



# RETT SYNDROME Communication Guidelines



# RETT SYNDROME Communication Guidelines:

A handbook for therapists, educators, and families



This UK and Ireland edition is printed with support  
from Rett UK



This project was financed by a HeART Grant from Rettsyndrome.org.

The international core work group was coordinated by the Rett Expertise Centre Netherlands-GKC.

Members of this group (the project team) were:

- **Gillian S. Townend, PhD CertMRCSLT**, Speech and Language Therapist and Researcher, Rett Expertise Centre Netherlands-GKC, Maastricht University Medical Center, Maastricht, The Netherlands.
- **Theresa E. Bartolotta, PhD CCC-SLP**, Speech-Language Pathologist and Adjunct Professor, Department of Speech-Language Pathology, School of Education, Monmouth University, NJ, USA.
- **Anna Urbanowicz, PhD**, Occupational Therapist and VC Postdoctoral Fellow, Social and Global Studies Centre, School of Global, Urban, and Social Studies, RMIT University, Melbourne, Australia.
- **Helena Wandin, PhD reg. SLP**, Speech-Language Pathologist, Swedish National Center for Rett Syndrome and Related Disorders, Frösön, Sweden.
- **Leopold M. G. Curfs**, Director of the Rett Expertise Centre Netherlands-GKC, Maastricht University Medical Center, and Professor of Intellectual Disabilities, Maastricht University, Maastricht, The Netherlands.

© Rett Expertise Centre Netherlands-GKC / Rettsyndrome.org

1st Edition: 2020

The material in this handbook is subject to copyright. It may be used and distributed freely as long as the authors are acknowledged. Translation into other languages is encouraged; however, permission to translate must be obtained from the authors prior to translation.

Contact: Gillian Townend, g.townend@maastrichtuniversity.nl

Journal reference for the guidelines:

Townend, G.S., Bartolotta, T.E., Urbanowicz, A., Wandin, H., Curfs, L.M.G. (2020). Development of consensus-based guidelines for managing communication in individuals with Rett syndrome. *Alternative and Augmentative Communication*, 36(2), 71-81.

Citation for this book:

Townend, G.S., Bartolotta, T.E., Urbanowicz, A., Wandin, H., Curfs, L.M.G. (2020). Rett syndrome communication guidelines: a handbook for therapists, educators and families. Rett Expertise Centre Netherlands-GKC, Maastricht, NL, and Rettsyndrome.org, Cincinnati, OH.

Erratum: December 2020

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.

---

## Acknowledgment from Authors

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

February 2020

## Acknowledgment from Rettsyndrome.org

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.

---

# Table of Contents

<b>Foreword</b> .....	2	<b>Section 7: Assessment of AAC System/Device</b> .....	46
<b>Introduction</b> .....	3	Trial Periods as Assessment for an AAC System or Device .....	47
<b>Section 1: Guiding Principles</b> .....	6	Assessment of Device-Specific Features .....	48
Rights of the Individual with Rett Syndrome .....	7	<b>Section 8: Intervention</b> .....	50
Beliefs and Attitudes.....	10	General Principles for Intervention .....	51
<b>Section 2: Professional Practice</b> .....	12	Developing Goals for Intervention .....	54
Principles of Teamwork .....	13	Targets and Goals for Intervention.....	55
Responsibilities of Professionals.....	14	Communication Functions .....	58
Rett Syndrome Specialist Clinics and Expertise Centres .....	15	AAC Systems.....	58
<b>Section 3: Features of Rett Syndrome and Coexisting Conditions</b> .....	16	Developing Vocabulary.....	62
Features Associated with Main or Supportive Clinical Criteria.....	18	Choosing and Organising Vocabulary .....	63
Coexisting Conditions.....	20	Access Methods.....	66
<b>Section 4: Strategies to Optimise Engagement</b> .....	22	Reading and Writing.....	70
Attitudes and Behaviours of Communication Partners.....	23	A Final Word on Intervention Techniques.....	72
Strategies Targeting Internal Factors that May Impact Communication.....	26	<b>Appendices</b> .....	74
Additional Considerations .....	30	<b>Appendix 1: Statements and Recommendations</b> .....	75
<b>Section 5: Assessment</b> .....	32	<b>Appendix 2: Glossary of Terms</b> .....	90
General Principles of Assessment.....	33	<b>Appendix 3: Resources for Assessment of Communication</b> .....	93
Assessment of the Individual .....	35	<b>Appendix 4: Resources for Development and Tracking of Communication Goals</b> .....	97
Assessment Procedures.....	36	<b>Appendix 5: Links to Useful Websites and Organisations</b> .....	98
Standardised Assessment or Dynamic Assessment?.....	36	<b>Appendix 6: Advisory Group and Expert Panel Members</b> .....	102
Other Considerations for Assessment.....	39		
<b>Section 6: AAC Assessment</b> .....	40		
Starting Point - Assessment of Readiness for AAC .....	42		
Components of AAC Assessment.....	42		
Models of Best Practice for AAC Assessment .....	43		
Assessment of Readiness for Eye-Gaze Technology .....	44		

All websites listed in this book can be accessed online at [communication.rettssyndrome.org](http://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.



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.
- 
- 29 Goals for developing or maintaining sound production are appropriate for individuals who already produce sounds voluntarily.
- 
- 30 Spoken words or sentences should be acknowledged as communicative in individuals with Rett syndrome, even if echolalic or highly repetitive in nature.
- 
- 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.
- 
- 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.
- 
- 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.
- 
- 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.
- 
- 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.
- 
- 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.
- 
- 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.
- 
- 65 Most individuals with Rett syndrome should be exposed to activities to develop phonemic awareness.
- 
- 66 Most individuals with Rett syndrome should be exposed to activities to develop an awareness of print.
- 
- 67 Most individuals with Rett syndrome should be exposed to activities to develop a sight vocabulary.
- 
- 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.
- 
- 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.



