



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 honor 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 maximize 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 completed 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 optimize 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 organizations 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.

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, vocalizations, 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 maximize an individual's skills in initiating communication and expressing ideas as independently as possible. If their communication attempts are not recognized 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 vocalize 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 customized 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 vocalizations 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 favored objects, foods, people, or activities, and to attend to others modeling 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 modeling, Mina will attend to aided language modeling 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 recognized 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 behavior 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

Vocalizations

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 individualized for each user – including gestures and facial expressions, vocalizations, 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 behaviors/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” behavior is identified, all communication partners should be informed so they can recognize and reinforce the behavior. By responding consistently to the behavior they are interpreting as a “yes,” communication partners can help to increase the frequency of that behavior (e.g., by saying, “You’re looking at me; I think you are saying yes.”) A “best yes” behavior can also be taught more directly (e.g., by saying, “Look at me for yes.”)

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

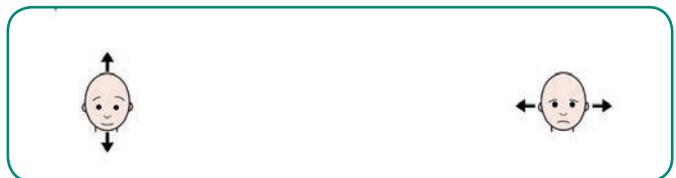
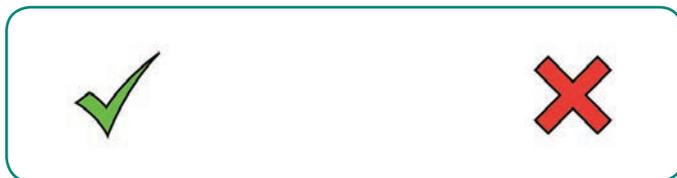
The forms used by the individual for expressing “yes” or “no” may become clearer and more specific over time. In the beginning, for example, an individual may confirm desired options with a smile. The communication partner can then say (while modeling a head nod and/or pointing at a symbol for “yes”), “Yes, you are smiling; I think that’s yes!” and provide the desired option. Over time, and with many opportunities to practice the behavior, 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 honored 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 programs 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 vocalizations.

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.

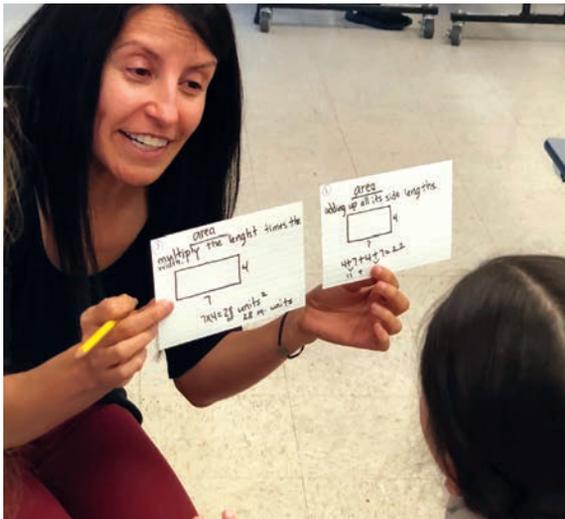
It is extremely important for an individual to have more than one AAC system or device so that they can be used in different situations/settings (e.g., an eye-gaze device indoors and a symbol chart outdoors).

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 maximize 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 modeling 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

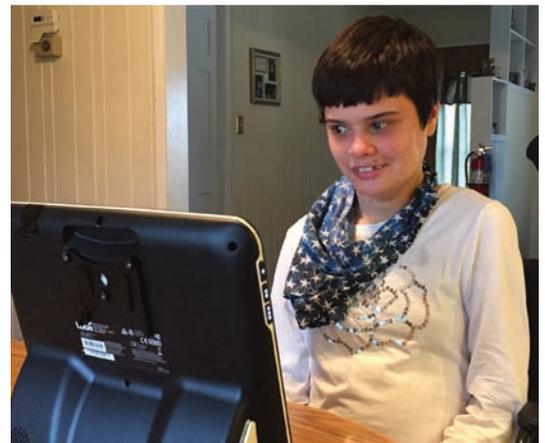
- Aided AAC can be used with individuals who are ambulatory. Portability is one important consideration when choosing an aided AAC system.
- Ambulatory individuals should also be provided with access to their aided AAC system when seated (e.g., at mealtimes).

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.

MODELING 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 MODELING 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 Modeling 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 trialed 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 trialed 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 Organizing Vocabulary

The organization 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 organized 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.

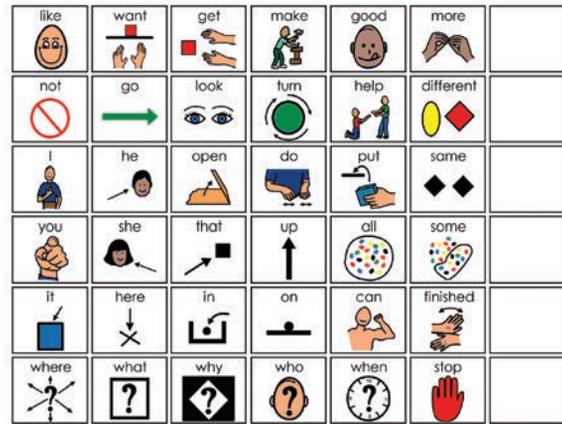
The words or phrases can be organized according to how often they are used or in categories, activities or contexts, and visual scene displays.

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 organizing 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 generalization 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 personalized 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 organized 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 favorite 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 modeling. 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 behaviors exhibited by Alyssa—such as head and body movements, eye-gaze, and vocalizations—are all treated by her parents as intentional behaviors that are communicative. In this way, they continually reinforce her behaviors by acknowledging that the behaviors 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 modeling the use of two words at a time and gradually move on to modeling 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, program, 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 trialed 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 center 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 organized by our Rett association 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 humor. One of her favorite 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 realize 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

Modeling

One way of learning new skills is to watch other people and imitate their actions. Modeling 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 Modeling, Aided AAC Modeling, and Augmented Language Input are all based on the concept of modeling (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 digitized speech. Aided language stimulation is often described as mirroring how children naturally learn to use speech as it follows a developmental framework.

Video Modeling

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 behavior through watching it used by others. The target behavior can be highlighted using video editing software so that the individual's attention is drawn to the behavior. Arrows or colored frames can be used to highlight the target behavior. Video modeling can also be used as a technique when training communication partners.

VIDEO MODELING IS...

a visual teaching method that involves watching a video of someone modeling a targeted behavior or skill and then imitating the desired behavior 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 modeling.

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)

