

CASE #2: TESTING JUNIOR

The New York Times recently reported on several scientists who have applied their craft to members of their own families, researching their own children.¹ Some used MRI scans on their children, some recorded their children's every word, and others merely parlayed their scientific knowledge and parental observations into ideas for future use in controlled studies. Three scientists – Dr. Arthur Toga, Dr. Deb Roy, and Dr. Deborah Linebarger discussed their research on their children and their views on the impact of such research. These researchers drew different lines with how they studied their children, though all expressed concern for the privacy and wellbeing of their children in the research process.

Dr. Toga allowed his children to participate in a longitudinal MRI study which aimed at outlining the maturational stages of brain development across many children. His children volunteered for the research on their own volition, and the results were rendered anonymously. Dr. Linebarger both observed and tested her four children, though primarily only in pilot studies. And Dr. Roy recorded over 250,000 hours of his son's life, focusing on his son's early language acquisition – his son was his first and only subject in the early stages of his research. His students now process small segments of the recordings of his son, and his research is being parlayed into much larger studies of children with autism.

All of these scientist parents express the belief that, if anything, involving their children in their research has strengthened their relationship with their children, by allowing their children access to, and understanding of, what mommy or daddy does for a living. However, such involvement does come with some risks. Dr. Linebarger discussed how even pilot testing proved difficult as a parent. When she tested her son five-year-old son, Dr. Linebarger became interested in her son's responses to some pilot questions about parenting, and pursued the questions beyond the scope of the study. After the fact, she realized that she would not have pursued that line of questions with other subjects, and subsequently made a rule for her studies: when piloting questions on her own children, she would not deviate from the scripted questions except insofar as necessary to fix or improve them.

Dr. Linebarger has also grappled with the issue of consent, and generally asks her husband to sign parental consent forms prior to conducting research. She additionally explains any studies she wishes to perform to her children, and then asks them whether they are comfortable being studied. Dr. Linebarger may not necessarily obtain her children's consent for observational studies for several reasons, though. First, such consent might interfere with the natural actions that she seeks to observe. Second, the potential harm from observation is so slight that she can feel comfortable providing the consent for them. Ultimately, Dr. Linebarger notes that no matter what sort of research she involves her children in, she would not involve her children in actual, publishable studies due to the potential for bias and diminished credibility.

¹ Belluck, Pam, "Test Subjects Who Call the Scientists Mom or Dad," <http://www.nytimes.com/2009/01/18/science/18kids.html?pagewanted=all>, *New York Times* (Jan. 17, 2009). Note that the remainder of this case contains original content obtained via electronic and telephone interviews obtained from Dr. Roy between Aug. 9 and 10, 2009, Dr. Deborah Linebarger on Aug. 11, 2009, and Dr. Arthur Toga on Aug. 12, 2009. Please respect these individuals' privacy and forward any questions to Rhiannon Dodds Funke at rfunke@law.stetson.edu.

Why engage one's children in research at all? Several reasons motivate Dr. Linebarger. First, she finds that her prior knowledge of her children, their experiences and their capabilities, enriches her research – it helps her to mold her methods and gauge her results. Second, she admits that participants, particularly in longitudinal studies, may be difficult to find, and by engaging her children in the pilot studies, she doesn't have to give up willing volunteers for the "real" study to pilot tests.

Dr. Roy's son is four years old now; he stopped recording his son over a year ago and his focus now is to "analyze the recordings made from ages 9-24 months." Roy states that his son "is still far too young to understand what 'research' means, although he does enjoy watching the occasional video clip." While Dr. Roy believes that his research has made him more attuned to his son's language skills, when asked, he states that he does not believe the research has affected his relationship with his son in other ways.

This may be, in part, due to the strong precautions he enacted to ensure his son's privacy and wellbeing were protected. He states that he and his wife had some reservations about the "possibility of the recordings affecting their everyday lives in adverse ways," and therefore "made a number of provisions to provide [them] with complete control of when recordings were made, multiple ways to delete recordings after the fact, etc."

Why not just test unrelated subjects? Dr. Roy believes studying his son provided benefits and useful insights that he would not have obtained without testing his own son. He states, "Due to the intimate nature of the recordings, I was not willing to record someone else's children until I knew that we had a properly worked out methodology not only for making recordings but also privacy policies governing future access of the recordings. As both subject of the study and investigator, I was able to reflect on the effects of the recordings on myself and my family and make adjustments to the method accordingly."

He further relates, "With the methodology now relatively mature and proven, we are extending our research to study children of other families with a focus on understanding early stages of autism. We have new funding from the National Institutes of Health and from an autism foundation to pursue these directions in collaboration with other researchers and clinicians. We do not plan to release the raw recordings to the public in order to respect the privacy of my son and others that were recorded in the course of the study."

Dr. Toga, when interviewed by the New York Times, related how some nonscientists chastised him for exposing his children to the risks of MRI scans. He notes, however, that MRI scans really pose no risk – that they are comparable to taking a photograph. When performing research, IRBs generally require scientists to disclose very extensive information about every conceivable risk to parents. Such a conservative approach might scare away less scientifically versed parents. Dr. Toga admits that, given his strong understanding of science, he believes that he might actually be more willing than the average parent to have his children participate in scientific research. However, he believes the minimal risks he would be willing to allow his children to undertake during scientific testing vastly outweighed by the learning they gain and their contribution to human knowledge (resulting from their participation). He further notes that he might not have consented to more risky procedures, such as PET scans.