

OPINION, Q&A

Questions for Iaina Singh: Ethics of 'baby sib' studies

BY NICHOLETTE ZELIADT

14 JULY 2015



For the past decade or so, researchers have been studying the infant siblings of children with autism. These siblings are about **20 times more likely than average** to be diagnosed with the disorder themselves. This makes them especially well suited for studies on how to detect and treat autism early.

But **research on these so-called ‘baby sibs’** raises unique ethical challenges, says **Ilina Singh**, professor of neuroscience and society at the University of Oxford in the U.K. The label alone may be stigmatizing, and therapies for these children — the majority of whom are never diagnosed with autism — may have unintended consequences.

We asked Singh about the risks and benefits of studying **baby sibs**, and strategies to make the research more ethical.

SFARI.org: Many baby sib studies evaluate early interventions. What ethical questions does this raise?

Ilina Singh: If you start with the ethical principle that you want to minimize harm and maximize benefits, then one premise of ethical intervention is that you know what you’re intervening upon. So there already you have a problem. You’re intervening because of familial risk, not because the child has any symptoms.

The second premise is that you want your intervention to be accurate; that is, you want it to treat the problem. Again, you don’t have a problem that you actually can see and measure, so your accuracy is going to be questionable.

The third premise of ethical intervention is that you provide families with a reliable risk-benefit analysis so they can make informed decisions about participation. But if we don’t know what problem we’re trying to solve with an intervention, how can we talk in a substantive way to families about the potential risks or benefits?

I’m not in any way saying that we shouldn’t be doing baby sibs research, because I do think it’s important. But at this stage, we have to think carefully about how we inform families about the risks and benefits.

S: What do you see as the potential risks and benefits?

IS: First, the intervention itself can be harmful. We certainly have data that suggest labeling someone with a particular diagnosis can shift his or her understanding of self and the family’s understanding of that individual. So we have to think about how labeling a child as a ‘baby sib’ as part of a research study might affect how the parents interact with him or her. It’s possible that parents or other people will start seeing signs and deficits in these children — or even behave in ways that exacerbate certain deficits — just because they’re worried about them.

Although the target of an intervention may be the child, we need to think more broadly about where the benefits and harms could be. On the family level, we know from other disorders that there can be a fair bit of blame cast between parents. For instance, before a child is diagnosed with attention deficit hyperactivity disorder, the mom tends to get very anxious because she feels she's not connecting properly with the child. The father, in the meantime, may watch these interactions and think the mom is being oversensitive and seeing problems where there aren't any. That causes tension that affects the child.

Then, of course, there are siblings. If there is a sibling in the household who has autism and is old enough to understand that this baby is being treated to minimize symptoms of the disorder, this might be confusing or upsetting to that child. One can imagine that if the baby sib grows up to not have autism, then the other sibling, who has autism, may feel a sense of shame or feel angry or devalued as a person. A lot will depend on how researchers communicate with parents around these delicate issues, and how parents are helped to communicate with other family members, including children, about the reasons for intervention.

S: Some advocates argue that society should be more accepting of 'neurodiversity' — that autism is part of the natural variation in the population. How does this play into the ethics of baby sib research?

IS: Certainly on the high-functioning end of autism there's a claim that early intervention represents some sort of intolerance of diversity, that everyone should be more 'normal' — whatever normal is. It really comes down to this question of which problem we are trying to fix with the intervention. Are we all agreed that autism is something that is so impairing for an individual that we should intervene before symptoms emerge, even if we don't know what that intervention is going to do? I don't think that we're all agreed on that. For the autism community, I think one of the main ethical questions is: What does our desire to intervene at this very early stage say about the value of a person with autism? Another question is: What does it say about society's willingness to adjust to people on the spectrum?

One of the responses of the research community is that early intervention isn't about trying to get rid of autism; it's about trying to better understand the capacities and the developmental trajectories of children who may develop autism so that it can become less impairing. This is actually critically important, because minimizing impairment is a key ethical principle of any medical treatment. And many autism researchers are themselves advocates for an appreciation of neurodiversity. So we need to ensure that early intervention research doesn't shrink appreciation and support for diversity, but we also need to ensure that the neurodiversity agenda doesn't prevent research.

S: How can we move toward early interventions in autism that are more ethical?

IS: We can analyze the ethical dimensions of early interventions, considering issues such as informed consent, personhood, or benefits and harms. But I would also like to see ethics research embedded in early intervention trials. We can use ethical concepts to develop and test hypotheses about positive and negative aspects of an intervention.

I'm particularly interested in how early interventions enable or diminish blame and responsibility for a child's difficulties, which mothers tend to feel particularly acutely. I'm also interested in how hope is configured in these settings. Does intervening when a child is labeled 'high-risk' but is not displaying any symptoms produce hope? Does it help people imagine good outcomes for the child? Or does early intervention somehow lower expectations, potentially threatening a child's future?

Some ethical questions may actually affect the outcomes that scientists are measuring. For example, parental feelings of blame, responsibility or hope may, through parenting behaviors, affect a child's development. I think these issues are scientifically important, as well as ethically important.