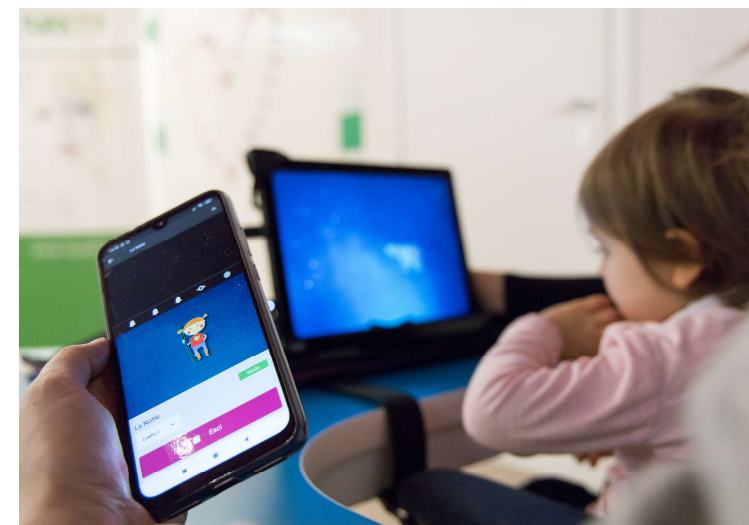


# Advanced technologies for cognitive and motor telerehabilitation in Rett Syndrome: Amelie and Tele-Airett

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**AIRETT'S TELEREHABILITATION:**  
If the patients can't go to the Airett center,  
the Airett therapists go to the patients



GENETIC RESEARCH



CLINICAL RESEARCH



**APPLIED/REHABILITATIVE RESEARCH**





Research in Developmental Disabilities  
Volumes 53–54, June–July 2016, Pages 73–85

## Cognitive training modifies frequency EEG bands and neuropsychological measures in Rett syndrome

Rosa Angela Fabio<sup>a</sup>, Lucia Billeci<sup>b</sup>, Giulia Crifaci<sup>b</sup>, Emilia Troise<sup>a</sup>, Gaetano Tortorella<sup>c</sup>, Giovanni Pioggia<sup>d</sup>

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DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

SCOPING REVIEW

## Rehabilitation interventions in Rett syndrome: a scoping review

JAN LIM<sup>1</sup> | DAYNA GREENSPOON<sup>1</sup> | ANNE HUNT<sup>1,2</sup> | LAURA MCADAM<sup>1,3,4</sup>

<sup>1</sup> Bloomview Research Institute, Holland Bloomview Kids Rehabilitation Hospital, Toronto; <sup>2</sup> Department of Occupational Science and Occupational Therapy, University of Toronto, Toronto; <sup>3</sup> Department of Pediatrics, University of Toronto, Toronto; <sup>4</sup> Holland Bloomview Kids Rehabilitation Hospital, Toronto, Canada.

Correspondence to: Laura McAdam, Holland Bloomview Kids Rehabilitation Hospital, 150 Kilgus Rd, Toronto, Ontario M6G1R8, Canada. E-mail: lmcadam@hollandbloomview.ca

**PUBLICATION DATA**  
Accepted for publication 2nd March 2020.  
Published online 30th May 2020.

**ABBREVIATIONS**  
ETT Eye-tracking technology  
RTT Rett syndrome

**AIM** To summarize existing interventions and their outcomes in Rett syndrome (RTT) rehabilitation and identify gaps in the literature.  
**METHOD** Five databases (Ovid MEDLINE, Ovid Embase Classic, Ovid PsycINFO, EBSCO CINAHL Plus, and ProQuest ERIC) were systematically searched up to 23rd July 2018 for studies describing rehabilitation interventions. Data on study participants, design, and outcomes were extracted.  
**RESULTS** Sixty-two articles were included in the final review. Evidence consistently demonstrated that females with RTT can improve their gross motor, fine motor, and communicative skills with rehabilitation. All 11 interventions targeting gross motor function, namely ambulation, achieved functional improvements. Twenty of 24 articles describing fine motor rehabilitation studies succeeded in decreasing stereotypies, improving functional hand use, and/or reducing self-injurious behaviors. Twenty-one of 22 studies describing communication interventions succeeded in training choice-making, communicative language, or socialization behavior. Other key findings include the positive interplay between physical and communicative rehabilitation outcomes, and the ability of females with RTT to improve their cognitive abilities during intervention.  
**INTERPRETATION** Rehabilitation can impact the daily lives of females with RTT and their caregivers in clinically meaningful ways.

# "THE LITERATURE UNDERLINES"

■■■■



Review

## Evidence-Based Physical Therapy for Individuals with Rett Syndrome: A Systematic Review

Marta Fonzo, Felice Sirico<sup>\*</sup> and Bruno Corrado<sup>\*</sup>

Department of Public Health, University of Naples "Federico II", 80131 Naples, Italy; ma.fonzo05@gmail.com (M.F.); sirico.felice@gmail.com (F.S.)

<sup>\*</sup> Correspondence: bruno.corrado@unina.it; Tel.: +39-081-7462795

Received: 14 June 2020; Accepted: 29 June 2020; Published: 30 June 2020



**Abstract:** Rett syndrome is a rare genetic disorder that affects brain development and causes severe mental and physical disability. This systematic review analyzes the most recent evidence concerning the role of physical therapy in the management of individuals with Rett syndrome. The review was carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses. A total of 17319 studies were found in the main scientific databases. Applying the inclusion/exclusion criteria, 22 studies were admitted to the final phase of the review. Level of evidence of the included studies was assessed using the Oxford Centre for Evidence-Based Medicine—Levels of Evidence guide. Nine approaches to physical therapy for patients with Rett syndrome were identified: applied behavior analysis, conductive education, environmental enrichment, traditional physiotherapy with or without aids, hydrotherapy, treadmill, music therapy, computerized systems, and sensory-based treatment. It has been reported that patients had clinically benefited from the analysed approaches despite the fact that they did not have strong research evidence. According to the results, a multimodal individualized physical therapy program should be regularly recommended to patients with Rett syndrome in order to preserve autonomy and to improve quality of life. However, more high-quality studies are needed to confirm these findings.

**Keywords:** Rett syndrome; intellectual disability; movement disorders; physical therapy modalities;



Research in Autism Spectrum Disorders  
Volume 3, Issue 2, April–June 2009, Pages 304–318

Review

## Communication intervention in Rett syndrome: A systematic review

Jeff Sigafoos<sup>a</sup>, Vanessa A. Green<sup>a</sup>, Ralf Schlosser<sup>b</sup>, Mark F. O'leary<sup>c</sup>, Giulio E. Lancioni<sup>d</sup>, Mandy Rispoli<sup>e</sup>, Russell Lang<sup>c</sup>

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Journal of Intellectual Disability Research  
VOLUME 48 PART 8 pp 730–735 NOVEMBER 2004

730

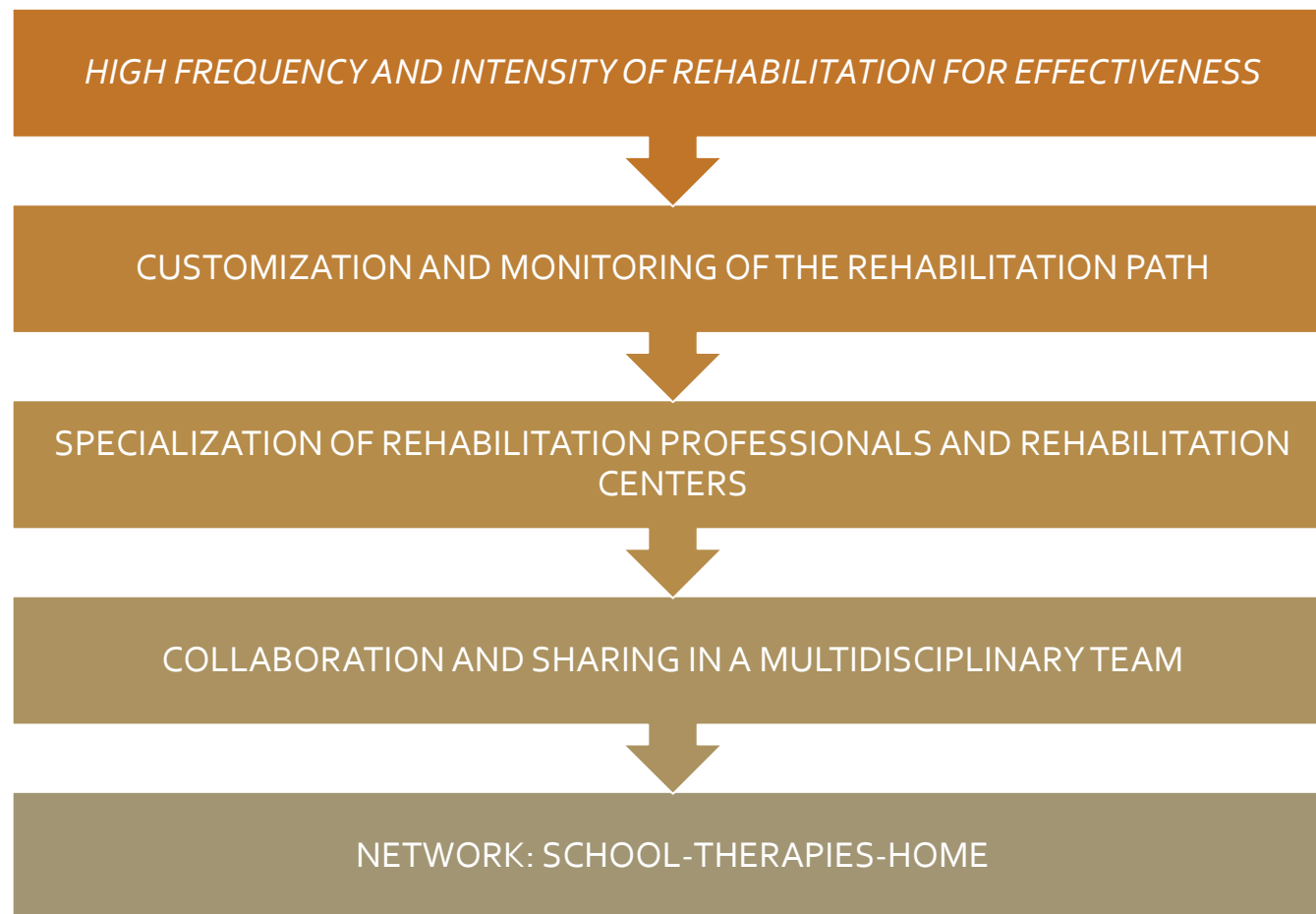
## Improving functional skills and physical fitness in children with Rett syndrome

M. Lotan,<sup>1</sup> E. Isakov<sup>2</sup> & J. Merrick<sup>3</sup>

<sup>1</sup> Zvi Grunman Residential Center, The Miller Shime Campus, Elzev Jerusalem, Israel

<sup>2</sup> Orthopedic Department, Levenstein Rehabilitation Hospital, Raanana, Sackler School of Medicine, Tel Aviv University, Tel Aviv, Israel

<sup>3</sup> National Institute of Child Health and Human Development, Office of the Medical Director, Division for Mental Retardation, Ministry of Social Affairs, Jerusalem, Zuman Child Development Center, Division of Pediatrics and Community Health, Faculty of Health Sciences, Ben Gurion University, Beer-Sheva, Israel



In the field of rehabilitation  
in Rett Syndrome and  
complex syndromes, the  
evidence emerging from  
the literature:  
**THE NEEDS.**

## Diapositiva 5

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- 6 Sigafos, J., Green, V. A., Schlosser, R., O'eilly, M. F., Lancioni, G. E., Rispoli, M., & Lang, R. (2009). Communication intervention in Rett syndrome: A systematic review. *Research in Autism Spectrum Disorders*, 3(2), 304-318.; Lim, J., Greenspoon, D., Hunt, A., & McAdam, L. (2020). Rehabilitation interventions in Rett syndrome: a scoping review. *Developmental Medicine & Child Neurology*, 62(8), 906-916; Fabio, Castelli, Marchetti, & Antonietti, 2013; Fabio, Giannatiempo, Oliva, & Murdaca, 2011; Lotan, 2016; Fonzo, M., Sirico, F., & Corrado, B. (2020). Evidence-Based physical therapy for individuals with Rett syndrome: a systematic review. *Brain sciences*, 10(7), 410.

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In the field of rehabilitation  
in Rett Syndrome and  
complex syndromes, the  
evidence emerging from  
the literature:  
**THE RESPONSES**

REDUCED NUMBER OF THERAPIES PER WEEK (INVERSELY PROPORTIONAL TO THE AGE OF THE PATIENTS)



LIMITED NUMBER OF SPECIALIZED PROFESSIONALS AND CENTERS



DIFFICULTY IN MOBILITY/TRAVEL DUE TO THE PSYCHOPHYSICAL CONDITIONS OF THE PATIENTS



DIFFICULTIES FOR CAREGIVERS IN ACCESSING SPECIALIZED CARE DUE TO GEOGRAPHICAL AND ECONOMIC CONSTRAINTS (OFTEN LIVING IN RURAL AREAS)



THE CONSTRAINTS OF WORK COMMITMENTS THAT PREVENT CAREGIVERS FROM EASILY TAKING TIME OFF.



DIFFICULTIES IN ORGANIZING MEETINGS AND SHARING AMONG THE REFERENCE FIGURES

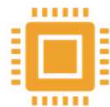
THESE ARE THE MOTIVATIONS THAT HAVE LED AIRETT T ON THE RESEARCH PATH IN TELE-REHABILITATION



*TR leverages new technologies such as video conferencing, websites, computer programs, and video call platforms.*



*It enables patients to receive therapeutic and rehabilitative treatments, guidance, and recommendations from the comfort of their homes.*



*TR technology relies on tools such as video calls and direct peripheral devices like motion capture systems with 3D cameras and eye trackers for assessment and supervision.*



*The scope of TR applications encompasses various domains, including neurology, speech therapy, occupational therapy, cardiology, and psychology.*



*TR has been found effective for both elderly populations and pediatric populations.*



*Multiple studies have affirmed the efficacy of TR in terms of improving patient performance and compliance with treatment, both by patients and their families.*



*The review studies on advanced TR evidenced the affordability, effectiveness, and suitability of the use of advanced technologies to improve cognitive, emotional, motor, and adaptive skills of children and adolescents with NDD*

# WHAT IS "TELEREHABILITATION"? THE LITERATURE UNDERLINES....



- 9 Schwamm, L.H.; Holloway, R.G.; Amarenco, P.; Audebert, H.J.; Bakas, T.; Chumbler, N.R.; Handschu, R.; Jauch, E.C.; Levine, S.R.; Mayberg, M.; et al. A review of the evidence for the use of telemedicine within stroke systems of care: A scientific statement from the American Heart Association/American Stroke Association. *Stroke* 2009, 40, 2616–2634. [CrossRef] [PubMed]; Brennan, D.M.; Mawson, S.; Brownsell, S. Telerehabilitation: Enabling the remote delivery of healthcare, rehabilitation, and self management. *Stud. Health Technol. Inform.* 2009, 145, 231–248; Theodoros, D.; Russell, T. Telerehabilitation: Current perspectives. *Stud. Health Technol. Inform.* 2008, 131, 191–209. [PubMed]; Marzano, G.; Ochoa-Siguencia, L.; Pellegrino, A. Towards a new wave of telerehabilitation applications. *Perspective* 2017, 1, 1–4. [CrossRef]; Pramuka, M.; van Roosmalen, L. Telerehabilitation technologies: Accessibility and usability. *Int. J. Telerehabilitation* 2009, 1, 85–98. [CrossRef]; Maresca, G.; Maggio, M.G.; De Luca, R.; Manuli, A.; Tonin, P.; Pignolo, L.; Calabrò, R.S. Tele-Neuro-Rehabilitation in Italy: State of the Art and Future Perspectives. *Front. Neurol.* 2020, 11, 563375. [CrossRef]; Stasolla, F. Virtual Reality and Wearable Technologies to Support Adaptive Responding of Children and Adolescents With Neurodevelopmental Disorders: A Critical Comment and New Perspectives. *Front. Psychol.* 2021, 12, 720626. [CrossRef] [PubMed]

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# AIRETT and TELEREHABILITATION

## Telerehabilitation for Improving Adaptive Skills of Children and Young Adults with Multiple Disabilities: a Systematic Review

Tindara Capri<sup>1</sup> • Andrea Nucita<sup>2</sup> • Giancarlo Iannizzotto<sup>2</sup> • Fabrizio Stasolla<sup>3</sup> • Alberto Romano<sup>4</sup> • Martina Semino<sup>5</sup> • Samantha Giannatiempo<sup>5</sup> • Virginia Canegallo<sup>6</sup> • Rosa Angela Fabio<sup>1</sup>

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© Springer Science+Business Media, LLC, part of Springer Nature 2020

### Abstract

We conducted a systematic review of telerehabilitation (TR) interventions on children and young adults with multiple disabilities (MDs). This review aimed to (a) examine the effectiveness of telerehabilitation (TR) on adaptive skills that have been targeted for intervention, (b) describe the type of devices used in the intervention procedures, (c) summarize the outcomes, and (d) examine the consumer/professional satisfaction of TR. Eleven studies met inclusion criteria. Results suggested that TR is an effective tool in improving the adaptive skills of children and young adults with MDs. Both consumers and professionals reported high levels of satisfaction and acceptance of TR services. Trends across different types of devices implemented in TR programs are considered and recommendations are made for future research.

**Keywords** Multiple disabilities · Telerehabilitation · Teleconferencing · Teleplay · Adaptive skills · Children · Young adults

**AIRETT's team conducted a systematic review of telerehabilitation interventions for children and young adults with multiple disabilities.** The review demonstrated that telerehabilitation is an effective tool for enhancing the adaptive skills of individuals with multiple disabilities. High levels of satisfaction and acceptance were reported by both consumers and professionals who used telerehabilitation services.

This review had four main objectives:

- To examine the effectiveness of Rehabilitation Therapy (RT) in the development of targeted adaptive skills.
- To describe the types of devices used in intervention procedures.
- To summarize the results of the interventions.
- To assess consumer and professional satisfaction with telerehabilitation.

The review provided a comprehensive overview of the current state of research on multiple disabilities (MDs) in children and young adults, including a total of 11 research studies, 4 pilot studies, and 6 experimental studies. All reviewed studies reported improvement in targeted adaptive skills. It is important to note that six out of the eleven studies examined the effectiveness of telerehabilitation on motor skill development, while only two studies explored the use of telerehabilitation to improve cognitive abilities. This underscores the need for further research to evaluate the impact of telerehabilitation programs on cognitive skills.

**Three main types of devices were identified in telerehabilitation systems: computers, video games, and video conferencing. All three categories demonstrated good validity as tools in the field of telerehabilitation. All studies included in this review reported positive outcomes, both in terms of participants' and professionals' perceptions, who rated their experience with telerehabilitation as satisfactory.**

AIRETT'S  
TELEREHABILITATION:

If the patients can't go to the  
Airett center, the Airett  
therapists go to the patients

AMELIE:  
THE FRIEND OF GIRLS  
WHO GIVES VOICE TO  
THEIR EYES

TELE-AIRETT:  
REMOTE  
REHABILITATION

AMELIE:  
THE FRIEND OF  
GIRLS WHO  
GIVES VOICE TO  
THEIR EYES



*Amelie*

## The beginning of the AMELIE journey....

The literature shows that augmentative and alternative communication (AAC) through eye gaze selection and/or eye-hand integration proves to be the most functional and suitable communication method for Rett Syndrome

The use of AAC software through eye tracking is extensively documented in Rett Syndrome, with studies demonstrating how the tool enhances attention parameters, eye control skills in communication, selection abilities, and learning possibilities

In relation to this, AIRETT conducted a longitudinal study in 2016 to demonstrate how the eye-pointing system allows for an increase in cognitive and communicative abilities in Rett Syndrome...

Fabio, R. A., Giannatiempo, S., Semino, M., & Capri, T. (2021). **Longitudinal cognitive rehabilitation applied with eye-tracker for patients with Rett Syndrome. Research in Developmental Disabilities, 111, 103891.**

Rett syndrome and eye-tracking technology: A brief review

Carotenuto, M.

2019

### Eye-gaze digital games improve motivational and attentional abilities in RETT syndrome

Capri, Tindara

2018-01-01

10

#### Abstract

Recently, there has been an increase in the use of eye-gaze digital games in the field of education. Most studies have underlined that the eye-gaze digital games use plays an important role in supporting students with intellectual disability. Digital Game-based Learning (DGBL) or educational game has the potential to provide effective and powerful learning environments in which the disabled and/or all learners need to develop or improve cognitive skills. The main focus of this paper is to study the role of eye-gaze digital games to improve motivational and attentional abilities in girls with Rett Syndrome (RTT). 30 Italian subjects with RTT (mean = 12.00 years, SD = 8.70) participated in the study. We employed an experimental design ABA: pre-test assessment, training, post-test assessment. In both pre-test and post-test phase, neuropsychological and behavioral parameters were measured using eye tracker technology. In the training phase, cognitive empowerment of attentional and motivational abilities was applied through eye-gaze digital games, pre-installed in the Tobii Series-I eye-tracker. Eye-gaze games were divided into 5 levels: Blank Screen Engagement, Object Displacement, Zoned Focusing, Active Exploration and Controlled Targeting. Performance measures (specific scores to each game) and subjective measures (happiness index) were evaluated. Our findings indicated an enhancement in attentional and motivational abilities. The results were discussed in terms of their implications for supporting the eye-gaze digital

Rosa Angela Fabio<sup>1,2</sup>, Samantha Giannatiempo<sup>2,3</sup> & Tindara Capri<sup>1,2</sup>

#### Abstract

*Rett Syndrome (RTT) is a developmental disorder, predominantly affecting girls, which causes Intellectual Disability and neuro-behavioral disability. Individuals with RTT present with apraxia and movement disorders and most of them are unable to speak, walk and use their hands. For these reasons, eye tracker technology is being increasingly used to their assess cognitive processes.*

*The aim of this study was to investigate three cognitive processes in girls with RTT compared with typical developing girls (TD): the ability to attend to visual stimuli, the ability to identify the same stimuli and the ability to identify the similar stimuli. With the help of Eye Tracker technology, three tasks were administered (1. Attention; 2. Identification of the same stimuli; 3. Identification of the similar stimuli) to 21 girls with RTT, compared with TD girls. Results show that girls with RTT performed worse than girls with TD in all conditions. The absence of*

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY ORIGINAL ARTICLE

### Rett syndrome: an eye-tracking study of attention and recognition memory

SUSAN A. ROSE<sup>1,\*</sup> | ALEKSANDRA DJUKIC<sup>1,2,\*</sup> | JEFFERY J. JANKOWSKI<sup>1,3</sup> | JUDITH F. FELDMAN<sup>3</sup> | IRIS FISHMAN<sup>2</sup> | MARIA VALICENTI-MCDERMOTT<sup>1,2</sup>

<sup>1</sup> Department of Pediatrics, Kennedy Center, Albert Einstein College of Medicine/Children's Hospital at Montefiore, Bronx, NY; <sup>2</sup> Rett Syndrome Center, Montefiore Medical Center, Albert Einstein College of Medicine/Children's Hospital at Montefiore, Bronx, NY; <sup>3</sup> Department of Social Sciences, Queensborough Community College, City University of New York, Bayside, NY, USA.

\*These authors share first authorship of this paper.  
Correspondence to: Dr Susan A. Rose, Department of Pediatrics, Kennedy Center, Albert Einstein College of Medicine/Children's Hospital at Montefiore, 1300 Morris Park Avenue, Bronx, NY 10461, USA. E-mail: susan.rose@montefiore.edu

This article is commented on by [Ryder and Symons](#) on pages 201–202 of this issue.

#### PUBLICATION DATA

Accepted for publication 17th October 2012

#### ABBREVIATIONS

ADL Area of interest  
VPC Visual paired-comparison paradigm

**AIM** The aim of this study was to examine attention and recognition memory for faces and patterns in Rett syndrome, a severely disabling neurodevelopmental disorder caused by mutations in the X-linked *MECP2* gene.

**METHOD** Because Rett syndrome impairs speech and hand use, precluding most neuropsychological testing, the visual paired-comparison paradigm (VPC) was used, together with eye tracking. In the VPC, two identical stimuli are presented for familiarization. On test, the familiar stimulus and a new one are paired, and recognition inferred from preferential looking to the novel target. Attention is measured by looking time, gaze dispersion, and number/length of fixations. Twenty-seven female patients with Rett syndrome (mean age 10y 10m; SD 3y 10m; age range 2–22y) from the Rett clinic at a children's hospital were assessed in this study, along with 30 age- and sex-matched typically developing participants (outpatients from the same hospital).

**RESULTS** Although patients with Rett syndrome showed recognition of both faces and patterns, with novelty scores greater than chance (50%), their performance was significantly poorer than that of the typically developing comparison group. Their attention to both was less mature and marked by a more narrowly focused gaze, with fewer and longer fixations. When inspecting faces, attention to the eyes was similar in both groups; however, patients with Rett syndrome tended to ignore the nose and mouth.

**INTERPRETATION** This is one of the first studies to characterize attention and memory in individuals with Rett syndrome. Visually based techniques, such as the VPC, open a new avenue for quantifying the cognitive phenotype associated with this syndrome.

Original Article

### Rett Syndrome: Basic Features of Visual Processing—A Pilot Study of Eye-Tracking

Aleksandra Djukic MD, PhD<sup>a</sup> | Maria Valicenti McDermott MD, MS<sup>a</sup>, Kathleen Mavrommatis<sup>b</sup>, Cristina L. Martins MD<sup>c</sup>

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<https://doi.org/10.1016/j.pediatrneurol.2012.04.009>

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- 10 Rose, S. A., Djukic, A., Jankowski, J. J., Feldman, J. F., Fishman, I., & Valicenti-Mcdermott, M. (2013). Rett syndrome: an eye-tracking study of attention and recognition memory. *Developmental Medicine & Child Neurology*, 55(4), 364-371; Djukic, A., McDermott, M. V., Mavrommatis, K., & Martins, C. L. (2012). Rett syndrome: Basic features of visual processing—A pilot study of eye-tracking. *Pediatric neurology*, 47(1), 25-29; Diana, P., Dansart, P., Micale, M., Carotenuto, M., Salerno, M., & Tripi, G. (2019). Rett syndrome and eye-tracking technology: a brief review. *Acta Medica Mediterranea*, 35(3), 1411-1416; Fabio, R. A., Capri, T., Nucita, A., Iannizzotto, G., & Mohammadhasani, N. (2018). Eye-gaze digital games improve motivational and attentional abilities in RETT syndrome. *DEFEKTOLOSKA TEORIJA I PRAKTIKA*, 19(3-4), 105-126.

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#### Introduction:

Research on the longitudinal effects of cognitive rehabilitation in Rett Syndrome (RTT) has been limited so far, and the mechanisms involved have not been thoroughly described.

#### Objectives:

The aim of this study was to examine the effects of cognitive rehabilitation using eye-tracking technology on attention, choice behaviors, and language over a 2-year period in patients with RTT.

#### Methods and Procedure:

Twenty-eight participants with RTT, aged between 4 and 22 years (mean = 13.85 years, standard deviation = 5.89), received 30 minutes of cognitive rehabilitation with an eye tracker for 3 days a week for a period of 1 month for 2 years. Subsequently, they underwent cognitive assessment to evaluate attention, choice, language, and overall functioning at four specific time points: before cognitive rehabilitation (T1), six months after the first phase of cognitive rehabilitation (T2), six months after the second phase of cognitive rehabilitation (T3), and at the end of the third phase of cognitive rehabilitation (T4).

#### Results:

Patients with RTT showed long-term improvements in attention seconds and the number of choice behaviors, with a barely noticeable improvement in overall functioning. No improvement in language was observed



## Longitudinal cognitive rehabilitation applied with eye-tracker for patients with Rett Syndrome

Rosa Angela Fabio<sup>a</sup>, Samantha Giannatiempo<sup>b</sup>, Martina Semino<sup>b</sup>, Tindara Capri<sup>a,\*</sup>

<sup>a</sup> Department of Clinical and Experimental Medicine, University of Messina, Via Bivona, 98100, Messina, Italy

<sup>b</sup> Centro AIRETT Ricerca e Innovazione (CARI), Research and Innovation Airett Center, Verona, Italy

### ARTICLE INFO

The paper is part of a special issue on Tech Adv in Dev Disabil.

#### Keywords:

Rett Syndrome  
Attention  
Choice behaviours  
Language  
Cognitive training  
Longitudinal study

### ABSTRACT

**Background:** longitudinal effects of cognitive rehabilitation in Rett Syndrome (RTT) have been poorly investigated and the mechanisms do not appear to have been described in detail.

**Aims:** the aim of this study was to examine the effects of cognitive rehabilitation with eye-tracker technology on attention, choice behaviours and language over a 2-year period in patients with RTT.

**Methods and procedures:** 28 participants with RTT, ranging from age 4–22 years old ( $M = 13.85$  years,  $SD = 5.89$ ), received 30 min of cognitive rehabilitation with eye-tracker for 3 days a week over a 1-month for 2 years. They then underwent cognitive assessment to evaluate attention, choice, language and global functioning in four specific times: before cognitive rehabilitation (T1), after six months of cognitive rehabilitation (T2), six months after the second cognitive rehabilitation phase (T3) and at the end of the third cognitive rehabilitation phase (T4).

**Outcome and results:** patients with RTT show long-term improvements in seconds of attention and number of choice behaviours, with barely any improvement in global functioning. No improvement in language was found.

**Conclusions and implications:** this is the first study aimed at examining longitudinal effects of cognitive rehabilitation in patients with RTT, demonstrating a linear improvement across time in attention and choice.

The following strengths  
emerge from the studies



## STRENGTHS POINTS



ENHANCEMENT OF COMMUNICATIVE PREREQUISITES



INCREASE IN COMMUNICATION POSSIBILITIES AND ABILITIES



INCREASE IN COGNITIVE ABILITIES



OPPORTUNITY TO PLAY



SOCIALLY HIGHLY APPROPRIATE AND FUNCTIONAL



The following  
weaknesses emerge  
from the studies



## WEAKNESSES POINTS



COST AND ACCESSIBILITY'



USABILITY AND PORTABILITY IN VARIOUS ENVIRONMENTS



TRAINING FOR CAREGIVERS' USE



COMPLEX CUSTOMIZATION MECHANISMS



STRUCTURAL AND FUNCTIONAL COMPLEXITY (SOFTWARE FOR OTHER MEDICAL CONDITIONS)



VERY LONG LEARNING TIMES FOR CAREGIVERS



VERY LONG MATERIAL CREATION TIMES

- **The project was initiated by the Airett Association in 2016**, in collaboration with the Vodafone Foundation, which funded the initial development of the project.
- **The software was developed by a multidisciplinary team entirely of Italian origin**, including specialized therapists, technical and computer engineers, under the supervision of researchers and university professors specializing in Rett Syndrome.
- **The purpose of the software is to provide an innovative solution for play, communication, and learning**, primarily intended for patients with Rett Syndrome and, in general, for severe cognitive and motor disabilities.
- **The involvement of families and the girls is a fundamental part of the project's development, with a 'spiral' working method** based on feedback, suggestions, and improvements from Airett therapists, families, the girls themselves, and their teachers.
- **The software and device evolved through various prototypes until the final creation of 'AMELIE'.**



It is built with and for Rett Syndrome but suitable for all severe cognitive and motor disabilities

A comprehensive software including games, communication tools, learning resources, and systematic data monitoring

A simple, clean, and organized interface that allows for easy and immediate use by both the patient and caregivers

It utilizes equipment already available in the market, significantly reducing costs

Highly customizable and adaptable to the patient



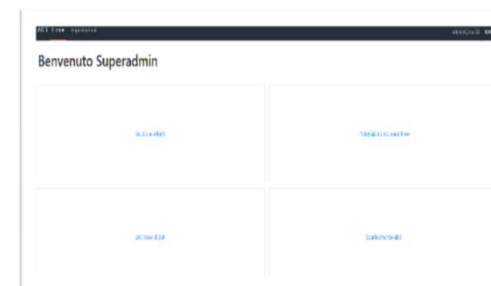
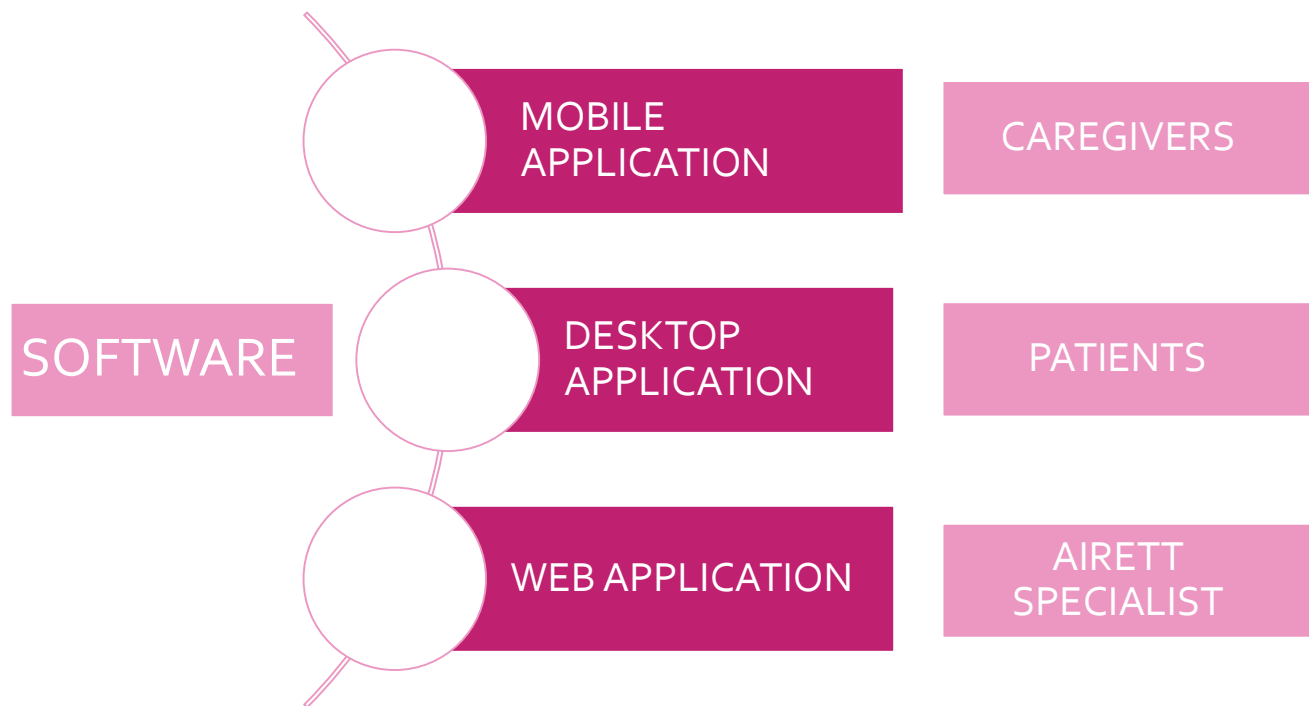
AMELIE

DEVICE

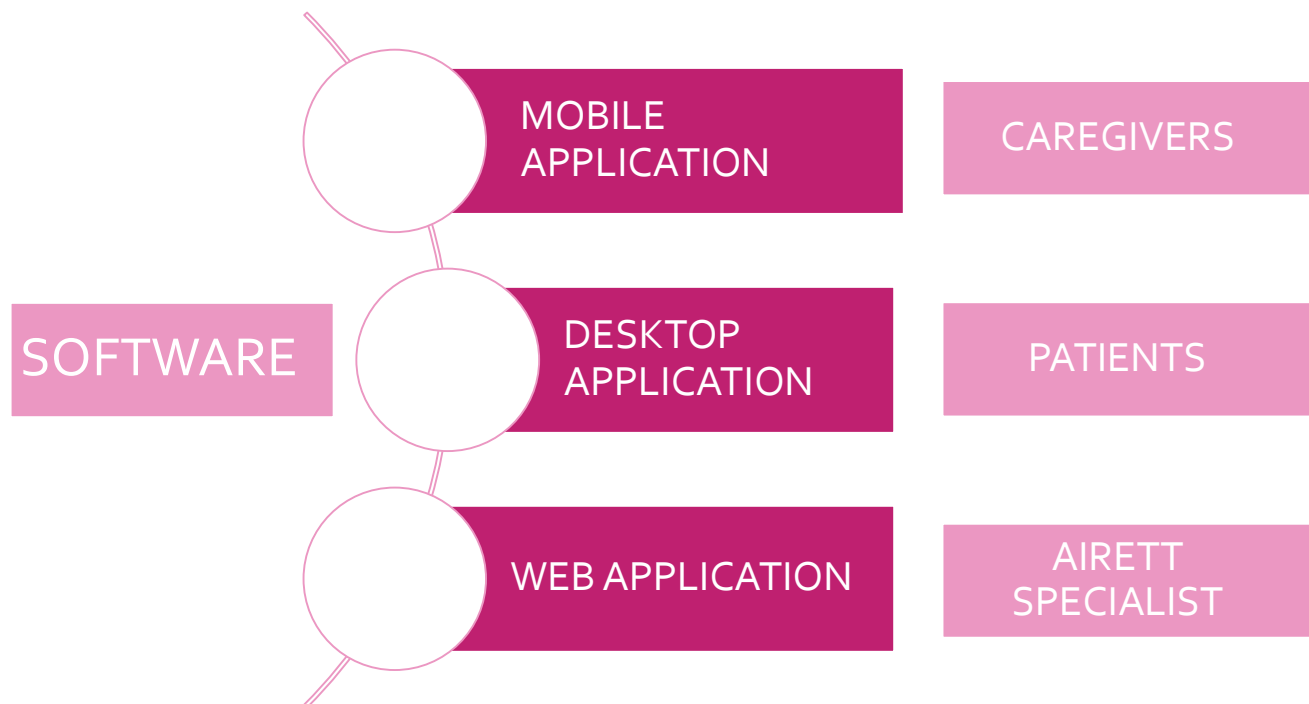
SOFTWARE



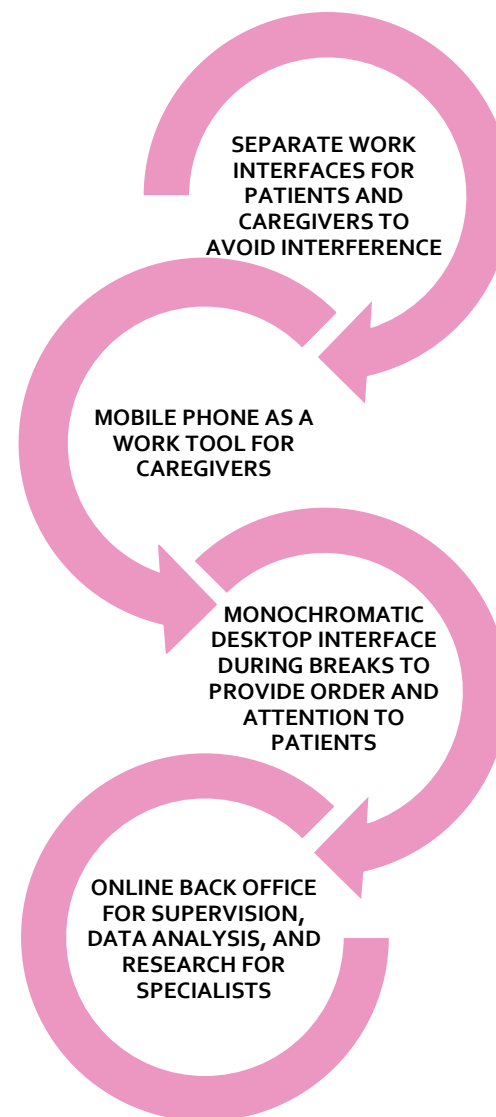
- Information:
- Equipment already commercially available with minimal technical specifications to enable the software's functionality.
  - Computer with touchscreen capability.
  - Mobile device with Android or iOS operating system.



***This is the entirely new and innovative component***



## Strengths and Innovation

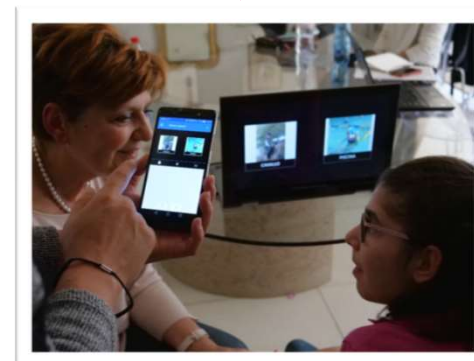
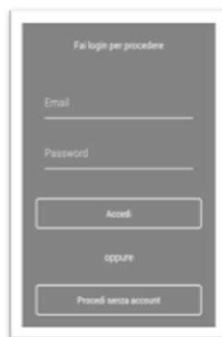


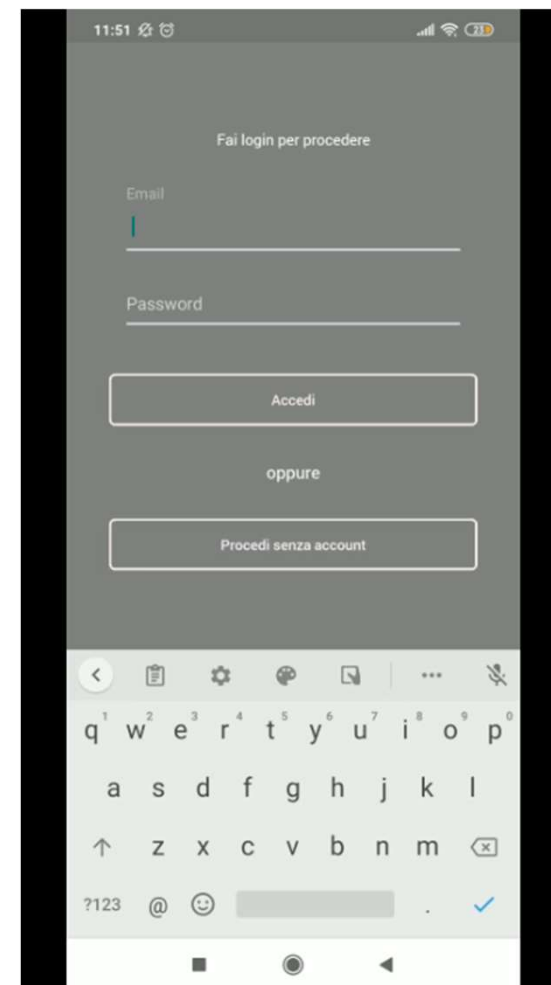
How do the various components interact with each other?

MATCHING DESKTOP AND  
MOBILE APPLICATION

LOGIN WITH CREDENTIALS  
OF SPECIFIC PATIENT

LET'S COMMUNICATE,  
LEARN AND PLAY.



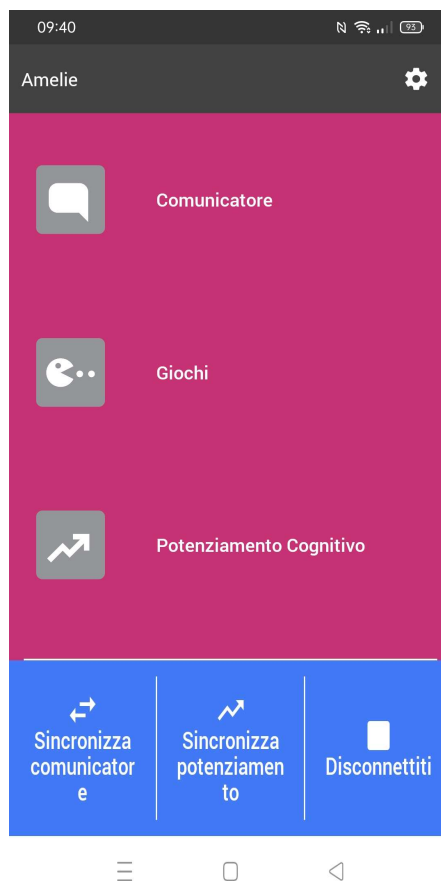




MOBILE/DESKTOP  
APPLICATION



**Communicative and Cognitive Synchronization**  
To share data, materials and performances



### Settings

To set up selection time

### Communicator Session

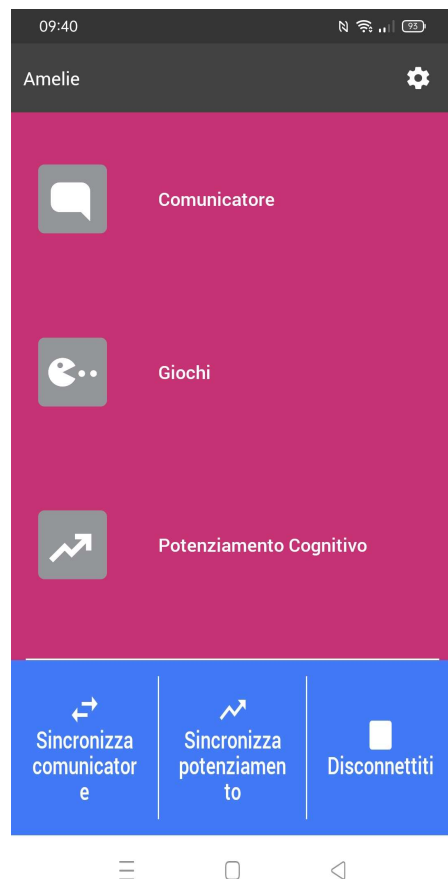
To create Augmentative and Alternative Communication (AAC) choices

### Game Session

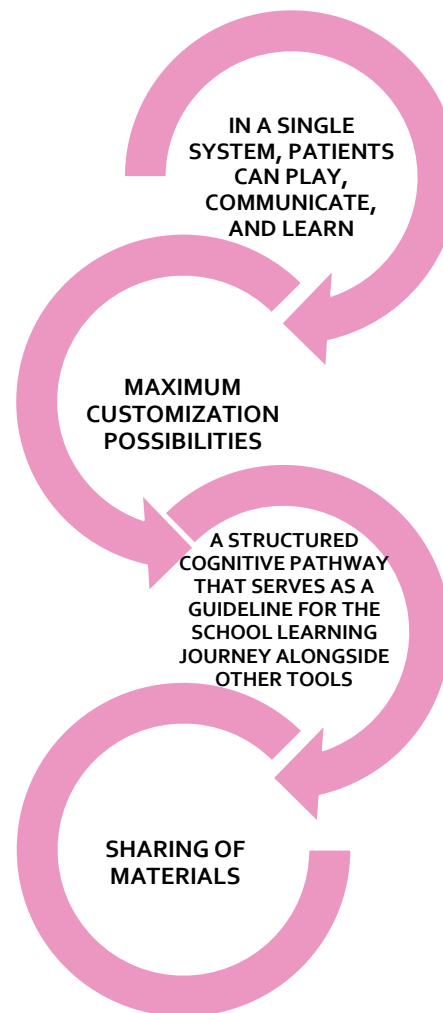
To train behavioral prerequisites

### Learning Session

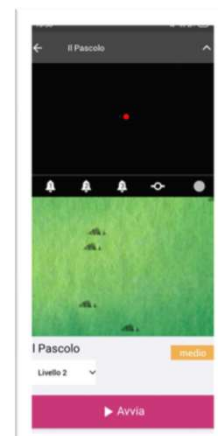
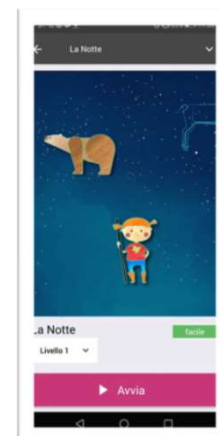
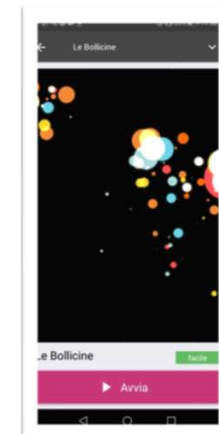
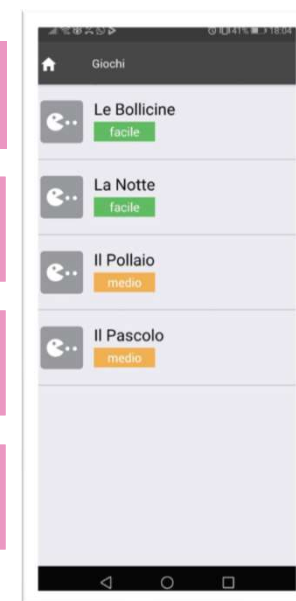
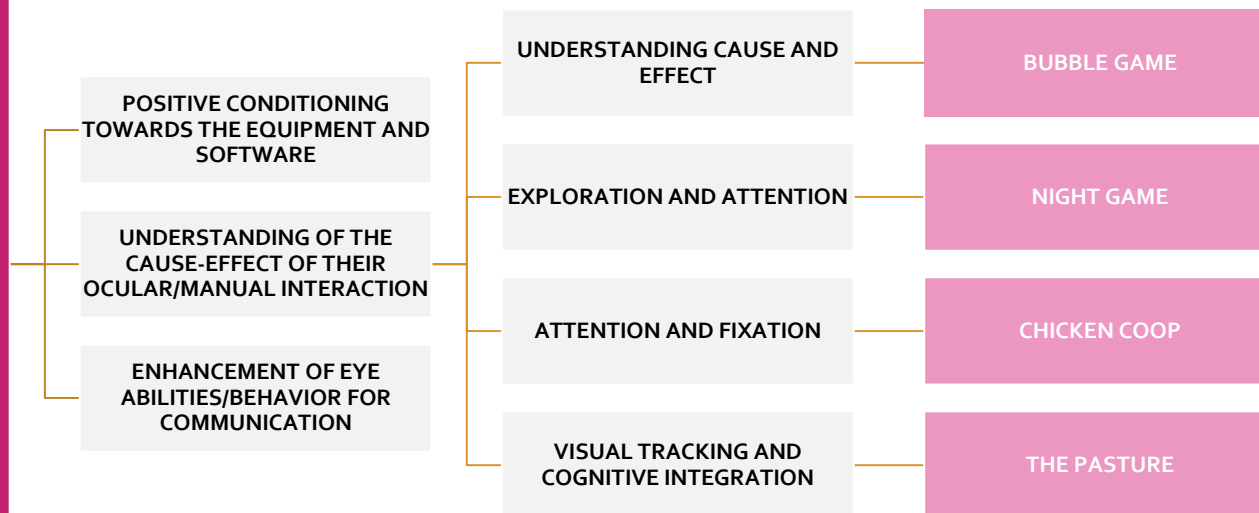
Exercises for learning academic/school concepts



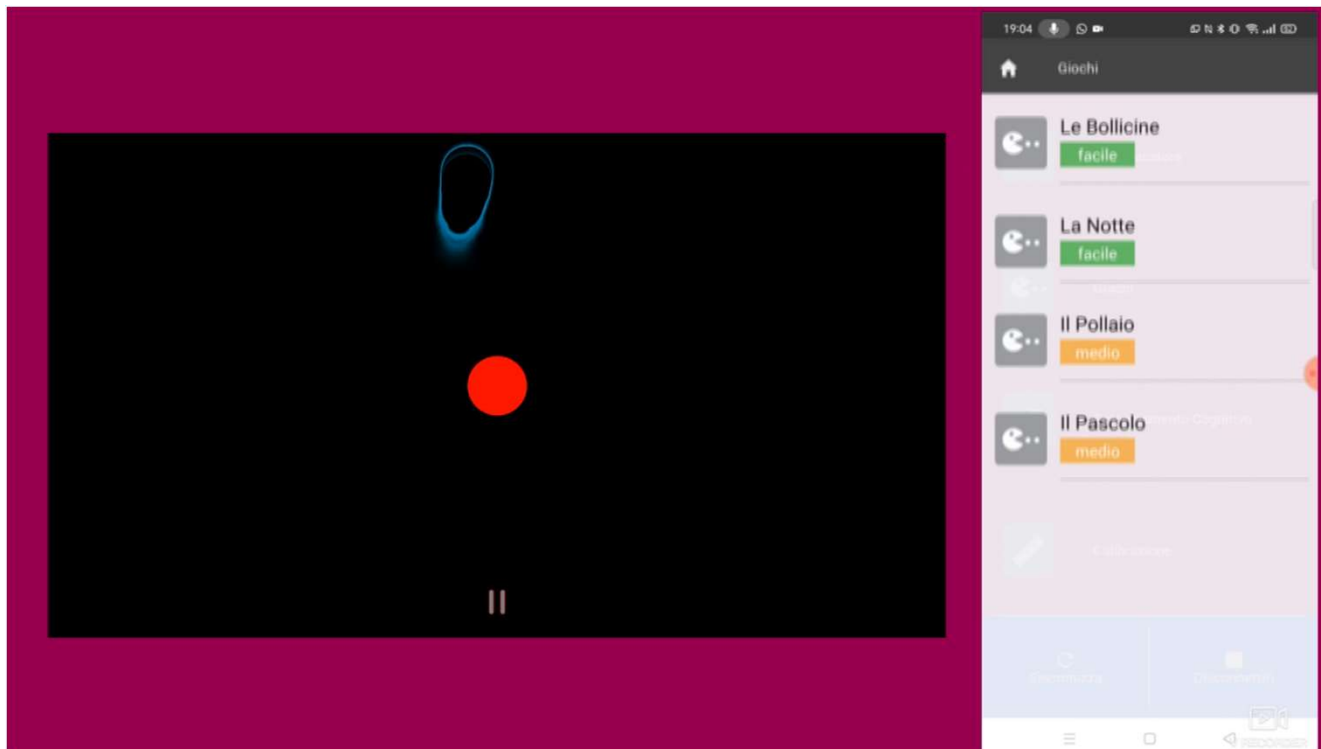
## Strengths and Innovation

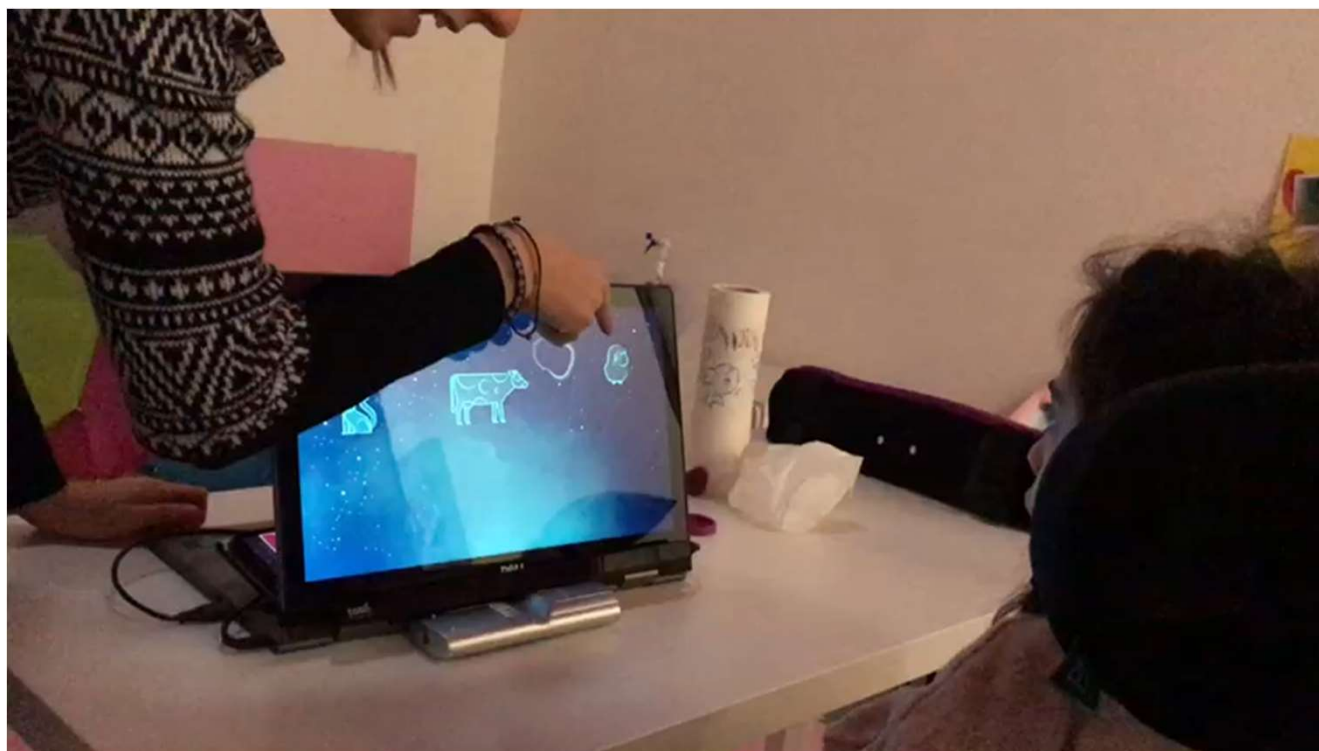


# GAME SESSION



Each game has different levels with a varying number of targets or different fixation times





# COMMUNICATOR SESSION

CREATION OF AN IMAGE VOCABULARY,  
IN A FUNCTIONAL AND FAST MANNER

PHOTOS/WEB/ARASAAC  
SYMBOLS/COMPUTER FOLDER/MOBILE  
GALLERY

CARDS WITH TEXT/TEXT + IMAGE/IMAGE  
WITH SPEECH  
SYNTHESIS/AUDIO/RECORDED VOICE

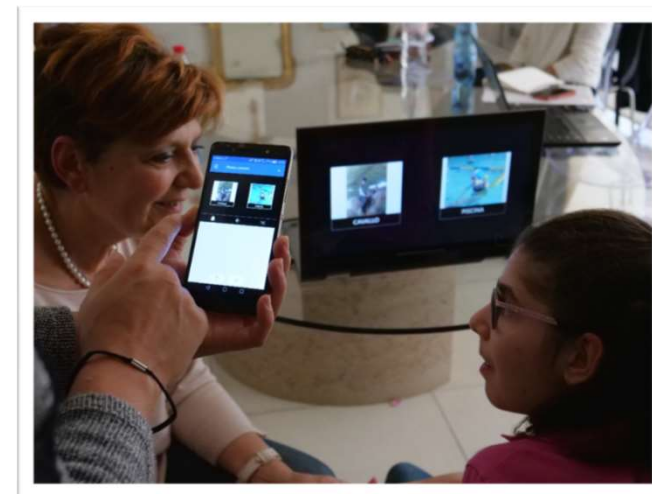
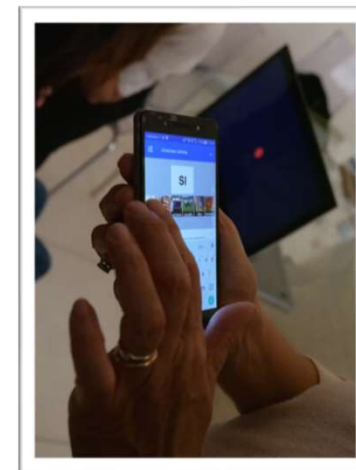
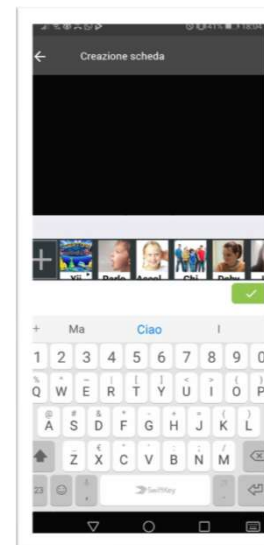
CREATION OF CUSTOMIZABLE  
COMMUNICATION CARDS

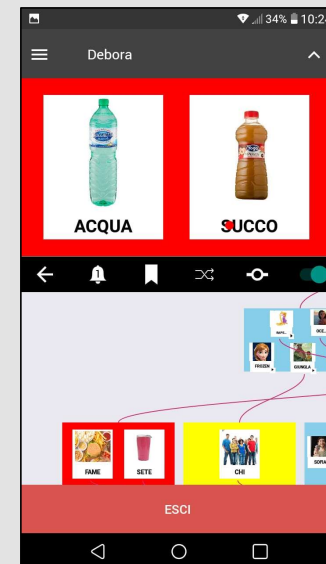
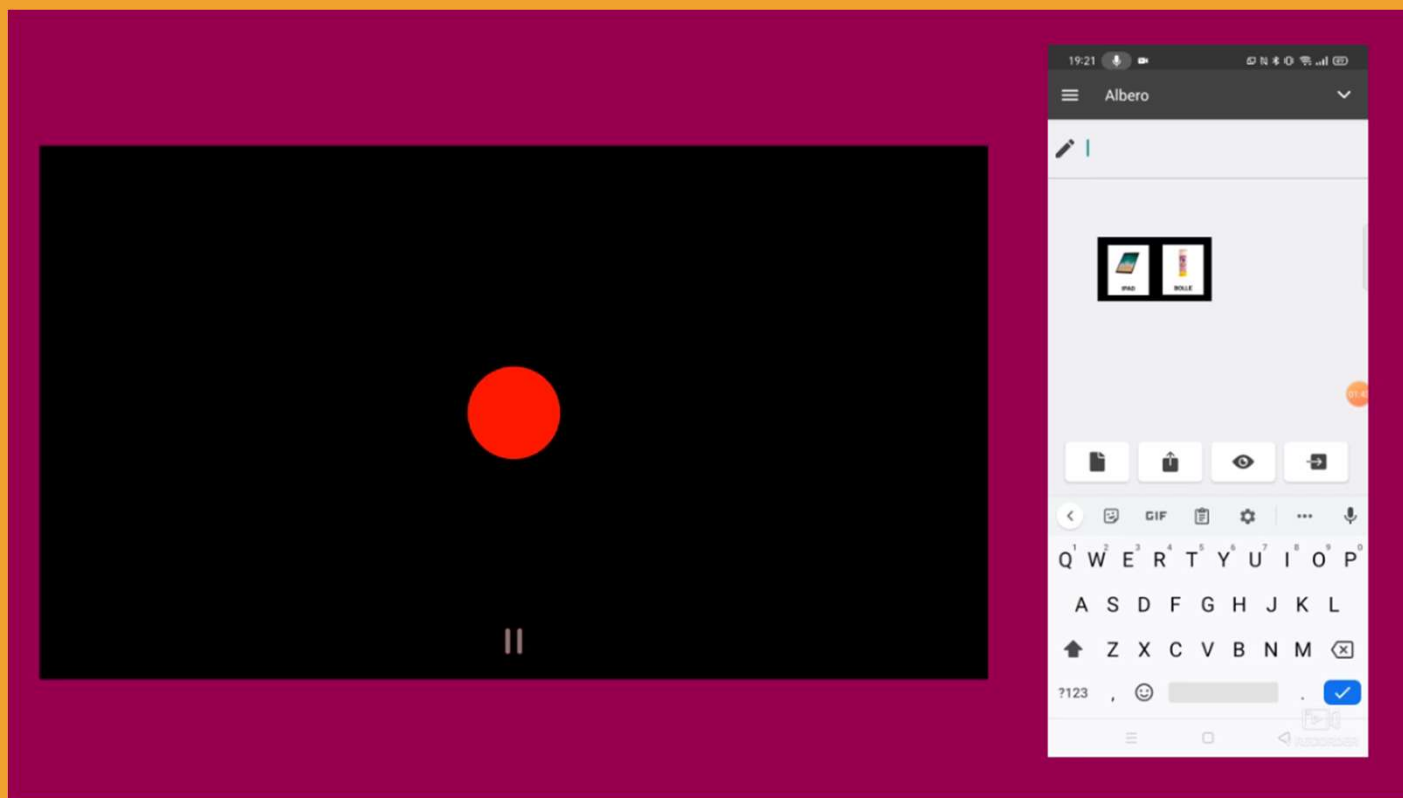
CUSTOMIZABLE NUMBER OF CARDS  
ADJUSTABLE CARD SIZES  
MODIFIABLE SPATIAL ORGANIZATION

CREATION OF COMMUNICATION FLOWS  
WITH SEQUENTIAL CARDS

EACH CARD CAN BE LINKED TO  
SEQUENTIAL SCREENS OF RELATED  
CHOICES

THE CREATION OF COMMUNICATION  
CARDS IS DONE FROM THE MOBILE, AND  
THE PATIENT RECEIVES THE  
STRUCTURED AND READY  
"COMMUNICATION FLOW"



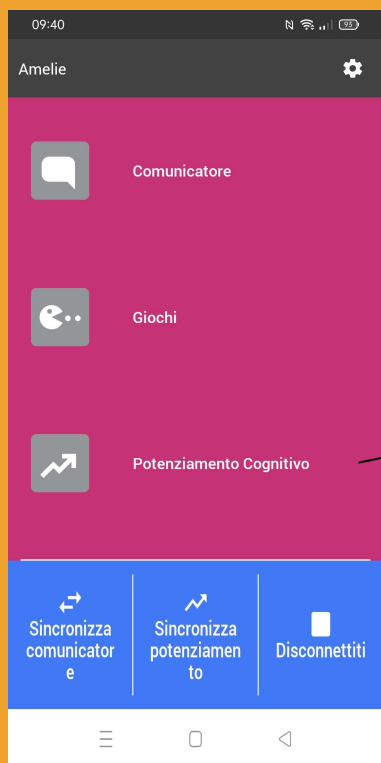


When a choice is presented, you can intervene with:

- Attention Prompt
- Shuffle for Change of Position
- Check if Posture is Adequate
- Activation or Blocking of Selection

Alice speaks  
with Amelie...





**LEARNING SESSION:  
EXERCISES FOR LEARNING  
ACADEMIC/SCHOLASTIC CONCEPTS**

**AMELIE IS DESIGNED NOT  
ONLY FOR COMMUNICATION  
BUT ALSO FOR LEARNING**

**FREQUENT AND HIGHLY REPETITIVE  
STIMULATIONS CAN IMPROVE  
COGNITIVE PERFORMANCE, INCREASE  
THE NUMBER OF ATTENTION  
SECONDS, AND THE NUMBER OF  
CHOICE BEHAVIORS.**

# LEARNING SESSION

EXERCISES RELATED TO SCHOOL  
LEARNING CONCEPTS AND  
USEFUL FOR THE PATIENTS'  
DAILY LIFE

STRUCTURING AND SEQUENCING  
PREPARED BY AIRETT  
SPECIALISTS IN THE 'BACKOFFICE'  
SESSION

FOR EACH EXERCISE, THE  
PRESENTATION OF REQUESTS  
AND RECORDING OF RESPONSES  
IS AUTOMATED AND RECORDED

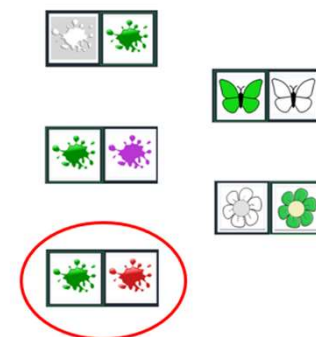
AUTOMATED RECORDING OF  
PATIENT PERFORMANCE

THE CONCEPTS CAN BE  
MODIFIED, UPDATED, AND  
EXPANDED

*Colors; Shapes; General Concepts;  
Common Objects; Body Parts; Places;  
Animals; Food; Drinks; Actions;  
Measurement Concepts; Spatial  
Concepts; Temporal Concepts;  
Measurement Concepts; Emotions;  
Mathematical Prerequisites;  
Categorization.*

*AUTOMATED SEQUENCE:  
VISUAL AND AUDITORY REINFORCEMENT FOR  
CORRECT RESPONSE  
ADVANCEMENT TO THE NEXT LEVEL: 3  
CONSECUTIVE CORRECT RESPONSES IN 3  
CONSECUTIVE SESSIONS*

- NUMBER OF SESSIONS
- NUMBER OF CORRECT PERFORMANCES/TOTAL PERFORMANCES
- SELECTION SPEED
- NUMBER OF LEARNED CONCEPTS



Alice learns  
with Amelie...

Debi learns  
with Amelie...

**SYNCHRONIZATION**

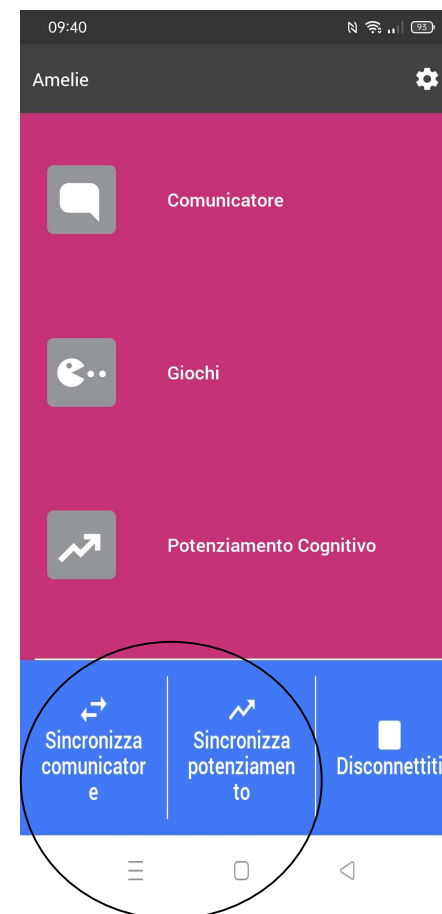
**IMMEDIATE AND  
FUNCTIONAL MATERIAL  
SHARING AMONG  
DIFFERENT PERSONNEL  
AND WITH REMOTE  
AIRETT SUPERVISORS**

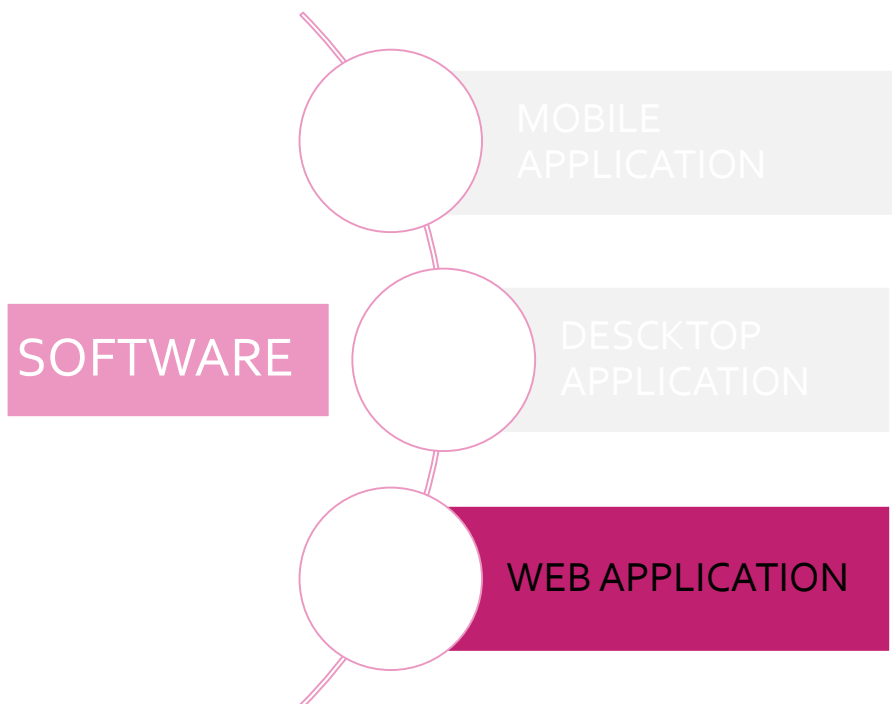
**UNIFORMITY OF  
COMMUNICATION  
MATERIALS**

**SHARING OF DATA  
RELATED TO  
ENHANCEMENT AND  
COMMUNICATION  
SESSIONS**

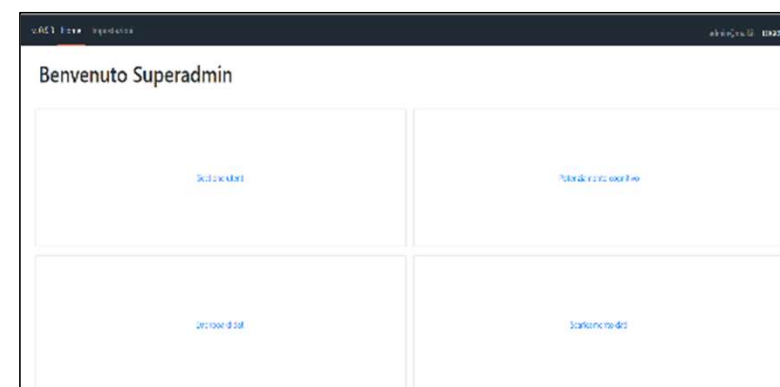
**REMOTE MONITORING OF  
COMMUNICATIVE AND  
COGNITIVE  
PERFORMANCES**

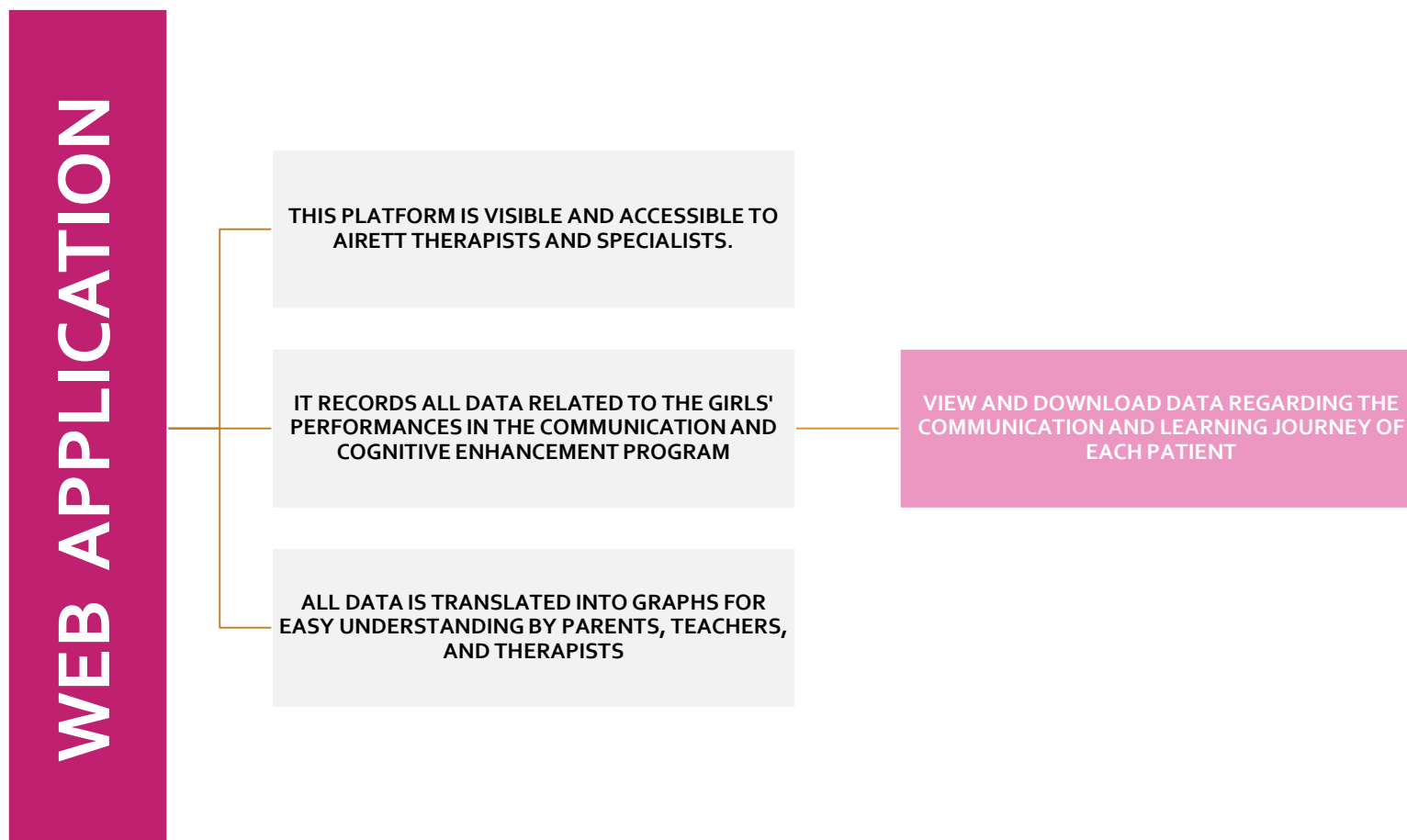
**WEB APPLICATION**





**AIRETT  
SPECIALIST**





## AMELIE'S BACKOFFICE

# Benvenuto Superadmin

Gestione utenti

**CREATE/ADD USERS**

Potenziamento cognitivo

**MODIFY/UPDATE COGNITIVE ENHANCEMENT PATH**

Dashboard dati

**VIEW COGNITIVE AND COMMUNICATIVE  
PERFORMANCES**

Scaricamento dati

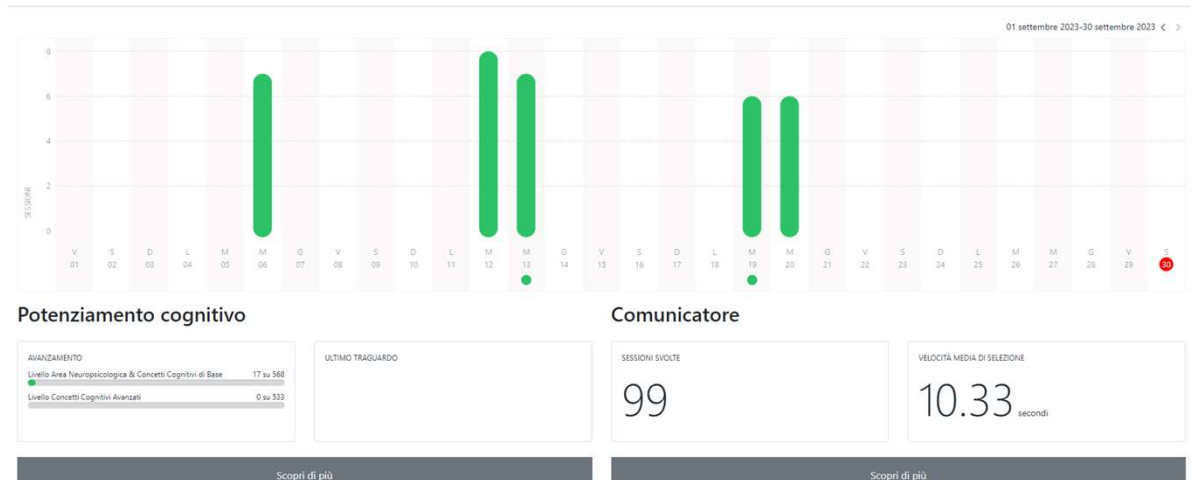
**DOWNLOAD DATA IN EXCEL FORMAT FOR  
SHARING AND RESEARCH**



## DASHBOARD DATA

- Number of sessions conducted (communication and cognitive)
- Average selection speed
- Number of correct responses
- Number of cards from which selections were made and the number of sequential links executed (communication)
- Number of learned targets (cognitive)"

Dashboard dati > Care Receiver: Mia Brezzo





- *Amelie is used at HOME, SCHOOL, and in THERAPY.*
- *All the individuals involved in communication and learning are trained.*
- *Thanks to content synchronization, material sharing is immediate and functional among different individuals and with remote Airett supervisors.*
- *Thanks to the simplicity of the structural components, Amelie is easily transportable and can be used in different environments quickly and seamlessly.*

## AMELIE IS PART OF TELE-REHABILITATION



**SOFTWARE INSTALLATION IS DONE REMOTELY BY ENGINEERS**



**GROUP TECHNICAL TRAINING MEETINGS ARE HELD  
ONLINE**



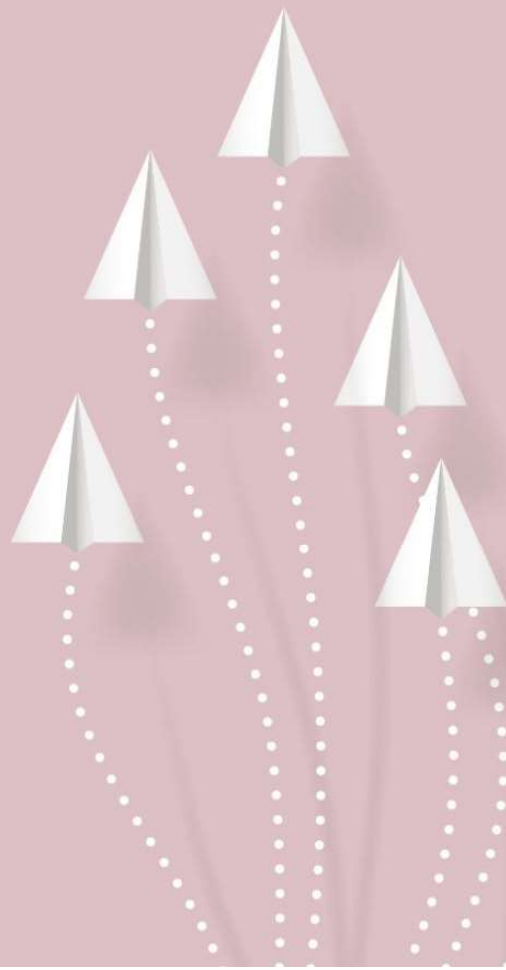
**Amelie**



**INDIVIDUAL ONLINE MEETINGS FOR CUSTOMIZING THE  
ENHANCEMENT OF PREREQUISITES, COMMUNICATION,  
AND COGNITIVE PATHWAYS**



**CONTINUOUS SUPERVISION FOLLOWED BY AIRETT  
SPECIALISTS, OF THE PROCESS TO MONITOR, ADAPT, AND  
UPDATE THE PATHWAYS OF EACH INDIVIDUAL GIRL**



Thank you for your attention.



# TELE-AIRETT

COMMUNICATIVE, COGNITIVE AND MOTOR  
REHABILITATION AT HOME

# A single online platform, two studies for rehabilitation of girls with Rett syndrome

## Cognitive and communication areas



## Motor area

- Comparing Advanced with Basic Telerehabilitation Technologies for Patients with Rett Syndrome—A Pilot Study on Behavioral Parameters

### Aim:

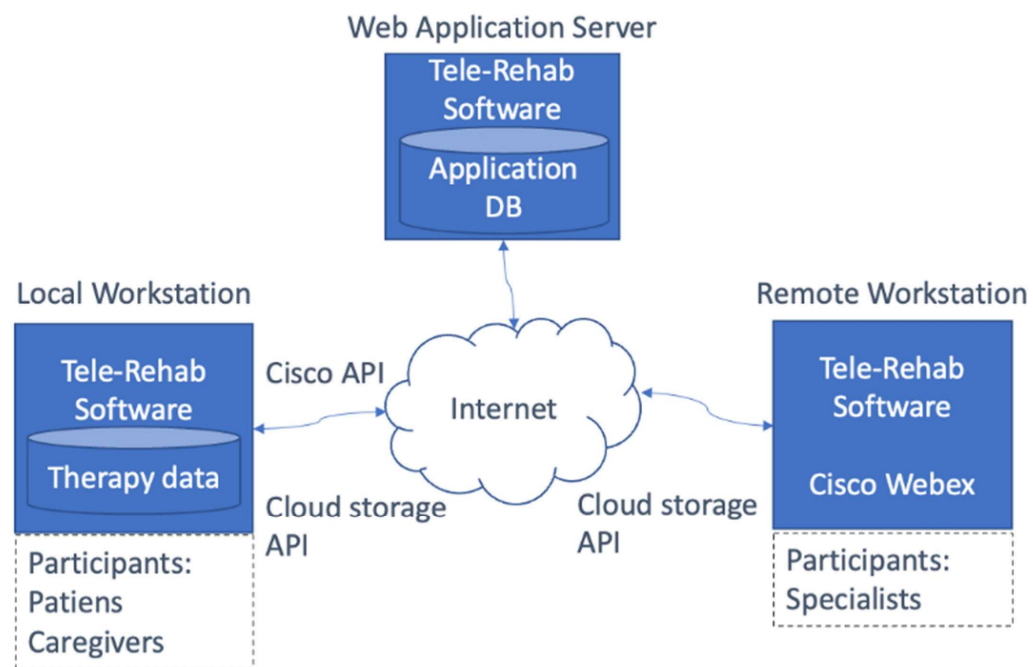
Comparing effects of distance training using 2 different technologies in two groups of girls with Rett Syndrome

- Telerehabilitation with Computer Vision-Assisted Markerless Measures: A Pilot Study with Rett Syndrome Patients

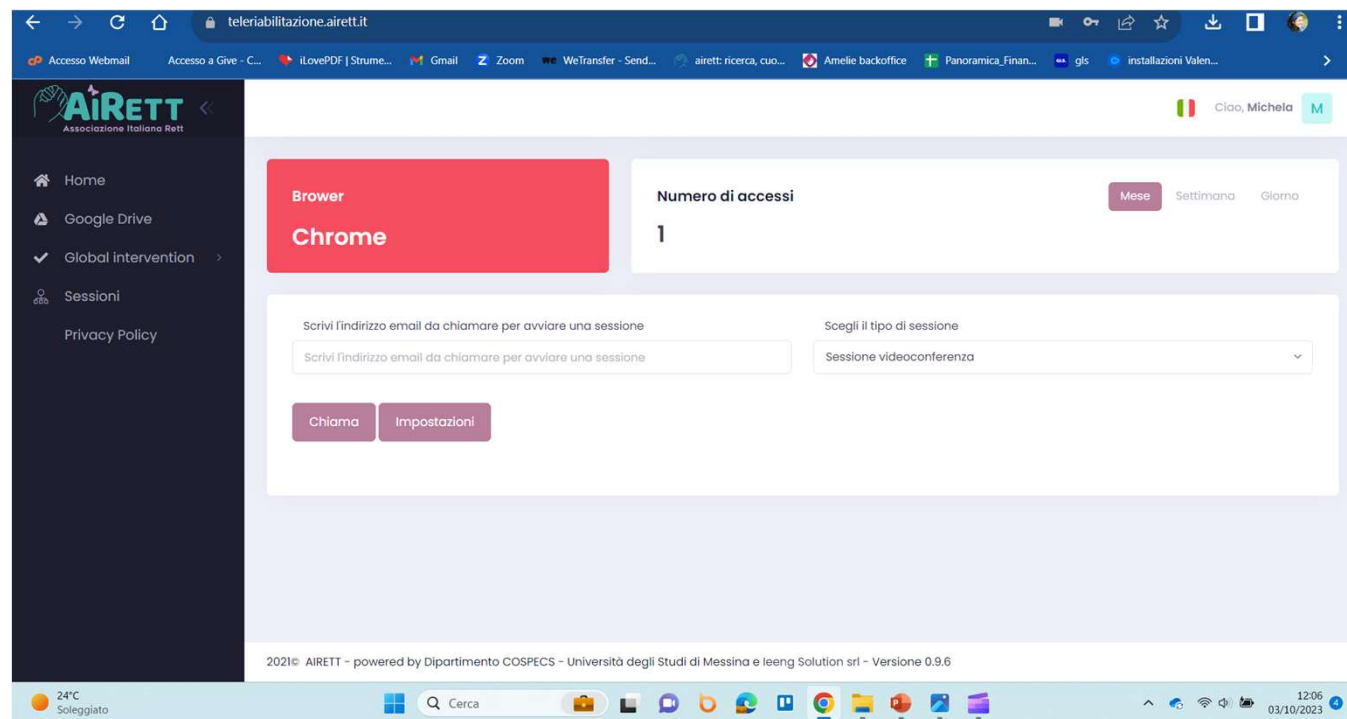
### Aim:

Assessing validity of a markerless measure during telerehabilitation Effects of motor rehabilitation in a group of girls with Rett Syndrome.

# System architecture



# The platform



The screenshot shows a web browser window with the URL `teleriabilitazione.airett.it`. The interface includes a dark sidebar with navigation links: Home, Google Drive, Global Intervention, Sessioni, and Privacy Policy. The main content area features a red 'Browser Chrome' card, a 'Numero di accessi' (Number of accesses) section showing '1' with filters for 'Mese', 'Settimana', and 'Giorno', and a session initiation form. The form has two input fields: 'Scrivi l'indirizzo email da chiamare per avviare una sessione' and 'Scegli il tipo di sessione' (set to 'Sessione videoconferenza'). Below these are 'Chiama' and 'Impostazioni' buttons. The footer indicates '2021© AiRETT - powered by Dipartimento COSPECS - Università degli Studi di Messina e leeng Solution srl - Versione 0.9.6'. The Windows taskbar at the bottom shows the date as 03/10/2023 and time as 12:06.



# The platform

Scegli il tipo di sessione

Sessione videoconferenza

Sessione videoconferenza

Sessione cognitiva

Sessione fisica - ZED Openpose

Sessione fisica - Posenet

# Cognitive session

## Therapist side:

What s/he can see:

- Face of the patient – behavioural aspects
- Gaze trace
- Screen of the patient's monitor

What s/he can do:

- Start and stop recording videos
- Take notes linked to the video frame

## Patient side:

What s/he can see:

- Screen with activities and tasks

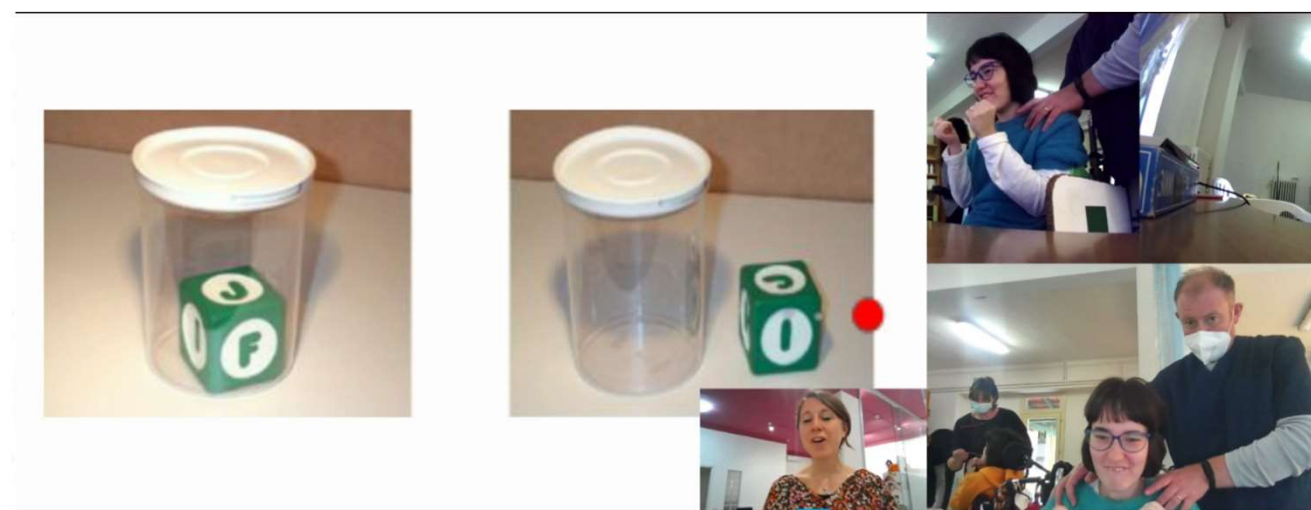
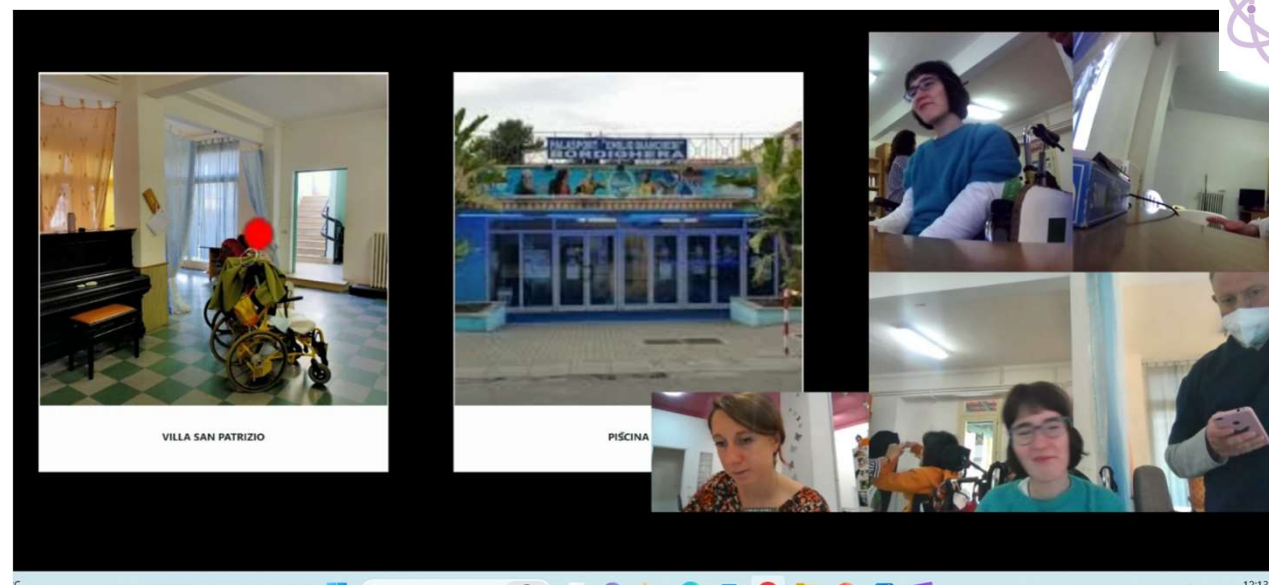
What s/he cannot see:

- Face of the therapist during tasks

What s/he can do:

- Perform tasks

# Cognitive session



# The platform

Scegli il tipo di sessione

Sessione videoconferenza

Sessione videoconferenza

Sessione cognitiva

Sessione fisica - ZED Openpose

Sessione fisica - Posenet

# Motor session

## Therapist side:

What s/he can see:

- Patient – behavioural aspects and posture
- Skeleton – validity of the single frame

What s/he can do:

- Start and stop recording videos
- Take notes linked to the video frame

## Patient side:

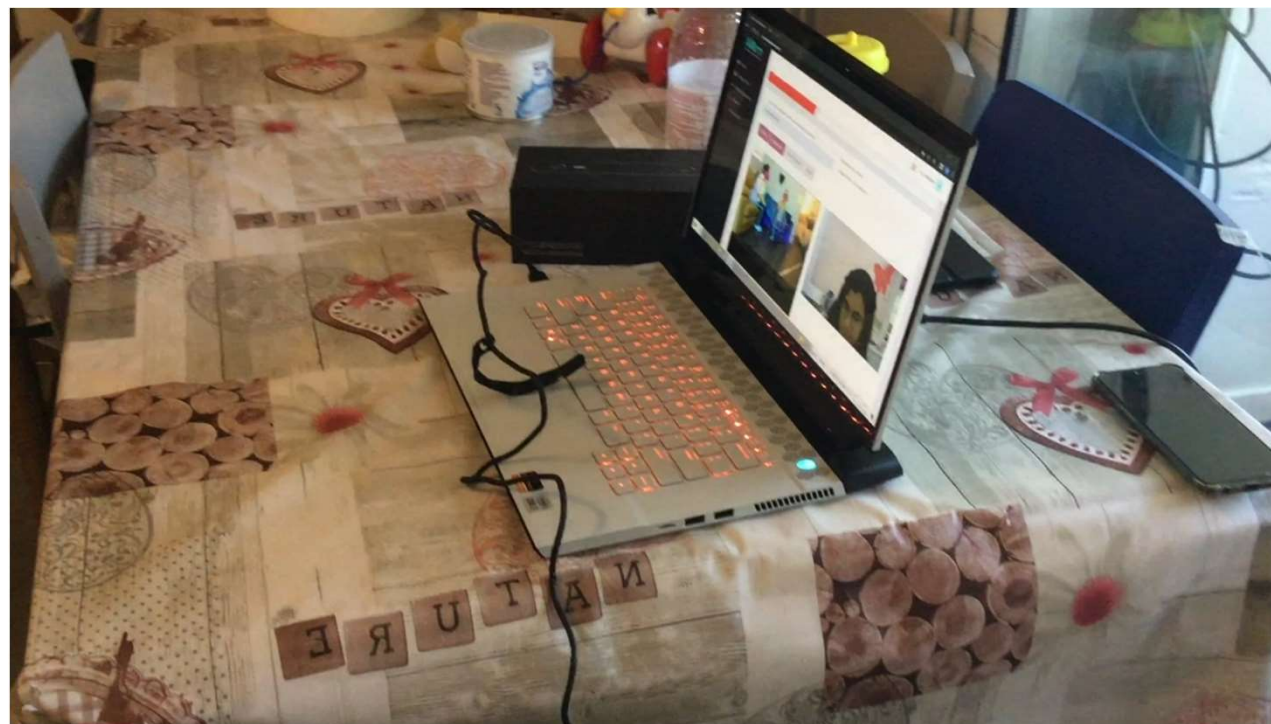
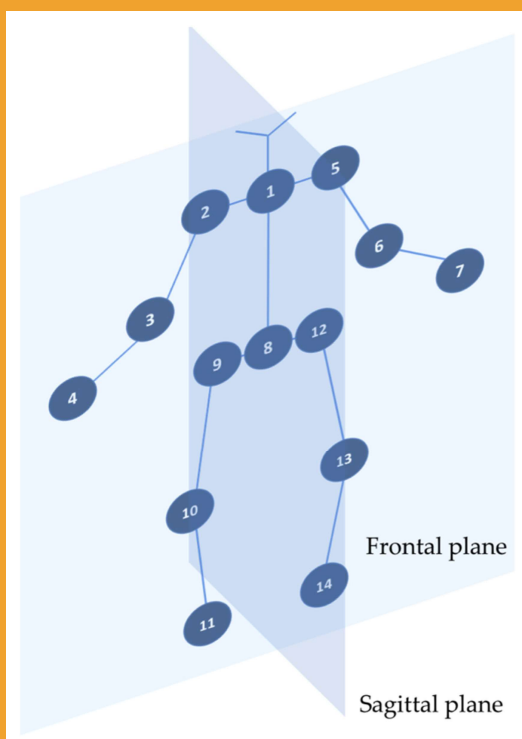
What s/he can see:

- Therapist

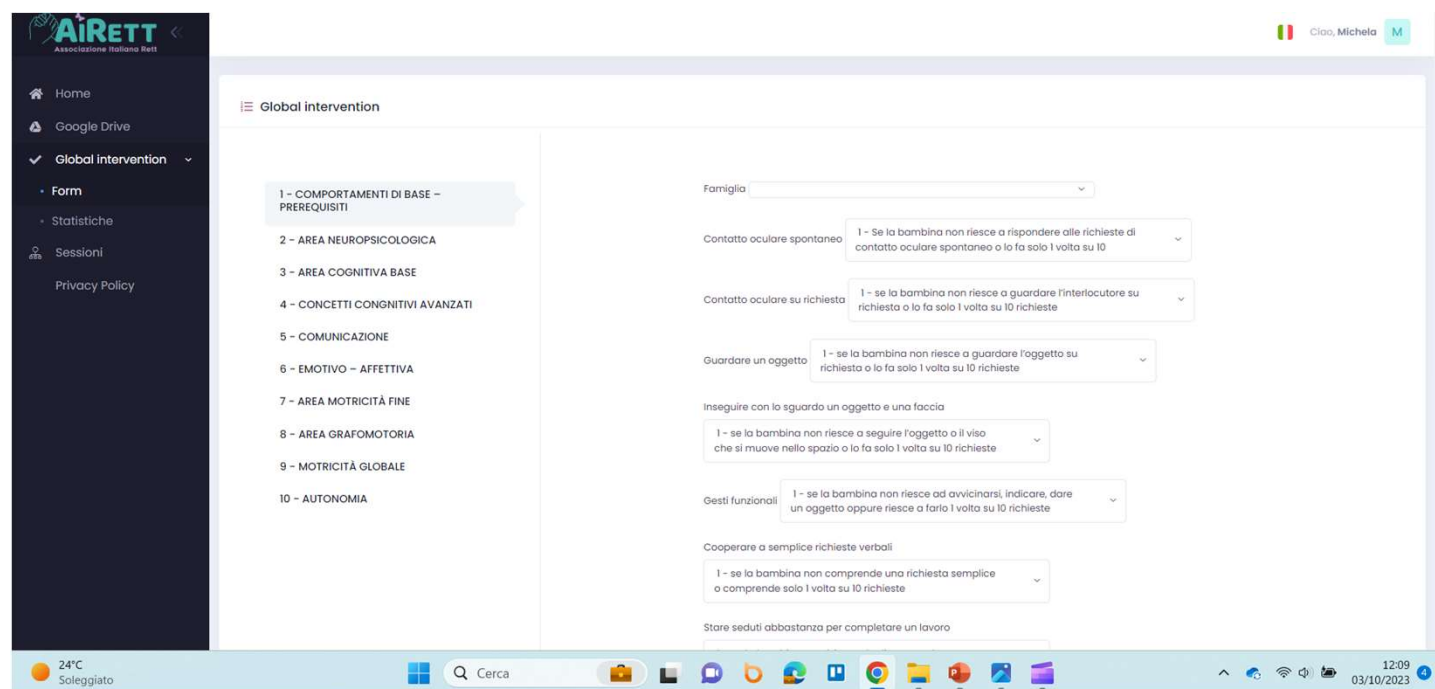
What s/he can do:

- Perform tasks

## Motor session



# The platform: Global Intervention Form



**AiRETT**  
Associazione Italiana Rett

Home  
Google Drive  
✓ Global intervention  
Form  
Statistiche  
Sessioni  
Privacy Policy

**Global intervention**

1 - COMPORTAMENTI DI BASE - PREREQUISITI  
2 - AREA NEUROPSICOLOGICA  
3 - AREA COGNITIVA BASE  
4 - CONCETTI CONGNITIVI AVANZATI  
5 - COMUNICAZIONE  
6 - EMOTIVO - AFFETTIVA  
7 - AREA MOTRICITÀ FINE  
8 - AREA GRAFOMOTORIA  
9 - MOTRICITÀ GLOBALE  
10 - AUTONOMIA

Famiglia

Contatto oculare spontaneo  
1 - Se la bambina non riesce a rispondere alle richieste di contatto oculare spontaneo o lo fa solo 1 volta su 10

Contatto oculare su richiesta  
1 - se la bambina non riesce a guardare l'interlocutore su richiesta o lo fa solo 1 volta su 10 richieste

Guardare un oggetto  
1 - se la bambina non riesce a guardare l'oggetto su richiesta o lo fa solo 1 volta su 10 richieste

Inseguire con lo sguardo un oggetto e una faccia  
1 - se la bambina non riesce a seguire l'oggetto o il viso che si muove nello spazio o lo fa solo 1 volta su 10 richieste

Gesti funzionali  
1 - se la bambina non riesce ad avvicinarsi, indicare, dare un oggetto oppure riesce a farlo 1 volta su 10 richieste

Cooperare a semplice richieste verbali  
1 - se la bambina non comprende una richiesta semplice o comprende solo 1 volta su 10 richieste

Stare seduti abbastanza per completare un lavoro

24°C  
Soleggiato

Cerca

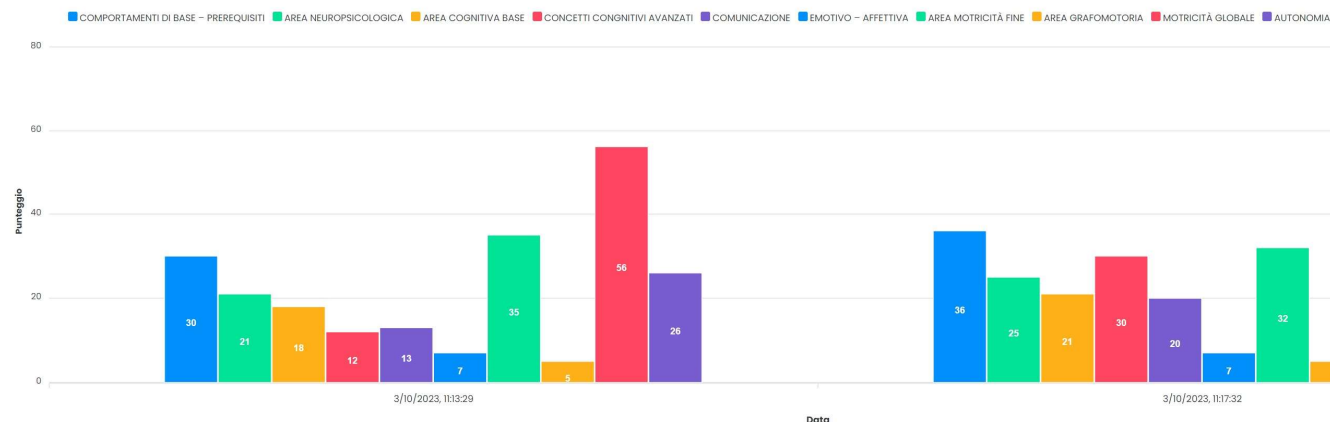
12:09  
03/10/2023

Statistiche Anna Ludovici

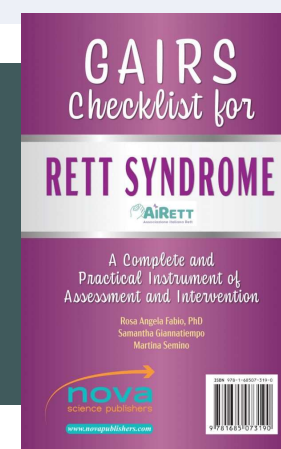
Carica file

Grafico 1

Grafico 2



# Global Intervention Form → Gairs Checklist





## Motor project:

# *Telerehabilitation with Computer Vision-Assisted Markerless Measures: A Pilot Study with Rett Syndrome Patients*

*Nucita, A.; Iannizzotto, G.; Perina, M.; Romano, A.; Fabio, R.A.*

### BACKGROUND

- Positive outcomes in multidisability, both for the participant and for the therapist. Valid method for taking care of children and adolescents (Caprì et al., 2021)
- Feasible in Rett syndrome, with improvements in gross motor skills and high caregiver satisfaction (Lotan, Downs, Elefant, 2021).

# Methods



Twenty-one Rett syndrome patients aged 4 to 31 (Median: 12.50; IQR: 9.50–17.25) were recruited for the study.

Evaluations: digitized version of the patient's skeleton superimposed on the video depicting the patient.

Exercise program: tailored on the individual, active/passive

## RESULTS

## ...but

### **EFFECTIVENESS OF THE PROGRAM**

The personalized rehabilitation intervention has led to improvements of the ROM and the items of the GAIRS scale, with implications on the performance of functional activities

### **FAMILY INVOLVEMENT**

Creation of a fundamental therapeutic alliance during the rehabilitation period

### **EVALUATION**

Only ROM was a parameter investigated through software, other elements such as balance or gait were not considered

### **EXERCISE PROGRAM**

The families had to carry out sessions independently without immediate feedback on the exercises.

## CONCLUSIONS

- Results demonstrate the reliability of our motor telerehabilitation system, ensuring accurate measurement and assessment of patient progress. Telerehabilitation has proved to be an effective tool in the improvement of motor parameters, such distance programs can be adapted to this population, in line with the existing literature and the technology used has proved able to identify improvements in joint mobility.
- Additional tools are needed to make an initial and final assessment of the motor functions of the subjects, and to evaluate objectively the proper performance of the prescribed exercises and performed in the absence of the therapist.

FUTURE

(present)

IMPLICATIONS

NEW FUNCTIONS OF THE  
SOFTWARE

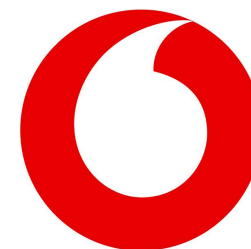
INERTIAL SENSORS TO  
PERFORM EXERCISE

- The training include personalized motor exercises, with focus on balance, transitions, functional use of the upper limbs → data recording
  - Motion tracking system
  - Measure of the area of postural oscillations
  - Measure of oscillations during linear gait
    - Measure of trunk inclination
- Use of non-immersive virtual reality for exercises performed autonomously through inertial sensors.

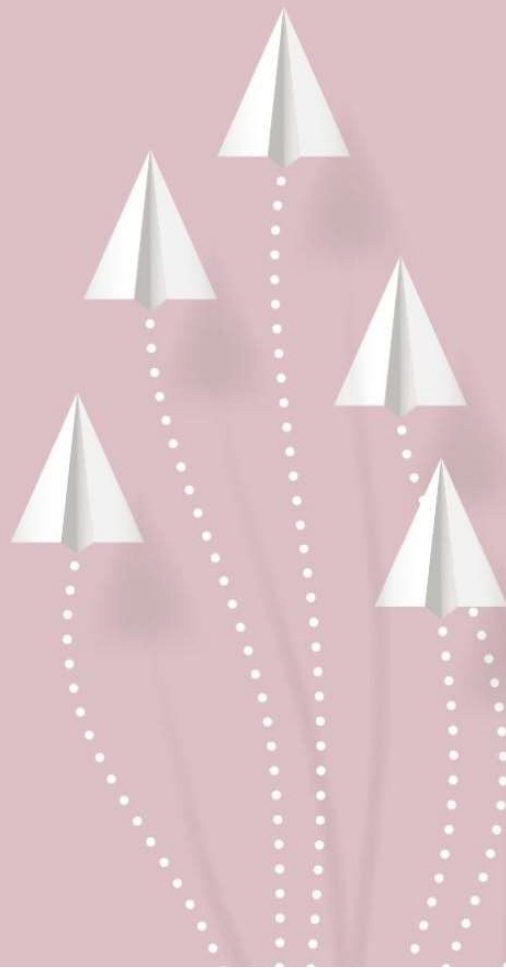
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- Fabio, R.A.; Semino, M.; Giannatiempo, S.; Caprì, T.; Iannizzotto, G.; Nucita, A. Comparing Advanced with Basic Telerehabilitation Technologies for Patients with Rett Syndrome—A Pilot Study on Behavioral Parameters. *Int. J. Environ. Res. Public Health* 2022, 19, 507. <https://doi.org/10.3390/ijerph19010507>
- Nucita, A.; Iannizzotto, G.; Perina, M.; Romano, A.; Fabio, R.A. Telerehabilitation with Computer Vision-Assisted Markerless Measures: A Pilot Study with Rett Syndrome Patients. *Electronics* 2023, 12, 435. <https://doi.org/10.3390/electronics12020435>

Grazie a...



**Fondazione  
Vodafone  
Italia**



Thank you for your attention.



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