Appendix E.8 Rights of Research Subjects Fact Sheet

Center for Autism and Development Disabilities Research and Epidemiology

National CADDRE Study: Child Development and Autism Rights of Research Subjects Fact Sheet

If you choose to be in this research study, you have the right to:

- 1. Be informed about study and why we are doing the study.
- 2. Have study procedures explained by study staff.
- 3. Be informed if there is a chance of any discomforts or risks from the study.
- 4. Have the benefits of participating in the study explained to you.
- 5. Be informed of any risks related to the study.
- 6. Ask any questions about the study or procedures.
- 7. Be told that you can withdraw from the study at anytime without penalty.
- 8. Be told where your information will be stored and how it will be shared.
- 9. Have the choice to decide to participate or not without the use of any force or undue influence on your decision.

The information you give will only be used for this study. Your information will remain confidential unless otherwise required by law. Your information will be combined with information from all other participants when results are made public. We will never use your name or your child's name in any report.

Because sensitive information is collected in this study, <<CDC>> received an <<'Assurance of Confidentiality.'>> This means that any information that <<CDC>> has that identifies you or your child will be used only for this project. It cannot be given to anyone else unless you give your written consent or unless required by law.

If you have questions about your rights as a subject in this research study, please call XXX, leave a message including your name and phone number, and someone will call you back within 2 business days.