

## Introduction

- Rett Syndrome (RTT) is a neurodevelopmental disability that affects 1 in 10,000 females and is one of the most common causes of profound disability in girls.<sup>1</sup>
- Individuals with RTT demonstrate significant deficits in communication skills, but may demonstrate a range of behaviors (e.g., shifting eye gaze, facial expressions, stereotyped hand movements, vocalizations) often interpreted as communicative (identified as potential communicative acts; PCAs).<sup>2</sup>
- Caregivers often agree communicative forms, but vary in their interpretation of functions.<sup>3</sup>
- PCAs appear to be sensitive to changes in environmental conditions, but it is unclear whether they are intentionally communicative, or responses to changes in physiological state.<sup>2</sup>
- Variability in communicative partners' interpretation of – and therefore responses to – potential communicative acts may place individuals with communication delays at risk for receiving inconsistent reinforcement for their behavior.<sup>4</sup>
- The purpose of the current study was to examine differences in how special education professionals and parents interpret the PCAs of individuals with RTT.

## Method

### VIDEO RECORDINGS OF POTENTIAL COMMUNICATIVE ACTS

- Primary caregivers identified daily routines in which PCAs were most likely to occur.
- For each participant, routines were video-recorded and 5 discrete instances of PCAs were selected by the researchers and spliced into 5-8 second clips.
- Putative functions for each clip were identified by the doctoral student researcher who made the video recordings. Clips included at least one potential comment, request and reject/protest per participant.
- A second doctoral student researcher served as independent coder for reliability purposes.
- Researcher agreement on the functions was 100%.

Table 2. *Examples of PCAs* (adapted from Sigafos et al., 2000)

Vocalizations	Body/Face/Eye Movement
Sound, noise, grunt	Wiggles, reaches, opens/closes eyes, purses lips
Stereotypic Movements	Challenging Behavior
Arm flapping, body rocking	Self-injury, tantrum

### ADULTS' RATINGS OF PCAs

- Adult participants included: special educators ( $n=10$ ) and parents ( $n=4$ ) of individuals with RTT
- Educators represented a range of professional designations: Special Education Teacher ( $n=2$ ), Paraprofessional ( $n=3$ ), Speech-Language Pathologist ( $n=2$ ), Occupational Therapist ( $n=2$ ), Physical Therapist ( $n=1$ ) with a wide range of experience with individuals with severe disabilities (2-34 years)
- Each adult viewed clips for all 3 participants. For each clip, the adult provided answers to the following questions:
  - Was the child communicating?
  - Was the child's intention clear?
  - What was the child communicating?
    - Choices Available: Comment, Request Action, Request Object, Request Comfort, Protest/Reject, Greeting, Other
- The adult participants also indicated how confident they were in their interpretations using a 6-point scale, with 6 representing very confident and 0 representing not confident.

## Results

- Majority of raters identified the PCAs as communicative (**89% of ratings**), with a variety of social functions
- **Commenting (24.5%), Protesting (23.3%), and Requesting Object (29.6%)** most frequently reported functions
- Special education professionals somewhat more likely to interpret PCAs to be *comments*
- Parents more likely to interpret behaviors to be *requests for object*

Table 3. *Percentage of ratings in which parents and special educators indicated the potential communicative act was communicative with a clear intention*

	Parents	Educators
Communicative	80.0%	92.7%
Clear Intention	79.2%	88.5%
Comment	18.40%	32.50%
Protest/Reject	21.10%	25.20%
Request Action	5.30%	11.40%
Request Object	63.20%	25.20%
Request Comfort	5.30%	1.60%
Greeting	2.60%	4.10%
Other	10.50%	13.00%

## Conclusion and Implications

- Special education professionals and parents interpret PCAs as having clear intentions and representing a variety of communicative functions.
- Different interpretations of communicative bids may lead to variation in the responses adult social partners provide to individuals with RTT.
- Future research is needed to assess whether interventions designed to increase consistency of responses to specific PCAs across social partners would lead to improvements in symbolic communication skills among individuals with RTT.

### Selected References

- <sup>1</sup>Ellaway, C., Christodoulou, J. (2001). Rett syndrome: Clinical characteristics and recent genetic advances. *Disability and Rehabilitation*, 23, 98-106.
- <sup>2</sup>Sigafos, J., Kagohara, D., van der Meer, L., Green, V. A., O'Reilly, M. F., Lancioni, G. E., et al. (2011). Communication assessment for individuals with Rett syndrome: A systematic review. *Research in Autism Spectrum Disorders*, 5, 692-700.
- <sup>3</sup>Sigafos, J., Woodyatt, G., Tucker, M., Roberts-Pennel, D., & Pittendreigh, N. (2000). Assessment of potential communicative acts in three individuals with Rett syndrome. *Journal of Developmental and Physical Disabilities*, 12, 203-216.
- <sup>4</sup>Meadan, H., Halle, J. W., & Kelly, S. M. (2012). Intentional communication of young children with autism spectrum disorder: Judgments of different communication partners. *Journal of Developmental and Psychological Disabilities*, 24, 437-450.
- <sup>5</sup>Fenson, L., Dale, P. S., Reznick, J. S., Thal, D., Bates, E., Hartun, J. P., Pethick, S., & Reilly, J. S. (1993). *MacArthur Communicative Development Inventory: Users guide and technical manual*. San Diego, CA: Singular Publishing Company.
- <sup>6</sup>Sparrow, S. S., Cicchetti, D., & Balla, D. A. (2005). *Vineland Adaptive Behavior Scales - 2nd Edition manual*. Minneapolis, MN: NCS Pearson, Inc.

Table 1. *Participant Characteristics*

Participants with RTT	Communication status (per parent report on MCDI <sup>5</sup> , Vineland-II <sup>6</sup> , and structured interview)
Jane (age 8)	<p><i>Comprehension:</i> Responds to spoken name and questions like, "Are you tired?"; reacts to environmental noises by turning her head</p> <p><i>Production:</i> Vocalizes pleasure; no spoken words, sign approximations or graphic symbols</p>
Sarah (age 14)	<p><i>Comprehension:</i> Reacts to environmental noises; understands, "Are you hungry"</p> <p><i>Production:</i> No spoken words, sign approximations or graphic symbols</p>
Judy (age 7)	<p><i>Comprehension:</i> Responds when name is called; points to common objects and body parts</p> <p><i>Production:</i> 2.5 years experience with speech-generating device (Tobii-C12); single home page with ~20 symbols (line drawings, photos, and videos); accuracy with symbols unclear</p>