

Dear Parents and Caregivers,

You are invited to participate in a research study conducted by Heather Hazlett, PhD with the Carolina Institute for Developmental Disabilities (CIDD).

What is the study about?

This research is funded by the National Center for Advancing Translational Sciences (National Institutes of Health). We want to see how our brief telehealth assessment compares to an assessment at a clinic like the CIDD.

This validation study is part of a larger study called the Brain Gene Registry (BGR) study, which looks at how changes in brain genes affect individuals. By participating in the validation part of the BGR study, you will help us figure out if the results of the telehealth assessment are valid (similar to the results from a clinic assessment).

Who can participate?

<You are eligible> or <Your son or daughter is eligible> because <you> or <they> have had an assessment at the TEACCH Autism Program, CIDD, or another UNC clinic.

Where does the study take place?

This is a remote study done in your home. You will not have to travel anywhere.

What is involved in participating?

- Online questionnaires (~1-2 hours) you will complete about <yourself> or <your son's or daughter's> development
- Telehealth Assessment (~30-45 minutes) with <you> or <you and your son or daughter> in your home by secure video (Zoom)
 - Includes a short neurological and dysmorphology screen and might include a brief cognitive and social/play assessment
- If willing, we will have you take some photos of <yourself> or <your son or daughter> as part of the dysmorphology screen
- We will gather information from <you> or <your son's or daughter's> medical and psychological records so we can compare the results of the telehealth assessment to the past clinic assessment
- We will provide a \$100.00 Visa gift card for participating

For more information, please contact Jessica Kinard, PhD at 919-533-9305 or jessica_kinard@med.unc.edu

Kind regards,

Heather Hazlett, PhD
Carolina Institute for Developmental Disabilities