



RETT SYNDROME Communication Guidelines

RETT SYNDROME Communication Guidelines:

A handbook for therapists, educators, and families



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

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

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

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

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

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

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

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

Gillian Townend
Theresa Bartolotta
Anna Urbanowicz
Helena Wandin
Leopold Curfs

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

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

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

Foreword

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

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

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

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

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

On behalf of all Rett parents everywhere,

Mariëlle van den Berg

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

Introduction

Background

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

Why we developed the communication guidelines

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

How we developed the communication guidelines

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

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

The purpose of this handbook

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

How to use this handbook

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

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

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

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

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

Language note:

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

ASSESSMENT



“Assessments should be ongoing and dynamic”

Assessment

General Principles of Assessment

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

Principles of Assessment

Assessment should be part of a team process.

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

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

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

Principles of Assessment

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

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

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

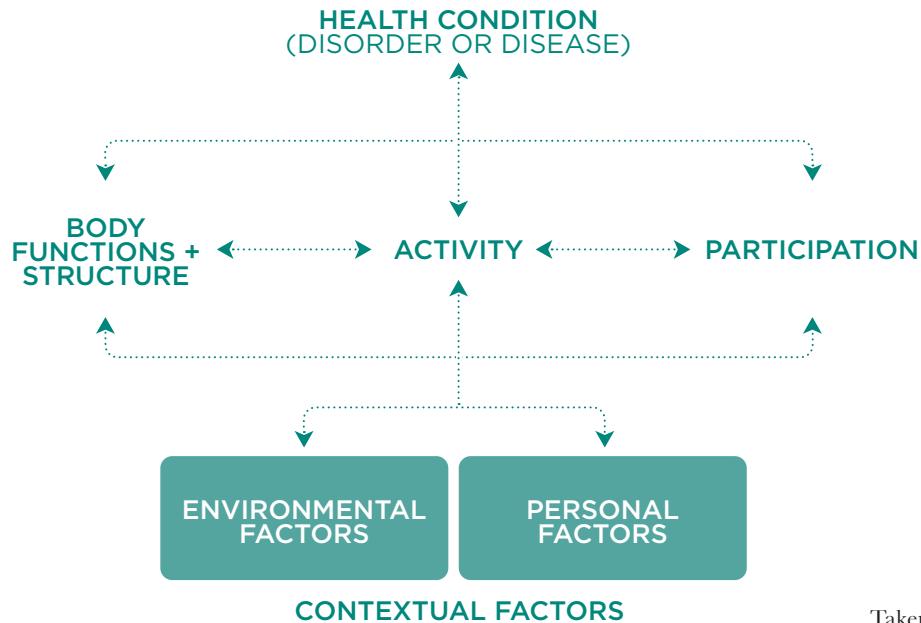
The ICF (World Health Organization, 2001)¹ is a framework that describes health and health-related domains. It is composed of four domains:

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

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

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

FIGURE 5: ICF MODEL



Taken from WHO, 2002, p.9²

Principles of Assessment

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

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

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

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

Principles of Assessment

Assessments should be undertaken in natural or naturalistic settings.

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

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

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

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

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



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

Professional

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

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

Expert panel

Social Networks Inventory

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

Means – Reasons – Opportunities Model

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

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

Assessment of the Individual

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

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

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

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

Principles of Assessment

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

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

Assessment Procedures

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

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

Standardised Assessment or Dynamic Assessment?

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

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



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

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

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

Professional

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

Expert panel

Principles of Assessment

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

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

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

Principles of Assessment

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

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

DYNAMIC ASSESSMENT IS...

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

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



“Formal assessment tools are not recommended.”

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

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

Professional

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

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

Expert panel



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

Professional

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



DYNAMIC ASSESSMENT – EXAMPLE:

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

1

TEST

- PROVIDE OPPORTUNITY
- WAIT

2

INTERVENE

- MODEL
- PROVIDE OPPORTUNITY
- WAIT

3

RETEST

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

STEP 1 – TEST

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

STEP 2 – INTERVENE

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

STEP 3 – RETEST

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

Other Considerations for Assessment

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

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

Principles of Assessment

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

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

Eye gaze is usually the best access method for:

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

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



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

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

Expert panel

