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A Developmental Approach to Obtaining Assent in Pediatric Research: Lessons from a Longitudinal Study of 0-to-5-Year-Olds.

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Abstract

Obtaining informed consent is a mandated research practice and is necessary for maintaining the health and safety of all research subjects. Pediatric research requires parents to provide consent on behalf of their children. To respect the developing autonomy of the child, researchers also seek to obtain child assent for research procedures. In longitudinal research, the extent to which a child understands research procedures changes as the child develops. Thus, researchers must take a developmental approach to obtaining child assent. While there are federal and institutional recommendations for navigating child autonomy in a research setting, a set of suggested assenting procedures corresponding to child developmental stages has not yet been articulated. The Prenatal Environment and Child Health (PEACH) study is a longitudinal study following a cohort of 310 birthing parent-infant dyads from gestation through five years post-delivery. Ongoing follow-up assessments (at 1-, 6-, 12-, 18-, 24-, 36-, 48-, and 60-months of age) are conducted to examine children's behavioral, cognitive, and physical development. As the children age, it has become evident that procedures for obtaining child assent should be reevaluated at each assessment timepoint and modified with respect to the child's emerging autonomy and increasing capacity to understand and provide assent. Based on observations from the PEACH study, we created a resource outlining the tools, actions, and language guidelines we developed to explain research procedures to children and obtain their assent at each study visit. This resource also considers the evolving role of the parent at each stage in the child assent process. We discuss this resource in the context of published child consent guidelines for longitudinal studies, while emphasizing that a developmental approach to assent procedures must account for neurodevelopmental differences. This summary and contextualization of our work is an important step toward encouraging positive and respectful research experiences for children.