Should We Tell the Parents? Balancing Science and Children’s Needs in a Longitudinal Study

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In the late 1980s and early 1990s, the United States was engaged in a massive natural experiment. More than 52% of women with children under age 6 had entered the workforce, and a new term, “dual career families,” was born. In this context, families wrestled with the question of whether they should send their young children to childcare and just how much alternative care was good or bad for their babies.

At the time, the scientific community offered parents a mixed bag of advice. Some studies stressed the importance of maternal care and found that placing children in childcare was a risk (Belsky, 1999, 2001; White, 1985). Others reported the opposite effects, demonstrating cognitive and social boosts from playing with other children in childcare (Clarke-Stewart, Gruber & Fitzgerald, 1994; Lamb, 1998). Still others suggested that placing a child in childcare had little or no effect on child outcomes (e.g., Scarr, 1998). Moving from the science to more personal accusations, there were assertions that the positive results from childcare studies emerged only when women were the experimenters, and counterclaims also emerged that findings against using childcare were promulgated by researchers searching to maintain an Ozzy and Harriet caricature of the mom at home. No broad spectrum and definitive research on the topic had been conducted—until now.

The NICHD issued a request for proposals in 1987 and called for a collaborative study that would be large enough and diverse enough to address questions about the role of childcare in children’s lives and development. Temple University was one of the 10 sites that earned a peer-reviewed seat at the table. Together the researchers who included voices from all perspectives, pro and con, designed a longitudinal study of children from 0 to 15 years. The study would examine children as they
grew up in the rich context of their lives and would collect data at home, in childcare, and in the laboratory. Set in a Bronfenbrenner model of ecological development (Bronfenbrenner, 1986), the researchers would collect outcomes in cognition, social development, and health and would ask how various and combined contexts related to child outcomes across time at 1, 6, 15, 24, 36, and 54 months of age as well as at kindergarten, first, third, and fifth grades and beyond. With 1,364 families enrolled, the study became its own experiment in big science within the social sciences. And along the way, the sheer grandeur of the study would enable scientists to give more definitive answers to the questions of the day on the role of the home environment on parenting practices, the demographic patterns associated with amount, quality, and characteristic of childcare use, and on the variety and stability of childcare use and relationships between the use of childcare and parent-child interactions. The study would also be positioned to look not only at immediate effects of childcare but at enduring effects as well.

As is probably evident, a study of this stature and of this potential visibility offers a grab bag of ethical considerations that range from the way the questions are posed, to the nature of eligible participants, to operational definitions of constructs such as childcare. Indeed, each of these areas sparked considerable debate among the team of researchers. By way of example, one rather controversial decision was how to define what we meant by childcare. Because maternal care was and remains the norm and because we wanted to have the opportunity to study paternal care separately, a decision was made to treat paternal care like one form of childcare — alongside center care, family care, nanny care, or grandparent care. This means that when fathers regularly spent more than 10 hours a week with their child when the mother was not present, the child would be considered in childcare. This decision allowed us to observe children in the care of their fathers and was in keeping with the question of the times about the impact of non-maternal care on child outcomes, but struck some as an inappropriate way to characterize father care.

While there are a host of such issues that could be raised, here we focus on one of the many that emerge in any number of longitudinal designs of child development. This decision is one that surfaces on the ground as the data are pouring in and is one that strikes at the very core of tension between science and individual rights.

When parents and their children enlist in a study of this nature, they accept the fact that they will be living in somewhat of a fishbowl and that their data and that of their children will be aggregated to present a snapshot of trends in childcare use. Then you reach the what if...
What if the initial results come in and you, the researcher, see that 1 or 2 of the children out of the 136 at your site look woefully below the average of the others? What if the children who you are looking at are but 18 months of age or 2 years old, and you think that if you can help these children get language or social interventions early, you might change their developmental trajectories for the better?

Faced with this dilemma, we worried that if we did alter the course of development — or tried to — then we were not being true to the science. We were, in effect, meddling with the potential results. On the other hand, if we did not intervene, we were potentially damning a child to poor outcomes that could otherwise be reversed with careful intervention. Moreover, although the parents did not volunteer for the study to get feedback on their child’s development, what if they did harbor concerns about the normality of their child’s development? Considering us experts, the lack of a comment or concern on our part could be communicating to parents that all is OK, and our silence might deter parents from seeking the help they might otherwise have sought.

We came to a conclusion that is not necessarily the right one, but that is one that we thought we could live with. We decided to hold off on telling the parents about our concerns until we had at least one more data point that converged with our initial observations. We are not conducting clinically valid tests, so it was best to know that the child in question remained at least a standard deviation below the mean for more than one epoch in our routine assessments. Further, we could comfort ourselves in knowing that waiting for six months was not likely to harm the child, who was still quite young and potentially pliable. Indeed, at these young ages, there are no agreed-on interventions. These rationales held us until the next wave of data collection.

What if the child continued to perform at well below average levels? At that point we decided that the individual need trumped the scientific one and we would tell the parents. The number of children involved was low — approximately 2 or 3 children from our sample of 136, so it was unlikely to alter the course of the results from our site even if the parents took immediate action. And how should we inform the parents? After all, we are not physicians or clinicians, just scientists with a bit of extra data that might prove useful. We decided to write a letter to the parents in question explaining the tests that we had used, what we had found, and why we were concerned. In the letter, we suggested that the parents consider approaching their pediatrician to conduct a more thorough investigation. We also offered to speak with their primary doctor if they thought that this would be helpful.
The decision that we made came on the heels of a number of internal discussions and reasoned opinions. In the end, we recognized that we were struggling with very central principles dictated by the Belmont Report (1979), which set forth the framework for how we evaluate research with human participants. The Report calls for a balance between principles of respect for persons (treating people as autonomous individuals who acted voluntarily to participate in our study), beneficence (minimizing harm and maximizing benefits), and justice (treating people fairly). In this case, it did not seem to us that we would be fair or minimizing potential harm if we held back the information from those who could potentially use it.

The case, however, was not straightforward and could have been argued either way. Given the gravitas of the policy issues being studied, one could easily argue that letting the children develop as they would have—in their normal context—would have been of more benefit to the society at large. We decided in favor of the respect, beneficence, and justice for the individual child and family.

REFERENCES


