

September 2010

Dear Family,

I am writing to you because you were contacted by the Center for Autism Research (CAR) at The Children's Hospital of Philadelphia, and you expressed interest in the *Autism and the Family* research study.

My name is Benjamin DiCicco-Bloom, and I am a doctoral candidate in the department of Sociology at the University of Pennsylvania. I am conducting the *Autism and the Family* research study, with the support of CAR, in order to learn more about the experience of families that have a child with autism. I want to learn about the relationships between children with autism and the people who love and care for them.

My introduction to autism came while working for four consecutive summers at the Eden Institute in Princeton, NJ as a classroom teacher, a physical education teacher, an after-school counselor, and a respite worker. At the Eden Institute, I was trained to work with individuals (ages 3-22), with a variety of diagnoses, including autism spectrum disorder. Through this work, I was made aware of the unique, moving, frustrating, and rewarding experiences of parents and families raising a child with autism. Learning about these challenges and rewards has motivated me to study these experiences in depth.

I want to answer questions like: How does autism influence your family's experience at home and in your community? How do you and your family obtain, process, and digest the large amount of information available on autism? How does having a child with autism affect the way you structure your world? However, this study is not limited to these questions. The most important thing I want to learn is what is important to you and your family; the information you and your family share with me will determine what this project is about.

I have designed this project to allow me, with you and your family's consent, to "hang out" in your home and to talk with you and your family about your experiences. In order to do this, I would like to join your family for dinner. By *dinner* I mean whatever it is that you call dinner at your house. In other words, do not change your routine for me; if everyone in your family eats together or at different times, if you cook dinner or order out, if you eat early or eat late—all of these things are fine. It is precisely *your* family's unique rhythm that interests me most. My hope is that I will be able to come to your house, eat, hang out for a bit, and, after dinner, conduct an interview with you and your spouse. (One or both of these interviews can be conducted at another time if more convenient.)

A select group of families will be asked to become further involved in the study, which would include follow-up dinners, interviews, and observation during other family activities. This further participation will be decided on a case by case basis.

I will be calling you soon to discuss the next steps in more detail. If you would prefer to meet me face-to-face before having me over for dinner, we can arrange a time to do so.

Enclosed please find the two (2) copies of the *study consent form*. Please have one parent sign one copy of this form and keep one copy for your records. Also enclosed are two (2) copies of the *interview consent form*. Both parents must sign one copy of this form (you will see that there is space for both of you to sign) and return to me; the other copy is for your records. I must collect both consent forms (2 copies total) when I arrive at your home for dinner.

Thank you very much for your participation in this project. I look forward to meeting you and learning about your family. Please don't hesitate to let me know if you have any questions or concerns.

Sincerely,

Benjamin DiCicco-Bloom
PhD. Candidate, Department of Sociology, University of Pennsylvania.

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If a member of the research team cannot be reached or you want to talk to someone other than those working on the study, you may contact the Office of Regulatory Affairs at the University of Pennsylvania with any questions, concerns or complaints by calling (215) 898-2614.