



# Application of the Instrument «Identify Emotion» of the IE Basic Program in children with Complex Communication Needs such as Rett Syndrome

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# SERIOUS CLINICAL COMPROMISSION IN COMPLEX SYNDROMES

## Rare Diseases and Cerebral Palsy

- Rare Genetic Syndromes like Rett Syndrome, Angelmann Syndrome, Pitt Hopkins, etc.
- Cerebral Palsy

## Rett Syndrome

- Childhood genetically based neurodevelopmental disorder (MECP2, CDKL5, FOXP1).
- Its occurrence is estimated from 1/8000 - 1/10000 of newborn females.
- Apparently normal early development with an onset of regression between 6 to 18 months old.
- Developmental arrest, loss of spoken communication, purposeful hand use, and motor skills.
- Stereotyped repetitive hands movements.

- Difficulty of interaction with the surrounding environment with consequent distortion of cognitive and affective relational development.
- Preserved the ability to recognize stimuli through the visual channel: intentional look to express needs and desires is present.
- Low or absent language ability/residual manual ability



- Lack of cognitive re-habilitation tools
- Need to proceed with specific intervention programs that go beyond basic labeling and discrimination tasks (Antonietti, 2005; Castelli, 2009)

**From "knowing how to do" to "knowing how to be"**

# Protocol for Identifying Emotions

## From the Pilot Research to today's experimental study

All starts with 3 girls between the ages of 6 and 14 but now we use this protocol usually as a tool for neurocognitive re-habilitation

Initially only diagnosis of RS with genetic confirmation of mutation in gene MECP2, classic form and now we also include the other genes

other genetic syndromes like Pitt Hopkins and Angelmann Syndromes, and diseases like Cerebral Palsy

The children did not follow any neurocognitive re-habilitation program before, while all of them follow a personalized program to support communication.

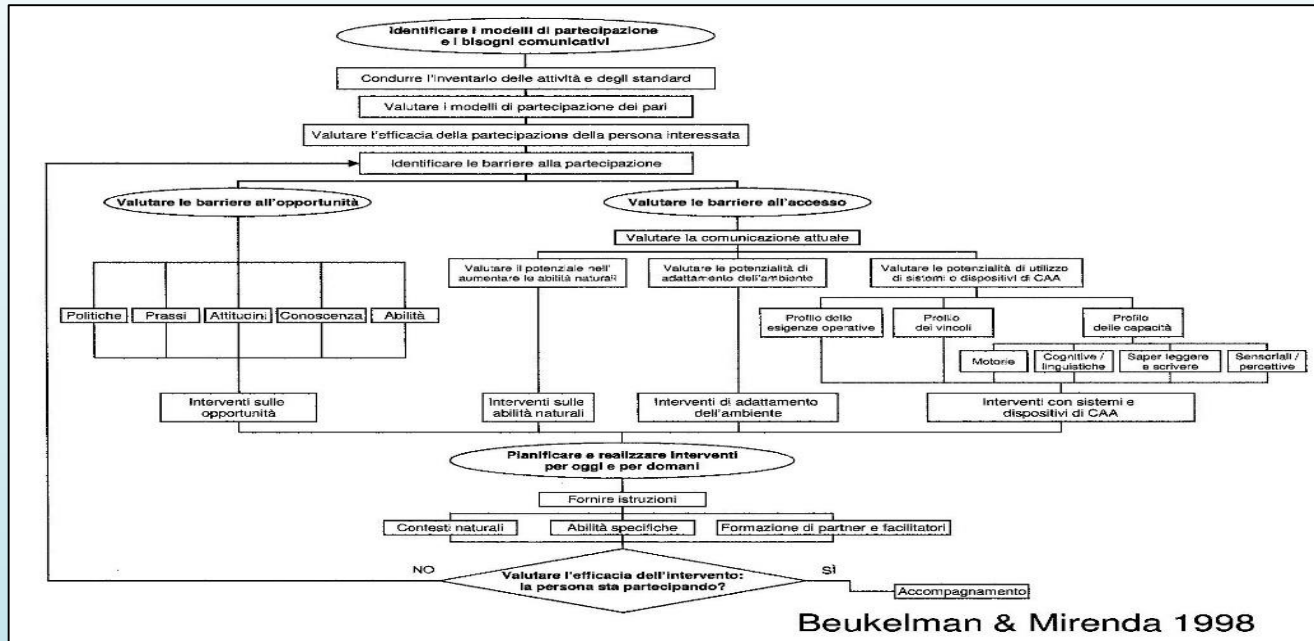
Psychometric assessment: Vineland, GMFM-88 and other specific scales.

Dynamic assessment - LPAD Basic and adapted tools like: Syntactic Comprehension Test, span of Short Term Memory, Test of ToM.

**NON  
STANDARDIZED  
RESULTS**

**RESIDUAL EVOLUTIONARY  
POTENTIALS**

# The Mediator as a Communicative Partner



## PARTICIPATION MODEL

«Without participation there is no one to talk to, nothing to talk about and no reason to communicate» (Beukelman e Mirenda, 1988)

### NEED TO IDENTIFY BARRIERS TO PARTICIPATION

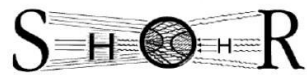
through the use of AAC it is possible to experiment the fundamental criteria of mediation and in particular:

INTENTIONALITY/RECIPROCITY

TRANSCENDENCE

MEDIATION OF MEANING

FEELING OF COMPETENCE



## FROM THE MLE TO THE ADAPTATION OF THE WORK SESSIONS



Puggioni, 2017 Isaac Italy Conference

The mediator functions as a sort of filter between the learner and the stimulus and at the same time he is also the "communicative partner" that makes a "conversation" possible. In this way the child becomes an active participant in the learning process.

# PRE-TRAINING

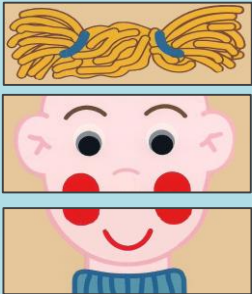
## steps I-VI



Step I – Presentation of real picture of emotions.



Step II – Presentation of drawn picture of same emotion.



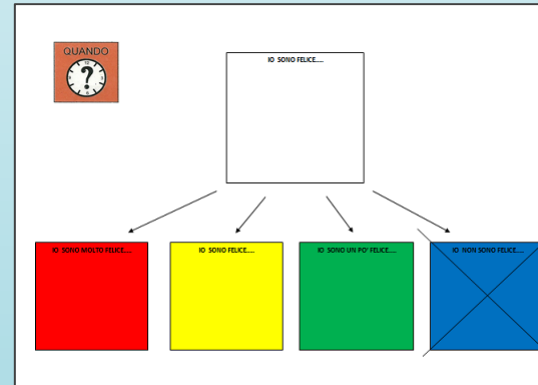
Step III – Reconstruction of drawn picture via the model of the real image.



Step IV – Presentation of image of real situation that may trigger the emotion.

Step V – Classification of the presented images

Step VI – Application of color code.



  
**BASE LINE**

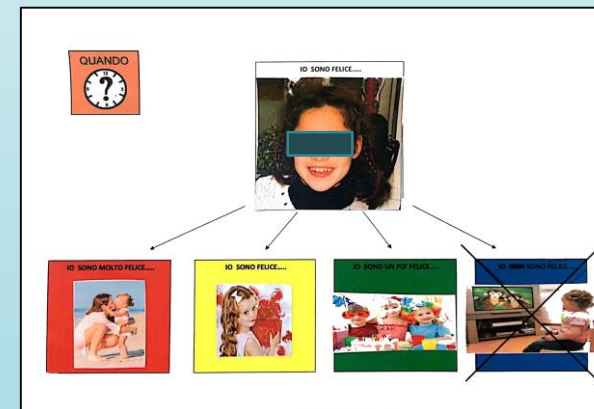
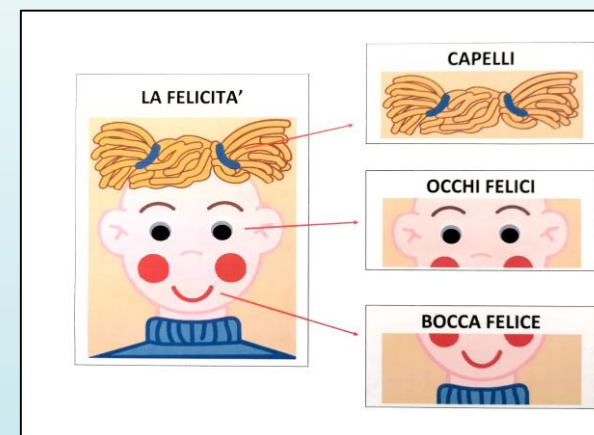
Puggioni P. et al., 2016



# Notebook of the traces

- Allows a narrative function by a conversation conducted by the Communicative Partner/Human Mediator.
- Promotes and allows participation and communication
- Supports the evolution of symbolic competence and the increase in vocabulary.
- Facilitates the internalization of lived experiences.
- Promotes the sharing of experiences (bridging).
- Provides an orientation in time.
- Supports the organization of internal thinking process and short and long-term memory.
- Tailor-made on the experience for each child and can be implemented later through the new experiences.
- It must be used in every context of life for generalization and with the support of every Communicative Partner/Human Mediator (parents, teachers, therapists)

Puggioni P. et al., 2016



Some examples of pre-training phase

# Adaptation of the Instrument

## THE COVER PAGE

The cover is modified according to the principles of Alternative Augmentative Communication (AAC):

- The page orientation changes from vertical to horizontal
- a photograph of the child is important to recall her/his attention to the task
- The title is expressed by a symbol
- the arrow helps to understand what to focus on
- The motto is expressed by a symbol and the same logo
- The symbols are taken from the Boardmaker software set because are the most transparent, but we can adapt the Instrument with the set or system of symbols in use by the children

Puggioni P. et al., 2016

# Adaptation of the Instrument

## THE PAGES

For each page a specific adaptation is proposed according to the principles of AAC. The images contained in each task are:

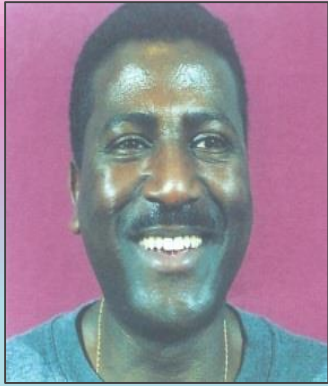
- photocopied, enlarged,
- cropped,
- isolated for the presentation of every single stimulus,
- plastified if necessary.

Puggioni P. et al., 2016

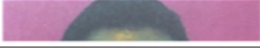


# TRAINING

## steps VII-XI



CAPELLI



OCCHI FELICI



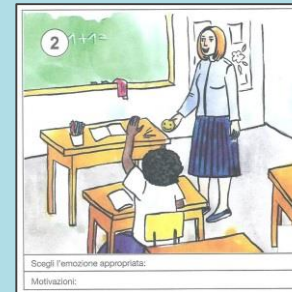
BOCCA FELICE



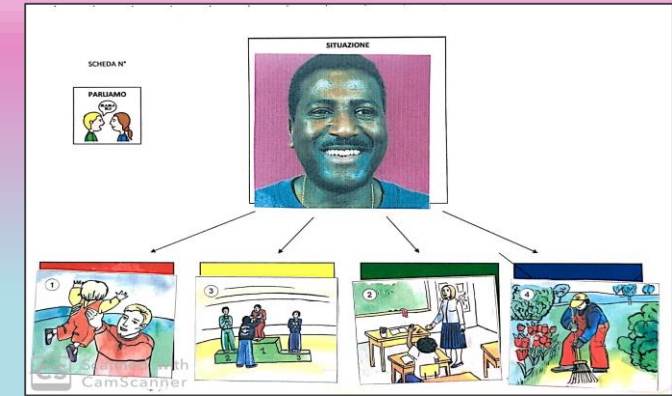
**STEP VII**  
PRESENTATION OF REAL IMAGE OF  
EMOTION PROPOSED IN THE ORIGINAL  
WORKSHEET AND ITS RECONSTRUCTION



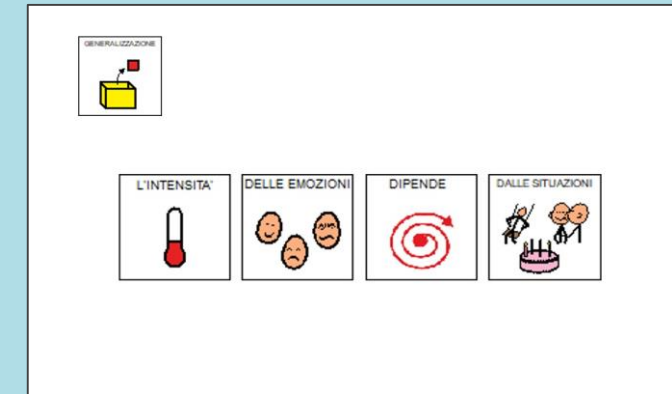
**STEP VIII**  
PRESENTATION OF THE DRAWN PICTURE  
PROPOSED IN THE ORIGINAL WORKSHEET



**STEP IX**  
CLASSIFICATION OF THE PRESENTED DRAWN  
PICTURES



**STEP X**  
APPLICATION OF COLOR CODE



**STEP XI**  
GENERALISATION OF CONTENT

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# Procedure

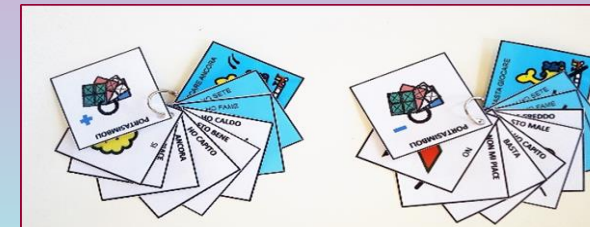
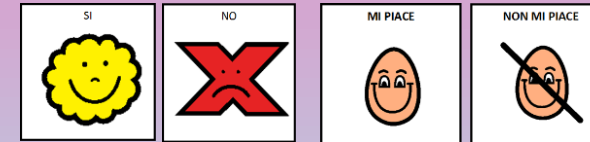
## TO SUM UP

- Use of an observation grid for each work session and specific for each instrument;
- there are always two therapists of us in the room and one parent or caregiver
- absence of time limits in the administration of each session;
- administration on binary presentation with alternation of the right / left targets and, in the case of children trained, through the use of 3-6 channels e-tran;
- Use of symbols to be able to talk;
- compilation of special cards for each cognitive task (“Notebook of the Traces”)
- application of the color code;
- Generalization and bridging;
- respect for times and rhythms with individualized programs.

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## AUGMENTATIVE ALTERNATIVE COMMUNICATION (AAC)

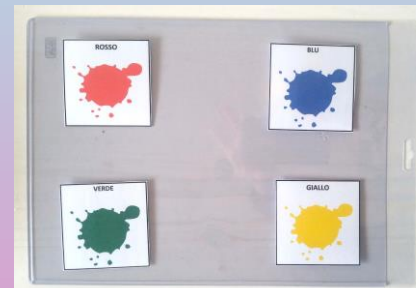
Low techology tools



SYMBOLS FOR BASIC COMMUNICATION  
REGULATORS OF BEHAVIOR



GENERALIZATION AND  
BRIDGING



E-TRAN: COLOR CODE  
4 CHANNELS



E-TRAN: EMOTIONS  
6 CHANNELS

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# Observation grid

The observation grid focused on the following features:

**Prerequisites:** is important to know what communicative channel is most easily used and if there is any residual manual skill manifested by the presence of deictic and/or indicative gestures.

**Emerging cognitive functions and distance of mediation.** As usual.

**Table of the task phases.** This table allows to establish, from time to time, the level of work and whether it has been internalized or not. The steps (I–VI baseline; VII–XI administration “Identify Emotion”) may be repeated in consecutive sessions if necessary.

**Evaluation of answers.** The scoring system was as follows: 1) right answer: +, 2) wrong answer: -.

**Frequency of stereotypes** 1) low = absent, 2) medium = inconstant, 3) high = always present.

**Selective attention:** 1) low = <30%, 2) medium = 30–70%, 3) high = >70%.

**Session Diary:** a session used to record any further annotation about the training.



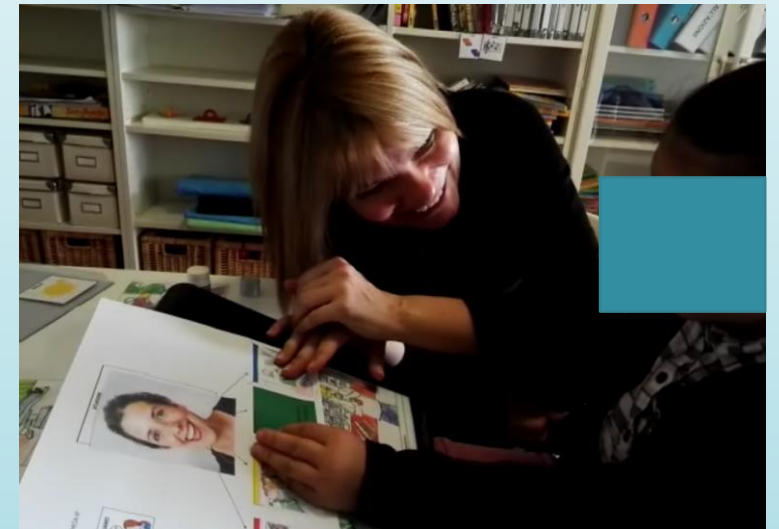
# Some moments....



The choice of intensity



The choice of color

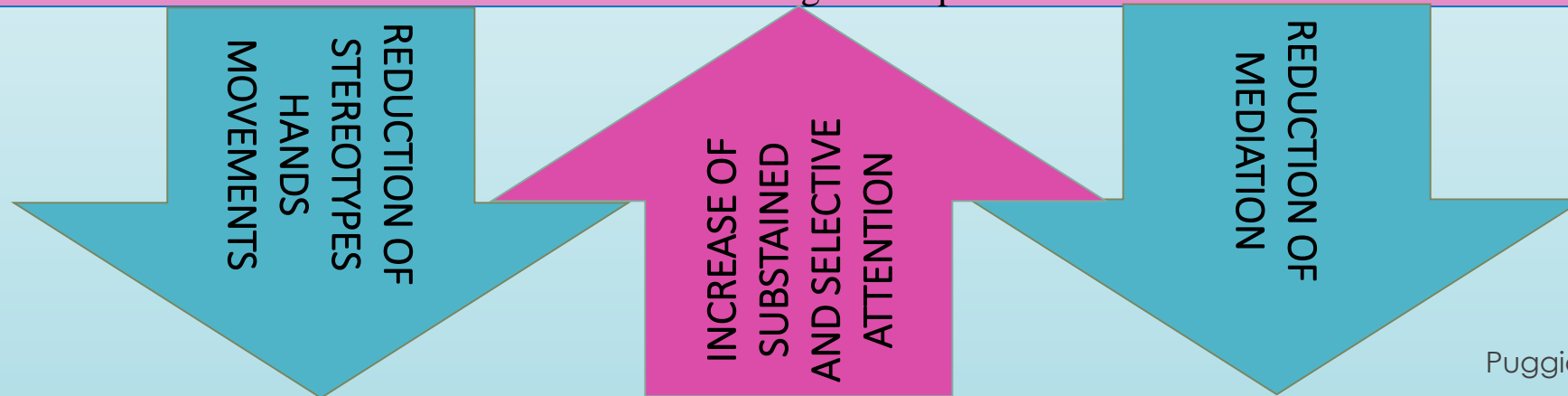


Pasting the image on the board

# Results

In all children the **motivation** has:

- encouraged the processing of the task;
- established rhythms in the priorities of the response systems;
- exchange opportunities through conversational communication shifts;
- allowed each to be an independent communicator with support  
(MEDIATOR = COMMUNICATIVE PARTNER);
- started self-regulation processes.

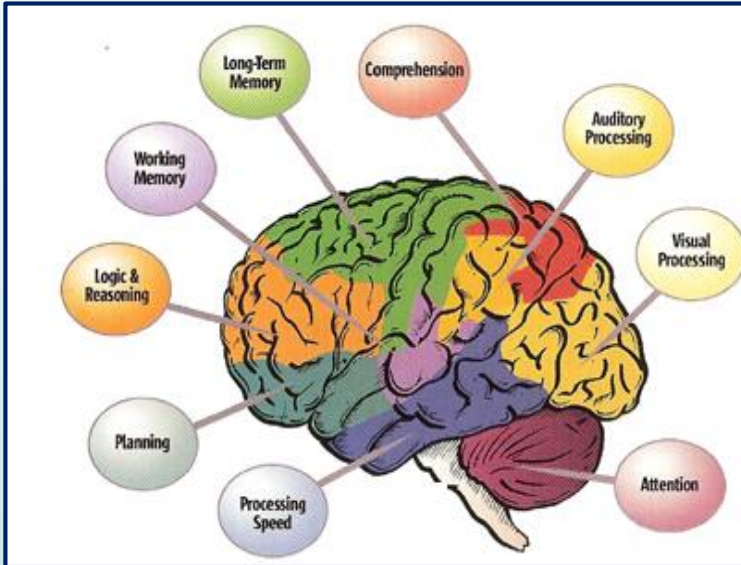


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“This confirms how the existing residual evolutionary potential can deviate much from the manifest level of current functioning and can be widely supported by the received mediation”

Feuerstein, 2006

# Conclusions



## OUR DREAM FOR THE FUTURE



Use of the adapted  
IE Basic  
in school  
for SEN and CCN

Training of teachers in particular qualified for  
school support combine with this approach

Research with IE Standard instruments  
has started

Treating higher basic cognitive tasks means trying to question the fixity of an evolutionary level to which many children are held to be firm with no possibility of deviations.

The motivation allows the elaboration of the task giving rise to plans capable of

**REGULATE BEHAVIOR, ESTABLISH PRIORITIES AND ANSWERS' SYSTEMS.**

Implements higher cognitive activities, through M.L.E. and the A.A.C. stimulates:

**CONCENTRATION AND ATTENTION, PROCESSES OF SYMBOLIC TYPE, MAJOR SENSE OF COMPETENCE**

that promote mental processes

of **RECOGNITION, ABSTRACTION AND GENERALIZATION;**

a **DECREASE OF DISADAPTIVE BEHAVIORS,**

a **GREAT MOTOR AND RESPIRATORY SELF-CONTROL**

conveying a better form of

**COMMUNICATION AND OPPORTUNITY OF PARTICIPATION.**

Puggioni P. et al, 2016

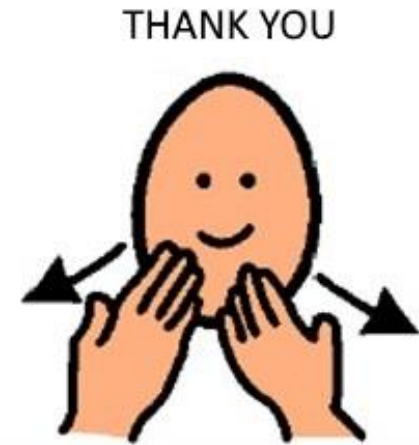
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- Puggioni et al. (2016). *The Feuerstein method and Rett Syndrome: a protocol of application of Instrumental Enrichment Basic Program «Identifying Emotions»*. *Formazione & Insegnamento XIV – ISSN 1973-4778 print – 2279-7505 on line*. doi: 107346/-fei-XIV-01-16\_07.
- Puggioni et al. (2017). *The importance of using AAC as a basis for the participation model in neurocognitive rehabilitation in Rett Syndrome or in children with similar diseases and complex communication needs*. *VI Conference Isaac Italy Proceedings*



**“All human beings are modifiable  
and everyone can be according to  
their potential”**

**R. Feuerstein, 1979**



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