologies are empirically still largely untested. Children who are psychiatric patients, and children who use neuro-interventions, might be vulnerable research subjects, but their assumed vulnerabilities might not be their actual

vulnerabilities. In what follows, I examine some of these actual vulnerabilities in children who are taking stimulant medication for ADHD. I draw on data from a pilot interview study with this population of children, which investigated dimensions of children's moral self-understandings, including conceptualizations of personal authenticity, responsibility and agency. Children were aged between 8 and 12 years; all interviews took place in the UK (Singh, 2007). Here, I discuss children's specific capacities in relation to understanding basic dimensions of informed consent, including capacity, confidentiality and anonymity. Because the capacity to give informed consent also raises questions about a child's status as a competent research participant, I briefly discuss children's agency and their ability to think autonomously in the research process.

A standard consent form includes assurances that any material provided by the research participant—such as blood, saliva, body tissue and interview data—is kept fully confidential and anonymized. In the pilot study, participants and their parents were given consent forms that asked them to tick a box if they felt they had understood the nature of anonymization and confidentiality in the research project. All children and all parents ticked these boxes.

But how well had the children actually understood these dimensions of the research process? How informed was their consent? Although these were not direct research questions, there were many instances during the interviews in which children demonstrated their understanding—or lack thereof—of anonymization and confidentiality. Their sensitivity to these issues was illustrated at the most basic level by a tendency to reconfirm the issue of confidentiality in particular. During the course of the interview, most children asked the interviewer to explain again the nature of confidentiality of the interview (see sidebar, 'Confidentiality'). They were concerned primarily with the possibility that their parents would learn what they had said in the interview.

Doubts about children's competence often involve concerns about their agency; that is, a child's ability to act as an independent or autonomous agent. In the context of interview-based

CONFIDENTIALITY

One example of a child who asked the interviewer to clarify the nature of confidentiality.

Oliver: I want to tell you about something but I don't think my parents would like this very much.

Interviewer: Well, if you want to tell me that's great, and like it said on the form where you signed your name saying you wanted to be part of the study, your parents won't know what you have told me. The only way I would need to tell them is if you told me that you were about to hurt yourself or someone else; or if you told me that someone else is hurting you.

Oliver: No, it's nothing like that!

Interviewer: Ok, well then your parents won't need to know what you're telling me.

Oliver: What if they ask?

Interviewer: When they signed the form they agreed that our interview should be something between us, that they don't need to know about. So if they ask me what you said, I'll remind them that they have agreed to confidentiality—which means they have agreed that they won't get to know what we've talked about except under those special circumstances I just told you about.

Oliver: Ok then, I'll tell you then.

Another child, Jonnie (aged 11), engaged with issues of confidentiality and anonymity, and demonstrated his capacity to understand the nuances of his consent to participate in the research, as he discussed with the researcher whether or not to turn off the recording device during part of the interview.

Jonnie: I don't want my parents to hear this.

Interviewer: They won't hear this tape.

Jonnie: Only if I tell you something really bad, right?

Interviewer: Yah.

Jonnie: Well, I don't want this to be part of, well, I just want to tell you but I don't want to tell anyone else. I don't want you to use this, ummm, you know, when you write about what all the children have said?

Interviewer: Are you worried about someone knowing that it's you who said it?

Jonnie: Ummm...

Interviewer: Because remember, when I use this interview with you, I use it in a way that makes it impossible for anyone to recognize that it's you talking.

Jonnie: Yeah. Well it's not that...

Interviewer: Ok. Tell me more.

Jonnie: It's embarrassing, and I haven't told anyone, and I just don't want this to be, like, official, you know what I mean?

Interviewer: Yes, I think I do. Ok, so I should turn the recorder off, right?

Jonnie: Yeah. Hey, but you also can't write anything down when I'm telling you, ok?

Interviewer: You know, if you tell me I can't use a part of our talking here today, then I can't use it. That's the rules. Unless, like we said, you tell me something that I have to tell someone. If you tell me that you are going to hurt someone, or hurt yourself, or that someone else is hurting you. Ok?

Jonnie: Yeah I know. You told me before.

research with children, concerns about agency mean that children's reports are often thought to reflect the experiences, beliefs and values of influential adults in their lives, and are therefore considered unreliable.

Clearly this does not take into account the reality of the context of children's development, in which a broad relational ecology supports their growth and learning (Bronfenbrenner, 1979). The attempt to separate children from this ecology to capture an 'objective' understanding is therefore artificial. Moreover, children do not simply 'parrot' what adults have said; from a young age, they are able to sift through incoming messages and narratives and to create independent

moral narratives and justifications for their actions (Gilligan, 1982).

In reality, children are often told what to do; they are generally eager to please, especially in a novel interview context; and their schooling rewards them when they come up with the 'right' answers. Researchers must purposefully negotiate these natural conditions of a child's relational ecology during the research process, if children are to be encouraged to have agency and to think autonomously. In the present study, this was done in several ways. One way was to encourage children to take the lead in interviews to support their agency and independent reporting of experiences, beliefs and values. Children were told that they were the

EXPERTISE

Two examples, from interviews with a boy (aged 11) and a girl (aged 10):

Agnes: A friend of mine says that children who have to take tablets are crazy.

Interviewer: And how do you feel about that?

Agnes: I don't want her to think I'm crazy.

Interviewer: Well, you know, children who take tablets for ADHD aren't crazy.

Agnes: Yes, yes, I know that. I don't think I'm crazy. You don't have to tell me that.

Simon: Maybe I'll have to be on the tablets forever – I don't know. Maybe I'll always need to take them.

Interviewer: Lots of children I talk to have that worry, so it's not unusual at all. We just don't know right now – some children seem to need tablets when they are grown up, and some don't. They seem to grow out of the behaviours that are causing the problems.

Simon: Ok, but I thought you were supposed to be learning from me?!

'experts' and that the interviewer hoped to learn from them. This message was repeated in information sheets and in personal communication with the child before and during the interview. The extent to which this effort was successful was particularly evident when children felt their expertise was being undermined (see sidebar, 'Expertise').

In addition to protesting when an interviewer seemed to take over the position of expert, children also did not hesitate to correct the interviewer when they felt that the interviewer had misunderstood them. It was not unusual for an interviewer to be told, "No, that's not what I said." Children had opinions and ideas, which they wanted to be understood.

Another way to work around children's natural conditioning—and one of the best examples of children's ability to shape research and the research process—is to allow them to participate in creating some tools for communication during the interview. For example, drawing was not originally part of these interviews; children were asked questions using a variety of tools and techniques including photographs, standardized pictures and toys. It soon became clear, however, that when children felt comfortable in the role of expert, they would consistently and spontaneously use drawings to help them communicate their ideas about complex phenomena (see sidebar, 'Drawings').

Owing to children's spontaneous introduction of this new tool for self-expression and communication, drawing was gradually integrated into the interviews and will be a standard part of a larger follow-up study. In this way, children contributed to, and shaped, both the research process and the potential research outcomes. They did this by acting as competent agents in the research process.

No child in this study could be described as a passive participant. This might be caused in part by a selection bias, reflecting the nature of children who choose to participate in interview studies. However, these children represented a range of cognitive and emotional styles; their shared willingness to participate should not be seen as reflecting group homogeneity. Their willingness to engage actively with the researcher and the research process strongly refuted assumptions that a lack of capacity and competence to understand basic aspects of research is part of children's vulnerability as research participants.

One aspect of the pilot study did prompt researchers to question the ability of children and parents to give truly informed consent. Children were given cameras and asked to take photographs as visual accounts of their experiences with and without ADHD medication. Children and their parents were asked to sign a separate consent form that covered the use of these photographs for research purposes. The form explained that the pictures might be used in contexts such as conferences, lectures, seminars and publications. Parents and children were asked to tick boxes that asked for specific consent to use pictures that depicted the child, family members, or their home to an extent that it might be recognized. No child or parent refused consent for use of these pictures.

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Approximately 30% of the photographs depicted the child and/or family members. Children tended to photograph themselves in various moods when off medication,

DRAWINGS

The following example is from an interview with Sean (aged 9):

Interviewer: So can you tell me what happens when you take your tablets—where do they go? And what happens?

Sean: I swallow them and they go down into my stomach and they get turned into juice or something like that. Then they travel up to my brain through my veins.

Interviewer: So when the tablets arrive in your brain they are in the form of juice?

Sean: Yeah.

Interviewer: And then what happens? What part of your brain does the juice go to?

Sean: Umm, I don't really know. I think it's... this is hard... if you think of my brain, ok?... [reaches for pen] Here it is, I'll draw it for you...

including tantrums, head banging, throwing things and destroying objects. In response to such behaviour, family members were depicted being angry or restraining the child. These more extreme photos raised the question whether their consent for using these photographs had been truly informed. Were parents and children able to understand the extent to which their privacy would be violated if these pictures were publicized? Were they able to imagine the various scenarios in which such public displays might occur? Were they able to understand the permanent nature of publication of these images, which would be appropriated in perpetuity?

In dealing with this dilemma of potentially uninformed consent, three possible responses were discussed. The first was to reject the argument that consent for using these pictures was uninformed. This was based on a view that researchers should not be overprotective of—or even paternalistic towards—children and parents. During the study, children had demonstrated a sophisticated ability to understand the implications of consenting to the research process. Moreover, it was possible that children and/or parents might enjoy seeing themselves personally depicted in talks and publications, regardless of concerns over violations of privacy.

The second response was to use these photographs in spoken or published presentations, but to organize them in such a way as to minimize the impact on a child's

or family's privacy. For example, photographic images of individual children and/or their families could be used for academic talks, but these images might be as part of a collage of various photographs. In this way, the images of individual children and their families would be less of a focal point, and individuals would not be as immediately recognizable. In addition, any accompanying narrative would focus less on individual pictures and more on the larger theme or idea. However, this response would not translate well into published research, as images could be scrutinized more carefully on the page than they could be during a presentation.

...children's relatively under-developed cognitive capacities should not inhibit their active participation in research

A third possible response was to contact participants to ask them again how to treat the photographs. Although this might seem most respectful of the participants' agency and engagement in the study, it also raises several complexities. For one, re-contacting research participants goes beyond the scope of the ethics approval for the study; therefore, further approval would be needed. Second, re-contacting participants and interviewing them in any form would involve additional costs. Third, parents and children might be confused or even resentful over the need to provide consent for use of photographs again; the re-consent process could be seen as paternalistic rather than ethically careful.

Given the pragmatic constraints on the third response, the decision was made to choose the second option. Photographic collages that include images of the child

and/or family have been used in presentations, but not in published work. This decision was based on children's agency in, and engagement with, the research process in this study; it was felt that children's and parents' consent for using the photographs had not been so much uninformed as it had been limited by an insufficient understanding of the potential violation of privacy. The second response represents an attempt to protect participants from potentially harmful outcomes of the research process, while acknowledging their voices and faces as active participants in research.

In this brief article, I have attempted to refute some assumptions about children's vulnerabilities as research subjects. In a research project that treats children in ways appropriate to their developmental status and gives them the opportunity to be active participants, children with a diagnosed mental disorder are shown to have task-specific capacities. They can understand and query key dimensions of informed consent, and they can actively shape the research process and even the form of research outcomes. The original strong protective impulse inherent in standard research ethics protocols should shift to encompass a greater awareness of the various conditions and circumstances of children as research participants. Researchers should be particularly aware of these conditions, and should seek ethical protections above and beyond informed consent when necessary. However, assumptions of children's global incapacity as competent research participants should be questioned, so that an increasing number of empirical investigations into the social and ethical implications of neurotechnologies include the voices and experiences of children.

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