FAQs

What is the purpose of the studies?
We are interested in examining the effects of behavior assessment conducted via telehealth on acquisition of communicative behavior for girls and women with Rett syndrome.

Where do these studies take place?
Assessment and training of communication is often most beneficial when studies take place in the natural settings of the individual. Therefore, assessment and intervention sessions will take place in homes and other natural settings. We will connect with your family via telehealth (video conferencing) to coach the assessments and interventions.

What do tele-health sessions look like?
Tele-health sessions use video-conferencing software to connect you in your home remotely with study personnel at the University to receive assessment, observation, and coaching on communication training.

Do I need special equipment/computer skills? No, we can loan needed equipment and will provide technology coaching to connect and manage the technology.

Are there any costs to participating? There is no cost and no compensation to participate in the study. All materials will be provided free of charge.

Are there potential benefits to participating? There may be potential benefits to participating through gains in communication and to contributing to the understanding of communication intervention in Rett syndrome.

Contact us!

To participate, get additional information or ask a question, please contact our project coordinator Jessica Simacek, at sima0034@umn.edu

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Rett syndrome: Tailoring treatment based on communication needs

Health and Behavior Studies
**Study Activity Descriptions**

**Functional assessment and functional communication training:** Functional assessment can be used to identify potentially communicative responses. We are interested in the effects of coaching caregivers over telehealth (video conferencing) in their home environment to deliver functional assessment and functional communication training intervention on the communication outcomes for girls and women with Rett syndrome.

**Augmentative and Alternative communication (AAC):** The functional communication training will involve the use of non-verbal communication modes that are matched to the individual’s needs, including low-tech AAC (pictures, microswitch) and high-tech AAC devices (e.g., devices with synthesized speech output and eye-gaze).

**Durability of functional communication training and maintenance of effects:** We are interested in if and how the effects of the intervention, such as acquired communication skills, last over time for girls and women with Rett syndrome. To study maintenance, we may ask to follow up with the participating individual over time.

**Inclusion criteria:** We are looking for girls and women with a diagnosis of Rett syndrome between the ages of 3 to 30 who currently have limited communication.