Developing a method for enhancing autonomy through AAC:
Supporting autonomy and self-determination in individuals with Rett syndrome

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Introduction

People with Rett syndrome can communicate with proper use of personalized strategies for Augmentative and Alternative Communication (AAC). They can learn to use yes-no communication and other strategies using both low- and high-tech AAC solutions in everyday situations. The Communication Guidelines (Townend et al., 2020) state that one should have open mind in regards to the communicative potential of people with Rett syndrome. However, their ability to communicate their own opinion is frequently underestimated.

Hence, the personal opinion of people with Rett syndrome is lacking in key phases of scientific research, such as the recruitment process, ethical approval and reports on experienced treatment effectiveness. To date, data has been primarily acquired from proxy reports by care givers obtained through questionnaires. What remains unexplored is the ability of people with Rett syndrome to provide assent or consent for receiving medical treatment or participating in scientific research,

Our aim is to explore the possibilities of people with Rett syndrome to communicate agreement or disagreement in regard to participation in scientific research. We are working towards protocol for informing potential participants with Rett Syndrome alongside their legal representatives, so that they might be able to give consent or at least assent for participation.

Results

All eight participants were able to provide consent to participate in the study, in consultation with a parent or caregiver after receiving the adapted study information. Additional agreement was obtained from a legal representative. Subsequently, participants expressed explicit consent during the interview regarding participation and video recording. Three participants indicated that they did not wish their videos to be shared in publications (e.g., posters or presentations). Others showed some hesitancy, which was resolved by offering the condition that no video material would be shared without prior opportunity for participant review.
Participants indicated personal preferences regarding AAC strategies to be used during the interviews, e.g., to indicate “yes” and “no” answers.

Table 1. Preferred signals for expressing agreement and disagreement of persons with Rett syndrome

	UNAIDED	AIDED
YES	• Un-aided signals for “yes”: o lateral tongue protrusion, o eye contact, o lifting eyebrows, o vocalizations, o intentional eye blinking,	• Aided signals for “yes”: o eye pointing towards yes-card o eye pointing towards the Talking Mat o tapping yes-card o taking hold of symbol on the answering strip o using the high-tech communication device
NO	• Un-aided signals for “no”: o turning head to the side/ looking away, o refraining from eye contact	• Aided signals for “no”: o eye pointing towards no-card o eye pointing towards the Talking Mat o tapping no-card o taking hold of the answering strip o using the high-tech communication device to say “no”

Across the interviews, participants’ sustained attention and responsiveness indicated the feasibility of our novel approach to obtaining assent and consent in Rett syndrome. Parents and caregivers reported an increased attention span and responsiveness during the interviews in comparison to daily life. Signs of stress and anxiety were only observed when the interviewer tried to use communication modalities other than the ones participants preferred. Once their preferred signals were confirmed, signs of stress and anxiety disappeared.

Participants

- 8 people with Rett syndrome (ages 12 – 37)
- 8 parents
- 5 caregivers

Method

Exploratory mixed methods study using;
1. Interviews about personal preferences of persons with Rett syndrome were performed using various AAC strategies, such as yes-no questions, Talking Mats and high-tech speech generating devices.
2. Collecting quantitative data on duration of sustained attention and preferred communication modalities.

The participant research information sheet was adapted into various accessible forms to meet personal support needs and preferences;
- A typical participation information sheet (B1-B2 language level)
- An adapted version of the participant information sheets (accessible A2 language level)
- Texts with and without the visual support of pictures and symbols
- Videos with subtitles
- Written transcripts and summaries of the videos

Prior to the interviews, all participants with Rett syndrome were asked to independently indicate their preferred modalities for communicating “yes” and “no”, followed by a series of consent questions and the remaining interview questions. The participants had access to their high-tech AAC devices at all times.

Discussion

These findings suggest that people with Rett syndrome have personal preferences regarding various aspects of daily life and are able to communicate them using preferred AAC-tools. This way they can be included as equal parties in the decision-making process. In addition, they were able to understand the purpose of this research and give their consent based on adapted participant information sheets. Improved participation of persons with Rett syndrome enriches research and has the potential to improve their quality of life.

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Townend, G. S., Bartolotta, T. E., Urbanowicz, A., Wandin, H., & Curfs, L. M. G. (2020). Rett Syndrome Communication Guidelines: A handbook for therapists, educators and families. Rettsyndrome.org.