



RETT SYNDROME Communication Guidelines

RETT SYNDROME Communication Guidelines:

A handbook for therapists, educators, and families



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Introduction, page 4: reference to “Appendix 6” was corrected to “Appendix 5”.

Section 4, page 27: “decreasing” was deleted in the heading “Fatigue, alertness, sensory regulation, stress and anxiety” so that the format was consistent with other headings in this section.

Section 8, page 51: “making” was corrected to “making choices” in the Communicative Functions text box.

Section 8, page 62: reference to “Appendix 2” was corrected to “Appendix 5”.

Appendix 1, pages 75, 79, 81-82, 84, 86-88: format was amended to aid clarity (line spacing and headings).

Appendix 3, pages 93-96: AAC Profile and ACETS were added; TASP and VB-MAPP were removed; and C-BiLLT entry was revised.

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Many thanks to everyone who has contributed to the development of these guidelines. This project has been a joint effort by many people over a number of years and a truly international collaboration, an example of the teamwork that is such a key element in communication assessment and intervention.

Developing language and communication is a lifelong process, and we hope the guidelines shared in this handbook will support individuals with Rett syndrome, their families, and the professionals working with them as they make that journey together.

Gillian Townend
Theresa Bartolotta
Anna Urbanowicz
Helena Wandin
Leopold Curfs

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As the International Rett Syndrome Foundation (known today as Rettsyndrome.org), we are proud to be a part of bringing this global research initiative to life for families affected by Rett syndrome and the community that is committed to helping them achieve more. The work of Gillian Townend, Theresa Bartolotta, Anna Urbanowicz, Helena Wandin, Leopold Curfs, and many other researchers and contributors is an excellent representation of the dedication and commitment to improving the quality of life for our children and loved ones living with Rett syndrome. It is our honour to support these distinguished researchers. We are grateful for their work.

We remain unwavering in our commitment to empowering you today while working to transform your tomorrow.

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All websites listed in this book can be accessed online at communication.rettssyndrome.org.

Foreword

When she was a year old, she spoke her first few words. When she was diagnosed with Rett syndrome 18 months later, she had completely lost her ability to speak. How was she to communicate her wants, needs, feelings, and opinions now?

For many families living with Rett syndrome, finding a way to communicate is one of their most challenging issues. Learning how to use augmentative and alternative communication (AAC) and learning how to facilitate their loved ones to maximise their potential takes belief in their abilities, a great deal of effort, and lots of support. Seeking knowledge and skills on how to adjust assessments and how to manage communication, parents (and professionals) find themselves in need of expert support, in need of a shared vision of how to approach these aspects. Yet, so far, little evidence-based guidance has been available to them.

To do justice to the specific challenges of Rett syndrome, such as apraxia, breathing disorder, and epilepsy, a broad consensus on assessment, intervention, and long-term management of communication is needed – for research as well as daily communication and education. The collaboration between parents, caregivers, professionals, and experts in the field of communication for Rett makes these international guidelines the valuable document that is presented here. These guidelines are an important step forward in enabling people with Rett syndrome to communicate more effectively.

Many girls, now teenagers and adults, have moved on from learning to use a few pictos to using a combination of low tech and robust vocabulary on eye-gaze devices. Young girls and boys are starting out with eye-gaze-controlled communication systems. They are learning to communicate, to tell us their wants, needs, feelings, and opinions. It is exciting to see how new possibilities are helping to change our perspective on their cognitive abilities.

Many thanks to the project team, to all the committed communication specialists and parents and caregivers who contributed to these guidelines. Our beautiful daughters and sons with Rett syndrome may be unable to use their own voices to speak, but surely these guidelines will help them move forward in communicating their needs and opinions and in speaking their minds.

On behalf of all Rett parents everywhere,

Mariëlle van den Berg

Chair, Rett Syndrome Association Netherlands (Nederlandse Rett Syndroom Vereniging)

Introduction

Background

Rett syndrome is a neurodevelopmental disorder affecting approximately 1 in 10,000 females. It occurs rarely in males. It is often associated with severe physical and communication disabilities. In most cases, the cause of Rett syndrome is linked to a mutation in the methyl-CPG-binding protein 2 (MECP2) gene.

Why we developed the communication guidelines

A severe disruption in communication skills is one of the characteristic features of Rett syndrome. This has a fundamental impact on the quality of life for individuals with Rett syndrome. Although the literature on best practices in communication assessment and intervention in Rett syndrome is growing, caregivers around the world continue to report their struggle to access appropriate, knowledgeable, timely, and ongoing assessments, interventions, technology, support, and advice tailored to the specific communication needs of the person with Rett syndrome. Communication professionals also report challenges in finding the information, training, and support they need to build up their knowledge and expertise in this area. Therefore, we developed the communication guidelines presented in this handbook to help caregivers, communication professionals, and others support the communication development of individuals with Rett syndrome.

How we developed the communication guidelines

The idea of creating guidelines came into being when we, a small group of motivated professionals working in the field of Rett syndrome and communication, joined together following the 3rd European Rett Syndrome Conference in Maastricht, The Netherlands, in October 2013. With funding from Rettsyndrome.org, we devised and led a project to develop the Rett Syndrome Communication Guidelines.

The project involved reviewing the literature and conducting surveys to identify best practices in the assessment, intervention, and longer-term management of communication in individuals with Rett syndrome around the world. Around 650 people from 43 countries participated in the project, with 490 caregivers and 120 communication professionals completing the surveys, and 36 professionals and parents forming our expert panel. As the project team, we developed draft statements and recommendations based on the findings of the literature reviews and the survey responses from caregivers and professionals. The draft statements and recommendations were then reviewed twice by our expert panel. The panel provided feedback to the project team, and we revised the statements and recommendations until consensus was reached. The final set of statements and recommendations that reached consensus became the Communication Guidelines. This means that these guidelines are firmly based on findings from the available literature combined with expert opinions from professionals and caregivers around the world.

The purpose of this handbook

This handbook was designed to share the recommended guidelines for the assessment, intervention, and longer-term management of communication in individuals with Rett syndrome and to provide relevant background information for caregivers and professionals. These guidelines are intended for all individuals with a diagnosis of typical or atypical Rett syndrome, both male and female, wherever they were born and wherever they live. The guidelines were created to be adaptable to different situations and circumstances. They do not offer step-by-step instructions that people in all countries and services must follow and apply in an identical way. They aim to provide basic information that families around the world can share with therapists and educators to enable any individual with Rett syndrome to meet their full communication potential.

How to use this handbook

The handbook is divided into eight sections, with information and recommendations relating to the following: (1) guiding principles; (2) professional practice; (3) features of Rett syndrome and coexisting conditions; (4) strategies to optimise engagement; (5) general communication assessment; (6) AAC assessment; (7) assessment of AAC system/device; and (8) intervention.

The handbook can be used in many different ways. It can serve as a guide for designing assessments that reflect best practices and enable teams to develop goals that are functional and meaningful. It can provide strategies for families and therapists to advance the communication skills of any individual with Rett syndrome. The handbook provides information on how to get started with communication as well as how to progress the skills of more experienced communicators. There is also key information that describes how the unique features of Rett syndrome may impact communication. Individuals looking for information on specific topics can consult the Table of Contents at the front of the handbook. Other readers who are new to Rett syndrome may find that the early chapters provide a foundation of information to help them as they begin their work with an individual. The handbook can serve as a tool for educating people about Rett syndrome and for advocating for the communication services and support they need.

Throughout the book, the guidelines are presented in several formats. Some are shown in boxes that stand out from the text; others are embedded within the text. All are equally important. The ‘raw’ guidelines (the complete, final set of statements and recommendations that reached consensus) are presented as tables in Appendix 1 at the back of the book.

Quotes from the caregivers’ and professionals’ surveys and from the expert panel are included throughout the handbook to highlight important information. Photographs of individuals with Rett syndrome illustrate a broad range of communication systems and settings, and short stories offer “A Parent’s Perspective” on different stages of the communication journey. We are indebted to the many families who have graciously shared their photographs and their stories with us and are grateful to the even greater number of caregivers and professionals who took time to complete the surveys and engage with the project on multiple levels.

Links to a number of resources and useful websites and organisations are given in Appendix 5. This list is not intended to be exhaustive and will vary according to country and language. It is recommended, therefore, that each country produce its own list to supplement the Appendix. As far as possible, technical language is avoided in this handbook. Where this could not be avoided, the definition is usually given the first time a term is used. However, the Glossary of Terms on page 90 (Appendix 2) may also be helpful as you read through this book.

Language note:

1. In this handbook the term “individuals with Rett syndrome” is used. In some places this is shortened to “individuals” to make the sentences easier to read. Therefore, it is important to remember while reading the handbook that “individuals” always means “individuals with Rett syndrome.”
2. In some places the gender neutral “they,” “their,” or “them” is used, but in other places “she” or “her” is used. This is not intended to exclude males with Rett syndrome, and everything in this handbook should always be read as applying to both males and females with Rett syndrome.
3. In this UK and Ireland edition spellings have been changed from the original American English to British English. The terms “speech-language pathologist” and “physical therapist” have also been changed to “speech and language therapist” and “physiotherapist” (except where these related to named people’s job titles in Appendix 6) to reflect common usage in the UK.

GUIDING PRINCIPLES



“Communication partners should have an open-mind to the communication potential of the individual”

Guiding Principles

Rights of the Individual with Rett Syndrome

The United Nations (UN) Convention on the Rights of Persons with Disabilities¹ is a human rights document that declares that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms.

The table below outlines the communication rights of individuals with Rett syndrome that were developed as part of the guidelines project. They are based on the UN Convention and were strongly endorsed by the expert panel. These communication rights underpin the guidelines, and the rest of the handbook explores what they mean in greater depth.

Rights of the Individual

In accordance with the UN Convention on the Rights of Persons with Disabilities, all individuals with Rett syndrome should:

- be treated with respect;
- have access to a comprehensive multidisciplinary assessment of their strengths and needs;
- have an appropriate communication system;
- have appropriate communication goals;
- have timely reviews and modifications of goals in line with changing needs;
- have access to advice, support, and services that start early and continue throughout life;
- have advice and support from knowledgeable and expert communication professionals;
- have communication partners who are trained in appropriate communication strategies and techniques;
- be offered activities appropriate to their age, interests, and culture;
- have the opportunity to make choices;
- be enabled to participate in society; and
- have the right to education.

Communication partners* should strive to uphold the communication rights of individuals with Rett syndrome. However, their ability to do so may be dependent on the resources that are available. For example, individuals living in rural or remote areas may not have access to a comprehensive multidisciplinary assessment of their strengths and needs, or the most appropriate communication system may be too expensive for them to purchase and may not be funded by the state or healthcare insurance. In addition, communication partners themselves may not be experienced in using the specific techniques or equipment needed to enhance and facilitate an individual's communication skills and will need some level of training if they are not already skilled. Yet, even in these situations, the basic rights outlined in the table should be aimed for as far as possible.

There are a number of similar documents that communication partners may also find helpful to share with others, including those responsible for policy/service development and planning, when discussing the communication rights of individuals with Rett syndrome. These include: **(a)** The Communication Bill of Rights developed by the United States National Joint Committee for the Communication Needs of Persons with Severe Disabilities (NJC).² It states that all people with a disability (to any extent or severity) have a basic right to influence, through communication, the conditions of their existence, and it outlines 15 specific communication rights that should be recognised and upheld in daily interactions. **(b)** A simplified and more accessible version of the Communication Bill of Rights created by SCOPE Australia. This can be particularly helpful when talking directly to individuals about their rights.

**Communication partner refers to anyone who interacts with an individual with Rett syndrome.*



“They have a right to make choices, and that should be part of a much bigger perspective on communication. They should have much more opportunities than just giving answers to choices.”


Expert panel

¹ For further information, see: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

² For further information, see: Brady, N.C., Bruce, S., Goldman, A., et al. (2016). Communication services and supports for individuals with severe disabilities: Guidance for assessment and intervention. *American Journal on Intellectual and Developmental Disabilities*. 121(2), 121-138.

The Communication Bill of Rights is a valuable resource for promoting communication as a basic right.

FIGURE 1: NJC COMMUNICATION BILL OF RIGHTS³



National Joint Committee for the Communication Needs of Persons With Severe Disabilities (NJC)

COMMUNICATION BILL OF RIGHTS

All people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence. Beyond this general right, a number of specific communication rights should be ensured in all daily interactions and interventions involving persons who have severe disabilities. To participate fully in communication interactions, each person has these fundamental communication rights:

1. The right to interact socially, maintain social closeness, and build relationships
2. The right to request desired objects, actions, events, and people
3. The right to refuse or reject undesired objects, actions, events, or choices
4. The right to express personal preferences and feelings
5. The right to make choices from meaningful alternatives
6. The right to make comments and share opinions
7. The right to ask for and give information, including information about changes in routine and environment
8. The right to be informed about people and events in one's life
9. The right to access interventions and supports that improve communication
10. The right to have communication acts acknowledged and responded to even when the desired outcome cannot be realized
11. The right to have access to functioning AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times
12. The right to access environmental contexts, interactions, and opportunities that promote participation as full communication partners with other people, including peers
13. The right to be treated with dignity and addressed with respect and courtesy
14. The right to be addressed directly and not be spoken for or talked about in the third person while present
15. The right to have clear, meaningful, and culturally and linguistically appropriate communications

For more information, go to the NJC website at: www.asha.org/njc

Brady, N. C., Bruce, S., Goldman, A., Erickson, K., Mineo, B., Ogletree, B. T., Paul, D., Ronski, M., Sevcik, R., Siegel, E., Schoonover, J., Snell, M., Sylvester, L., & Wilkinson, K. (2016). Communication services and supports for individuals with severe disabilities: Guidance for assessment and intervention. *American Journal on Intellectual and Developmental Disabilities*, 121(2), 121-138.

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³This printable version of the NJC Communication Bill of Rights is available at: <https://www.asha.org/uploadedFiles/NJC-Communication-Bill-Rights.pdf>

FIGURE 2: SCOPE AUSTRALIA COMMUNICATION BILL OF RIGHTS⁴



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⁴ This printable version of the SCOPE Australia Communication Bill of Rights is available at: https://www.scopeaust.org.au/wp-content/uploads/2017/01/Bill-of-rights-2017_a4.pdf



Beliefs and Attitudes

Beliefs and Attitudes

The potential to communicate is frequently underestimated in individuals with Rett syndrome.

Individuals with Rett syndrome usually have better receptive language (understanding) than expressive ability. Caregivers and communication professionals frequently report that individuals with Rett syndrome know more than they are able to express or demonstrate. This is often due to the complex conditions that coexist with Rett syndrome, making it difficult for individuals to use speech, gestures, and other conventional ways to communicate. Section 3 has more detailed information regarding features of Rett syndrome and coexisting conditions that influence communication.

Beliefs and Attitudes

It is extremely important that communication partners have an open mind to the communication potential of the individual with Rett syndrome.

All communication partners should believe that individuals are capable of communicating and that, given the opportunity, they will be able to communicate with support from augmentative and alternative communication (AAC). Belief in each individual's ability to understand and potential to communicate is central when developing goals for communication and setting targets to improve communication skills. Caregivers and communication professionals often report that lack of belief in an individual's potential can be demotivating and have a negative effect on the individual. This does not mean that everyone should be expected to achieve the same level of complex communication, but everyone should at least be given opportunities to develop their skills as far as possible. Being open to possibilities is a key starting point.



“Believe that she is fully capable of communication if given the right circumstances!”

Caregiver

“The assumption that girls and women with Rett syndrome are severely or profoundly cognitively challenged is extremely damaging to these individuals. While these children and adults likely have neurological differences, their limited access to communication and education is much more disabling than anything else.”

Professional

“The underestimation of communication abilities has become more obvious with the advent of newer augmented communication techniques.”

Expert panel



A PARENT'S PERSPECTIVE

Tilly was 18 months old when diagnosed with Rett syndrome and 24 months when she started using an eye-gaze device. We always believed Tilly was intellectually aware, despite being told she was significantly delayed.

Augmentative and alternative communication (AAC) has given us a window into what she could achieve, from initially doing cause-and-effect games on an eye-gaze device and after a few minutes using it to ask for bubbles. Then asking to play with her friends at nursery as well as talking us through her day.

We always believed in Tilly; we modelled with symbols, demonstrating how to communicate with her, using both the eye-gaze device and low-tech communication book. I established a best “yes” and “no” using movements Tilly finds easy to make with her head.

It wasn't and it isn't easy, but consistency is key because Tilly understands and needs to feel valued, heard, and understood. We model and communicate, giving her options of how she wants to communicate so when she wants to talk, she can; when she wants to play games, she can; or when she wants to just have access to her voice, it is there and available.

Tilly knew how to use eye gaze immediately and asks for her food, asks to paint and draw, ignores you and puts it on rest, tells you it is hers, and tells you she is tired or uncomfortable. She finds symbols I don't even know exist and they make sense in the context. She has only just turned three!

Medical professionals said Tilly would never have met the criteria for an eye-gaze device and wouldn't have put her forward for funding, but we are pleased we did it anyway with the support and loan device from Rett UK. Now Tilly's medical team sees what Tilly is achieving, and it has helped them understand progress made in this area with people with Rett.

Thanks to Rett UK, without them I dread to think where we would be. Screaming has stopped, hope is restored, communication is key.

Collaborative and partnership working were essential to success. Tilly's speech therapist came to the Rett UK communication course with me; she said seeing what Tilly could achieve was the reason she became a therapist in the first place.

Her paediatrician has been hugely supportive and is always open to hearing about what we have learned.

Self-belief, belief in your child, the confidence to positively challenge professional opinion, working in partnership with professionals, modelling, modelling, modelling, and talking to Tilly in a variety of ways using a variety of AAC methods are what has worked for us. Whether that is eye gaze, intensive interaction, low-tech communication, or partner-assisted scanning, but always having her voice available to her.

Consistency is key, it isn't easy, and nothing worth having ever is. But communication and being heard are a basic human right, Tilly just accesses it in a different way than us, but she is proving to all of us just how effective it is.

PROFESSIONAL PRACTICE



“The team should share a common vision.”

Professional Practice

Principles of Teamwork

Principles of Teamwork

Every individual with Rett syndrome should be supported by a multidisciplinary team.

Where possible, the team should incorporate all significant communication partners and may include the following:

- The individual with Rett syndrome
- Parents and other family members
- AAC specialists
- Speech and language therapists (SLT)
- Occupational therapists (OT)
- Physiotherapists (PT)
- Rett syndrome specialist staff (e.g., a neurologist or paediatrician)

At a minimum the team should ideally consist of an SLT, the main caregivers, and the individual with Rett syndrome. However, not everyone may have access to an SLT. Therefore, the term *communication professional* is used in this handbook in preference to SLT. This refers to any professional with expertise (education & experience) in communication and in the assessment and treatment of communication disorders. The communication professional who works with individuals with Rett syndrome is often, but not always, an SLT.

Principles of Teamwork

The team should share a common vision and work collaboratively to define and agree on communication goals and support plans.

Team members should discuss expectations and define each other's roles (e.g., who will be responsible for programming devices or modifying page sets). This should occur at the start of their work and whenever a team member changes.

Principles of Teamwork

One person in the team should be identified as the “key person” with responsibility for monitoring* communication goals.

**Monitoring refers to making sure the therapy plan is being carried out as agreed and alerting the rest of the team when changes are needed.*

The “key person” should be someone who is knowledgeable about Rett syndrome and works with the individual with Rett syndrome regularly. This may be a teacher, teaching assistant, family member, or other person on the team.

Responsibilities of Professionals

Responsibilities of Professionals

Professionals should use an evidence-based practice model to guide their clinical decision-making, incorporating information from the literature, clinical experience, and the wishes of the individual with Rett syndrome and their family.

Professionals should keep their knowledge and understanding of Rett syndrome and AAC up-to-date so that they are aware of recent trends in the literature and in clinical practice. They should also engage with the broader Rett syndrome community and be able to direct caregivers and other communication partners to relevant information and support networks in their community (e.g., through social networks, conferences, websites, and online courses).

Please note, these guidelines are not intended to replace professional codes of conduct, but rather to complement them. This should include any requirements for continuing professional development.

Responsibilities of Professionals

Professionals who are inexperienced in working with individuals with Rett syndrome should seek training in relevant topics, as well as advice and support from colleagues with more specialised knowledge and expertise in this area.

Organisations employing new or inexperienced professionals to work with individuals with Rett syndrome have a duty to enable those professionals to receive training in relevant topics. Professionals should also engage in reflective practice,* with the aim of building their own confidence and knowledge about this area.

**Reflective practice means the ability to analyse one's actions and associated impacts, and to engage in a process of continuous study and self-improvement.*

Responsibilities of Professionals

Professionals who are working in isolation (e.g., working as an independent practitioner) should connect with the other members of the broader team who are working with the individual and family so that support and advice and recommendations are coordinated.

It is the role of the communication professional to:

- train other communication partners in communication techniques and strategies that will benefit the individual with Rett syndrome;
- reinforce training by providing easy-to-read handouts and instructions;
- work with the family and other communication partners to choose the appropriate page sets and/or vocabulary to build into any AAC system or device; and
- work with caregivers/communication partners to problem solve.

Rett Syndrome Specialist Clinics and Expertise Centres

Rett Syndrome Specialist Clinics and Expertise Centres

The individual and family may be referred to a Rett Syndrome Specialist Clinic or Expertise Centre in order to get a diagnosis, specialised assessment and advice, or second-opinion at any point following diagnosis.

Some countries and cities have established Rett Syndrome Specialist Clinics or Expertise Centres. Visits to a Rett Specialist Clinic or Expertise Centre may be as a single visit or at regular (e.g., annual) intervals. It is unlikely that the Specialist Clinic or Expertise Centre will deliver ongoing, day-to-day therapy and intervention.

Communication professionals attached to the Specialist Clinic or Expertise Centre should:

- make contact with the locally-treating communication professional(s) to discuss the individual's communication, to share the results of any assessments, and to discuss goals for intervention;
- be available to offer advice and support to, and answer questions from, locally-treating therapists;
- provide training and instruction, and access to resources for locally-treating therapists; and
- be available to respond to questions from parents and caregivers and individuals with Rett syndrome.

Rett Syndrome Specialist Clinics or Expertise Centres may provide consultations and support through video conferencing for individuals who are unable to visit a clinic or centre in person (e.g., for individuals living out of the city or country of the Clinic or Centre).

FEATURES OF RETT SYNDROME AND COEXISTING CONDITIONS THAT CAN IMPACT COMMUNICATION

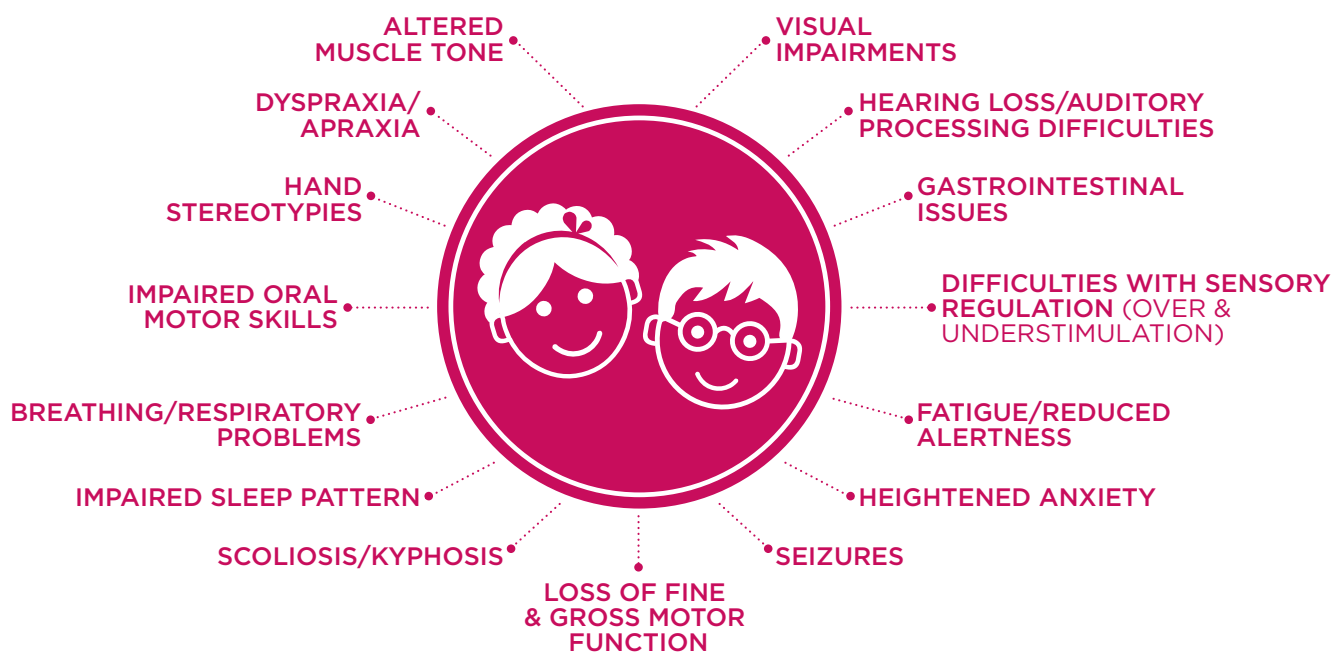


“Expect inconsistency”

Features of Rett Syndrome and Coexisting Conditions That Can Impact Communication

Rett syndrome affects multiple body systems and functions. A number of features have been identified as core or supportive criteria for the diagnosis, including the complete or partial loss of acquired spoken language.¹ Other conditions also commonly coexist with Rett syndrome. Many of these (for example, breathing irregularities, epilepsy, and heightened anxiety) can impact communication (see Figure 3). However, each individual with Rett syndrome is unique — features and coexisting conditions may manifest differently in different people, in different settings, and at different times; not all of the features and conditions outlined below may appear in any one individual, or they may appear with differing levels of severity at different times during an individual’s lifespan.

FIGURE 3: FEATURES OF RETT SYNDROME AND COEXISTING CONDITIONS THAT CAN IMPACT COMMUNICATION



Outlined in this section are brief descriptions of the main features of Rett syndrome and coexisting conditions, along with their possible impact on communication. Strategies for dealing with/reducing their impact can be found in Section 4.



“All of these impact communication but do not limit an individual with Rett syndrome from reaching or demonstrating his/her communication potential. Just need to support their communication with these in mind.”

Expert panel

¹Neul, J., Kaufmann, W.E., Glaze, D.G., et al. (2010). Rett Syndrome: Revised Diagnostic Criteria and Nomenclature. *Annals of Neurology*. 68(6), 944-950.

Features Associated with Main or Supportive Clinical Criteria

Movement disorders

Hand stereotypies and loss of fine motor skills

Stereotypic hand movements — such as involuntary hand wringing/squeezing, clapping/tapping, mouthing, and washing/rubbing — are one of the main clinical criteria for Rett syndrome. Complete or partial loss of acquired purposeful hand skills is also a main clinical criterion for Rett syndrome.

Impact on communication:

Hand stereotypies and/or the loss of purposeful hand skills can make it difficult for an individual to use their hands for communication. They may be unable to point, pick up objects or pictures, or push a switch or buttons, or they may do so inconsistently/unreliably. This will also limit their use of hand gestures, and manual signing is unlikely to be a realistic or successful communication method. Use of a manual exchange system (e.g., Picture Exchange Communication System, PECS) is also unlikely to be an appropriate way for most individuals with Rett syndrome to communicate, and most will find use of a Speech Generating Device (SGD) with touch access difficult or will need to use a more limited set of options if using touch access.

Loss of gross motor skills

Impaired (dyspraxic) gait or absence of walking is one of the main clinical criteria for Rett syndrome.

Impact on communication:

When an individual is unsteady on their feet and/or is unable to walk unaided, their ability to explore their environment and initiate interactions with others is likely to be reduced. They are likely to be reliant on others to approach them to begin a conversation and to help them explore unless they are able to access an SGD to help them call for attention and initiate interaction/conversation.

Dyspraxia/apraxia

Dyspraxia and apraxia are terms that are often used interchangeably. Dyspraxia means a difficulty in converting an intention into an action, while apraxia is a complete inability to convert an intention into an action. One result is that an individual has difficulty or is unable to perform motor tasks on command. The breakdown may be at any stage of the motor-planning process.

Impact on communication:

While dyspraxia and apraxia are recognised as affecting the motor skills of individuals with Rett syndrome, dyspraxia and apraxia can also have a severe impact on learning ability and communication. It may take an individual more time to respond and sometimes they may be unable to respond at all. This does not necessarily mean they have not understood the task but that the problem is with the execution of the task.

Altered muscle tone

Altered muscle tone is a supportive criterion for Rett syndrome. Individuals may have high tone (hypertonia), low tone (hypotonia), and/or involuntary movements (dystonia). Hypertonia and hypotonia can affect an individual's positioning and their ability to move affected muscles. With dystonia, an individual may experience involuntary spasms and contractions, with writhing, twisting movements in any part of their body and/or altered posture. Episodes can last for varying lengths of time and cause varying degrees of pain. Generalised hypotonia may also cause fatigue.

Impact on communication:

Altered muscle tone has an impact on an individual's ability to engage in communication and on their positioning for communication. They may also become 'locked' in a dystonic posture which freezes their movement for a period of time, thereby reducing their ability to interact with other people.

Oral-motor skills

Oral-motor skills may be affected by dyspraxia, apraxia, and/or altered muscle tone.

Impact on communication:

Oral-motor dysfunction can limit an individual's ability to communicate through oral speech. It can also affect eating and drinking.

Please note, eating and drinking are outside the scope of this handbook, but nutritional status can impact levels of alertness as well as overall health. *If oral intake is affected, the individual and their caregivers should consult with an SLT or other feeding specialist for advice on the safety of oral feeding and the need for alternative feeding/nutritional intake.*

For more information, refer to the Nutritional and Digestive Health booklet² and the Growth and Nutrition in Rett Syndrome checklist³ produced by the Telethon Kids Institute in Perth, Western Australia.

Breathing/respiratory irregularities

Breathing disturbances when awake are a supportive clinical criterion for Rett syndrome. Common irregularities in Rett syndrome include breath holding, hyperventilation, and air gulping (which can lead to abdominal bloating). Breathing irregularities may also trigger seizures or be a sign of anxiety.

Impact on communication:

Breathing and respiratory difficulties can make it hard for individuals with Rett syndrome to speak. They can also prolong response time (e.g., while an individual is caught in a breath hold, their whole body may go rigid).

Impaired sleep pattern

Impaired sleep pattern is a supportive clinical criterion for Rett syndrome.

Impact on communication:

A lack of quality sleep can make it hard for individuals with Rett syndrome to be alert and to concentrate. Individuals may take longer to respond when tired.

Scoliosis and kyphosis

Scoliosis and kyphosis are supportive clinical criteria for Rett syndrome. Scoliosis occurs when there is a side-to-side deviation in the alignment of the vertebrae in the spine. This may affect around 80% of individuals with Rett syndrome. Kyphosis is the excessive outward curvature of the spine, causing hunching of the back. Among other reasons, scoliosis can occur as a result of altered muscle tone.

Impact on communication:

Scoliosis and kyphosis can make it hard for the individual with Rett syndrome to access AAC. Kyphosis can also make it hard for the individual to engage in eye contact and for the communication partner to read their facial expressions. Scoliosis and kyphosis can be painful and cause secondary issues (due to compression of the lungs and other internal organs).

For further information, see the Scoliosis in Rett Syndrome booklet⁴ produced by the Telethon Kids Institute in Perth, Western Australia.



“Motor impairments can make positioning extremely difficult for AAC.”

“Apraxia is the biggest problem!! Teachers often don't think that Rett-girls know a lot, but [they] cannot show it because of apraxia.”

Professional

² Downs, J., Leonard, H., Croft, D., et al. (2013). *Nutritional and Digestive Health: An Information Booklet for Families and Carers*. Telethon Institute for Child Health Research. Perth, Western Australia. https://rett.telethonkids.org.au/siteassets/media-docs---rett-syndrome/growth_and_nutrition-booklet.pdf

³ Downs, J., Leonard, H., Croft, D., et al. (2013). *Growth and Nutrition in Rett Syndrome: Checklist for Clinicians on Assessment and Management*. Telethon Institute for Child Health Research. Perth, Western Australia. https://rett.telethonkids.org.au/siteassets/media-docs---rett-syndrome/guidelines_nutrition_and_growth.pdf

⁴ Downs, J., Bergman, A., Carter, P., et al. (2009). *Scoliosis in Rett Syndrome: A Collaboration Between Parents, Clinicians and Researchers*. Telethon Institute for Child Health Research. Perth, Western Australia. https://rett.telethonkids.org.au/siteassets/media-docs---rett-syndrome/scoliosis_booklet.pdf

Coexisting Conditions

Seizures

Sixty to eighty percent of individuals with Rett syndrome are reported to have seizures, though more may have an abnormal EEG recording without other evidence of seizures. Epilepsy often begins around 4/5 years of age in individuals with typical Rett syndrome. There is a huge variation in the type and frequency of seizures. Sometimes individuals are described as having ‘Rett episodes’ or non-epileptic seizures. These may be related to breathing/respiration and/or other autonomic disturbances.

Impact on communication:

Frequent seizures will reduce an individual’s opportunities for interaction, especially as they may be extremely fatigued and need to sleep a lot following a seizure. Two common side effects of medication to control seizures are fatigue/tiredness and reduced alertness.

Fatigue and reduced alertness

Fatigue and/or reduced alertness may be due to any number of factors or the interaction of several factors. These include low quality/disrupted night-time sleeping, seizures, side-effects of medication, poor nutritional status, and difficulties with sensory regulation (especially, low levels of sensory stimulation – see below).

Impact on communication:

An individual will be less aware of the people, environment, and activities around them, and less likely to be in a state of readiness to communicate or learn when they are tired/fatigued and/or less alert.

Difficulties with sensory regulation

Sensory regulation is the ability to adjust or regulate alertness depending on the levels of stimulation in the surrounding environment and/or the sensory stimuli presented. Individuals may experience difficulties with over and/or understimulation.

Impact on communication:

Some individuals may require a lot of sensory stimulation to arouse them/get their body into a state of alertness so that they are ready to engage; others may be easily overstimulated so that their bodies become overloaded and shut down, needing a period of calm before they can reengage.

Mood and anxiety

Generalised anxiety levels are often reported to be higher in individuals with Rett syndrome compared with their neurotypical peers. Rapid breathing, breath holding, and increased hand wringing behaviours may be signs of increased anxiety. Episodes of anxiety can also increase the likelihood of dystonia and seizures. A large number of individuals, especially in adulthood, are reported to experience problems with low mood and depression.

Impact on communication:

Anxiety, stress, low mood and depression may all reduce the individual’s willingness and desire to communicate.



“After seizures she sleeps a lot... sometimes there is no communication at all for even three days because she is nearly unconscious.”

Caregiver

“I think that seizures can have an impact on their communication in a way where they become tired/exhausted after a seizure.”

Expert panel

“Extreme variation in arousal alertness, sometimes able to scan several items on a page, navigate between pages and answer complex questions, other times frozen [by] fatigue and cannot imitate action on response.”

Professional

Gastrointestinal issues (GI)

Common GI issues in individuals with Rett syndrome can include reflux, abdominal bloating, constipation, and/or diarrhoea, with associated abdominal pain.

Impact on communication:

Many parents often report that sometimes an individual with Rett syndrome appears to be in pain but is unable to communicate exactly where the pain is or how severe it is. This is often thought to relate to GI issues. Being in pain and discomfort as a result of GI issues may also reduce an individual's readiness to interact and overall level of engagement with others.

For further information, see the Gastro-intestinal Disorders in Rett Syndrome checklist⁵ produced by the Telethon Kids Institute in Perth, Western Australia.

Hearing-related conditions

As with the general population, individuals with Rett syndrome may experience hearing loss and/or auditory processing difficulties.

Impact on communication:

Any level of hearing loss or difficulty with the processing of auditory information will affect an individual's ability to understand and respond to the speech of others.

Vision/sight-related conditions

Impaired visual acuity

As with the general population, individuals with Rett syndrome may suffer from impaired visual acuity—i.e., a reduction in clarity or sharpness of vision that can be corrected by wearing glasses. An impaired visual field may also cause problems—i.e., a reduction in the area of sight, especially to the sides (peripheral vision) while focusing on a central point.

Cortical visual impairment (CVI)

Some individuals with Rett syndrome may suffer from CVI, a form of visual impairment caused by problems with the visual cortex and pathway in the brain rather than a problem with the eyes. Vision can be variable. Individuals with Rett syndrome can have difficulty with depth and field of vision, interpreting visual images, and distinguishing items when there is a lot of visual 'clutter' in the background.

Oculomotor apraxia

Oculomotor apraxia is also sometimes reported in individuals with Rett syndrome (i.e., a reduction in the voluntary control of purposeful eye movements). Recent research indicates, however, that individuals with Rett syndrome demonstrate the same range of movements as their neurotypical peers although they may be a little slower.

Impact on communication:

Individuals with Rett syndrome may have difficulty in seeing items clearly or interpreting visual symbols. This will affect the choice of appropriate AAC system (e.g., whether picture symbols can be used and if so, the style, size, number, colour, and complexity of the symbols chosen). Attentional issues may also affect the ability to track, fix, maintain, and shift gaze which could impact interaction with others and the environment, as well as the ability to learn through observation.

Use of eye gaze for communication is, however, generally considered to be a strength in Rett syndrome, with “intense eye communication—eye pointing” being one of the supportive clinical criteria for diagnosis of typical Rett syndrome.

⁵ Downs, J., Leonard, H., Croft, D., et al. (2013). *Gastro-intestinal Disorders in Rett syndrome: Checklist for Clinicians on Assessment and Management*. Telethon Institute for Child Health Research. Perth, Western Australia. https://rett.telethonkids.org.au/siteassets/media-docs---rett-syndrome/guidelines_gastro_intestinal.pdf

STRATEGIES TO OPTIMISE ENGAGEMENT



“ Make AAC available at all times ”

Strategies to Optimise Engagement

Communication skills of individuals with Rett syndrome will fluctuate based on internal and external factors. Expect inconsistency.

Communication partners can use a number of strategies to initiate and maintain engagement with an individual with Rett syndrome. These strategies can be used in everyday life at home, school, work, and other settings. They can also be used during more specific communication assessment and intervention sessions. Different strategies may work better for some individuals than others and, even for one individual, at different moments in time. This may depend on factors such as their current mood, emotional state, quality of sleep, effects of breathing and respiratory abnormalities, epilepsy, medication, gastrointestinal issues, and dyspraxia/apraxia, as described in Section 3.

A PERSONAL COMMUNICATION PASSPORT¹ CAN BE...

an invaluable resource for sharing information about an individual's communication style, strategies that are most appropriate to use, and any personal/health-related factors that may affect their behaviour and the choice of strategies/communication methods.

Attitudes and Behaviours of Communication Partners

Engagement Strategies

Address and talk directly to the individual with Rett syndrome.

When communicating with individuals with Rett syndrome in any situation, it is extremely important that communication partners address and talk directly to the individual with Rett syndrome rather than talking about them in their presence. This is extremely important for initiating and maintaining engagement. This may include not speaking over the individual with Rett syndrome or ignoring them in the presence of others. Sometimes communication partners might need to talk about the individual in front of them (e.g., a professional may need to ask a question the individual with Rett syndrome is unable to answer themselves). In these circumstances, the individual with Rett syndrome should still be included in the conversation. This might involve the professional explaining to the individual with Rett syndrome why they need to talk about them and/or asking the individual with Rett syndrome for confirmation of the information provided by their caregiver.

Engagement Strategies

Make eye contact and use multimodal communication.



“Always include her in any conversations. Never speak over her or ignore her when having a conversation with somebody else.”

“... make direct eye contact, move into her space slightly and be patient.”

Caregiver

“Communication should be multi-modal and change over time as all of ours does.”

“Follow the client's interests; use animated affect/voicing, playful obstruction.”

Expert panel

¹ For further information, see: Millar, S. & Aitken, S. (2003). Personal Communication Passports: Guidelines for Good Practice. *CALL Centre*. University of Edinburgh, Edinburgh. See also: <https://www.communicationpassports.org.uk/resources/>

It is also extremely important that communication partners make eye contact with the individual and use multimodal communication (facial expressions, gestures, vocalisations, speech alongside AAC) to attract and maintain the individual's attention. This may be accomplished, for example, by varying tone and intensity of voice, and using varied body movements, facial expressions, and gestures. Making eye contact can help the individual with Rett syndrome know their communication partner is talking to them and make it easier for them to pick up on non-verbal communication like facial expressions. It also helps the communication partner to perceive and respond to subtle communicative signals from the individual.

It should be noted, however, that some individuals may not like direct eye contact and may actively avoid it. In this case, other strategies need to be adapted to suit the individual's needs. Communication partners are not expected to use all modalities in every interaction but to be sensitive to the individual's preferences, needs, and mood, and to adapt their own behaviour and interaction style accordingly.



In many cases, communication partners can maintain the individual with Rett syndrome's attention by being engaging, fun, and interesting. This includes making sure vocabulary, topics, and activities are interesting to the individual with Rett syndrome, keeping in mind that interests may or may not be age appropriate. Many caregivers and professionals report that music is an interest shared by most individuals with Rett syndrome. However, everyone is different, so it is important for communication partners to find out what is of interest to the specific individual and provide varied activities aligned with their interests.



“Communication is most successful if it starts with fun activities.”

“Putting all her favourite music as choices in both the PODD book and on the eye-gaze device has been the best way to motivate her to use the AAC.”

Caregiver

“Taking the time to understand how each individual uses natural communication skills, e.g., existing eye gaze and how it is used, yes/no responses.”

Professional

Engagement Strategies

Make sure vocabulary, topics, and activities are appropriate to the interests of the individual with Rett syndrome.

It is extremely important that communication partners spend time getting to know the individual with Rett syndrome in order to build a relationship. This involves being patient and persistent; it may take time to develop trust between an individual and a new communication partner. This is a vital step for development of communication skills and is especially important to keep in mind when gains in communication can be slow.

Communication partners should:

- be responsive in their interactions, acknowledging and reinforcing all communication attempts;
- follow the individual's lead;
- give feedback and attribute meaning (saying aloud what they think the individual's response/action/behaviour means); and
- be consistent (in approach, language, and vocabulary used).

Consistently responding, acknowledging, and reinforcing all communication attempts helps individuals with Rett syndrome develop and maintain their communication abilities. It is very common that communication between individuals who rely on AAC and their speaking communication partners is unbalanced, with the communication partner often being the one to direct the interaction. By following the individual's interests and focus and providing wait time, the individual with Rett syndrome can be given opportunities to initiate communication, and the communication partner can follow the individual's lead. This may involve setting up activities of interest that allow the individual to take a lead and go at their own pace.

Engagement Strategies

Providing access to AAC systems and devices increases the individual's possibilities to initiate and take control/direct conversations more clearly.

Interaction with peers can also be invaluable in encouraging communication. This includes having other AAC users and neurotypical peers who can engage in age-appropriate topics and activities and can use their own or the individual's AAC system/device with them.



A PARENT'S PERSPECTIVE

Being around Sofia, another AAC user with Rett syndrome who is older than Tilly, was incredible in improving Tilly's communication. Having a positive AAC role model meant Tilly became more vocal and used her device and low-tech communication more. She even used Sofia's eye gaze spontaneously, too, to talk about her physiotherapy. Both Sofia's neurotypical sister as well as Tilly's neurotypical friends at nursery, using Tilly's device and interacting with her using AAC, have also been essential in normalising AAC and helping Tilly to feel more confident using it. The introduction and nursery pages to help Tilly say their names and say what she wants to do have also been important at nursery.

Giving feedback and attributing meaning to the behaviour of individuals with Rett syndrome, even if the meaning seems unclear, can also help to shape an individual's communicative behaviours and develop consistency of use. For example: "You looked at X and smiled; I think you are telling me you like X." "You looked at X and then at the word LIKE; I think you are telling me you like X." "You closed your mouth and turned away; I think you are telling me you don't want more Y." In this way, even if the communication partner's interpretation is wrong, the individual should begin to realise the connection between their behaviour and the interpretation.

Engagement Strategies

Adapt natural situations and activities so that opportunities for communication are created.

If the individual with Rett syndrome uses one or more AAC systems or devices, it is extremely important that they are available at all times to enable the individual to make the most of every opportunity for communication. Opportunities to use their AAC system/device should be provided throughout the day and incorporated into all situations and activities involving the individual, such as when bathing, eating, changing clothes, and shopping. Words like "more," "finished," "like," and "don't like" can be used frequently throughout the day. Providing opportunities helps build vocabulary and language.



"In all communication there is interpretation, say your interpretation out loud and repeat it, then the child will know whether you have the same understanding."

Caregiver

"Acknowledge any attempt at communication."

"[Provide] feedback immediately, e.g., this is what I am seeing and this is what I think it means."

Professional



Engagement Strategies

Make the individual's AAC system(s) or device(s) available at all times.

For more examples, see *Building Foundational Communication Support for Individuals with Rett Syndrome*² from Rett University.

Engagement Strategies

Keep communication in the 'here and now.'

Keeping communication in the here and now (i.e., talking about current thoughts, feelings, and activities) allows for a stronger link between words and their meaning. This may be especially beneficial, for example, when learning new vocabulary.

Individuals with Rett syndrome often have better receptive language abilities than expressive. Although it may sometimes appear that they do not understand, it is important to explain what you are doing now and what you will be doing next, and to let them know when you will be changing and/or moving on to another activity. For example, use visual supports to indicate that an activity is ending and a new one will begin. This may be particularly helpful for individuals who have high levels of anxiety.

Strategies Targeting Internal Factors That May Impact Communication

Movement disorders

Containing stereotypies with an embrace or placing a hand over the individual's hand(s) has been shown to help to focus attention and learning. Gently restraining the non-dominant hand or arm using a hand wrap or elbow splint may also be helpful. It is important, however, to refer to the relevant restraint policies and procedures in the country, location, or organisation in which the individual resides and/or receives therapy or education before using any restraints. Seek advice from an OT.

Voluntary control over, and coordination of, motor movements requires a lot of physical and cognitive effort that can be taxing for individuals with Rett syndrome. Therefore, it is recommended that the motor demands of a task or activity are decreased as the cognitive load increases. For example, limiting the number of options on a page or use partner-assisted scanning (see page 58) for educational tasks.

Engagement Strategies

Decrease motor demands as the cognitive load of a task increases.

"Access to a system in all aspects of life (school, home, community) where the entire team is on board with implementing the same system."

"Use and train the communication in an everyday context (not an isolated context)."

Professional

"She needs access to AAC 100% of the time."

"...attempt to get the communication to be a natural part of the everyday life."

Caregiver

"Need multiple opportunities to practice all modes across their day to increase communication abilities."

Expert panel

"If the student has extremely limited physical abilities for direct selection, balance the physical effort of communication against the physical/mental effort for academic learning/ responding vs the physical effort to activate environmental controls."

Professional

² Rett University, (n.d.). *Building Foundational Communication Support for Individuals with Rett Syndrome*. <https://rettuniversity.org/wp-content/uploads/2015/05/RettU-Communication-One-Page-FINAL.pdf>

Breathing/respiration irregularities

Observe the individual closely for episodes of breath holding and hyperventilation, and wait for these to pass. Seek medical help and advice when necessary.

Epilepsy

Be vigilant and observe for any signs of a seizure. Wait for it to pass. Seek medical help and advice when necessary.

Scoliosis/kyphosis

Make sure the individual is well supported in whatever position they are in (e.g., if seated, make sure they have a supportive system if required). Observe for signs of pain or discomfort. Consult with an OT, PT, and/or orthopaedic consultant. You can also refer to the Scoliosis in Rett Syndrome booklet³ produced by the Telethon Kids Institute.

Fatigue, alertness, sensory regulation, stress and anxiety

Ask the individual or their caregivers about their sleep patterns. Observe for signs of fatigue. If the individual is tired, keep activities short or do things that do not require a lot of concentration. Be aware, however, that for some individuals falling asleep may be a sign of understimulation, and they may need more stimulation/activity to increase their alertness.

Engagement Strategies

Individuals may need help to regulate their levels of alertness and their readiness to participate in daily living and educational activities.

Some individuals may, for example, find it easier to engage while they are standing or after a short break during which they were able to move around. Others may find that short bursts of watching television/films or listening to music help to regulate their body. Different sorts of music can have different effects (calming or stimulating) and can be used at different times for different purposes.

Engagement Strategies

Pay attention to behaviours that indicate the need for a change in position or a change/break in activity.

It is important to observe the individual's preferred positions for different activities and to look for signs that they need a change in position or in sensory stimulation, or a break/change in activity. Ask if they would like a change or a break and, if necessary, assist them in changing position or type of sensory stimulation, and/or provide them with a change of activity. It is important to incorporate words and phrases into an individual's AAC system that allow them to ask for a break or change of position/activity. These words and phrases should be easy to access and should be modelled to demonstrate their use.

Individuals with Rett syndrome may show signs of stress/anxiety when there is either (a) excessive stimulation and a high level of demand or (b) a lack of stimulation and/or demand. It is important to consider how to maintain a balance between activating/stimulating activities and breaks in activity. Providing the individual with a high level of control can offer protection from stress and anxiety.

A high level of control may be achieved when the individual:

- understands and is prepared for what is happening,
- has means to express themselves and is listened to, and
- can influence what is happening.

³ Downs, J., Bergman, A., Carter, P., et al. (2009). *Scoliosis in Rett Syndrome: A Collaboration Between Parents, Clinicians and Researchers*. Telethon Institute for Child Health Research. Perth, Western Australia. https://rett.telethonkids.org.au/siteassets/media-docs---rett-syndrome/scoliosis_booklet.pdf

Signs of the need to increase alertness or sensory input/change activity include:

- falling asleep/drowsiness and
- inattentiveness.

Suggested strategies include:

- increasing the intensity of your interaction (e.g., increasing the loudness of your voice and becoming more animated);
- changing position (e.g., getting everyone to stand up if you have been seated so that the individual can move from sitting-to-standing);
- using sensory input (e.g., vibration, music, and movements); and
- changing activity.

Signs of the need to decrease sensory input/change to a “recovery activity” include:

- grimacing or complaining, and restless motor activity;
- tensing of the body;
- getting up/walking away from a situation; and
- changes in breathing (e.g., hyperventilation and breath holding).

There are individuals with Rett syndrome who experience respiratory changes that are not under their control, so they may hyperventilate or breath hold regardless of the situation they are in. However, changes in breathing may occur with substantial sensory input, when the individual is excited, or when experiences demands are high. Interviews with caregivers and communication partners can provide insight into the impact of stress on the respiratory behaviour of an individual.

Suggested strategies include:

- decreasing the intensity of the interaction (e.g., decreasing the loudness of your voice);
- providing a break;
- decreasing demands; and
- providing calming tactile input (e.g., squeezing shoulders, arms, hugging the person tightly, and/or placing a weighted blanket or pillow on the person’s lap).

REMEMBER THAT EACH PERSON IS DIFFERENT AND WHAT CALMS ONE PERSON MAY AGITATE ANOTHER.

These suggestions are general strategies – make sure you talk to the person and other people who know them well about what works for them. The demands of a particular situation may also be too high or too low for the individual, which then can result in increased stress. Communication partners should learn about the individual with Rett syndrome and create an atmosphere that is supportive yet challenging.

Suggested strategies to reduce anxiety include:

- asking open-ended questions that don’t have a right or wrong answer,
- giving a high chance of success by minimising any pressure on responding, and
- modelling – not testing.



“The higher the cognitive demand, the lower the physical demand needs to be.”

Professional

“She fatigues and requires periodic breaks.”

Caregiver

“Breaks should be determined according to the girl’s response and attention at the time.”

Expert panel

The “traffic light system” developed by Judy Lariviere can be helpful for training caregivers to recognise levels of sensory arousal and to develop the strategies needed to adjust them. It also helps individuals with Rett syndrome to recognise their own internal state. The Sensory Regulation Chart⁴ (see below) provides a colour-coded version of the various levels of sensory regulation based on how an individual is processing sensory input in their environment. It includes a description of some of the strategies that can be used to support someone in returning to Level 1 (functional state of arousal) so that they are in an optimal condition (ready) to communicate and to learn.

FIGURE 4: SENSORY REGULATION CHART

OVERSTIMULATED Agitated/sensory overload	Level 3	<ul style="list-style-type: none"> • Needs strong sensory input from sensory diet to assist in calming down; overwhelmed by sensory input. • Will take longer to return to Level 1 when sensory system moves into Level 3 or “red zone.”
OVER RESPONSIVE Needs to be “calmed down”	Level 2	<ul style="list-style-type: none"> • Needs sensory input or a sensory break based on sensory diet to help return to Level 1; snack or drink; music can help re-engage; change of activity; movement and/or change of position
FUNCTIONAL STATE OF AROUSAL “Regulated state”	Level 1	<ul style="list-style-type: none"> • Ready to learn, communicate, and actively participate • Calm; body supported and relaxed • Sitting upright and/or remaining seated • Establishing eye contact; smiling; giggling • Interactive; easily looking between different things • Communicating with communication partner(s) • Engaged, playing, having fun • Does not seem anxious or tired
UNDER RESPONSIVE Needs to be “revved up”	Level 2	<ul style="list-style-type: none"> • Needs sensory input based on sensory diet to help return to Level 1; typically needs a break involving movement/change of position or snack to re-energise and/or listening to favourite music; change of activity.
UNDERSTIMULATED Falling asleep/shutdown	Level 3	<ul style="list-style-type: none"> • Needs strong sensory input from sensory diet with extended break to assist in “waking up” or “revving up” sensory system.

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⁴ For further information, see: Lariviere, J. (2015). Eye-Gaze Technology for Girls with Rett Syndrome: From Trials to Conversations. *Closing the Gap Solutions*. December 2014/January 2015, 4-13.



Auditory processing difficulties

Referral to an audiologist may be helpful in understanding how an individual perceives and processes auditory stimuli.

If an individual appears to have difficulties functioning with high levels of background noise, reducing unnecessary auditory input may help (e.g., turning off the radio/TV).

Visual impairments

Referral to an eye specialist, such as an ophthalmologist or optometrist, may be helpful in understanding how the individual perceives and processes visual stimuli.

For some individuals it may help to increase the size of symbols, simplify the complexity, use high-contrast symbols, or arrange the display so that the symbols are placed to one side (left or right), laid flat on a horizontal surface, or arranged vertically. Others may benefit from a reduction in visual distractions (e.g., placing the individual’s AAC device directly in front of them while moving other items outside of their visual field).



“Some individuals need distraction-reduced settings to show true communication potential.”

Expert panel

Additional Considerations

Structured settings

Engagement Strategies	Reduce distractions.
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In a more structured setting — i.e., in an assessment or intervention (therapy or teaching) session — it is very important to reduce distractions. Some individuals with Rett syndrome will find it harder to concentrate in a noisy and busy environment. Reducing distractions, particularly when learning a new skill, can initially help the individual focus, attend, and learn. Reducing distractions not only benefits the individual, but also the communication partner who is better able to focus and attend to communicating with the individual. However, so as not to limit the individual, it is important that they also get used to communicating in a more typical environment (i.e., with higher levels of background noise or visual stimuli). As with motor challenges, there must be a balance of sensory and cognitive demands.

Response time

Engagement Strategies

Be aware of delayed response time.

Individuals with Rett syndrome may have a delayed response in communication interactions. Response delay may be for a few seconds or up to a minute or more. This can vary from day to day and throughout the day, depending on a wide range of factors, such as the presence of dyspraxia/apraxia and levels of motivation and fatigue. Therefore, a slow response or an absent response is not necessarily an indication of a lack of understanding.

To determine sufficient wait time for a particular individual, communication partners can do the following:

- Observe the individual to identify typical communication behaviour.
- Review videos of communication interactions to identify typical communication behaviour.
- Discuss typical communication behaviour with familiar communication partners.
- Consider how the features of Rett syndrome and any coexisting conditions may impact response time.



“The answering time can sometimes be extra-long and sometimes extra quick.”

“She has apraxia and may take a while to respond.”

Caregiver

“Sufficient time to wait will vary from individual to individual and this should be identified following observational assessment.”

Expert panel

ASSESSMENT



“Assessments should be ongoing and dynamic”

Assessment

General Principles of Assessment

The general principles described in this section apply to all assessments, including AAC assessment (see Section 6).

Principles of Assessment

Assessment should be part of a team process.

The outcome should not rely on the judgement of one professional in isolation. Assessment of communication skills and needs should include contributions from as many key communication partners* as possible. For example: parents and other family members or caregivers, teachers, therapists (e.g., speech and language therapist (SLT), occupational therapist (OT), physiotherapist (PT), and music therapist), and, if possible, peers. It is important that parents/caregivers are included and able to work with the professionals as each partner brings their own particular perspective on the individual.

**Key communication partners are the people who are the most frequent communication partners of an individual with Rett syndrome.*

All members of the team involved in the assessment should have an understanding of Rett syndrome in general (its core features and associated characteristics) and an awareness of the needs of the individual in particular.

Principles of Assessment

Assessments should be informed, comprehensive, and holistic,* focusing on the skills and needs of the individual with Rett syndrome as well as the skills and needs of their communication partners.

**Holistic means that assessment should provide a view of the individual as a whole person, rather than looking at particular characteristics or challenges in isolation.*

The World Health Organization’s International Classification of Functioning, Disability, and Health (ICF) is an appropriate model around which to structure holistic assessment of the individual.

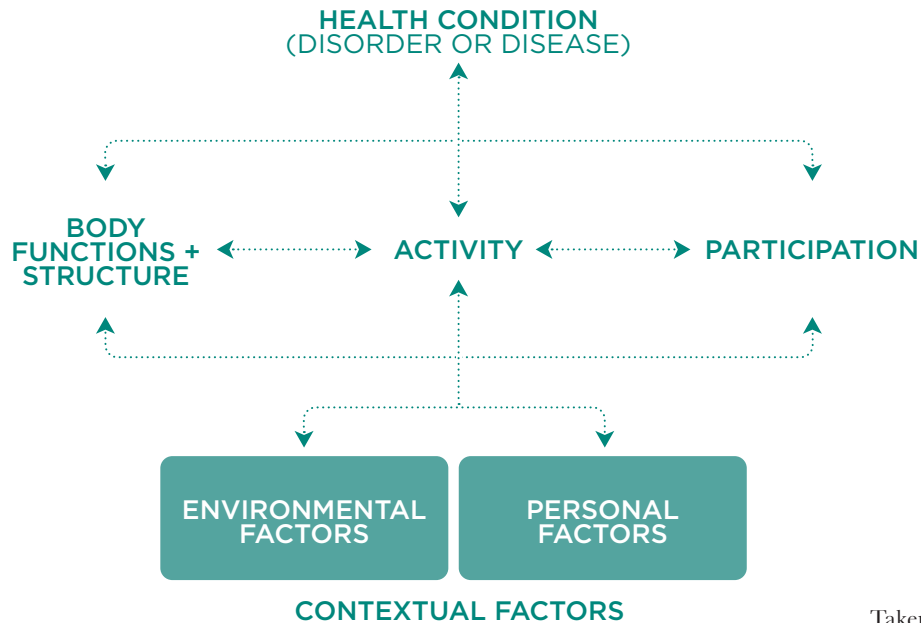
The ICF (World Health Organization, 2001)¹ is a framework that describes health and health-related domains. It is composed of four domains:

- 1. Body Functions and Structures.** This domain describes the physiological functions and the parts of an individual’s body.
- 2. Activities and Participation.** Activities are the tasks performed by an individual and include communication. Difficulties in carrying out activities are referred to as activity limitations. Participation describes an individual’s engagement in a life situation, and difficulties in participation are referred to as participation restrictions.
- 3. Environmental Factors.** This domain describes the physical, social, and attitudinal environments surrounding an individual, such as products, technology, attitudes, support, and relationships. Environmental factors may be classified as either barriers or facilitators to functioning.
- 4. Personal Factors.** This domain refers to those features of an individual (such as age, gender, and lifestyle) which are not directly a part of a health condition but which may impact them.

¹ The World Health Organization. (2001). *International Classification of Functioning, Disability and Health*. WHO. Geneva. <https://www.who.int/classifications/icf/en/>

These domains are classified under the umbrella terms *functioning* (body functions, activities, and participation), *disability* (impairments, activity limitations, and participation restrictions), and *contextual factors* (environmental and personal factors). An individual's level of functioning in a specific domain is an interaction between their health condition and contextual factors.

FIGURE 5: ICF MODEL



Taken from WHO, 2002, p.9²

Principles of Assessment

Assessments should consider the opportunities and barriers to communication that may be present in various environments (e.g, home, school, and social settings).

Assessment of the broader context around an individual should include identification of:

- social networks and communication partners;
- the knowledge, skills, and training needs of communication partners; and
- opportunities for communication and barriers to communication within the social environment.

This will include gathering information on the different settings the individual attends each day, where they live, what activities they engage in, and whom they interact with.

Principles of Assessment

Assessments should be undertaken in natural or naturalistic settings.

Observations should be conducted in a range of communication environments and with a range of communication partners.

Barriers include things such as communication partners who are not aware of or do not recognise an individual's subtle communication signals, lack of opportunities to communicate, and no/limited availability of AAC equipment and resources.

Opportunities include things such as communication partners who are open-minded to the individual's potential and who look for any communication signals, access to AAC equipment and resources, communication partners who model* use of AAC, and activities in which the individual is encouraged to engage and communicate.

*Modelling use of AAC is when the communication partner uses the individual's own AAC system to communicate when talking to them, (e.g., pointing to picture symbols while speaking). (See page 62.)

² The World Health Organization. (2002). *Towards a Common Language for Functioning, Disability and Health: ICF*. WHO. Geneva.



“Interview family and school-based professionals to learn how [an] individual communicates, what strategies have been tried, been successful, not successful.”

Professional

“Barriers are important to assess. These often impact communication the most. Consider environmental and cultural factors.”

“Assess in a place and environment where the individual feels relaxed, at ease, and happy without being under any pressure.”

Expert panel

Social Networks Inventory

The Social Networks Inventory (Blackstone, 2003, revised 2012)³ is an example of a tool that can be helpful here. In this, an individual’s social networks or their “circles of communication partners” are identified on 5 levels (family, friends, acquaintances, paid workers, and unfamiliar partners/people in the wider community). The modes of communication used and their effectiveness in each network are also inventoried.

Means – Reasons – Opportunities Model

Another useful tool is the Means – Reasons – Opportunities Model by Money & Thurman (1994, updated 2002)⁴. This is based on the premise that without a means of communication, an individual cannot express themselves; without reasons to communicate, they have no need to communicate; and without opportunities to communicate, there cannot be any communication.

With both of these tools, any gaps that are identified help point towards areas in need of intervention.

Assessment of the Individual

Initial assessment should include a detailed history of medical and physical status, including any visual and hearing problems, breathing and respiratory difficulties, seizures, and fine and gross motor control (including ambulation, head control, postural control, hand function, and scoliosis). For features of Rett syndrome and coexisting conditions that can impact communication, see Section 3.

A wider group of professionals may be involved in the assessment of specific areas, such as hearing, vision, and motor control. This could include an audiologist, ophthalmologist, PT, OT, neurologist, and others. Assessments should always capture information on current medical and physical status.

³ Blackstone, S. & Hunt, Berg, M. (2003, updated 2012). *Social Networks Inventory: A Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners*. Augmentative Communication Inc. Monterey. <https://www.achievementcompany.com/social-networks-package>

⁴ For further information, see: The Means-Reasons-Opportunities Model in: Money D & Thurman S. (2002). Inclusive Communication. *Speech and Language Therapy in Practice*. Autumn issue. 4-6. See also: Money, D. & Thurman, S. (1994). Talkabout Communication. *Bulletin of the College of Speech and Language Therapists*. 504, 12-13.

Principles of Assessment

Assessment of the individual should gather information on a broad range of communication-related aspects:

- The individual's nonverbal skills (e.g., referential gaze, eye pointing, and joint attention)
- The individual's level of cognitive awareness (e.g., understanding of cause and effect, vocabulary, and reasoning)
- How the individual communicates currently
- The range of communicative functions used by the individual with Rett syndrome
- The strategies/systems that have been tried in the past (including those that have been successful and those that have been unsuccessful)
- The types of activities and topics that the individual is interested in and motivated by
- The status of the individual's oral-motor skills



“Interview family to learn how individual communicates, what strategies have been tried, been successful, not successful. Interview school-based professional to learn how individual communicates, what strategies have been tried, been successful, not successful.”

“Use tools and checklists to help partners think of all the ways the individual communicates and for what purposes.”

“Conduct an informal assessment using photos and objects, written letters, words.”

Professional

“Assessments should be functional and incorporate all methods of communication. Rather than using standardised assessments, assessments looking at functional performance and then guiding language/communication intervention would be more beneficial than giving an age equivalency.”

Expert panel

Assessment Procedures

A variety of assessment procedures should be used to provide a comprehensive assessment of the communicative, cognitive, and interactive skills of an individual with Rett syndrome. Assessment can be conducted through any combination of the following:

- Interviews with significant communication partners
- Questionnaires completed by significant communication partners
- Observations of the individual in natural settings
- Videotaping of the individual in natural settings
- Videotaping of the individual in structured sessions
- Informal assessments in modified natural settings or structured sessions
- Modified formal (standardised) assessments and dynamic assessments (see below).

Standardised Assessment or Dynamic Assessment?

Standardised assessments are conducted and scored according to a standardised procedure so that the results of one individual can be compared with the results of others. A number of formal or standardised assessments of communication may be available to members of an assessment team. These will vary according to country and language. Use of one or more of these assessments may be required in some settings or countries when applying for services, equipment, and/or support.

There are many concerns about the use of formal or standardised assessment tools with individuals with significant developmental challenges like Rett syndrome. Standardised assessments of language and cognition are likely to indicate that individuals with Rett syndrome have an intellectual disability. It is important to keep in mind that standardised assessments may not accurately reflect an individual's underlying ability nor their communicative and learning potentials, but they may be adapted to obtain information on certain specific skills.

Principles of Assessment

Standardised assessments may not accurately reflect an individual's underlying ability nor their communicative and learning potentials.

Adaptions to standardised assessments can include modifying presentation of test materials, such as mounting test items on a board, and use of partner-assisted scanning (see page 58), eye gaze, or other AAC strategies as response modalities. Adapted standardised assessments can be used to assess expressive language, receptive vocabulary, and cognition.

A number of formal and standardised assessments and possible ways to adapt them for use with individuals with Rett syndrome were suggested by communication professionals who responded during the survey stages of the project. These can be found in Appendix 3. In sharing this information, these guidelines do not endorse any specific tools for standardised assessment.

Principles of Assessment

Assessments should not take place at a single moment in time; they should be ongoing and dynamic.

Team members who conduct assessments should consider adopting a model of Dynamic Assessment – a method that involves assessment of a specific skill, followed by a phase of teaching. Dynamic Assessments aim to identify strategies that promote development rather than to compare the results of one individual with other individuals. A Dynamic Assessment process can include any of the assessment procedures outlined above—e.g., using interviews or modified formal (standardised) assessments to inform what strategies or skills to target. Dynamic Assessment means that there will often be an overlap between assessment and intervention.

DYNAMIC ASSESSMENT IS...

“an interactive, test-intervene-retest model of psychological and psychoeducational assessment.” (Haywood & Lidz, 2007)⁵

In the teaching phase of Dynamic Assessment, individuals are provided with supportive strategies — such as modelling, cues, and feedback — to help them develop their communicative attempts. After a period of teaching, a new assessment is conducted with as little support provided as possible. Assessors who follow a process of Dynamic Assessment can learn a great deal about the strategies they can use during intervention to help advance communication skills.



“Formal assessment tools are not recommended.”

“Standardised assessments for cognition will likely yield results that demonstrate that individuals with RTT have intellectual disability.”

“Formal assessments can be modified to obtain information on specific skills.”

Professional

“Standardised assessments don't take into consideration a lot of the difficulties that the individuals with RTT do have, i.e., the lack of spoken language, the inability to use their hands, their dyspraxia and dystonia.”

“Elements of standardised assessments can be used as a guide for assessment, with acknowledgement of any adaptation used, such as eye pointing instead of direct hand selection or layout of the test materials.”

Expert panel



“A dynamic assessment approach is preferred, where assessment is used to guide intervention.”

Professional

⁵ Haywood, H. & Lidz, C. (2007). *Dynamic Assessment in Practice: Clinician and Educational Applications*. Cambridge University Press. New York.



DYNAMIC ASSESSMENT – EXAMPLE:

Task – to assess how an individual communicates about a favourite movie and whether modelling and providing a wait time elicits a greater response.

1

TEST

- PROVIDE OPPORTUNITY
- WAIT

2

INTERVENE

- MODEL
- PROVIDE OPPORTUNITY
- WAIT

3

RETEST

- PROVIDE OPPORTUNITY
- WAIT
- (MODEL - PROVIDE OPPORTUNITY - WAIT)

STEP 1 – TEST

The assessor engages the individual in a conversation about the movie and waits to see how the individual responds. If the responses are unclear or if there is no response, the assessor moves on to Step 2.

STEP 2 – INTERVENE

The assessor engages the individual in a conversation about the movie again and models how to communicate about the movie using various modes of communication (e.g., pointing to pictures, activating a switch, and looking at an eye-gaze device) to give possible responses. The assessor provides strategies to help the individual, such as an extended waiting time.

STEP 3 – RETEST

Using the same type of question, the assessor provides as little support as possible and then, if necessary, provides support and records which types of strategies facilitate communication. These strategies can then be used during intervention and modified as the individual makes progress in their communication skills.

Other Considerations for Assessment

Informal assessment can include the use of objects, photographs, picture symbols, and written letters and words.

Music can be a valuable medium for observing the behaviour of an individual with Rett syndrome and can be a valuable component of assessment.

Principles of Assessment

Videorecording is a valuable tool that can be used during assessment.

Recording an individual's responses allows for a closer evaluation than may be possible in real time and may help to identify more subtle communication behaviours that could otherwise be missed.

Eye gaze is usually the best access method for:

- assessment of cognition, and
- assessment of receptive and expressive language skills.

This is especially so when using adapted formal (standardised) assessments.



“In assessment, video can be of value as anecdotal evidence and can also provide opportunities for professionals to reduce interobserver variability and to review assessment so subtle signs will not be missed.”

“Analysis of video (of assessment and trial use) often shows abilities that were not demonstrated during an assessment session.”

Expert panel

AAC ASSESSMENT



“No prerequisite skills must be demonstrated”

AAC Assessment

AAC may be unaided or aided.

Unaided AAC means not using external tools to communicate but relying on the user's own body to convey messages. Examples include gestures, signs, or vocalisations.

Aided AAC means using external tools, devices, or systems to enhance communication. These may be electronic or non-electronic (high-tech or low-tech).

Aided AAC includes a range of communication methods, from using a small number of objects or pictures for choice making, to robust language systems with a large number of symbols. These pictures and symbols can be presented on a single page, in a multi-page communication book, or on an electronic device such as a computer, tablet, or a dedicated device that is only used for communication.

A low-tech AAC system is not electronic and does not require a power source (e.g., individual objects, photos, and communication board/book).

A high-tech AAC system is an electronic device with speech output. The screen can have a static or a dynamic display, and the output can be recorded/digitised speech or synthesised speech. High-tech systems range from simple single message devices to complex computer-based systems.

A speech generating device (SGD) is a type of high-tech device, usually used to refer to a more complex computer-based system rather than a simple single-message device.

Both low- and high-tech systems can be accessed a number of ways, including direct touch or eye gaze.

An eye-gaze device (eye-gaze technology) is a type of SGD that is controlled by eye gaze. The device has either a built-in eye tracker or an eye-tracker module that connects to the device to detect and track where the user is looking. Usually, the speed and accuracy of selection can be adjusted to the needs of each user—e.g., the length of time the user must look at an item on screen in order to select it (dwell time) and the size/number of items on the screen.



“The very first barrier that needs to be taken away in many situations is the lack of sufficient AAC due to the expectations of the professionals (SLT, teacher). All doctors that are informing parents about the diagnoses should direct them to AAC and aided language and their opportunities and NOT mention anything about cognitive disabilities.”

Professional

“AAC can be introduced for children or adults who are pre-intentional and have no means to demonstrate “cause and effect” cognition. AAC can support the development of these skills.”

Expert panel



Starting Point - Assessment of Readiness for AAC

AAC Assessment

No prerequisite skills must be demonstrated before aided AAC should be considered.

According to current practices, no prerequisite skills must be demonstrated before aided AAC should be considered. Aided AAC can be an option even before an individual has demonstrated understanding of cause and effect, clear choice making, or communicative intent. Aided AAC can assist development of these skills. Therefore, individuals should be referred for AAC evaluation at the time of diagnosis or shortly thereafter in order to maximise their communicative and linguistic development and to prevent negative effects, such as learned helplessness, that can arise from a lack of communicative opportunities.

Components of AAC Assessment

Any AAC assessment should consider multiple modalities, both unaided (facial expression, gestures, vocalisations) and aided communication (low-tech and high-tech options, depending on availability).

AAC Assessment

AAC assessment should include consideration of:

- a range of symbol systems,
- layout (e.g., size and number of options/pictures on the communication board or screen), and
- complexity of vocabulary on offer.

Although the availability of certain symbol systems will vary according to country and language, the number and range of systems available around the globe is growing rapidly. Some symbols may be more suited to one individual than another (e.g., high-contrast symbols designed specifically for people with visual difficulties). Individuals may also have their own personal preferences that need to be taken into account.

In addition, attention must be paid to the layout and complexity of vocabulary during an AAC assessment. Issues relating to organisation of vocabulary will be explored further in Section 8.



“Try as much software as possible and then begin with the most suitable one.”

Caregiver

“When reviewing symbol systems, it is important to take into consideration preferences and accessibility.”

Expert panel

AAC Assessment

AAC assessment should include consideration of:

- options for alternative access (e.g., eye gaze, touchscreen, and switch control), and
- positioning (of individual and device, and AAC system).

Assessment should include identification of the most appropriate access method for an individual (e.g., eyes and hands). This will influence their potential to access and use the vocabulary on offer to them. How the device and the individual are positioned can be crucial to their success.

Models of Best Practice for AAC Assessment

AAC Assessment

There are a number of models of best practice in AAC that are appropriate to use with individuals with Rett syndrome. These include:

- the Six-Step Process,
- the Participation Model, and
- the Model of Communicative Competence.

The Six-Step Process (Dietz et al, 2012)¹

This model follows a process similar to that of Dynamic Assessment. It suggests that AAC assessment consists of a series of steps, with the entry point determined by an individual's needs:

- Assessing communication using scenarios
- Considering the need for alternative access
- Incorporating multiple modalities (e.g., low-tech options)
- Providing AAC instruction
- Assessing a range of symbol systems
- Arranging device trials

The Participation Model (Beukelman & Mirenda, 2013)²

In this model, participation is central. A Dynamic Assessment approach is used to assess an individual's participation according to their opportunity and access barriers. The needs of the communication partners are also considered. The steps include the following:

- Identifying how the individual currently participates
- Assessing barriers to participation, including the potential to use AAC systems and/or devices
- Planning and implementing interventions, including provision of instruction to both the individual and their communication partners
- Evaluating how effective the intervention is, i.e., whether the individual's participation is increased
- If need be, the assessment starts again and the cycle repeats.

The Model of Communicative Competence (Light & McNaughton, 2014)³

In this framework, four specific areas of skill are assessed, together with two broader factors. Each of these is important for the development of an individual AAC user's communicative competence and forms a starting point for the identification of targets for intervention.

These are the four skills:

- Linguistic
- Operational
- Social
- Strategic

These are the other two factors:

- Psychosocial (internal to the individual – motivation, attitude, confidence, and resilience)
- Environmental (external to the individual – policy, practice, knowledge, attitude, and skills)

¹ For further information, see: The Six-Step Process in: Dietz, A., Quach, W., Lund, S. K., & McKelvey, M. (2012). AAC assessment and clinical-decision making: the impact of experience. *Augmentative and Alternative Communication*, 28(3), 148-159.

² For further information, see: The Participation Model in: Beukelman, D. R., & Mirenda, P. (2013). *Augmentative and alternative communication: supporting children and adults with complex communication needs*. Brookes, Baltimore, MD.

³ For further information, see: The Model of Communicative Competence in: Light, J. & McNaughton, D. (2014). *Communicative competence for individuals who require augmentative and alternative communication: a new definition for a new era of communication?* *Augmentative and Alternative Communication*, 30(1), 1-18.



Assessment of Readiness for Eye-Gaze Technology

Overall health, oculomotor skills, visual attention and memory, motivation, ability to focus on the screen, and prior experience with aided AAC will all impact ability to access eye-gaze technology. A careful and comprehensive assessment of these features can help to determine whether an individual is a strong candidate for eye gaze, if they will benefit from additional investigation, if they need a trial of an alternative access method, or perhaps if a combination of eye-gaze technology and other access methods are needed.



“Some people with very complex health issues use eye-gaze very successfully; if you wait for someone to be well, it will never happen!”

Expert panel

Readiness for eye-gaze technology

Assessments of readiness to use eye-gaze technology are best conducted through informal activities.

Assessment activities should be personalised as far as possible (e.g., introducing photographs of familiar people into on-screen activities or using motivating activities in the assessment). This may enhance the individual’s engagement. There are currently no formal assessments that reliably predict how the individual will communicate using eye-gaze technology. In accordance with the principles of Dynamic Assessment, the same activities used to assess readiness can also be used to train/build the skills that are necessary for use of eye-gaze technology for communication.

Readiness for eye-gaze technology

An individual does not have to ‘pass’ assessment at an early level of screen use (e.g., demonstrate cause-effect understanding) before their response to more advanced levels of eye-gaze technology use can be assessed (e.g., introducing them to grids for communication).

If an individual does not seem to be interested or motivated to engage with eye-gaze technology during the assessment, it should not be discounted as a possible access method. Lack of interest or motivation may be due to lack of experience on the part of the individual (i.e., they did not know what to expect from the activity/device or the activities used in the assessment were not sufficiently challenging/stimulating or interesting for the individual). Prior experience of picture communication and exposure to engaging on-screen activities may increase the individual’s engagement with eye-gaze technology. For some individuals, using communication grids to interact/converse with a communication partner may be more motivating than, for example, simple cause-effect games designed to practice controlling eye-gaze technology.

Readiness for
eye-gaze technology

It is not necessary to achieve successful calibration on an eye-gaze device in order to assess eye gaze as an access method.

Some individuals may not be able to achieve a good calibration immediately. Initially, a default calibration or a parent's calibration may work well enough. It is also possible to do a simple one-point calibration or to adjust the calibration settings in other ways. Interactive games, if the individual finds them interesting, can be used to establish calibration of eye gaze over time (e.g., by providing experience of 'chasing' a target with the eyes). Any use of on-screen activities, including the use of communication applications, may increase the chances of a successful calibration at a later stage of the assessment process.

Readiness for
eye-gaze technology

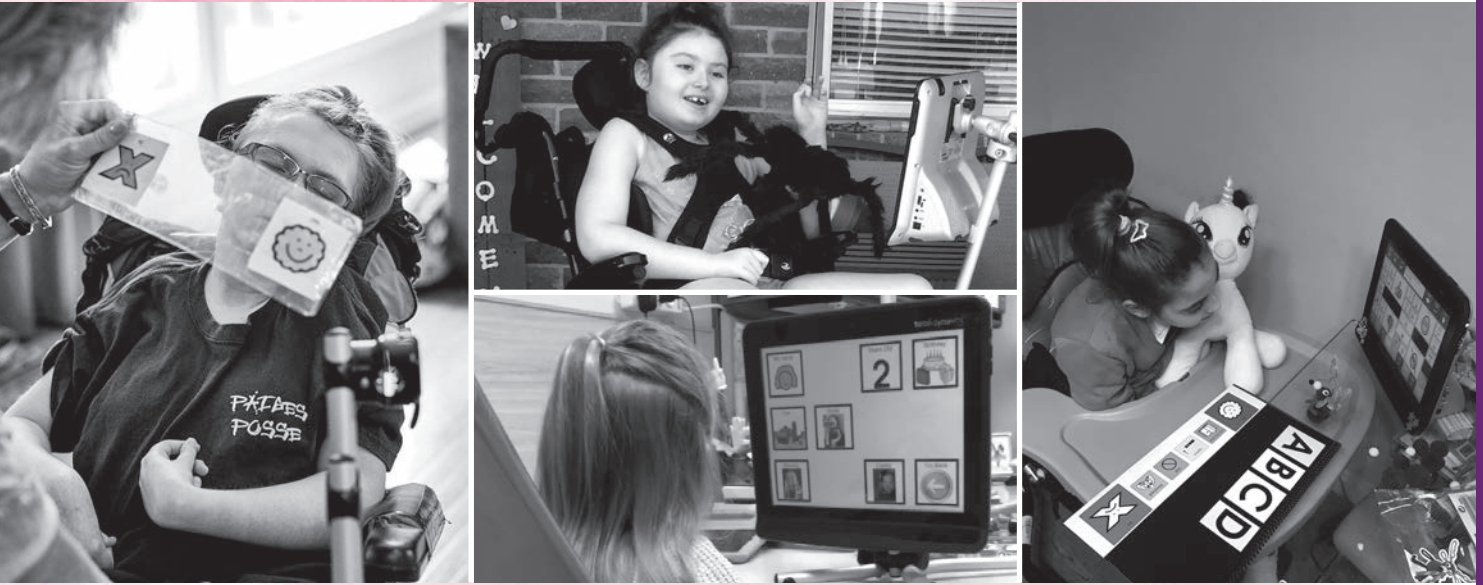
It is valuable to track and record an individual's eye movements and on-screen gaze pattern during assessments for eye-gaze technology.



“It is not essential to obtain a good calibration and one should not spend time on this, especially in the initial stages as it could prevent moving on to other more important tasks. When the need for more accurate access becomes apparent, e.g., smaller and more symbols per page, then better calibration is required.”

Expert Panel

ASSESSMENT OF AAC SYSTEM/DEVICE



“Trial periods are essential”

Assessment of AAC System/Device

Trial Periods as Assessment for an AAC System or Device

Trial periods are essential for assessing whether any AAC system or device is appropriate for an individual. This applies to both low- and high-tech systems or devices. Suitability of any AAC system or device cannot be judged adequately from a single session or a single point in time. Often, in the case of individuals with Rett syndrome, trial periods are used to assess the suitability of eye-gaze technology.

Trial Periods

During trial periods, the individual and their key communication partners should be well-supported by knowledgeable and experienced professionals who are familiar with/trained to use the system/device on trial.

To a large extent, the success of a trial depends on how well the individual and their key communication partners are instructed and supported during the trial. This can place demands on one of the members of the team to support the other communication partners; to offer training, advice, and feedback; and to adjust the device settings and content according to individual needs. The professionals who offer support during a trial may include advisors who work for the communication aid company supplying the device and/or an SLT, OT, AAC/Assistive technology specialist advisor, and/or others who are experienced with the device/system on trial.

Trial Periods

During trial periods, the system/device should be used in multiple environments and with multiple communication partners.

The personal needs and preferences of the individual and their key communication partners may differ between systems and devices. Therefore, individuals should be able to trial more than one/multiple AAC systems and devices. They should also be allowed more than one trial of the same AAC system or device (e.g., if the first trial was judged unsuccessful due to the individual's poor health at that point in time).

Trial periods should be free/at no cost to the end user at point of use.

Trial Periods

Trial periods should be for a minimum of 8 weeks to ensure the following:

- The individual with Rett syndrome gets a real chance to learn about and (attempt) to use the device/system.
- The individual's primary/key communication partners get a real chance to learn about and to use the device/system.

Assessment of Device-Specific Features

During a trial period/device assessment, a number of device-specific features need to be considered.

Trial Periods

When assessing the suitability of a device for an individual, it is important to take the following features into consideration:

- Portability
 - Options for mounting on a wheelchair, table, and wall
 - Robustness (durability)
 - Size
 - Weight
 - Battery life
 - Use in different environments (e.g., outside in sunshine and rain)
 - Ability to adjust response time/sensitivity of responses
 - Capacity/functions available within the device (including potential to access the internet and social media as well as control the environment)
-
- Range of software available (including language programmes and symbol sets and any the individual is already familiar with)
 - Availability of pre-made page sets in the relevant language
 - Complexity of programming required to personalise/adapt the device to suit the end user
 - Level of technical skill/knowledge required by communication partners
 - Support from a wider community of families using the same device/software, including online communities (e.g., for sharing of page sets, and help with troubleshooting)
-
- Support and training offered by supplier during a trial period
 - Long-term technical support and after-care offered by the supplier
 - Ease of repair in case of problems/breakdown
 - Obsolescence (age of model and remaining length of time that support, updates to software, parts, etc. will be available)
 - Cost to purchase
 - Cost of insurance
 - Availability of funding/approval for funding

Many of these aspects are brought together in Feature Matching.

Feature Matching is a model for best practice in AAC assessment that can be utilised for individuals with Rett syndrome. The aim of feature matching is to match an individual's needs and abilities with a suitable (aided) AAC system or device.

Feature Matching (Glennen & DeCoste, 1997)¹

These system/device features should be considered:

- Type of symbols
- Language complexity, including options for expanding the language
- Type of synthetic voices and languages that are available
- Access methods
- Display and editing options (e.g., flexibility of grid sizes and settings as well as navigation)
- Portability and positioning options
- Operational and other features

¹ For further information, see: Feature Matching in: Glennen, S. & DeCoste, D. (1997). *The handbook of augmentative and alternative communication*. Singular: San Diego, CA.

INTERVENTION



“Communication should be multi-modal”

Intervention

General Principles for Intervention

General principles for intervention

Communication intervention should aim to develop functional communication skills, promote cognitive development, provide a foundation for literacy development, and improve social communication.

Functional communication skills are those skills that enable us to interact and communicate in everyday life. Through interacting with others, an individual develops an awareness and understanding of cause and effect, connects experiences and language, and learns concepts, all of which promote cognitive development. Communication also assists development of reading and writing skills through storytelling and talking about books. Communication intervention has the potential to improve social communication and assist the development of relationships between the individual and their family, friends, teachers, therapists, and people in the wider community.

COMMUNICATIVE FUNCTIONS INCLUDE:

greeting, protesting, commenting, describing, making choices, requesting, asking and answering questions

COMMUNICATION FORMS INCLUDE:

gestures, facial expressions, vocalisations, manual signs, oral speech, picture-symbols, and written forms of communication

General principles for intervention

Communication intervention will help the individual with Rett syndrome to become more autonomous as a communicator.

The long-term goal of communication intervention is to increase an individual's autonomy so that they are able to choose what, when, with whom, and how they want to communicate. To be able to communicate as autonomously as possible, each individual needs a communication system that allows them to generate their own messages, in a range of situations, using a range of communication forms that are valued by their communication partners.

AUTONOMOUS COMMUNICATION MEANS:

being able to communicate what you want to say, to whomever you want to say it, whenever and wherever you want to say it, using any form of communication.

It is important that communication intervention is started as early as possible to provide positive communication experiences and maximise an individual's skills in initiating communication and expressing ideas as independently as possible. If their communication attempts are not recognised and responded to, some individuals may develop a more passive role and stop initiating communication – a 'learned helplessness.' However, it is never too late to start communication intervention and provide opportunities that can significantly improve the individual's quality of life. The needs of the individual, as well as the communication partners, will change during their lifetime, partly because skills and capabilities will change and develop over time and partly because life situations and communication demands will change. In addition, existing communication technologies will change and new technologies will be developed, meaning that there will be a need for ongoing support throughout life.



Interventions should take place in settings that are as natural as possible so that skills that are used frequently throughout the day can be taught and practiced. It is important to involve regular communication partners in the intervention so that they can learn how to use and reinforce new skills.



“Parents need to know that the child has potential to learn and to grow into using AAC strategies.”

Expert panel

“Early intervention is crucial for everyone involved (family, caregivers, educators) to adopt an attitude of seeing the individual with Rett syndrome as a communicator.”

Caregiver

General principles for intervention

- Advice and information about the potential for communication should be provided to individuals with Rett syndrome and their families at diagnosis or shortly thereafter.
- Communication intervention and management should start early and be lifelong.
- Communication intervention and management should be reviewed regularly to make sure that it is always appropriate to the needs of the individual.
- Intervention should take place in a naturalistic context.
- Individuals should be given frequent opportunities for practice.



A PARENT'S PERSPECTIVE

Our second daughter, Jip, was born in February 2013. In the beginning, she appeared to develop well, then around the time of her first birthday, her development suddenly stopped. When she was 18 months old, she was diagnosed with Rett syndrome.

Within two months of her diagnosis, we bought her an eye-gaze computer because we read that that was what she needed, and she has not been parted from it since. As soon as she was introduced to it, she showed us she was able to use it, and very quickly she had access to thousands of words. At that time, there was no full (or robust) vocabulary available in our own language. So she depended on home-made page sets, page sets that I made for her, with as many words as I could add. In the difficult regression phase that followed, the eye-gaze device was such a help. Like many Rett children, she had frequent episodes of uncontrollable crying and screaming, but at least, using the eye-gaze device, she could often tell us what the problem was – a headache, a restlessness, or a pain somewhere in her body.

Now she is six years old and everything is getting a little calmer, even though she suffers a lot from epilepsy and dystonic episodes, is wholly dependent on a wheelchair, and has almost no useful hand function. Yet Jip is a cheerful, sweet, cheeky, and funny girl that we all love very much. She and her sister (aged 9) love playing together.

As well as using her eye-gaze device, we have also found many other ways to communicate. We use E-tran frames and card holders, and we hold up our hands so that she can eye point. Jip doesn't only use her eye-gaze device to speak but to control infra-red toys, play games, draw pictures, and read books. She uses her eye-gaze device to tell us when she wants to go to the toilet and, through this, she is toilet-trained.

As far as possible, we give her control over her life. She picks out her own clothes, arranges playdates with friends after school, has a say in what we eat at home in the evening, and always chooses what she wants to do/play with. She understands everything but because of her dyspraxia does not always find it easy to make herself clear to others.

Since the age of three, she has gone to regular school, with support from a personal assistant. She is learning to read, write, and count. She has developed friendships with her classmates and is able to keep up with the school work.

We are so thankful that we were able to give her the chance to begin using an eye-gaze device at such a young age. It has given our family so many wonderful moments.

Developing Goals for Intervention

Setting goals

Goals for intervention should include development of nonverbal, low-tech, and high-tech communication strategies.

It is important to consider that individuals will present with a range of communication abilities. There are those who can speak in sentences, some who are able to say a few words or vocalise sounds, and others who are completely non-speaking. All individuals will benefit from some form of communication intervention to improve their participation and quality of life. The full range of communication strategies should be made available to all individuals regardless of their verbal abilities. These strategies can then be customised based on the specific needs of the individual. For example, those who have verbal skills may benefit from use of an augmentative device to develop and support their writing, academic work, or expression of complex ideas. Those who are non-speaking may benefit from a voice-output device, along with coaching/instruction on how to use body movements (e.g., a head nod, looking to their partner, and looking away) or vocalisations to express concepts such as “yes” and “no.”

Setting goals

Goals for intervention should aim to increase the frequency, variety, complexity, and clarity of communication so that individuals can interact with a wide range of communication partners.

The individual, their parents, and other members of the team should all be involved and should be given the opportunity to make informed decisions about the intervention. The preferences and needs of the individual should always be considered.

Setting goals

Goals should be developed that consider the needs and preferences of the individual, their caregivers, and other important communication partners.



“Work with parents... find out about their expectations and discuss whether what they would like to work on matches with our assessment of current functioning and realistic goal areas.”

“Use what you know about child development to help inform appropriate communication goals.”

Professional

Goals should be planned to follow the typical stages of communication and language development. When setting goals, skills that emerge in the various stages of development can inform the intervention. For example, initial goals could focus on the development of a way to protest or object to something said or done by another person. This could include developing a consistent way to say “no” or “stop” as well as developing a “yes” response. Other initial goals could be used to establish a consistent way to request favoured objects, foods, people, or activities, and to attend to others modelling in a communication book or on a device. Intervention goals could then be expanded to include more complex vocabulary with a variety of verbs (action words) and adjectives (describing words), ways of expressing preferences and opinions (“like/don’t like,” “nice/yucky,” “funny/silly”), and different types of social phrases to help with conversation (e.g., “How are you?” “What did you do this weekend?” “Let’s go to” “Did you like...?”)

Goals for intervention should be SMART, i.e., they should be:

- **Specific** – The more specific the goal is, the easier it is for all members of the team to understand what is to be achieved and how to reach it.
- **Measurable** – The goal should have a clear way of being measured (e.g., defining how many times the skill should be demonstrated).
- **Agreed-upon** – All members of the team should agree the goal is important and how they will work towards it.
- **Realistic** – The goal should be achievable with the resources, knowledge, and time available.
- **Time-based** – It should be possible to reach the goal in a defined (relatively short) period of time.

Examples of SMART goals for communication:

1. To increase expressive communication, Tia will spontaneously produce at least three two-word sentences each school day.
2. To increase attention to modelling, Mina will attend to aided language modelling when engaged in an activity with three different communication partners during one school day. This will be shown by looking in the book when the partner is pointing.
3. To increase literacy skills, Natasha will communicate at least two ideas about a book using Partner Assisted Scanning or an eye-gaze device during a shared reading activity.

Note: A number of tools that can be used for developing and tracking goals were suggested by communication professionals who responded during the survey stages of the project. These can be found in Appendix 4. In sharing this information, these guidelines do not endorse any specific tools.

Targets and Goals for Intervention

Ways of Communicating

Communication should be developed across multiple modalities informed by the comprehensive and holistic assessment of the individual and their communication partners.

Communication intervention should consider the various ways, or modalities, individuals use to communicate. These include facial expressions, body movements, gestures, sounds, eye gaze, and use of pictures, photos, and symbols. All of an individual's expressions should be recognised as communicative. If an individual seems to have voluntary control over a certain movement, it could also be developed so that it is used more frequently to indicate a particular meaning. The behaviour could also be modified so that it is more easily interpreted by others. For example, if the individual looks at something, the partner can interpret that they want the object and then confirm it and respond. A certain sound may be interpreted as a request for attention. If all communication partners respond in the same way when the sound is made and they model a more complex sound combination in response, the sound may eventually be modified by the individual so that it is a clear request for attention.



Ways of Communicating

The following should be acknowledged as potentially communicative in individuals with Rett syndrome:

Facial expressions, such as smiling and frowning

Body movements, such as leaning and/or moving towards or away from objects or people

Gestures, such as reaching, pointing and/or waving

Vocalisations

Spoken words or sentences, even if echolalic or highly repetitive in nature

Looking at objects, individuals, and/or pictures

Use of graphic symbols, photos, and text

Goals

The following goals may be appropriate for some but not all individuals with Rett syndrome:

Goals for maintaining body movements are appropriate for individuals who already use body movements (such as walking towards items for communicative purposes).

Goals for developing or maintaining gestures (such as reaching, pointing, and/or waving) are appropriate for individuals who already demonstrate some voluntary hand control.

Goals for developing or maintaining sound production are appropriate for individuals who already produce sounds voluntarily.

Goals for developing or maintaining spoken words or sentences are appropriate for individuals who already produce spoken words or word approximations.

Intervention for developing or maintaining sound production, spoken words, or sentences should always be combined with aided AAC.

Goals

The following goals are appropriate for all individuals with Rett syndrome:

Goals for developing or maintaining eye gaze (such as looking at objects, individuals and/or pictures)

Goals for developing or maintaining use of graphic symbols, photos, and text



“Developing a multimodal communication system individualised for each user – including gestures and facial expressions, vocalisations, a clear yes/ no (or just yes) responses, use of no-, low- and high-tech devices when and where appropriate [is the most important goal for communication].”

Professional

“Yes/No”-Responses

If an individual has a reliable “yes/no” response, this can be used in different situations for different reasons (e.g., to make choices, to answer questions, or to say whether other people have interpreted their behaviours/understood their intentions correctly.)

Developing Communication Functions

- Developing a “yes/no” response is important for all individuals with Rett syndrome.
- “Yes/no” responses can be used to express agreement or disagreement, make choices, and/or answer questions.

Some individuals may not be able to say “yes” in a conventional manner (head nod or spoken word) and their communication partners may agree to accept an alternative response. The “best yes” is an alternative way for an individual to express “yes.” This could take many forms, such as turning the head, looking to the communication partner, blinking both eyes, or moving an arm. To establish a “best yes,” communication partners must first observe an individual carefully to see how they respond to liked and disliked activities. Once a “best yes” behaviour is identified, all communication partners should be informed so they can recognise and reinforce the behaviour. By responding consistently to the behaviour they are interpreting as a “yes,” communication partners can help to increase the frequency of that behaviour (e.g., by saying, “You’re looking at me; I think you are saying yes.”) A “best yes” behaviour can also be taught more directly (e.g., by saying, “Look at me for yes.”)

Identifying a behaviour for “no” can also be important. For example, this could be turning the head away, looking down, or even a non-response.

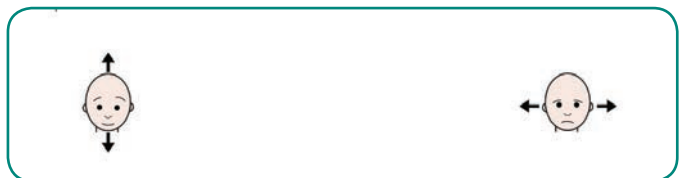
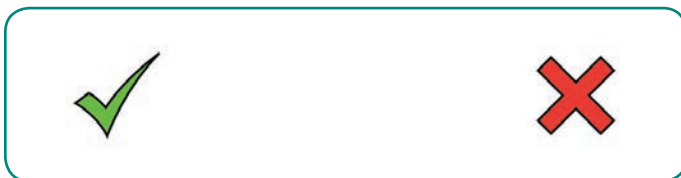
The forms used by the individual for expressing “yes” or “no” may become clearer and more specific over time. In the beginning, for example, an individual may confirm desired options with a smile. The communication partner can then say (while modelling a head nod and/or pointing at a symbol for “yes”), “Yes, you are smiling; I think that’s yes!” and provide the desired option. Over time, and with many opportunities to practice the behaviour, less verbal encouragement may be needed from the partner as the response is mastered.



“Children with RS typically use eye-pointing to access the ‘YES/NO’ but often have other ways of communicating YES/NO that should be honoured as their motor abilities fluctuate requiring a back-up plan if one method does not work.”

~ (Norwell 2017, p. 41)¹

EXAMPLES OF YES/NO STRIPS:



Both strips were created using ARASAAC symbols².

Examples of ways individuals with Rett syndrome may say “yes” or “no”:

- Looking at the communication partner/giving eye contact
- Smiling and giving eye contact
- Nodding their head for “yes” and looking away for “no”
- Blinking their eyes (maybe a long, slow blink or more rapid eye movement)
- Making a hand gesture or arm movement
- Eye pointing or leaning towards a symbol for “yes” or “no”(e.g., on a “yes/no” strip)
- Making a specific sound
- Doing nothing for “no”

For further information on establishing and using “yes/no” responses, see Appendix 5.

¹ Norwell, S. (2017). Writing with Children with Rett Syndrome: Effective Foundations for Ideation and Mechanics. *Closing the Gap Solutions*, June/July, 38-44.

² See: <http://www.arasaac.org/>

Partner-Assisted Scanning (PAS)

Once a “best yes” or “yes/no” response has been established, this may be used with partner-assisted scanning.

PARTNER-ASSISTED SCANNING (PAS) IS...

a strategy in which the communication partner reads out the options and the individual indicates the one they want to choose.

PAS is useful for choice making when eye pointing at symbols or objects is not possible (e.g., when there are too many options on a page or when the options are not tangible objects). Providing a range of options to choose from gives the individual substantially more autonomy than when the communication partner guesses what the individual wants. The partner may point to symbols or objects as they speak, read from a list of written words, or speak aloud without visual prompts.

For example, to learn why an individual doesn't want to wear a sweater, the partner could provide a variety of choices, such as:

“Is it too hot, uncomfortable, too small, doesn't look nice, or something else?”

Initially, the communication partner will say what all the options are, then repeat them more slowly, pausing after each to give the individual enough time to respond with a “yes” or “no.”

Communication Functions

Communication has many different functions — e.g., to request objects or activities, to ask and answer questions, to comment on what is happening, to share information, and to follow social etiquette (e.g., saying hello, please, and thank you). Requesting and choosing are communicative functions that usually develop early in life. These are important functions to target, however, communication should not stop there. Intervention should also include goals to expand the range of communicative functions further. Examples of additional functions to target include greeting, protesting, commenting, asking questions, and expressing opinions.

Developing Communication Functions

Goals to expand the range of communicative functions (e.g., requests, answers, protests, comments, questions, descriptions, and greetings) should be included in intervention programmes for individuals with Rett syndrome.

AAC Systems

AAC may be unaided or aided.

Unaided AAC means not using external tools to communicate but relying on the user's own body to convey messages. Examples include gestures, signs, or vocalisations.

Aided AAC means using external tools, devices, or systems to enhance communication. These may be electronic or non-electronic (high-tech or low-tech).

For further explanation of the different forms of AAC, see page 41.

AIDED AAC

An individual can be presented with two different AAC systems at the same time or asked to use more than one system at a time.

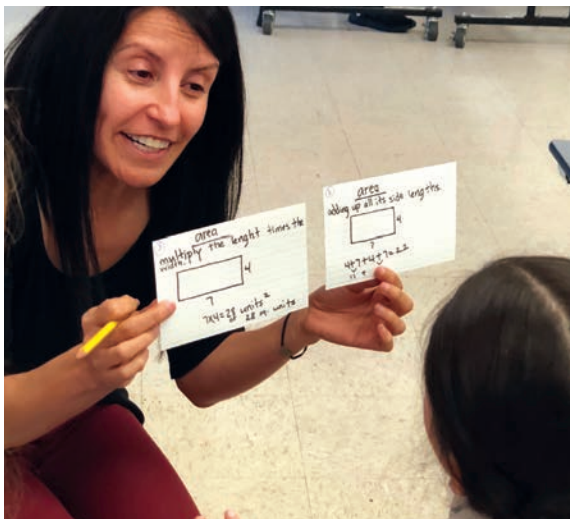
It is extremely important for an individual to have more than one AAC system or device so that they can be used in different situations/settings (e.g., an eye-gaze device indoors and a symbol chart outdoors).

A low-tech AAC system should always be available as a back-up for any individual who has a high-tech AAC system.

In line with the need for a communication system that uses multiple modalities (e.g., body movements and a picture symbol system), it is important to have access to, and learn to use, more than one AAC option. Different systems may work better in certain situations and for different purposes. For example, an individual may be most successful using an eye-gaze device when they are at school, as they spend most of the day seated at a desk. At home, they may use an eye-gaze board that their communication partner points to, as this is effective while riding in the car, sitting on a couch, and lying in bed. A low-tech backup system is especially important when high-tech AAC systems are used as these may break down or not function in all environments, such as outside in the rain, in a pool, or in the bath.

Aided AAC

The same device can be used for communication and learning activities (e.g., for accessing the curriculum in school) as long as the individual is still able to access their full vocabulary.



One consideration is whether the same device can be used for both communication and education purposes. Having relevant pages for schoolwork on the same device enables the individual to look at them and talk about them with other people whenever they want. However, if an individual is using their communication device for their education too, it is important that their communication pages are accessible at all times. The primary purpose of the device should always be communication; a secondary purpose can be education. There is a risk that using the device for learning activities will result in a negative attitude towards the device because it becomes associated with performing tasks and being tested. An alternate strategy would be to use the high-tech device for communication only and to use low-tech AAC for responses to academic tasks. For example, during a math lesson, the possible answers to problems can be posted on an eye-gaze board.

Aided AAC

The individual with Rett syndrome, their communication partner, and the aided AAC device should be positioned in a way to maximise joint attention in the communicative interaction.

Joint attention is when both communication partners attend to the same topic, objects, and activities and to each other. Using aided AAC places more demands on shifting attention for both the individual and their communication partner. During interactions, both partners need to attend to each other as well as to the device. It is important to consider how to position oneself and the device to allow for optimal eye contact. Sitting to the side of an individual at a perpendicular angle allows the partner to provide modelling on the device while also facilitating eye contact with the individual. If the individual prefers to look to one side over another, the communication partner can consider sitting on the preferred side to facilitate eye contact.

It is also important to be aware that shifting gaze focus is more effortful (demanding) and extra time should be built into conversations to allow for this. However, it is also worth noting that this may get easier when the individual is more familiar with, and used to communicating with, a device.



“An equally robust low-tech language system can be used in conjunction with the high-tech device for situations where the high-tech option is not appropriate.”

“Make sure they have a robust low-tech system and a “best yes” too so they’re not relying on the computer.”

Expert panel

EXAMPLE: PARTNER POSITION TO MAINTAIN EYE CONTACT



Aided AAC

- Aided AAC can be used with individuals who are ambulatory. Portability is one important consideration when choosing an aided AAC system.
- Ambulatory individuals should also be provided with access to their aided AAC system when seated (e.g., at mealtimes).

For more information on how aided AAC can be adjusted for individuals who are ambulatory or who struggle with head control, please see pages 69-70.

Aided AAC

Aided AAC can be introduced and used successfully in adulthood.

Aided AAC can be introduced at a young age, but that does not mean older individuals are not also good candidates for this technique. There may be a misconception that it is “too late” to learn, or to start to use, new forms of communication (especially technology) in adulthood. An increasing numbers of research papers and anecdotal reports demonstrate that adults with Rett syndrome can learn to use aided AAC successfully.





A PARENT'S PERSPECTIVE

When my daughter was about 7 years old, I was convinced she could read, as was her local primary school; and in those days, she would hammer out sentences on a school computer, proving that she could write too. Sadly, her fine motor skills are not so good these days, so we don't see any of the writing in that format now.

In the early days when my daughter was quite young, some people suggested that I was making it up and it was me who was doing the work, not my daughter. This was before anyone in the Rett world had been introduced to any eye-gaze equipment, so I was only using a "yes/no" board and a notebook for her to make choices.

I never stopped believing in my daughter, but I learned not to keep pushing against people who didn't believe in her; and every time we met someone new, we'd have to start all over again. I am really happy that later on someone else felt they could draw attention to what people with Rett syndrome can do.

Twenty years on from those early days of believing in my daughter's ability to communicate, she now uses eye gaze. My regret is that she was not introduced to it earlier, as I know she finds it tough going at age 35; but in her usual indomitable way, she keeps going.

Eye gaze is now an important tool in her communication tool box. She has been using her device for two years now and willingly uses it with her support team as well as her family. The second time she used the software at age 33, she told me that she loved me. It was momentous, all those years I dearly loved her through thick and thin and she was now able to tell me that she loved me too.

It is now two years since she was introduced to eye gaze, and my daughter is using it more and more. She has told her support team where she wants to go; since using eye gaze, she has expressed a desire to be far more cultural. She always has the news on over breakfast and is keen to listen to audio books and classical music. She's not a vegetarian but prefers to eat less meat, and she knows when she is in pain and asks for paracetamol. All this has come from her use of eye gaze.

There are days when my daughter will say nothing to anyone through eye gaze, and that is why it is important to have other ways of communicating, like a best "yes/no" and a notebook to write words in. From now on, it is onward and upward for her and time for me to be as indomitable as she is.

Developing Vocabulary

Interventions that aim at developing language should usually begin with exposure to a robust vocabulary.

A robust vocabulary includes words that can be used in many situations and settings throughout the day.

Developing Vocabulary

Language intervention should begin with exposure to a robust vocabulary (including core and fringe words) so that potential for communication is unlimited.

‘Exposure’ to a robust vocabulary system does not mean that the individual is expected to use the words from the robust vocabulary to express themselves straightaway. Communication partners should use the words to model vocabulary as they talk to the individual throughout the day. In this way, the individual will experience the vocabulary in use and make associations between the meanings of the words and symbols and learn how they can be used to communicate.

MODELLING IS...

a strategy in which the communication partner uses the individual’s own AAC system when talking with them in order to teach by example.

AIDED LANGUAGE MODELLING IS...

a strategy in which the communication partner speaks while pointing at symbols in order to support receptive language and to provide vocabulary. The partner may select vocabulary on the individual’s own AAC system or use another AAC system as they talk.

Aided Language Modelling may also be known as Aided Language Stimulation or Augmented Language Input.

For further explanations of how to model, see Appendix 5.

Developing Vocabulary

To expand an initial vocabulary, goals should include words that cover a range of ideas, interests, and meanings, including emotions, social, and academic language.

Some individuals may start using words from a robust vocabulary right away, but many individuals will need a smaller set of options to choose from initially. A robust vocabulary can be used in conjunction with a smaller set of choices that are appropriate for specific situations. For example, during a family meal, a robust vocabulary can be used for conversation, while the individual is also presented with a smaller set of options to choose what to eat and drink.

Developing Vocabulary

An individual’s vocabulary will change according to age, communication partner, language development, environment, mood, and context. The vocabulary used in an AAC system should allow for the same change and flexibility.

It is easier to find a symbol when the device has a small vocabulary, but this reduces the diversity of messages that can be composed and limits the linguistic potential of the individual. It may be appropriate to begin with a smaller number of vocabulary items if the individual or communication partners find a robust vocabulary too difficult to manage initially. The communication partners can then create a series of separate activity or context-based boards as an introduction to a robust vocabulary.

A smaller number of items may be appropriate for some individuals who find it too demanding to select from a large number of options. An individual with a visual impairment may need large symbols or be limited to a smaller size display because of a restricted visual field. Difficulties with head control can impact the accuracy of eye pointing and influence the size and shape of a display. In these circumstances, partner-assisted scanning may be a useful technique to increase access to a larger number of vocabulary items.

Developing Vocabulary

Limiting the options or choices given is appropriate for some individuals with Rett syndrome when there is a risk of frustration, an access issue, or a robust language system has been trialled for at least 12 months with limited success.

It may be advisable to try limiting the number of available choices for a time when a large number of choices has been tried and not found to be successful for the individual. Before deciding that a robust vocabulary is not suitable, the individual should have been exposed to multiple opportunities with communication partners using the vocabulary and have been provided with the appropriate means to access the vocabulary themselves. If these criteria have been fulfilled, and the system trialled for at least 12 months, and the individual does not appear to show interest in using the vocabulary or seems frustrated when trying to access the vocabulary, it may be appropriate to reduce the available items to allow the individual to practice consistently using a smaller number of options. Later on, the vocabulary can be expanded more slowly, depending on the individual's needs.

In general, communication partners should continue to use a wider, robust vocabulary system to model language.

For further ideas of how to develop early and more advanced communication skills, see Appendix 5.



Choosing and Organising Vocabulary

The organisation and layout of the pictures and symbols in an AAC system have an impact on how easily an individual can find their way around (navigate) a system to communicate. An individual's vocabulary may include phrases or single symbols.

Phrases

In many instances, it is important to be able to say a message quickly. Having access to whole phrases, such as "I like this," provides a fast way to participate in a conversation. Phrases can generally be used in multiple contexts and can help individuals engage more easily in conversations. In a high-tech AAC device, phrases can be programmed behind a single cell/button to provide access to messages with more complexity, without taking up a great deal of space on the layout. However, partners and users should be aware that ready-made phrases are less flexible and may not be suited to all situations.

Single Symbols

Single symbols allow the individual to create the message and are, therefore, considered to support language development. However, creating messages using single symbols takes more time and effort and slows down the speed of conversation. Single symbols can be classified as core or fringe words in a vocabulary.

Core Words

Core words are those that are used most frequently in conversations on a daily basis. Core words provide a flexible way for AAC users to engage in many types of conversations. Examples of common core words include articles (*the, a*), pronouns (*I, you, they, me, we, us*), and words like *yes, no, want, go, mine*.

Fringe Words

Fringe words are those that are used in specific types of conversations and occur less frequently. For example, words about food, birthday parties, or sports would not be used in conversations about other topics, such as trips to the hospital or a visit to the zoo.

A vocabulary can be organised onto different boards or pages based on the needs of the individual. The number of pages will vary based on the size of the vocabulary and the person's interests. An individual may have a core word board that includes single words and phrases that are used frequently.

The words or phrases can be organised according to how often they are used or in categories, activities or contexts, and visual scene displays.

Core Boards or “Quick Fire Boards”

Core boards or “Quick fire boards” contain words or phrases that are used in many situations throughout the day.

Sample core phrases are “I like that,” “I want more please,” and “Where are you going?”

SAMPLE CORE WORDS BOARD



From Project core.³ Reprinted with permission.

Activity Boards

Activity boards are a way of organising vocabulary for a particular activity. The boards are composed of fringe words that are most relevant to that activity (e.g., arts and crafts activity, or a music or physical activity). They may be made as low-tech communication boards or as pages on a high-tech device. These boards can increase participation in the activity and help develop grammar and syntax by encouraging use of multiword combinations.

Example of phrases for this activity are “This is my favourite song,” “Let’s do the movements for this song,” and “This is too loud.”

SAMPLE ACTIVITY BOARD

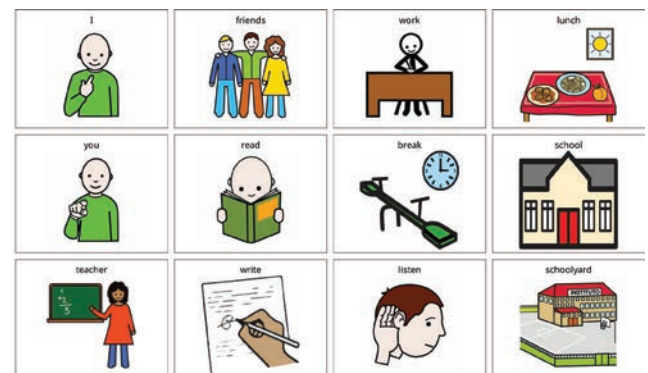


Made with Bildstöd.se⁴ grid-making software and ARASAAC⁵ symbols.

Context-based Boards

Context-based boards are similar to activity boards but designed for a specific context or environment. These boards contain vocabulary items or phrases that allow for greater generalisation than vocabulary designed around a single, specific activity. A context-based board can be used for regularly occurring events during the day (e.g., phrases used in school or at the restaurant).

SAMPLE CONTEXT-BASED BOARD



Made with Bildstöd.se⁶ grid-making software and ARASAAC⁷ symbols.

³ See: <http://www.project-core.com>

⁴ See: <http://bildstod.se>

⁵ See: <http://www.arasaac.org/>

⁶ See: <http://bildstod.se>

⁷ See: <http://www.arasaac.org/>

Visual Scene Display

Visual scene displays can be a useful starting point when introducing high-tech AAC. In these displays, photos or pictures that depict scenes, objects, or people are created, and “hot spots” are added. These “hot spots” are high-interest areas that contain vocabulary items.

For example, if someone wants to talk about a trip to a zoo, they can use a visual scene display in which animals are the “hot spots.” Looking at or touching one of the hot spots will cause the name of the animal or a phrase related to the trip to be spoken. Vocabulary that is embedded in visual scene displays has been found to be easier to learn than vocabulary in traditional boards. These displays can be personalised and provide contexts that facilitate learning.

SAMPLE VISUAL SCENE DISPLAY



Note: Further information relating to the free communication resources that are available through Project Core, Bildstöd.se, and ARASAAC can be found in Appendix 5.

At present, there is no evidence to support one type of language system or type of vocabulary over another. Individuals and their communication partners should try out different layouts and weigh the benefits and drawbacks of each type of board and vocabulary. Most ready-made robust vocabulary sets include phrases and single words, core and fringe words, and pages organised in categories and activities and contexts. Vocabulary sets should be flexible, allowing for expansion over time, according to the growth in the individual’s skills and their changing needs (e.g., transition to a new school, development of new interests, and meeting new communication partners).

ALYSSA

Alyssa’s parents begin language intervention/vocabulary development by making choice boards (on cardboard) on which they place pictures and photos of Alyssa’s favourite toys and activities. Alyssa is encouraged to choose what she wants to do. During the activity, her parents point at the photos while speaking, using the technique of modelling. They also use a choice board with symbols for “more,” “finished,” and “like,” “don’t like.” They point at these symbols while speaking and also give Alyssa the opportunity to choose if she wants to do more, to tell them she is finished, or to indicate that she likes/does not like things and events. They comment on Alyssa’s reactions and use the symbols as they speak to her (e.g., saying “I see you are looking/reaching for... I think you want more...” while pointing to the symbols.) Her parents then advance the vocabulary by using activity boards, which have pictures and/or symbols for the vocabulary specific to a particular activity. Using these boards, they continue to model language as well as interpret Alyssa’s reactions to what they say. The behaviours exhibited by Alyssa—such as head and body movements, eye-gaze, and vocalisations—are all treated by her parents as intentional behaviours that are communicative. In this way, they continually reinforce her behaviours by acknowledging that the behaviours are meaningful.

MARIA

Maria receives an eye-gaze device with a robust vocabulary and her parents start to model core words, such as “want,” “go,” and “more,” and slowly expand the number of words and pages they use with her. They also start to model fringe vocabulary, such as names of foods, places, and activities that Maria enjoys. When using the device with Maria, they consistently respond to whatever she selects. When they are all comfortable with using the device, Maria’s parents start to expand phrase length by modelling the use of two words at a time and gradually move on to modelling longer sentences. In this way, Maria learns to join words to express more complex thoughts. Her parents acknowledge all of her attempts as meaningful and do not demand that she use correct grammar. Over time, they model complex combinations to show different language structures as Maria expands her skills—e.g., verb tenses (I am going/I went), pronouns (her and his), descriptive words (big, bigger, biggest, quickly, and slowly).

Access Methods

Choice of access method can vary according to changes in motor control and general health. Different contexts and types of aided AAC also place different demands on access. For example, an individual may lean towards an object or gesture with their hand when making choices from only a few options but use eye gaze or partner-assisted scanning when accessing a larger vocabulary.

Access Methods

- Choice of access method can vary according to the individual's abilities at a given moment, type of aided AAC, and context.
- Direct selection can be used when individuals have a way of directly activating aided AAC, including eye-gaze, touching or pointing with finger or hand, and operation of a switch and/or a head pointer.

For most individuals, eye-gaze is the most reliable motor function. However, it is important to keep in mind that there are other parts of the body that can be used for direct selection.

Access Methods

Eye gaze is usually the best way for an individual with Rett syndrome to access AAC, but eye gaze is not the only way.

For most individuals, the movement disorders associated with Rett syndrome significantly impact the effective use of their hands. Some individuals may have good control and be able to use a finger to point to many symbols on a page, while some individuals may only be able to point to a small number of symbols or options reliably.

Access Methods

Individuals who can touch or point to access aided AAC should be encouraged to use this access method as long as it does not limit the variety and complexity of their communication.

If an individual does not already use their hands easily or reliably, direct selection using fingers should not be considered as their primary access method for communication.

However, when an individual has reliable hand function, touching or pointing may be encouraged and reinforced. This may be useful when choosing a breakfast cereal, for example, or which shoes to wear. Developing hand motor skills may also be useful for other reasons, such as participating in activities. These skills can be reinforced during everyday activities or play (e.g., drawing, playing instruments, or using a switch to participate in a game or a song).

Access Methods

A head pointer could be considered when other access methods are not available or effective.

Sometimes, eye-gaze devices are not an option (e.g., when a school, programme, or healthcare system does not provide eye-gaze devices and the family does not have the economic means to purchase a device). A family may also not have reliable access to electricity or to resources to upgrade or repair devices. In these cases, a head pointer may be considered. However, it is important to remember that movement disorders can also affect head movements, so the pointer should be trialled in different contexts before deciding on whether to adopt this option.

Access Methods

- Scanning can be used when individuals are unable to use direct selection to access aided AAC.
- Partner-assisted scanning can be used with individuals who have developed or are developing a “yes/no” response and are unable to independently operate a scanning system.

Scanning occurs when items are presented sequentially (over time) and the user makes a selection. Often the user activates one or two switches to scan through the items on screen and to select their choice. Alternatively, partner-assisted scanning may be used, as described above. For this, the communication partner reads out the options and the individual indicates the one they want by giving a “yes/no” or “best yes” response.

Access Methods

The following forms of aided AAC can be appropriate for individuals with Rett syndrome:

- An eye-gaze board, such as an E-tran frame
- Eye-tracking technology, such as a computer fitted with an eye tracker

Eye-gaze boards (or Eye-transfer/E-tran frames) are sheets of stiff, often transparent plastic onto which symbols or words can be positioned with tape, glue, or velcro so that the individual can select their preferred option by looking. There may be a hole cut in the centre of the board to allow the communication partner to make eye contact with the individual when they sit face-to-face with the board in between them. The partner can then follow the individual’s eye-gaze when they look to their preferred option. Eye-gaze boards are useful when the number of options are limited.

Skills that are helpful for successful eye pointing are the ability to first look at all the choices, then look at their preferred choice, and then shift their eye-gaze to the communication partner. Such clear eye pointing may be challenging for many individuals due to dyspraxia/apraxia or other movement disorders. An individual who cannot accomplish all of those steps can still be a successful eye-gaze user when paired with a communication partner who knows them well and takes time to learn their eye-gaze patterns.

EXAMPLE: USING AN E-TRAN FRAME



Eye-Tracking Technology

Eye-tracking technology provides opportunities for users to eye point to significantly more options and thus access a large number of symbols. This technology also enables the individual to control many different aspects of their environment (e.g., using eye gaze to turn lights on and off, to paint/draw, to play games, to access the internet, and to perform many other activities). However, the direct access to aided communication is the greatest advantage from a communication point of view.

In some cases, caregivers and professionals report that individuals experience difficulties in using eye-tracking technology. The strategies outlined on pages 69-70 were all offered by respondents to the caregivers, professionals, and expert panel as possible ways to enable all individuals — including ambulatory individuals, individuals who wear glasses, and individuals who have difficulties in controlling their head movements — to use eye gaze for communication.



“I agree that it’s more complex, amongst others because of their dyspraxia. But it’s not impossible. Which strategies I use, depends on her level of ability.”

Expert panel



A PARENT'S PERSPECTIVE

For some years, I have been very interested in the way our younger girls have learned to communicate, especially using eye-gaze devices. My emotions were a mix of delight at their achievements but sad that, in my view, it was too late for our daughter who is now 36.

I decided to attend a communication event organised by Rett UK with a view to convincing myself that it wasn't for us. I did so because I didn't want to live the rest of my life thinking that I hadn't done the best for my daughter.

Within minutes, I was convinced of several things. Yes, it definitely was for us, it really is never too late, and a robust system of language by whatever means is something that should never be denied. I went home that night and within an hour we had taught her a secure "yes." I hugged her and told her that I was so excited because I was going to give her a voice. She looked me straight in the eye and sobbed. We are absolutely certain this was relief. She was going to be able to tell us things.

Further training and an extended loan of an eye-gaze device followed, with amazing results. She took to it amazingly. I worried that I would not be able to cope with the technology (help is always available and it is very easy to use). I was concerned that I wouldn't have the time to teach her to use it (I didn't need to worry. It's so exciting I can't get enough of it). It is a long-term learning experience, as we were told, "It's a marathon, not a sprint."

Pauline has been able to demonstrate her needs ("I need some privacy please," "I need to use the toilet," "I am uncomfortable; reposition me please"). She has been able to give us nicknames. Our other daughter is "the child," and I am regularly called "plonker." She has been well able to demonstrate her feelings, telling me off for being unwell "sick, sick, embarrassing, feel better, worse, disgusting!!!" (How she managed to navigate to all of that stunned me). She was able to tell a carer off for mocking her bubble machine, and when her Dad was checking her smartwatch to see how well she had slept, she instantly asked him, "What time?" (I think meaning, "How long did I sleep?") She can join in; she can demonstrate her personality and her sense of humour. One of her favourite buttons is one I attached to several of her pages, which says, "Please talk to me." It is so easy for people to disregard someone who apparently cannot talk; it is so much more powerful if Pauline asks them.

What the eye-gaze device has given Pauline is truly amazing. For her and other young people like her, having an eye-gaze device in front of them gives them credibility to the outside world. We know that they understand but often the general public doesn't realise this. The eye-gaze device allows them to show it.

However, not everything she says is what I want to hear, but I have come to terms with this and discuss things with her. Only two weeks into her trial, she waited for me to leave the room and said to her friends, "I want to talk; I want to talk alone. Nobody understands how I feel. I am frustrated." It upset me very much, but on reflection, no matter how hard we try we probably don't really know how it feels to have Rett syndrome. At least now Pauline can express herself and we can talk it through with her.

Pauline was 34 when we started. We have been using eye-gaze now for 18 months, and I am so very glad that we now have the means to allow Pauline to talk to us. I cannot imagine being without it. The most important thing that Pauline has said to us is "I LOVE YOU."—the words all parents want to hear. That is priceless.

Eye-tracking technology

Eye-tracking technology can be used with individuals who are ambulatory. Strategies to support ambulatory individuals in using eye-tracking technology include positioning the device on a wall or table or in another area that the individual is able to access consistently.

When using eye-tracking technology with an individual who is ambulatory, the following strategies may be helpful:

- Use the device during activities when the individual is sitting down (e.g., when reading, doing arts and crafts, or listening to music).
- Supported seating may help.
- Designate a certain spot that they often pass by as somewhere the eye-gaze device is always placed when not in use for an activity. The individual may be able to activate the device on their own. If not, they can learn to walk up to the device and then the communication partner can help to activate it.
- If the individual is not able to go and stand in front of the device independently, it must be placed in a location where they can look at it when they want to say something. It is extremely important that the device is with the individual as much as possible.
- Make sure the device is turned on and ready to use at all times.
- Communication partners should be very aware of any signs/expression that might indicate the individual has something to say.
- An equally robust low-tech language system can be used in conjunction with the high-tech device for situations when the high-tech option is not appropriate.

Eye-tracking technology

Eye-tracking technology can usually be used with individuals who wear glasses. If there is a problem, consider trying frameless glasses or non-reflective lenses.

If glasses appear to interfere with eye tracking, the following may be considered:

- Check if the glasses have a coating that interferes with the eye gaze.
- Try non-reflective lenses.
- If the calibration was made without glasses, recalibrate with glasses on.
- Try another eye-tracking system.
- Try another frame size or shape.

Eye-tracking technology

Eye-tracking technology can be used with individuals who have difficulties with controlling head movements when their body and head are appropriately supported and when the device is appropriately positioned.

Whenever difficulties with head control interfere with using eye tracking, it is important to find optimal seating so that the body and head are supported. It is useful to consult physical and occupational therapists (PTs, OTs) to determine appropriate seating. Sometimes a reclined position is best or positioning the eye-gaze device to one side may be helpful. It is also important to allow for extra time for the individual to learn to use the device and to build up vocabulary, with easy access to pages, phrases, and words that are most frequently used. It may also be worthwhile to consider trying another brand of device if there are difficulties with access.

When introducing eye-tracking devices to an individual who has difficulties with head control, the following may be helpful:

- Consult PTs and OTs to learn if changing position or using another type of chair can improve control of body movements.
- Work with the PTs and OTs to develop better head control and posture.
- Reposition the device at various angles and distances.
- If the individual is easily fatigued, begin with short work sessions and gradually increase time. Provide a relevant and motivating vocabulary to increase engagement.
- Change position frequently.
- Be sure to have a robust low-tech system and a “best yes” already established.

Reading and Writing

Literacy is closely related to communication, and there is considerable interest in promoting literacy for all. All individuals have the right to receive well-thought-out literacy instruction to help them progress as far as they can on their literacy path. It is suggested that individuals can only be truly autonomous in their communication once they are able to spell and write words to supplement any other language systems they use.

In 1997, the Literacy Bill of Rights (Yoder, Erickson & Koppenhaver)⁸ was published to provide a foundation for literacy instruction for all individuals, including those with significant developmental challenges like Rett syndrome. This can be a useful starting point for discussion with educators and education-based services.



FIGURE 6: LITERACY BILL OF RIGHTS⁹

All persons, regardless of the extent or severity of their disabilities, have the basic right to use print. Beyond this general right, there are certain literacy rights that should be assured for all persons. These basic rights are:

1. The right to an opportunity to learn to read and write. Opportunity involves engagement in active participation in tasks performed with high success.
2. The right to have accessible, clear, meaningful, culturally and linguistically appropriate texts at all time. Texts, broadly defined, range from picture books to newspapers to novels, cereal boxes, and electronic documents.
3. The right to interact with others while reading, writing, or listening to a text. Interaction involves questions, comments, discussions, and other communications about or related to the text.
4. The right to life choices made available through reading and writing competencies. Life choices include, but are not limited to, employment and employment changes, independence, community participation, and self-advocacy.
5. The right to lifelong educational opportunities incorporating literacy instruction and use. Literacy educational opportunities, regardless of when they are provided, have potential to provide power that cannot be taken away.
6. The right to have teachers and other service providers who are knowledgeable about literacy instruction methods and principles. Methods include but are not limited to instruction, assessment, and the technologies required to make literacy accessible to individuals with disabilities. Principles include, but are not limited to, the beliefs that literacy is learned across places and time, and no person is too disabled to benefit from literacy learning opportunities.
7. The right to live and learn in environments that provide varied models of print use. Models are demonstrations of purposeful print use such as reading a recipe, paying bills, sharing a joke, or writing a letter.
8. The right to live and learn in environments that maintain the expectations and attitudes that all individuals are literacy learners.

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⁸ Yoder, D.E., Erickson, K.A., Koppenhaver, D.A. (1997). *A Literacy Bill of Rights*. Center for Literacy and Disability Studies. University of North Carolina at Chapel Hill. Chapel Hill, NC.

⁹ This table is taken from: Yoder, D. (2001). Having My Say. *Augmentative and Alternative Communication*. 17(1), 2-10.

Reading and Writing

Reading stories together is an activity that is appropriate for all individuals with Rett syndrome to develop language, communication, and literacy skills.

Being exposed to reading, writing, and storytelling is beneficial for the development of communication, language, and literacy skills. Shared reading is an activity that is appreciated by many individuals and their communication partners. Books and stories can be adapted in many ways to suit the individual's preferences, interests, and needs.

Reading and Writing

Most individuals with Rett syndrome should be exposed to activities to develop:

- phonemic awareness,
- an awareness of print,
- sight vocabulary, and
- writing skills. This can include 'scribbling' (with an on-screen keyboard or using partner-assisted scanning) or writing letters or words.



"[Reading stories together is a] great context for learning new vocabulary."

"Exposure to books builds relationships and vocabulary."

"Need to be able to share stories with others. This can be simplified so the individual can choose from selected words and phrases to create their own stories."

Expert panel

Development of literacy skills should include reading, reading comprehension, and writing. Depending on the individual's current level of literacy, emergent or conventional literacy instruction should be applied.

Goals for emergent literacy instruction should include developing an understanding of:

- print (e.g., by writing shopping lists together),
- alphabet (e.g., by reading alphabet books and talking about the letters, and by pointing out letters in text in the environment, such as on the daily schedule or in the names of known persons);
- phonological awareness (e.g., by reading poems or rhymes or clapping the rhythm of words); and
- communication skills required to interact with others about reading and writing (e.g., by commenting when reading a book, pausing, and then waiting for any response).

Conventional literacy instruction consists of more formal literacy instruction that follows the regular school curriculum. These lessons may be adapted for individuals with Rett syndrome.

Narrating and storytelling are foundation skills for writing but can also be used as teaching opportunities to deal with real-life events.

Reading and Writing

Most individuals with Rett syndrome should be encouraged to create their own narratives or stories.

Strategies to elicit co-constructed stories or narratives include:

- using open-ended questions,
- fill-in-the-blank-sentences, and
- visual story maps.

When assisting someone to create a co-constructed story, it is important to follow the individual's lead and not to aim to produce "a correct" story from an adult perspective.

Note: A list of free literacy resources and software, training modules, and webinars can be found in Appendix 5.

A Final Word on Intervention Techniques

Modelling

One way of learning new skills is to watch other people and imitate their actions. Modelling is, therefore, an important intervention technique (see page 62). Different terminologies, and some variations in methodology, are used by different groups. For example, Aided Language Stimulation, Aided Language Modelling, Aided AAC Modelling, and Augmented Language Input are all based on the concept of modelling (or demonstrating) language use. These methods share the goal of teaching language and provide a vocabulary by having the communication partner point at symbols while speaking. The symbols may be in a communication book or on a device, with or without digitised speech. Aided language stimulation is often described as mirroring how children naturally learn to use speech as it follows a developmental framework.

Video Modelling

This is a technique in which someone demonstrates target vocabulary or skills in a video clip. The individual watches the clip with the therapist, teacher, or communication partner, and learns the target behaviour through watching it used by others. The target behaviour can be highlighted using video editing software so that the individual's attention is drawn to the behaviour. Arrows or coloured frames can be used to highlight the target behaviour. Video modelling can also be used as a technique when training communication partners.

VIDEO MODELLING IS...

a visual teaching method that involves watching a video of someone modelling a targeted behaviour or skill and then imitating the desired behaviour or skills.

Other intervention techniques include expanding, recasting, errorless learning, and prompting/cueing.

Intervention Techniques

- Expanding is a technique used to reword and increase the complexity of a word or a phrase to make it more complete.
- Recasting is a technique used to correct errors so that communication is not obstructed. When an error is produced, the communication partner will repeat the error back to the learner in a corrected form.
- Errorless learning involves providing prompts or cues immediately following a stimulus to ensure the individual provides a correct response.
- Prompts or cues — such as gestures, demonstrations, touch, and signals — can be used to increase the likelihood that individuals will make correct responses.

Expanding or Recasting

To develop the individual's skills without explicitly correcting their errors, the communication partner can repeat the message in a more complex form or use the correct form of the message. This technique is referred to as expanding or recasting. For example, if the individual says, "He sad," the communication partner can say, "Yes, he is sad." Expansions or recasts may be most effective when they are tied to a specific language goal and are often provided in combination with other strategies, such as modelling.

Errorless Learning

With this technique, the communication partner helps the individual to produce a correct response by giving sufficient prompts or cues to ensure that they will succeed. This can be achieved by using prompts based on the individual's level of need. The communication partner provides a prompt at the lowest level that will enable the individual to be successful. Over time, the level of prompt is reduced so that the individual requires less support.

Providing prompts like this, to facilitate errorless learning, is only useful when there is a correct way to answer. The partner knows the answer in advance so they can provide the appropriate level of prompting.

An alternative way to use errorless learning, however, is to introduce tasks in which there is no correct answer (e.g., asking the individual, "Which letter do you want me to write?") In this scenario, any response produced by the individual would be treated as correct. This type of teaching can help reinforce attempts at communication to become more consistent and complex.

Examples of prompts and cues are:

- pointing at the individual's AAC device or drawing attention to it in other ways (indirect visual),
- pointing at possible messages in the AAC system without saying anything (direct visual), and
- suggesting possible messages by saying them aloud (direct verbal).

Prompt Hierarchy

This arranges prompts from least to most intrusive. One example of a prompt hierarchy is provided in the text box below. This hierarchy can be adapted to the individual based on their needs.

PROMPT HIERARCHY – EXAMPLE:

- **Expectant delay** (wait and look encouraging)
- **Indirect visual prompt** (point/gesture toward the AAC device)
- **Direct verbal model** (suggest a message – say, "Maybe you mean ..." and point to symbols on the individual's AAC device)

APPENDICES



“Never too early,
never too late”

Statements and Recommendations

Section 1: Guiding Principles

Rights of the Individual with Rett Syndrome

In accordance with the UN Convention on the Rights of Persons with Disabilities, all individuals with Rett syndrome have the following rights with regard to communication:

- 1 Right to be treated with respect

- 2 Right to comprehensive multidisciplinary assessment of their strengths and needs

- 3 Right to an appropriate communication system

- 4 Right to appropriate communication goals

- 5 Right to timely review and modification of goals in line with changing needs

- 6 Right to advice, support, and services which start early and continue throughout life

- 7 Right to advice and support from knowledgeable and expert communication professionals

- 8 Right to communication partners who are trained in appropriate communication strategies and techniques

- 9 Right to be offered activities appropriate to their age, interests, and culture

- 10 Right to make choices

- 11 Right to participate in society

- 12 Right to education

13 The Communication Bill of Rights is a valuable resource for promoting communication as a basic right.

Beliefs and Attitudes

- 14 All communication partners should believe that the individual with Rett syndrome is capable of communicating.

- 15 The potential to communicate is frequently underestimated in individuals with Rett syndrome.

- 16 For any individual with Rett syndrome, their level of receptive language (understanding) is usually better than their ability to express themselves.

- 17 Communication partners should believe that, given the opportunity, individuals with Rett syndrome will be able to communicate using AAC.

- 18 Communication partners should have an open mind to the communication potential of the individual with Rett syndrome.

- 19 Communication partners should spend time getting to know the individual with Rett syndrome in order to build a relationship.

- 20 Communication partners should be patient and persistent.

Section 2: Professional Practice

Principles of Teamwork

- 1 Every individual with Rett syndrome should be supported by a multidisciplinary team.

- 2 The team should share a common vision and work collaboratively to define and agree on communication goals and support plans.

- 3 The team should incorporate all significant communication partners and may include the individual with Rett syndrome, their parents/other family members, AAC specialists, SLP, OT, PT, Rett specialist staff, and other key people in the individual's life.

- 4 At a minimum, the team will consist of the SLP, parents or other family members/caregivers, and the individual with Rett syndrome.

- 5 Team members should discuss expectations and define each other's roles (e.g., who will be responsible for programming devices or modifying page sets). This should occur at the start of their work and whenever a team member changes.

- 6 One person in the team should be identified as the "key person" with responsibility for monitoring communication goals. Monitoring refers to making sure the therapy plan is being carried out as agreed and alerting the rest of the team when changes are needed.

- 7 The "key person" should be someone who is knowledgeable about Rett syndrome and works with the individual with Rett syndrome regularly. This may be a teacher, teaching assistant, family member, or other person on the team.

- 8 It is the role of the communication professional to train other communication partners in communication techniques and strategies that will benefit the individual with Rett syndrome.

- 9 It is the role of the communication professional to reinforce training by providing easy-to-read handouts and instructions.

- 10 It is the role of the communication professional to work with the family and other communication partners to choose the appropriate page sets and/or vocabulary to build into any AAC system or device.

Responsibilities of Professionals

- 11 Professionals should engage in reflective practice, with the aim of building their own confidence and knowledge about the area.

- 12 Professionals should keep their knowledge and understanding of Rett syndrome up-to-date so that they are aware of recent trends in the literature and in clinical practice.

- 13 Professionals should keep their knowledge and understanding of AAC up-to-date so that they are aware of recent trends in the literature and in clinical practice.

- 14 Professionals should use an evidence-based practice model to guide their clinical decision-making, incorporating information from the literature, clinical experience, and the wishes of the individual with Rett syndrome and their family.

- 15 Professionals who are inexperienced in working with individuals with Rett syndrome should seek training in relevant topics.

- 16 Organisations employing new or inexperienced professionals to work with individuals with Rett syndrome have a duty to enable those professionals to receive training in relevant topics.

- 17 Professionals who are inexperienced in working with Rett syndrome should seek advice and support from colleagues with more specialised knowledge and expertise in the area.
-
- 18 Professionals who are working in isolation (e.g., working as an independent practitioner) should connect with the other members of the broader team who are working with the individual and family so that support, advice, and recommendations are coordinated.
-
- 19 Professionals should engage with the broader Rett syndrome community and be able to direct caregivers/communication partners to relevant information and support networks in that community (e.g., through social networks, conferences, websites, online courses, etc.).
-
- 20 Professionals should work with caregivers/communication partners to problem solve.

Rett Specialist Clinics and Expertise Centres

- 21 The individual and their family may be referred to a Rett Specialist Clinic or Expertise Centre in order to get a diagnosis, for specialised assessment and advice, or for a second-opinion at any point following diagnosis.
-
- 22 Visits to a Rett Specialist Clinic or Expertise Centre may be as a one-off or at regular (e.g., annual) intervals.
-
- 23 It is unlikely that the Rett Specialist Clinic or Expertise Centre will deliver ongoing, day-to-day therapy and intervention.
-
- 24 Referral to a Rett Specialist Clinic or Expertise Centre will be dependent on location as these services are not available everywhere.
-
- 25 Communication professionals attached to the Rett Specialist Clinic or Expertise Centre should always make contact with the locally treating communication professional(s) to discuss the individual's communication, to share the results of any assessments, and to discuss goals for intervention.
-
- 26 Communication professionals attached to a Rett Specialist Clinic or Expertise Centre should be available to offer advice and support to, and answer questions from, locally treating therapists.
-
- 27 Communication professionals attached to a Rett Specialist Clinic or Expertise Centre should provide training, instruction, and access to resources for locally treating therapists.
-
- 28 Communication professionals attached to a Rett Specialist Clinic or Expertise Centre should be available to respond to questions from parents, caregivers, and individuals with Rett syndrome.
-
- 29 Rett Specialist Clinics or Expertise Centres may provide consultations and support through video conferencing for individuals who are unable to visit a clinic or centre in person.

Section 3: Features of Rett Syndrome and Coexisting Conditions that Impact Communication

- 1 Communication skills of individuals with Rett syndrome will fluctuate based on internal and external factors. Expect inconsistency.

The following features of Rett syndrome are likely to impact communication:

- 2 Hand stereotypies
- 3 Breathing/respiratory difficulties
- 4 Impaired sleep pattern
- 5 Scoliosis/kyphosis

The following conditions that may coexist alongside Rett syndrome are likely to impact communication:

- 6 Epileptic seizures
- 7 Vacant spells
- 8 Fatigue/reduced alertness
- 9 Heightened anxiety
- 10 Dyspraxia/apraxia
- 11 Dystonia
- 12 Difficulties with sensory regulation (over or understimulation)
- 13 Hearing loss
- 14 Auditory processing difficulties
- 15 Impaired visual acuity
- 16 Impaired visual field
- 17 Oculomotor apraxia
- 18 Cortical visual impairment
- 19 Gastrointestinal issues

Section 4: Strategies to Optimise Engagement with Individuals with Rett Syndrome

When communicating with individuals with Rett syndrome in any situation, it is extremely important that communication partners do the following:

- 1 Make eye contact with the individual with Rett syndrome.
- 2 Address and talk directly to the individual with Rett syndrome rather than talking about them in their presence.
- 3 Are consistent (in approach, language, and vocabulary used).
- 4 Are engaging and fun.
- 5 Are responsive by acknowledging and reinforcing all communication attempts.
- 6 Give feedback and attribute meaning (say aloud what you think the individual's response/action/behaviour).
- 7 Explain what is happening now and what is going to happen next.
- 8 Use multimodal communication (facial expression, gestures, vocalisations, and speech alongside AAC) whenever talking to an individual with Rett syndrome.
- 9 Make the individual's AAC system(s) or device(s) available at all times.
- 10 Adapt natural situations and activities so that opportunities for communication are created.
- 11 Follow the individual's lead.
- 12 Make sure vocabulary, topics, and activities are appropriate to the interests of the individual with Rett syndrome.
- 13 It is extremely important to provide access to a range of activities.
- 14 It is also very important to incorporate music into activities.

When communicating with individuals with Rett syndrome in any situation, it is very important that communication partners do the following:

- 15 Attract and maintain the individual's attention by varying tone and intensity of voice.
- 16 Attract and maintain the individual's attention by using varied body movements, facial expression, and gestures.
- 17 Keep communication in the 'here and now.'

When communicating with individuals with Rett syndrome in any situation, communication partners should do the following:

- 18 Decrease motor demands as the cognitive load of a task increases.
- 19 Pay attention to behaviours that indicate the need for a change in position or a change/break in activity.
- 20 When in a more structured setting, i.e., in an assessment or intervention (therapy or teaching) session, it is very important to reduce distractions.
- 21 Individuals with Rett syndrome may have a delayed response in communication interactions.
- 22 Response delay may be for a few seconds up to a minute or more.

To determine sufficient wait time for a particular individual with Rett syndrome, communication partners can do the following:

- 23 Observe the individual with Rett syndrome to identify typical communication behaviour.
- 24 Review videos of communication interactions to identify typical communication behaviour.
- 25 Discuss typical communication behaviour with familiar communication partners.
- 26 Consider how the features of Rett syndrome and any coexisting conditions may impact response time.

Section 5: Assessment

General Principles of Assessment

- 1 Assessment should be informed (based on an understanding of Rett syndrome in general and the needs of the individual in particular), comprehensive, and holistic.

- 2 Initial assessment should include a detailed history of medical and physical status, including any visual and hearing problems, breathing and respiratory difficulties, seizures, fine and gross motor control (including ambulation, head control, postural control, hand function, and scoliosis).

- 3 Subsequent assessments should always capture information on current medical and physical status.

- 4 Assessment should consider the skills and needs of the individual with Rett syndrome as well as the skills and needs of the communication partners.

- 5 Assessment should consider the opportunities and barriers to communication that may be present in various environments (e.g., home, school, and social settings).

- 6 Dynamic assessment is “an interactive, test-intervene-retest model of psychological and psychoeducational assessment” (Haywood & Lidz, 2007). Given this definition, assessment should not take place at a single moment in time; it should be ongoing and dynamic.

- 7 Dynamic assessment means that there will often be an overlap between assessment and intervention.

- 8 Standardised assessments may not accurately reflect an individual’s underlying ability nor their communicative and learning potentials, but they may be adapted to obtain information on certain specific skills.

- 9 Standardised assessments of language and cognition are likely to indicate that individuals with Rett syndrome have an intellectual disability.

- 10 Adaptions to standardised assessments can include modifying presentation of test materials (e.g., mounting test items on a board, use of partner-assisted scanning, eye gaze, or other AAC strategies as response modalities).

- 11 Adapted standardised assessments can be used to assess expressive language, receptive vocabulary, and cognition.

- 12 The World Health Organization’s International Classification of Functioning, Disability, and Health (ICF) is an appropriate model around which to structure a holistic assessment of the individual.

People Involved in Assessment

- 13 Due to the complexity of their communication needs, assessment of individuals with Rett syndrome should be part of a team process.

- 14 The outcome of the assessment should not rely on the judgement of one professional in isolation.

- 15 Assessment of communication needs and skills should include contributions from all significant communication partners. This means parents and other family members, caregivers, teacher(s), therapists (e.g., SLT, OT, PT, and music), and peers.

- 16 A wider group of professionals may be involved in the assessment of specific areas (e.g., hearing, vision, and motor control). This could include an audiologist, ophthalmologist, physiotherapist, occupational therapist, neurologist, and others.

Assessment of the Individual

Those assessing the individual should gather information on a broad range of communication-related aspects, including the following:

- 17 The individual's nonverbal skills (e.g., referential gaze, eye pointing, and joint attention)
- 18 The individual's level of cognitive awareness (e.g., understanding of cause and effect, vocabulary, and reasoning)
- 19 How the individual communicates currently
- 20 The range of communicative functions used by the individual with Rett syndrome
- 21 The strategies/systems that have been tried in the past
- 22 The strategies/systems that have been successful and unsuccessful
- 23 The types of activities and topics that the individual with Rett syndrome is interested in and motivated by
- 24 The status of the individual's oral-motor skills

- 25 Assessment should include identification of the most appropriate access method for an individual (e.g., eyes and hands).

Assessment of the Broader Context

Assessment of the broader context around an individual should include the following:

- 26 Identification of social networks (Blackstone, 2012) and communication partners
- 27 Identification of the knowledge, skills, and training needs of communication partners
- 28 Identification of opportunities for communication and barriers to communication within the social environment

Assessment Procedures

- 29 A variety of assessment procedures should be used to provide a comprehensive assessment of the communicative, cognitive, and interactive skills of an individual with Rett syndrome.

Assessment can be conducted through any combination of the following:

- 30 Interviews with significant communication partners
- 31 Questionnaires completed by significant communication partners
- 32 Observations of the individual in natural settings
- 33 Informal assessments in modified natural settings or structured sessions
- 34 Modified formal (standardised) assessments
- 35 Videotaping of the individual in natural settings
- 36 Videotaping of the individual in structured sessions

Assessment Settings

- 37 Assessments should be undertaken in natural or naturalistic settings.
- 38 Observations should be conducted in a range of communication environments and with a range of communication partners.

Other Considerations for Assessment

- 39 Informal assessment includes the use of objects, photographs, picture symbols, and written letters and words.
- 40 Music can be a valuable medium for observing the behaviour of an individual with Rett syndrome and can be a valuable component of assessment.
- 41 Eye gaze is the best access method for assessment of cognition.
- 42 Eye gaze is the best access method for assessment of receptive and expressive language skills.

Section 6: AAC Assessment

Starting Point – Assessment of Readiness for AAC

- 1 There are no prerequisite skills that must be demonstrated before aided AAC should be considered.
- 2 At the time of diagnosis, individuals with Rett syndrome should be referred for AAC evaluation.

AAC Assessment – Models of Best Practice

- 3 The Six-Step Process (Dietz et al., 2012) is an appropriate model to use for the assessment of individuals with Rett syndrome.
- 4 The Participation Model (Beukelman & Mirenda, 2013) is a model for best practice in AAC assessment that should be utilised for individuals with Rett syndrome.
- 5 Feature Matching (Beukelman & Mirenda, 2013) is a model for best practice in AAC assessment that should be utilised for individuals with Rett syndrome.
- 6 The Model of Communicative Competence (Light & McNaughton, 2014) can guide AAC assessment and intervention.

Components of AAC Assessment

AAC assessment should include consideration of a broad range of aspects:

- 7 Multiple modalities e.g., unaided (facial expressions, gestures, and vocalisations) and aided communication (low- and high-tech)
- 8 Both high- and low-tech AAC (depending on availability)
- 9 A range of symbol systems
- 10 Layout (e.g., size and number of options/pictures on the communication board or screen)
- 11 Complexity of vocabulary on offer
- 12 Options for alternative access (e.g., eye gaze, touchscreen, and switch control)
- 13 Positioning (of individual, device, and AAC system)

Assessment of Readiness for Eye-Gaze Technology

- 14 Overall health, motor skills, visual attention and memory, motivation, ability to focus on the screen, and prior experience with aided AAC will impact ability to access eye-gaze technology. A comprehensive assessment of these features can determine whether an individual is a strong candidate for eye gaze or if the individual will benefit from additional investigation or trial of an alternate access method.

- 15 Assessments of readiness to use eye-gaze technology are best conducted through informal activities.

- 16 Assessment activities should be personalised as far as possible (e.g., introducing photographs of familiar people into on-screen activities).

- 17 The same activities used to assess readiness can also be used to train/build the skills that are necessary for use of eye-gaze technology for communication.

- 18 If an individual does not seem to be interested or motivated to engage with eye-gaze technology during the assessment, it should not be discounted as a possible access method.

- 19 An individual does not have to 'pass' assessment at an early level of screen use (e.g., demonstrating cause-effect understanding) before their response to more advanced levels of eye-gaze technology use can be assessed (e.g., introducing them to grids for communication).

- 20 It is not necessary to achieve successful calibration on an eye-gaze device in order to assess eye gaze as an access method.

- 21 Interactive games can be used to establish calibration of eye gaze over time.

- 22 It is important to make video recordings of an individual's responses during assessments for eye-gaze technology.

- 23 It is valuable to record/track an individual's on-screen gaze pattern and eye movements during assessments for eye-gaze technology.

Section 7: Assessment of AAC System/Device

Trial Periods as Assessment for an AAC System or Device

- 1 Trial periods are essential for assessing whether any AAC system or device is appropriate for an individual.

- 2 Trial periods are essential for assessing suitability of both low- and high-tech systems or devices.

- 3 Suitability of an AAC system or device cannot be judged adequately from a single session or a single point in time.

- 4 Trial periods should be for a minimum of 8 weeks to ensure the individual with Rett syndrome gets a real chance to learn about and (attempt) to use the device/system.

- 5 Trial periods should be for a minimum of 8 weeks to ensure the individual's primary/key communication partners get a real chance to learn about and use the device/system.

- 6 Trial periods should be free/at no cost to the end user at point of use.

- 7 Individuals should be allowed more than one trial of the same AAC system or device (e.g., if the first trial was judged unsuccessful due to poor health at that point in time).

- 8 Individuals should be able to trial multiple AAC systems and devices.

- 9 During trial periods, the system/device should be used in multiple environments and with multiple communication partners.

- 10 During trial periods, the individual with Rett syndrome and their primary/key communication partners should be well-supported by knowledgeable and experienced professionals who are familiar with/trained to use the system/device on trial.

- 11 The professionals who offer support during a trial may include advisors who work for the communication aid company supplying the device, an SLT, an OT, an AAC/assistive technology specialist advisor, and others who are experienced with the device/system on trial.

Assessment of Device-Specific Features

When assessing the suitability of a device for an individual, it is extremely important to take the following features into consideration:

- 12 Portability

- 13 Options for mounting on a wheelchair, table, and wall

- 14 Robustness (durability)

- 15 Ability to adjust response time/sensitivity of responses

- 16 Availability of funding/approval for funding

- 17 Support from a wider community of families using the same device/software, including online communities (e.g., for sharing of page sets and help with troubleshooting)

- 18 Ease of repair in case of problems/breakdown

When assessing the suitability of a device for an individual, it is very important to take the following features into consideration:

- 19 Size

- 20 Weight

- 21 Battery life

- 22 Use in different environments (e.g., outside in sunshine or rain)

- 23 Range of software available (including language programmes, symbol sets, and any software the individual is already)

- 24 Availability of pre-made page sets in the relevant language

- 25 Complexity of programming required to personalise/adapt the device to suit the end user

- 26 Level of technical skill/knowledge required by communication partners

- 27 Support and training offered by supplier during a trial period

- 28 Long-term technical support and after care offered by the supplier

- 29 Obsolescence (age of model and remaining length of time that support, updates to software, parts, etc. will be available)

- 30 Capacity/functions available within the device

- 31 Cost to purchase

- 32 Cost of insurance

- 33 The potential for the individual to access the internet and social media as well as control their environment

Section 8: Intervention

General Principles of Intervention

- 1 Advice and information about the potential for communication should be provided at diagnosis or shortly thereafter.

- 2 Communication intervention and management should start early and be lifelong.

- 3 Communication intervention will help to develop functional communication skills, promote cognitive development, provide a foundation for literacy development, and improve social communication.

- 4 Communication intervention will help the individual with Rett syndrome to become more autonomous as a communicator. Autonomous refers to an individual being able to communicate what they want to say, to whomever they want to say it, and whenever and wherever they want to say it while using any form of communication.

- 5 Communication intervention and management should be reviewed regularly to make sure that it is always appropriate to the needs of the individual.

- 6 It is preferable that intervention takes place in a naturalistic context.

- 7 Individuals should be given frequent opportunities for practice.

Developing Goals for Intervention

- 8 Goals for intervention should include development of nonverbal, low-tech, and high-tech strategies.

- 9 Goals should be planned to follow the typical stages of child development.

- 10 Goals for intervention should aim to increase the frequency, variety, complexity, and clarity of communication so that individuals can interact with a wide range of communication partners.

- 11 Goals should be developed that consider the needs and preferences of the individual, their caregivers, and other important communication partners.

- 12 The SMART (Specific, Measurable, Agreed upon, Realistic, Time-based) framework can be used to develop communication goals.

Targets and Goals for Intervention

Communication Functions

- 13 Goals to expand the range of communicative functions (e.g., requests, answers, protests, comments, questions, descriptions, and greetings) should be included in intervention programmes for individuals with Rett syndrome.

- 14 Developing a “yes/no” response is important for all individuals with Rett syndrome.

- 15 “Yes/no” responses can be used to express agreement or disagreement, make choices, and/or answer questions.

- 16 To expand an initial vocabulary, goals should include words that cover a range of ideas, interests, and meanings, including emotions and social and academic language.

- 17 Language intervention should begin with exposure to a robust vocabulary (including core and fringe words) so that potential for communication is unlimited.

- 18 Limiting the options or choices given is appropriate for some individuals with Rett syndrome when any of the following exist: a risk for frustration, access issues, or a robust language system has been trialled for at least 12 months with limited success.

- 19 An individual’s vocabulary will change according to age, communication partner, language development, environment, mood, and context. The vocabulary used in an AAC system should allow for the same change and flexibility.

Ways of Communicating

- 20 Communication should be developed across multiple modalities informed by the comprehensive and holistic assessment of the individual and their communication partners.

Facial Expressions

- 21 Facial expressions (e.g., smiling and frowning) should be acknowledged as potentially communicative in individuals with Rett syndrome.

Body Movements

- 22 Body movements (e.g., leaning and/or moving towards or away from objects or people) should be acknowledged as potentially communicative in individuals with Rett syndrome.
-
- 23 Goals for maintaining body movements are appropriate for individuals who already use body movements (e.g., walking towards items for communicative purposes).

Gestures

- 24 Gestures (e.g., reaching, pointing, and/or waving) should be acknowledged as potentially communicative in individuals with Rett syndrome.
-
- 25 Goals for developing or maintaining gestures (e.g., reaching, pointing, and/or waving) are appropriate for individuals who already demonstrate some voluntary hand control.
-
- 26 Strategies can be developed to reduce hand stereotypies if they are judged to interfere with communication.
-
- 27 Strategies to reduce hand stereotypies must be tailored to the individual, be well-tolerated, and be acceptable to the individual and their significant others. These strategies can include splinting, holding or positioning the arm, and/or use of highly motivating activities.

Oral Speech Skills

- 28 Vocalisations should be acknowledged as potentially communicative in individuals with Rett syndrome.
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- 29 Goals for developing or maintaining sound production are appropriate for individuals who already produce sounds voluntarily.
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- 30 Spoken words or sentences should be acknowledged as communicative in individuals with Rett syndrome, even if echolalic or highly repetitive in nature.
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- 31 Goals for developing or maintaining spoken words or sentences are appropriate for individuals who already produce spoken words or word approximations.
-
- 32 Interventions for developing or maintaining sound production, spoken words, or sentences should be combined with aided AAC.

Eye Gaze

- 33 Looking at objects, individuals, and/or pictures should be acknowledged as potentially communicative in individuals with Rett syndrome.
-
- 34 Goals for developing or maintaining eye gaze (e.g., looking at objects, individuals, and/or pictures) are appropriate for individuals with Rett syndrome.

Symbols

- 35 The use of graphic symbols, photos, and text by individuals with Rett syndrome should be acknowledged as potentially communicative.
-
- 36 Goals for developing or maintaining use of graphic symbols, photos, and text are appropriate for individuals with Rett syndrome.

Aided AAC

- 37 It is extremely important for an individual to have more than one AAC system or device so that they can be used in different situations/settings (e.g., an eye-gaze device indoors and a symbol chart outdoors).
-
- 38 A low-tech AAC system should always be available as a back-up for any individual who has a high-tech AAC system.
-
- 39 An individual can be presented with two different AAC systems at the same time or asked to use more than one system at a time.
-
- 40 The same device can be used for communication and learning activities (e.g., for accessing the curriculum in school) as long as the individual is still able to access their full vocabulary.
-
- 41 The individual with Rett syndrome, their communication partner, and the aided AAC device should be positioned in a way to maximise joint attention in the communicative interaction.
-
- 42 Aided AAC can be used with individuals who are ambulatory. Portability is one important consideration when choosing an aided AAC system.
-
- 43 Ambulatory individuals should also be provided with access to their aided AAC system when seated (e.g., at mealtimes).
-
- 44 Aided AAC can be introduced and used successfully in adulthood.
-
- 45 Organisation of an AAC system affects the individual's ability to communicate effectively and efficiently. It plays a role in language learning and development, and it needs to be customised and modified over time.
-
- 46 Vocabulary can be organised according to semantic category in aided AAC.
-
- 47 Visual scene displays can be used as a starting point for aided AAC.
-
- 48 Activity grids (designed for a specific activity) can be used as a starting point for aided AAC.
-
- 49 Activity grids can increase participation and syntactic development by encouraging use of multiword combinations.
-
- 50 Context-based grids (similar to activity grids but designed for a specific context or environment) allow for greater generalisation than vocabulary designed around a single, specific activity.

Developing and Using Different Access Methods

- 51 Choice of access method can vary according to the individual's abilities at a given moment, type of aided AAC, and context.

Scanning

- 52 Scanning can be used when individuals are unable to use direct selection to access aided AAC.
-
- 53 Partner-assisted scanning can be used with individuals who have developed or are developing a "yes/no" response and are unable to independently operate a scanning system.

Direct Selection

- 54 Direct selection can be used when individuals have a way of directly activating aided AAC, including eye gaze, touching or pointing with finger or hand, operation of a switch, and/or a head pointer.
-
- 55 Eye gaze is usually the best way for an individual with Rett syndrome to access AAC.
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- 56 Eye gaze is not the only way for individuals with Rett syndrome to access AAC.
-
- 57 Individuals who are able to touch or point to access-aided AAC should be encouraged to use this access method as long as it does not limit the variety and complexity of their communication.
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- 58 A head pointer could be considered when other access methods are not available or effective.

Eye Gaze

- 59 An eye-gaze board (e.g., an E-tran frame) can be an appropriate form of aided AAC for individuals with Rett syndrome.
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- 60 Eye-tracking technology (e.g., a computer fitted with an eye tracker) can be an appropriate form of aided AAC for individuals with Rett syndrome.
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- 61 Eye-tracking technology can be used with individuals who are ambulatory. Strategies to support ambulatory individuals in using eye-tracking technology include positioning the device on a wall or table or in another area that the individual is able to access consistently.
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- 62 Eye-tracking technology can usually be used with individuals who wear glasses. If there is a problem, consider trying frameless glasses or non-reflective lenses.
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- 63 Eye-tracking technology can be used with individuals who have difficulty controlling head movements when their body and head are appropriately supported and when the device is appropriately positioned.

Reading and Writing

- 64 Reading stories together is an activity that is appropriate for all individuals with Rett syndrome to develop language, communication, and literacy skills.
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- 65 Most individuals with Rett syndrome should be exposed to activities to develop phonemic awareness.
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- 66 Most individuals with Rett syndrome should be exposed to activities to develop an awareness of print.
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- 67 Most individuals with Rett syndrome should be exposed to activities to develop a sight vocabulary.
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- 68 Most individuals with Rett syndrome should be exposed to activities to develop writing skills. This can include ‘scribbling’ (with an on-screen keyboard or using partner-assisted scanning) or writing letters or words.
-
- 69 Most individuals with Rett syndrome should be encouraged to create their own narratives or stories.

Intervention Techniques

- 70 Expanding is a technique used to reword and increase the complexity of a word or a phrase to make it more complete. Expanding can be used in communication interventions for individuals with Rett syndrome.
-
- 71 Aided language stimulation is a strategy in which the communication partner combines verbal output with aided AAC in order to support receptive language and to provide vocabulary. The partner may select vocabulary on the individual’s own AAC system or use another AAC system as they talk. Aided language stimulation can be used in communication interventions for individuals with Rett syndrome. Aided language stimulation may also be known as aided-language modelling or augmented-language input.
-
- 72 Modelling is a strategy where the communication partner uses the individual’s own AAC system when talking with them in order to teach by example. Modelling can be used in communication interventions for individuals with Rett syndrome.
-
- 73 Video modelling is a visual teaching method that involves watching a video of someone modelling a targeted behaviour or skill and then imitating the desired behaviour or skill. Video modelling can be used in communication interventions for individuals with Rett syndrome.
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- 74 Recasting is a technique used to correct errors so that communication is not obstructed. When an error is produced, the communication partner will repeat the error back to the learner in a corrected form. Recasting can be used in communication interventions for individuals with Rett syndrome.
-
- 75 Prompts or cues (e.g., gestures, demonstrations, touch, and signals) can be used to increase the likelihood that individuals will make correct responses.
-
- 76 Errorless learning involves providing prompts or cues immediately following a stimulus to ensure the individual provides a correct response. Errorless learning can be used in communication interventions for individuals with Rett syndrome.

Glossary of Terms

AAC techniques/strategies	Tools used by communication professionals to maximise communication in AAC users. These can include direct instruction, environmental instruction, routines and scripts, language intervention, manipulation of the environment, development of core vocabulary, instruction of communication partners, literacy instruction, social skills training, and role playing.
Access method	The way in which an individual is able to activate/control a low-tech or high-tech AAC system (e.g., by direct touch, by eye gaze, or by using a switch).
Aided communication	Using external tools, devices, or systems to enhance communication. These may be electronic or non-electronic (high-tech or low-tech).
Aided language modelling/ Aided language stimulation/ Augmented language input	Similar to above, this strategy focuses on modelling AAC use in language-rich environments that provide lots of opportunities for using AAC.
Assessment	Ways of finding out about an individual's strengths and needs in order to identify what forms of support are needed and/or to plan next steps/goals for future development.
Augmentative and alternative communication (AAC)	All forms of communication (other than oral speech) that are used to express thoughts, needs, wants, and ideas.
Best yes	This is the method used by the individual with Rett syndrome to answer "yes," in a way that is clear to their communication partners. The "yes" is highly individualised and can take different forms, including a head shake, a nod, a smile, a look at something, or a movement of the hand, arm, or body. The best "yes" is often identified by observing the individual with Rett syndrome in a variety of communication environments and discerning how they answer "yes/no" questions.
Caregiver	A parent or other person who has the main caring role for an individual with Rett syndrome.
Communication environment	The setting in which an individual with Rett syndrome has the potential to communicate. The environment includes the physical setting along with other individuals who are present and any particular demands of the setting (e.g., instructional, social, and medical).
Communication partner	Someone who interacts with an individual with Rett syndrome. They may/may not be experienced in using specific techniques to enhance and facilitate the interaction, and are likely to need some level of training in suitable techniques if not already skilled.
Communication professional	A professional with expertise (education and experience) in communication and in the assessment and treatment of communication disorders. The communication professional who works with individuals with Rett syndrome is often a speech and language therapist (SLT).
Communicative competence	"The state of being functionally adequate in daily communication and of having sufficient knowledge, judgement, and skills to communicate effectively in daily life" (Light, 1989). Communicative competence depends on knowledge, judgement, and skills in four interrelated domains: linguistic, operational, social, and strategic.

Core vocabulary	High-frequency words that make up about 80% of the words used by most people every day, especially pronouns, verbs, descriptors, and question words.
Dynamic display	Selection of a word/symbol on the screen automatically leads to a change in the word/symbol set displayed (e.g., leads to a new page).
Eye-gaze device	A type of speech generating device that is controlled by eye gaze. The device has either a built-in eye tracker or an eye-tracker module that connects to the device to detect and track where the user is looking. Usually, the speed and accuracy of selection can be adjusted to the needs of each user—e.g., the length of time the user must look at an item on screen in order to select it (dwell time) and the size/number of items on the screen.
Fringe vocabulary	Lower-frequency words (mostly nouns) which are usually context specific.
High-tech AAC system	An electronic device with speech output. The screen can have a static or a dynamic display, and the output can be recorded/digitised speech or synthesised speech. High-tech systems range from single message devices to complex computer-based systems.
Holistic	A rounded view of the individual with Rett syndrome as a complete person, rather than seeing/working with particular characteristics or challenges in isolation.
Intervention	Strategies and techniques used specifically to achieve short-term goals.
Key communication partners	People who are frequent communication partners of an individual with Rett syndrome.
Linguistic competence	The individual's receptive and expressive language abilities.
Low-tech AAC system	A system that is not electronic and does not require a power source (e.g., individual objects, photos, and communication board/book).
Management	Support offered in the longer-term, including strategies, techniques, and systems used on a daily basis to facilitate the individual's communication and which help them to participate in everyday activities.
Modelling	A strategy whereby the communication partner “leads by example” (e.g., pointing to symbols on a low-tech system or high-tech device as they talk to the individual with Rett syndrome).
Multimodal communication	Communicating through a combination of modalities (different ways)—e.g., facial expressions, body movements, gestures, sounds, eye gaze, pictures, photos, symbols, and written words. May also include oral speech.
Occupational therapist (OT)	An allied healthcare professional who works to help people achieve a full and satisfied state in life through the use of purposeful activity or interventions. An OT may assist individuals with Rett syndrome to participate to their maximum capacity in activities of daily living, such as feeding and dressing, and in occupational pursuits that are meaningful and engaging. They may also consult on access methods for communication.
Operational competence	The individual's skill in development, operation, and use of AAC systems.

Page set	The way words are organised on an AAC device. This can vary according to the choice of words/vocabulary items selected for display, the number and size of items on each page, and the symbols that are used. Page sets can be organised in a number of ways (e.g., by semantic category, activity/topic, context, and core and fringe vocabulary).
Partner-assisted scanning (PAS)	A strategy to assist choice-making or accessing vocabulary in a communication board or book. The communication partner lists a range of options and then goes back through the options one by one, giving time for the individual with Rett syndrome to say “yes” to the option they want.
Personal communication passport	A way of organising and sharing key information about how an individual communicates and what techniques, strategies, and equipment they need/use so that all communication partners can act in a consistent manner. They are usually written in the first person so that the individual has ownership of the information.
Physiotherapist (PT)	An allied healthcare professional who works to promote mobility, physical function, and quality of life through examination and physical intervention. A PT may assist individuals with Rett syndrome by developing programmes to improve range of motion, strength, and ambulation skills. They may also consult on seating and positioning when using adaptive equipment such as wheelchairs and standers. May also be known as a physical therapist.
Recorded/digitised speech	Natural speech (often the voice of a communication partner) that is recorded, stored, and replayed by a device.
Reflective practice	The ability to analyse one’s actions and associated impacts, and to engage in a process of continuous study and self-improvement.
Robust vocabulary/system	This includes a combination of core and fringe words that can be used in many situations and settings throughout the day.
Social competence	The individual’s skill in interpersonal communication and discourse.
Speech generating device (SGD)	A type of high-tech device, usually used to refer to a more complex computer-based system than a simple/single message device.
Speech and language therapist (SLT)	An allied healthcare professional who will identify communication strengths and challenges and design therapy programmes to maximise the communication potential of individuals with Rett syndrome. They will also provide instruction to communication partners and participate in design and management of AAC systems. May also be known as a speech-language pathologist (SLP).
Static display	Words/symbols remain fixed when selected.
Strategic competence	The individual’s skill in using strategies to overcome challenges in communicating using AAC.
Synthesised speech	Electronic, computer-produced speech that can often be set to match a user’s gender, age, and ethnicity.
Unaided communication	Not using external tools to communicate but relying on the user’s own body to convey messages. Examples include gestures, signs, or vocalisations.

Resources for Assessment of Communication

The assessment tools listed in this table were recommended by respondents to the survey of communication professionals who work with individuals with Rett syndrome. All assessments were then submitted to the Delphi survey panel for their feedback. Those listed here earned either an ‘agree’ or ‘neither agree nor disagree’ rating from the Delphi panel when asked about their value as an assessment tool for use with individuals with Rett syndrome. The information below is based on the personal clinical experience of the individuals who responded to the communication professionals survey. This is not meant to be an exhaustive list. Specific recommendations are available for some, but not all, assessment tools. All data was up-to-date as of the time of the printing of this document. All assessments are published in English unless otherwise indicated. Refer to the Assessment section of the Guidelines for specific strategies to use in situations where communication skills are being assessed.

NAME OF TOOL	AUTHOR/PUBLISHER/WEBSITE	PURPOSE	AGE RANGE	NOTATIONS/ADAPTATIONS
Augmentative & Alternative Communication Profile: A Continuum of Learning (AACP)	Tracy M. Kovach, Ph.D., www.linguisystems.com	Measures subjective, functional skills for communication using AAC devices, re-evaluates skill level, and monitors progress.	2 - 21 years	Can be administered by a speech and language therapist or used by members of a multidisciplinary team who have knowledge about the individual's physical, cognitive and social skills related to AAC.
ACETS Eye Gaze Technology Screening Checklist	Sharon Lenz, M.Sc., R.SLP, SLP(C), Nadene Krack, M.Ed., BMR, OT(C). Developed by ACETS (Augmentative Communication and Educational Technology Service) at Alberta Children's Hospital. http://streaming.syncrocloud.com/rettssyndrome/item_file_sc515ca980d24da_289995c1.pdf	Comprehensive screening tool that identifies appropriate candidates for full eye gaze technology assessment. Gathers information on general vision, eye health, eye skills, visual memory & attention, communication, access abilities, positioning, computer skills, caregiver support, environment, intended activities, motivation, overall health, and equipment availability.	Age not specified	Checklist can be completed by any individual who is familiar with the person with Rett syndrome.
British Picture Vocabulary Scale (BPVS3)	GL Assessment. www.gl-assessment.co.uk	Tool for receptive language assessment. Identifies delays in vocabulary development, suitable for non-readers, individuals with language, and/or motor impairments.	3 - 16 years	Responses can be given through pointing or gesture. Test can be adapted by mounting individual pictures on a board or E-TRAN frame.

NAME OF TOOL	AUTHOR/PUBLISHER/WEBSITE	PURPOSE	AGE RANGE	NOTATIONS/ADAPTATIONS
Computer-Based Instruction for Low Motor Language Testing (C-BiLLT)	Johanna Geytenbeek, Ph.D., SLP www.c-billt.com	Computerised test for assessing spoken language comprehension in unintelligible or non-speaking children with motor challenges.	1.6 – 7.0 years	The original (Dutch) version uses vocabulary from two Dutch receptive language measures (the Streeflijst woordenschat and Lexilijst) and the Reynell Developmental Language Scales. The test is being piloted in Norwegian, German, English, Swedish and Romanian, with further languages also planned. Responses can be made through reaching, pointing, or eye gaze, using a touchscreen, switch or eye gaze device.
Clinical Evaluation of Language Fundamentals - Preschool Third Edition (CELF-P 3)	Elisabeth Wiig, Ph.D., Eleanor Semel, Ph.D., Wayne Secord, Ph.D. www.pearsonclinical.com	Assessment of receptive and expressive language	3.0 – 6.11 years	Selected subtests can be used to gather specific information.
Clinical Evaluation of Language Fundamentals - Fifth Edition (CELF 5)	Elisabeth Wiig, Ph.D., Eleanor Semel, Ph.D., Wayne Secord, Ph.D. www.pearsonclinical.com	Assessment of receptive and expressive language.	5 – 21 years	Selected subtests can be used to gather specific information.
Communication Matrix	Charity Rowland, Ph.D. www.communicationmatrix.org	Free assessment tool for families and professionals to identify communication status, progress, and unique needs of individuals at the early stages of communication or those using augmentative communication.	All ages	Data can be gathered over time, not in just one session. Information can be gathered through interview, elicitation, or observation.
Dynamic AAC Goals Grid (DAGG-2)	Tobii Dynavox. http://tdvox.web-downloads.s3.amazonaws.com/MyTobiiDynavox/dagg%20%20-%20writable.pdf	Provides a systematic means to assess (and reassess) an individual's current skills in AAC and to assist partners in developing a comprehensive, long-reaching plan for enhancing the AAC user's communicative independence.	All ages	Can be used with a variety of AAC users.

NAME OF TOOL	AUTHOR/PUBLISHER/WEBSITE	PURPOSE	AGE RANGE	NOTATIONS/ADAPTATIONS
Functional Communication Profile – Revised (FCP-R)	Larry Kleiman, M.A., CCC-SLP. www.linguisystems.com	Provides an inventory of the individual's communication abilities, mode of communication (e.g., verbal, sign, nonverbal, and augmentative), and degree of independence. Subtests include sensory/motor, attentiveness, receptive/expressive language, pragmatic language, speech, voice, oral, fluency, and non-oral communication.	3 years – adult	Individuals are assessed and rated in the major skills categories of communication through direct observation, teacher and caregiver reports, and one-on-one testing.
Inventory of Potential Communicative Acts (IPCA)	Jeff Sigafoos, Ph.D., Michael Arthur-Kelly, Ph.D., Nancy Butterfield, M.Ed. (2006). Inventory of potential communicative acts, in <i>Enhancing everyday communications for children with disabilities</i> . Baltimore MD: Paul H. Brookes Publishing Co.	A tool to collect data on the potential communicative acts of individuals with severe communication impairment associated with a range of developmental and physical disabilities.	No age specified	Data is collected through interviews completed by parents, teachers, and therapists.
New Reynell Developmental Language Scales (NRDLS)	GL Assessment. https://www.gl-assessment.co.uk/products/new-reynell-developmental-language-scales-nrdls/	Identifies speech and language challenges in young children.	3 – 7.6 years	Can be adapted to obtain eye-gaze responses.
Peabody Picture Vocabulary Test, Fifth Edition (PPVT-5)	Douglas M. Dunn, Ph.D. www.pearsonclinical.com	Assesses receptive vocabulary.	2.6 years – adult	Can be adapted by mounting the pictures on an eye-gaze board or frame. The number corresponding to each picture could also be displayed on a board. Alternatively, the pictures can be displayed on a computer screen and accessed through eye gaze. Clinicians can also use partner-assisted scanning and ask the individual to respond when the appropriate item is named or pointed to.

NAME OF TOOL	AUTHOR/PUBLISHER/WEBSITE	PURPOSE	AGE RANGE	NOTATIONS/ADAPTATIONS
Pragmatics Profile of Everyday Communication Skills in Children (Revised Edition) AND Pragmatics Profile of Everyday Communication Skills in Adults	Hazel Dewart, Susie Summers. http://complexneeds.org.uk/modules/Module-2.4-Assessment-monitoring-and-evaluation/All/downloads/m08p080c/the_pragmatics_profile.pdf https://www.flexiblemindtherapy.com/uploads/6/5/5/2/65520823/pragmatics_profile_adults.pdf	Provides a profile of a child or an adult as a communicator within the context of daily life.	Birth – 10 years and Teenage – elderly	Data is collected through interviews and can be gathered over time. The child profile includes 2 interview formats for use with parents and teachers (<4 years and 5-10 years). The adult version includes 2 formats ('self-report' and 'other report') for use with the adult as well as their key communication partners.
Pragmatics Profile for People who use AAC	Suzanne Martin, Katherine Small, Rachel Stevens. https://acecentre.org.uk/resources/pragmatics-profile-people-use-aac/	Adapted for users of all ages from the Pragmatics Profile of Everyday Skills in Children (see above)	No age range specified	Designed to be used with individuals who have used AAC in the past, are currently using AAC, or are using informal modes of AAC and there is a goal to introduce more formal methods.
Preschool Language Scales, Fifth Edition (PLS-5)	Irla Zimmerman, Ph.D., Violette Steiner, B.S., Roberta Pond, M.A. www.pearsonclinical.com	Assesses receptive and expressive language skills for children.	Birth – 7.11 years	The individual with Rett syndrome can use eye gaze to indicate choices on a page. Alternatively, some pages can be mounted on an eye-gaze board. A number of the items can be scored using parent or caregiver report.
Test of Early Communication and Emerging Language (TECEL)	Mary Huer, Linda Miller. Available from multiple sources, including: www.pearsonclinical.com www.superduperinc.com	A revision of the Non-Speech Test. Assesses communication, including nonverbal and symbolic communication.	2 weeks – adult	Appropriate for nonverbal individuals and those who use AAC.
The Triple C: Checklist of Communication Competencies	Karen Bloomberg, Denise West, Hilary Johnson, Teresa Iacono. www.spectronics.com.au	Assesses communication skills in adolescents and adults who are nonverbal.	Adolescent – adult	Communication partners complete a checklist about the individual's communication skills.
Vineland Adaptive Behavior Scales – Third Edition (Vineland-3)	Sara S. Sparrow, Ph.D., Domenic V. Cicchetti, Ph.D., Celine A. Saulnier, Ph.D. www.pearsonclinical.com	Measure of personal and social skills for individuals with developmental disabilities.	Birth – 90 years	Parents, caregivers and teachers can provide information. Caregiver forms available in English and Spanish.

Resources for Development and Tracking of Communication Goals

The resources listed in this table were recommended by respondents to the survey of communication professionals who work with individuals with Rett syndrome. All resources were then submitted to the Delphi survey panel for their feedback. The resources listed here earned either an ‘agree’ or ‘neither agree nor disagree’ rating from the Delphi panel when asked about their value as a tool for use with individuals with Rett syndrome. The information below is based on the personal clinical experience of the individuals who responded to the communication professionals survey. This is not meant to be an exhaustive list. Specific recommendations are available for some, but not all, resources. All data was up-to-date as of the time of the printing of this document. All resources are published in English unless otherwise indicated. Refer to the Assessment section of the Guidelines for specific strategies to use in situations where communication skills or goal achievement are being assessed.

NAME OF TOOL	AUTHOR/PUBLISHER/WEBSITE	PURPOSE	AGE RANGE	NOTATIONS/ADAPTATIONS
Canadian Occupational Performance Measure (COPM)	www.thecopm.ca	An evidence-based outcome measure designed to capture a client's self-perception of performance in everyday living, over time. Focuses on occupation in all areas of life, including self-care, leisure, and productivity.	Ages not specified	Parents/caregivers of individuals with Rett syndrome can be asked to report on skills they have observed even if the skill is inconsistent. Available in 35 languages.
Goal Attainment Scaling (GAS)	Thomas Kiresuk, Robert Sherman. Available from a number of sources: https://www.sralab.org/rehabilitation-measures/goal-attainment-scale	A method to measure the extent to which an individual's goals are achieved in the course of intervention. This provides for an individualised outcome measure. The scoring is completed in a standardised way to allow for statistical analysis.	Ages not specified	Goals and benchmarks to measure success are agreed upon before the start of intervention.
The SETT Framework (Student, Environments, Tasks, Tools)	www.joyzabala.com	A four-part model to promote collaborative decision making for choosing, implementing, and evaluating assistive technology.	3.0 – 6.11 years	Handouts to use to implement the model are available at the author's website.
Talking Mats	www.talkingmats.com	A set of communication symbols that can be used to allow nonspeaking individuals, or those with limited verbal skills, to convey a range of ideas or opinions. The symbol system can be used as part of an assessment to determine a starting point for communication and for development of goals.	5 – 21 years	Symbols are easily recognisable and do not require literacy skills. Individuals from multiple linguistic or cultural backgrounds may use them.

Links to Useful Websites and Organisations

As this would be too long a list to cover information specific to all countries and regions, a few examples are offered on this page that may be of interest internationally or that sign-post links to Rett Associations in different countries. It is recommended that where a Rett Association exists, they should be your first point of contact for information relating to that country.

Please note: In this UK-version of the Handbook, links that are specific to the UK and Ireland have been added at the end of this Appendix on pages 100-101.

Health-Related Resources for Rett Syndrome

- Rettsyndrome.org – Rett Syndrome Primary Care Guidelines
https://www.rettsyndrome.org/wp-content/uploads/RSO_PrimaryCareGdlns_Final1919-1.pdf
- Rettsyndrome.org – RettEd webinars (range of Rett-related research and care topics)
<https://www.rettsyndrome.org/for-families/education/>
- Rett Syndrome Europe – Rett Resource
<https://www.rettsyndrome.eu/rett-resource/>
- Rett Disorders Alliance UK – Rett Syndrome Healthcare Checklist
<https://www.rettuk.org/resources/resources-for-families/rett-disorders-alliance-health-checklist/>
- Rett UK Health Passport
<https://www.rettuk.org/wp-content/uploads/2018/04/Rett-Health-Passport-Fillable.pdf>
- French National Rett Syndrome Guidelines
https://www.has-sante.fr/upload/docs/application/pdf/2017-05/dir4/pnds_-_syndromes_de_rett_et_apparentes_2017-05-03_14-15-56_224.pdf

Links to Rett Clinics and National Rett Associations

The links given here are to websites that share information/links to multiple countries.

- US and international Rett clinics
<https://www.rettsyndrome.org/for-families/rett-syndrome-clinics/>
- European Rett associations
<https://www.rettsyndrome.eu/member-associations/>

International AAC-Related Organisations

- International – ISAAC – <https://www.isaac-online.org>

Free Resources/Advice Sheets for AAC & Literacy

Free Vocabularies

Project Core, Universal Core Vocabulary – <http://www.project-core.com/communication-systems/ARASAAC> – <http://www.arasaac.org/>
Bildstöd.se – <http://bildstod.se/>
SymbolsForAll – <https://www.symbolsforall.org.uk/>

Developing Yes/No Responses

Project Core – Quick Reference Guides – Communicating Yes or No -
https://www.dropbox.com/s/dl/6orcxy9jjj5ctdv/Communicating_Yes_and_No.pdf
Rett UK – Communication Resources – Getting Started.
<https://www.rettuk.org/wp-content/uploads/2017/03/formatted-website-yes-no.pdf>

Modelling

Project Core – Quick Reference Guides – Modelling the Universal Core -
https://www.dropbox.com/s/dl/yvx09fxe4t8mx2o/Project_Core_Modelling_One-pager.pdf
Rett UK – Communication Resources – Modelling -
<https://www.rettuk.org/wp-content/uploads/2017/03/formatted-website-modelling.pdf>

Partner-Assisted Scanning (PAS)

Project Core – Quick Reference Guides – Partner Assisted Scanning -
https://www.dropbox.com/s/dl/1cccs133h7q4voi/Partner_Assisted_Scanning.pdf
Rett UK – Communication Resources – Partner Assisted Scanning -
<https://www.rettuk.org/wp-content/uploads/2017/03/formatted-website-pas.pdf>

Literacy

Project Core – <http://www.project-core.com/>
Dynamic Learning Maps – <https://www.dlmpd.com/>
Tar Heel Reader (free, accessible online books for all ages) – <https://tarheelreader.org>
Tar Heel Shared Reader – <https://sharedreader.org>
Reading Avenue by Tobii Dynavox (free resource as part of Boardmaker Online) –
<https://www.tobiidynavox.com/en-US/software/web-applications/boardmakeronline/>
Rett UK – Communication Resources – Getting Started with Reading –
<https://www.rettuk.org/wp-content/uploads/2017/03/formatted-website-reading1.pdf>
Rett UK – Communication Resources – Getting Started with Writing –
<https://www.rettuk.org/wp-content/uploads/2017/03/formatted-website-writinga.pdf>

UK and Ireland Websites and Organisations

Rett Associations

- Rett UK – <https://www.rettuk.org>
- Reverse Rett – <https://www.reverserett.org.uk>
- Rett syndrome Ireland – <http://rettsyndrome.ie>

Branches of ISAAC

- Communication Matters (UK-wide) – <https://www.communicationmatters.org.uk>
- ACiP:S (Augmentative Communication in Practice: Scotland) – <https://acipscotland.wordpress.com>

Professional Associations

- RCSLT (Royal College of Speech and Language Therapists) (UK-wide) – <https://www.rcslt.org>
- IASLT (The Irish Association of Speech and Language Therapists) – <https://www.iaslt.ie>

AAC Suppliers – High and Low Tech Systems

- Tobii Dynavox – <https://www.tobiidynavox.com/en-GB/>
Written information/resources – <https://www.tobiidynavox.com/en-GB/support-training/>
Recorded webinars – https://www.youtube.com/channel/UCUFS2me2uk6qV1wj2o_9jg
- Smartbox – <https://thinksmartbox.com>
Written information – <https://thinksmartbox.com/smart-support/learning-resources/>
Recorded webinars – <https://thinksmartbox.com/smart-support/webinars/>
- Safe Care Technologies (Tobii Dynavox reseller in the Republic of Ireland)
– <http://www.safecaretechnologies.com/>
- Liberator – <https://www.liberator.co.uk>
Written information/resources – <https://www.liberator.co.uk/resources>
Recorded webinars – <https://www.youtube.com/user/LiberatorAACvideos>
- Sensory Guru – <http://www.sensoryguru.com>
- Inclusive Technology – <http://www.inclusive.co.uk>
- EyeTech – <https://eyetechds.com>
- AssistiveWare – <http://www.assistiveware.com/>

AAC Suppliers – Low Tech Systems

- Widgit – <https://www.widgit.com>
- Talking Mats – <https://www.talkingmats.com>
- Ability World – <http://www.ability-world.com>

Mounting & Environmental Control Systems

- Mounts & More – <http://www.aacmounts.com>
- Possum – <http://www.possum.co.uk>
- Steeper – <https://www.steepergroup.com>

AAC Assessment Services

NHS England Specialised AAC Services

A postcode search can be used to locate services – <https://servicefinder.acecentre.net>

See also: <https://www.communicationmatters.org.uk/assessment-routes/#types-of-assessment-services>

Specialised Commissioning Region	Service Name	Website
North West	Ace Centre (Oldham)	http://www.acecentre.org.uk
North East	Regional Communication Aid Centre (Newcastle)	https://www.cntw.nhs.uk/resource-library/regional-communication-aid-service/
Yorkshire and Humber	Barnsley Assistive Technology Team (Barnsley)	http://www.barnsleyhospital.nhs.uk/at
West Midlands	Access to Communication & Technology (Birmingham)	http://www.bhamcommunity.nhs.uk/act
East Midlands	Lincoln Electronic Assistive Technology Service (Lincoln)	http://www.eatslincoln.co.uk
East of England	Communication Aid Service East of England (Cambridge)	https://www.cuh.nhs.uk/our-services/communications-aid-service-east-of-england-casee/
South East	Kent & Medway Communication and Assistive Technology Service (Canterbury)	Adults – http://www.ekhuft.nhs.uk/acad Children – http://www.kelsi.org.uk/support-for-children-and-young-people/support-for-schools/kent-and-medway-communication-and-assistive-technology-service
	Chailey Communication Aid Service (Lewes)	http://www.sussexcommunity.nhs.uk/services/chailey-communication-aid-service.htm
Wessex & Thames Valley	Ace Centre (Abingdon)	http://www.acecentre.org.uk
South West	AAC West (formerly Bristol Communication Aid Service)	http://www.nbt.nhs.uk/bcas
London	Compass Assistive & Rehabilitation Technology Service (London)	https://www.rhn.org.uk/what-makes-us-special/services/compass/
	Augmentative Communication Aid Service – Great Ormond Street (London)	https://www.gosh.nhs.uk/medical-information/clinical-specialties/neurodisability-information-parents-and-visitors/clinics-and-services/augmentative-communication-service
	Guys & St Thomas Assistive Communication Service (London)	http://www.guysandstthomas.nhs.uk/ACS
	Assistive Communication Service (London)	https://clch.nhs.uk/services/assistive-communication-service

Scotland, Wales, Northern Ireland and Republic of Ireland

Service Name	Website
CALL Scotland	http://www.callscotland.org.uk
SCTCI (Scottish Centre of Technology for the Communication Impaired)	https://www.nhsgcc.org.uk/your-health/health-services/westmarc/westmarc-services/scici/
Ayrshire & Arran AAC Resource	https://www.nhsaaa.net/allied-health-professionals-ahps/speech-and-language-therapy/augmentative-and-alternative-communication/
FACCT (Fife Augmentative and Alternative Communication Team)	https://www.nhsfife.org/services/services-and-departments/speech-and-language-therapy/alternative-and-augmentative-communication-aac/
Keycomm (Lothian Communication Technology Service)	http://www.keycommaac.wordpress.com/
TASSCC (Technological Assessment and Support Service for Children and the Curriculum), Aberdeen	https://live.cloud.servelec-synergy.com/Aberdeen/PublicEnquiry_FS/Search.aspx?BX=PGv-VJeYGGuA%3D
NCEAT (National Centre for Electronic Assistive Technology), Cardiff	https://cavuhb.nhs.wales/our-services/electronic-assistive-technology/the-aac-hub/
The Communication Advice Centre, Belfast	https://advicefinder.turn2us.org.uk/Home/Details/6600
CRC (Central Remedial Clinic), Dublin	https://www.crc.ie/who-we-are/clinics-and-specialist-services/national-consultative-services-and-specialist-clinics/augmentative-and-alternative-communication-aac/

Advisory Group and Expert Panel Members

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