



**When Sense Makes Sense:**  
Educational and Developmental Outcomes  
of Children Born Pre-term or with Exceptional Health Needs

**Glasgow – May 9<sup>th</sup>, 2019**

**EARLY PARENTING INTERVENTION  
IN INFANTS WITH  
NEURODEVELOPMENTAL  
DISABILITIES**

**Rosario Montirosso**  
Psychologist and Psychotherapist





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0-3 Centre  
for the at-Risk Infant

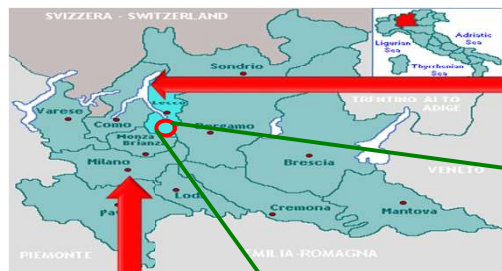
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**Scientific Institute "Eugenio Medea"**








**Milan**

**Lake Como**





**Neurorehabilitation hospital ruled by the Italian Ministry of Health**

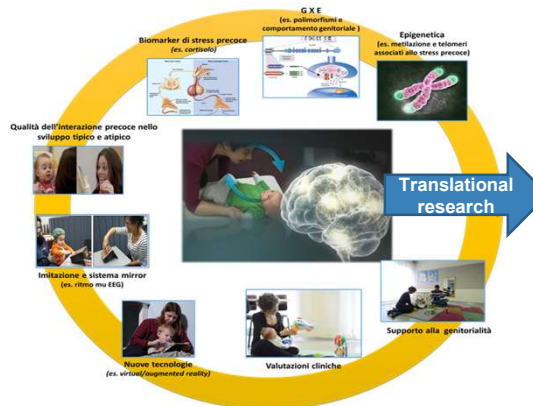
Infants with neurodevelopmental disabilities (cerebral palsy, genetic syndromes, severe prematurity, psychomotor delay, pediatric tumors)

0-3 Centre for the at-Risk Infant

## Neuropsychiatry and Neurorehabilitation Department




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Translational research


Scientific Institute IRCCS Eugenio Medea


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## What happens when the preterm infant goes home?

**Eva,  
born at 29 weeks**

For all photos, credit: Red Methot: <http://www.boredpanda.com/premature-baby-portraits-les-premas-red-methot/>

## Prematurity and long-term outcomes

### An overview of mortality and sequelae of preterm birth from infancy to adulthood

Saroj Saigal, Lex W Doyle

www.thelancet.com Vol 371 January 19, 2008



	Gestational age range (weeks)	Years of birth	Age at assessment	Disability diagnosis	Rate of disability
Farooqi, <sup>100</sup> Sweden	23–25	1990–92	11 years	Moderate or disabling cerebral palsy, visual acuity <6/60 in at least one eye, sensorineural deafness with hearing aids, or special school education*	21% (18/86)
Doyle, <sup>28</sup> Victoria, Australia	23–27	1991–92	2 years†	Moderate or severe cerebral palsy, visual acuity <6/60 in better eye, sensorineural deafness with hearing aids, developmental quotient <–2 SD relative to controls	21% (46/219)
Bohin, <sup>46</sup> Trent region, UK	23–25	1991–93	18–24 months†	Cerebral palsy, visual acuity ≤6/24 in better eye, hearing loss more than 60 dB, Griffiths scale <70 or developmental quotient <–2 SD, any growth measurement <–2 SD, epilepsy requiring regular medication, any other serious condition	35% (19/55)
Tin, <sup>38</sup> northern region, UK	23–25	1991–94	1 year	Not stated	26% (13/50)
Sutton, <sup>39</sup> New South Wales, Australia	23–27	1992–93	1 year†	Cerebral palsy, visual acuity <6/60 in better eye, hearing aids, developmental quotient <–2 SD (Griffiths)	29% (74/255)
Wood, <sup>27</sup> UK, Ireland	22–25	1995	30 months†	Unable to walk without assistance, blind, impaired hearing uncorrected with hearing aids, no clear speech	23% (64/283)
Rijken, <sup>47</sup> Netherlands	23–26	1996–97	2 years†	Cerebral palsy, developmental quotient <–2 SD (Bayley I)	35% (9/26)
Mikkola, <sup>48</sup> Finland	22–26	1996–97	5 years	Moderate or severe cerebral palsy, severe visual impairment, deafness with hearing aids, epilepsy, shunted hydrocephalus, intelligence quotient <50	25% (25/102)
Doyle, <sup>28</sup> Victoria, Australia	23–27	1997	2 years†	Moderate or severe cerebral palsy, visual acuity <6/60 in better eye, sensorineural deafness with hearing aids, developmental quotient <–2 SD relative to controls (Bayley II)	28% (41/148)

\*Outcomes assessed largely by questionnaires, with no formal cognitive assessment. †Corrected for prematurity.

Table 2: Neurological disability rates for survivors of borderline viability by gestational age from geographically defined cohorts

## Care system redesign for preterm infants after discharge

### Care System Redesign for Preterm Children After Discharge From the NICU

Dennis Z. Kuo, MD, MHS,\* Robert E. Lyle, MD,<sup>3,c</sup> Patrick H. Casey, MD,<sup>3,c</sup> Christopher J. Stille, MD, MPH<sup>d</sup>

PEDIATRICS Volume 139, number 4, April 2017:e20162969



- management of acute and chronic conditions
- prevention of medical complications
- timely developmental screening & intervention
- proactive recognition and management of behavioral disorders
- support for families



## Resources after discharge is equally critical

### Parenting Preemies

*A Unique Program for Family Support and Education  
After NICU Discharge*

Valerie Willis, *Advances in Neonatal Care* • Vol. 8, No. 4 • pp. 221-230, 2008

- Clinical practices and research support the importance of family-centered care in the NICU.
- The significance of continuity in family-centered care beyond the NICU has only slowly gained attention (Bakewell-Sachs and Gennaro, 2004).

## Do current early intervention practices engage families?

### ❑ Self-report (Scarborough et al., 2004)

- 44% of time focused only on the child.

### ❑ Observation (Peterson et al., 2007)

- 51% teaching the child directly.
- 33% engaging in adult interactions.



Very little time is focused directly on enhancing parenting behaviors through the coaching of parent-child interactions.

## Beyond conventional interventions

- Early childhood intervention provided by professionals twice a week for 50 weeks in the absence of parent involvement accounts for about 4 percent of a 2-year-old's waking hours
- Caregiver-child interactions that occur just one hour a day seven days a week would include about 200,000 learning opportunities each year compared to 30 minutes of once per week therapy sessions that would provide a child just 7,500 learning opportunities each year (Mahoney and MacDonald, 2007).
- To promote child skill acquisition in the context of everyday routines would provide a child significantly more learning opportunities per episode compared to once a week therapy or educational intervention sessions (McWilliam, 2000).



Need to effectively engage parents if we expect child developmental growth.



**Felix,  
born at 24 weeks**

**When something goes  
wrong...**

## When something goes wrong...

- What happens when something goes wrong and neurodevelopmental conditions or psychomotor delay are present?

*Davide is a 13 month old infant, with a severe psychomotor delay and frequent seizures.*

- | <b>Parent</b>   | <b>Infant</b>  |
|---|--|
| <ul style="list-style-type: none"> <li>• Less signal-reading easiness               <ul style="list-style-type: none"> <li>• Less sensitive touch</li> <li>• More intrusiveness</li> </ul> </li> <li>• Less responsivity to infants' signals</li> <li>• Risk of emotional and/or physical remoteness</li> </ul> | <ul style="list-style-type: none"> <li>• Less eye contact and vocalizations</li> <li>• Less responsivity and reduced intentionality</li> <li>• Less referential gaze and shared/joint attention</li> <li>• Less emotional regulation competence</li> <li>• Temperamental difficulties</li> </ul> |

*What is “parental sensitivity” in a context like this?*



**Margot,  
born at 29 weeks**

**Evidence about the early  
parental intervention effects**



## Early intervention programs: a systematic Cochrane review

### Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants (Review)

Spittle A, Orton J, Anderson PJ, Boyd R, Doyle LW  
Cochrane Database of Systematic Reviews 2015, Issue 11. Art. No.: CD005495.  
DOI: 10.1002/14651858.CD005495.pub4.



#### Types of studies

- Random or quasi random allocation

#### Types of participants

- Born at < 37 weeks GA

#### Types of intervention

- Early intervention that aimed to improve motor or cognitive outcomes
- Commenced within the first 12 months of life
- Commenced before or after discharge
- Carried out by health or educational professionals

#### Types of outcome measures

- Cognitive and/or motor outcomes in infant (<3 years), preschool (3 to 5 years) and/or school-aged children (<5 to <13 and 13 to 18 years) age.

## Early parental interventions vs. standard follow-up: infants

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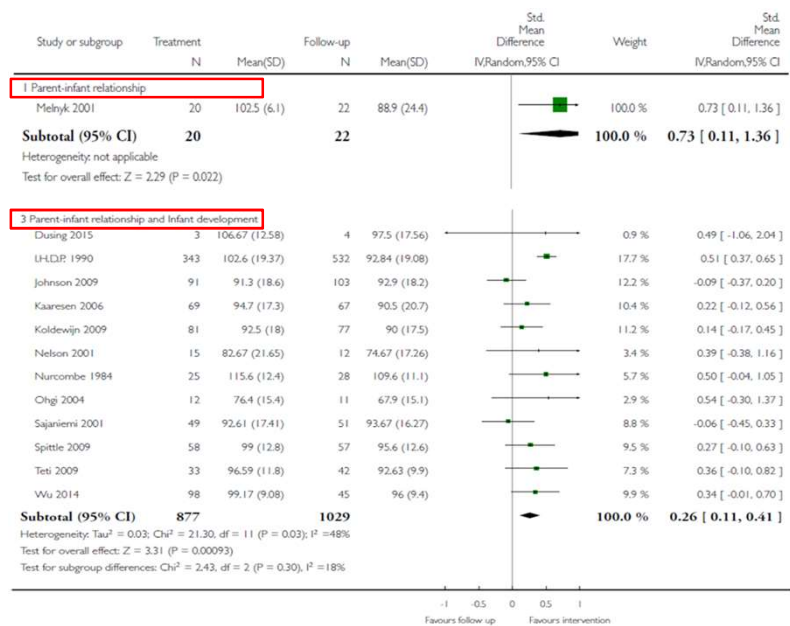


#### Outcome:

Cognitive outcome at infancy  
DQ (BSID-MDI, Griffiths GCI)

#### Main finding:

Infants who received early intervention reported a development quotient which was higher than the one reported by infants who received a standard follow-up.



## Early parental intervention vs. standard follow-up: preschool age

Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants (Review)

Spittle A, Orton J, Anderson PJ, Boyd R, Doyle LW  
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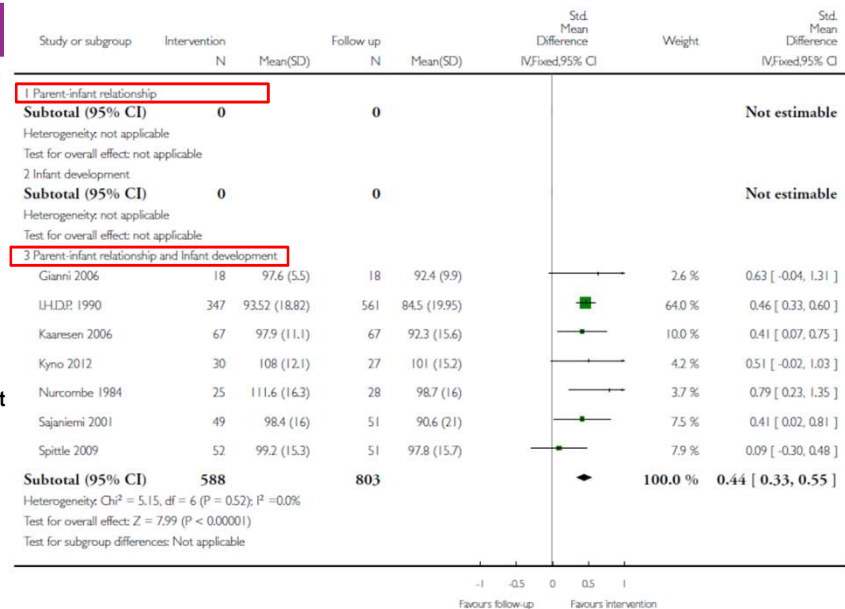


### Outcome:

Cognitive outcome at preschool age - IQ  
(Stanford-Binet, McCarthy)

### Main finding:

Infants who received intervention that focused on both the parent-infant relationship and infant development had, in average, a higher intelligence quotient compared to infants who received standard follow-up at preschool age.



## The impact of EPI on infant outcomes and caregiver's mental health

Results  
at 2 years

- Improved behavior (less externalizing and dysregulation behaviors and increased competence)

- Primary caregivers less anxiety and depression

Preventive Care at Home for Very Preterm Infants Improves Infant and Caregiver Outcomes at 2 Years

AUTHORS: Alicia J. Spittle, PhD,<sup>a,b,c</sup> Peter J. Anderson, PhD,<sup>a,d</sup> Katherine J. Lee, PhD,<sup>a,c</sup> Carmel Ferretti, MPsych,<sup>a,d</sup> Abbey Eeles, BOT,<sup>a,c,d</sup> Jane Orton, MPhysio,<sup>c</sup> Roslyn N. Boyd, PhD,<sup>f</sup> Terrie Inder, MD,<sup>e</sup> and Lex W. Doyle, MD<sup>a,b,h</sup>

PEDIATRICS Volume 126, Number 1, July 2010

Long-term Benefits of Home-based Preventive Care for Preterm Infants: A Randomized Trial

AUTHORS: Megan M. Spencer-Smith, PhD,<sup>a</sup> Alicia J. Spittle, PhD,<sup>a,b</sup> Lex W. Doyle, PhD,<sup>a,c,d</sup> Katherine J. Lee, PhD,<sup>c,f</sup> Lucy Lorefice,<sup>a,b</sup> Anastasiya Suetin,<sup>a,f</sup> Leona Pascoe,<sup>e</sup> and Peter J. Anderson, PhD<sup>a,f</sup>

Pediatrics 2012;130:1094-1101

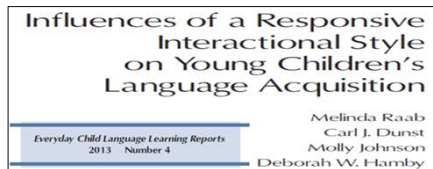
- Improved behavior (less internalizing behaviors)

- Primary caregivers less anxiety

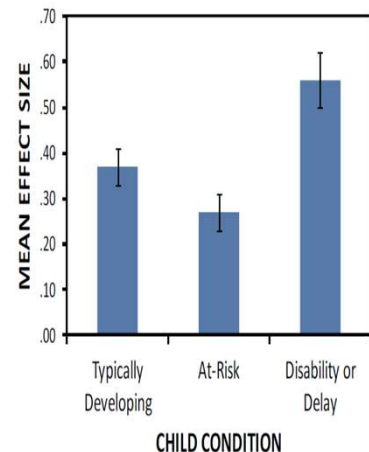
Results  
at 4 years



## Influences of a responsive interactional style



- The relationships between parenting interactional behaviors and child communication and language development were examined in 46 studies including more than 5800 infants, toddlers, and preschoolers with and without disabilities or delays.
- Responsive interactional behaviors were related to the children's nonverbal communication and expressive and receptive language development.
- The relationships between the interactional behaviors and the child outcomes were similar for children with and without disabilities



## Responsive interaction interventions (RII) for children with or at risk for developmental delays

**Responsive Interaction Interventions for Children With or at Risk for Developmental Delays: A Research Synthesis**  
 Topics in Early Childhood Special Education  
 33(1) 4-17 2011  
 Na Young Kong, MEd<sup>1</sup> and Judith J. Carta, PhD<sup>2</sup>

□ 31 papers: a majority of studies (more than 90%) indicated that implementation of RII resulted in significant positive changes in adults' responsive behaviors and children's emotional and social-communicative outcomes.

- **For infants:** The most frequently reported positive outcomes were in the social-communication domain.
- **For parents:** significant positive outcomes were in the social-verbal responsiveness.

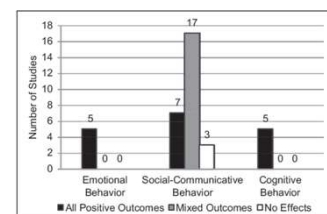


Figure 2. Studies reporting child outcomes in different domains.

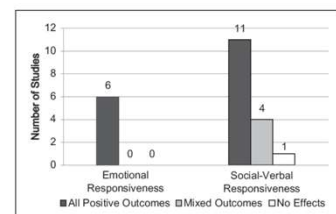
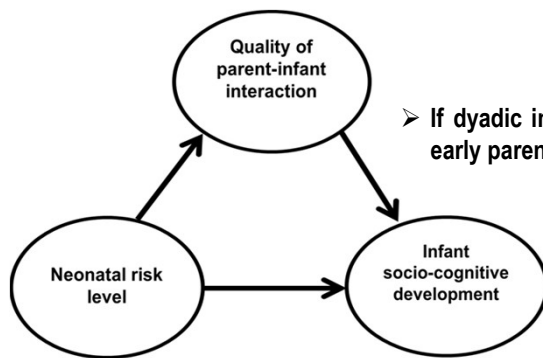


Figure 1. Number of studies reporting adult outcomes in different domains.

## Parent-infant interaction is a mediating factor

- Research suggests that the relation between neonatal health status and development delays is, at least partially, influenced by environmental factors, such as quality of parent-infant interaction.



- If dyadic interaction patterns can mediate the effects of neonatal risk, then early parental intervention could be critical for infant development.



There is increasing evidence that early parental intervention is effective for the improvement of children's social and cognitive skills



Alice,  
born at 27 weeks

Working with family of infant with  
neurodevelopmental disabilities

## Not only overt skills.....

### Caregiver Characteristics

- Sensitivity to child initiations (following the infant's lead)
- Engagement-facilitating caregiver behavior
- Contingent responsiveness to child behavior
- Positive caregiver affect
- Turn taking and joint attention
- Caregiver support and encouragement

### Child Characteristics

- Incorporating child interests into learning opportunities
- Incorporating child strengths into learning opportunities

### Activity Setting Characteristics

- Collaborative approach
- Situationally interesting activities
- Everyday learning opportunities

**The Face-to-Face Still-Face (FFSF) Paradigm in Clinical Settings: Socio-Emotional Regulation Assessment and Parental Support With Infants With Neurodevelopmental Disabilities**

Lorenzo Giusti, Livio Provenzi\* and Rosario Montirosso

**frontiers**  
in Psychology

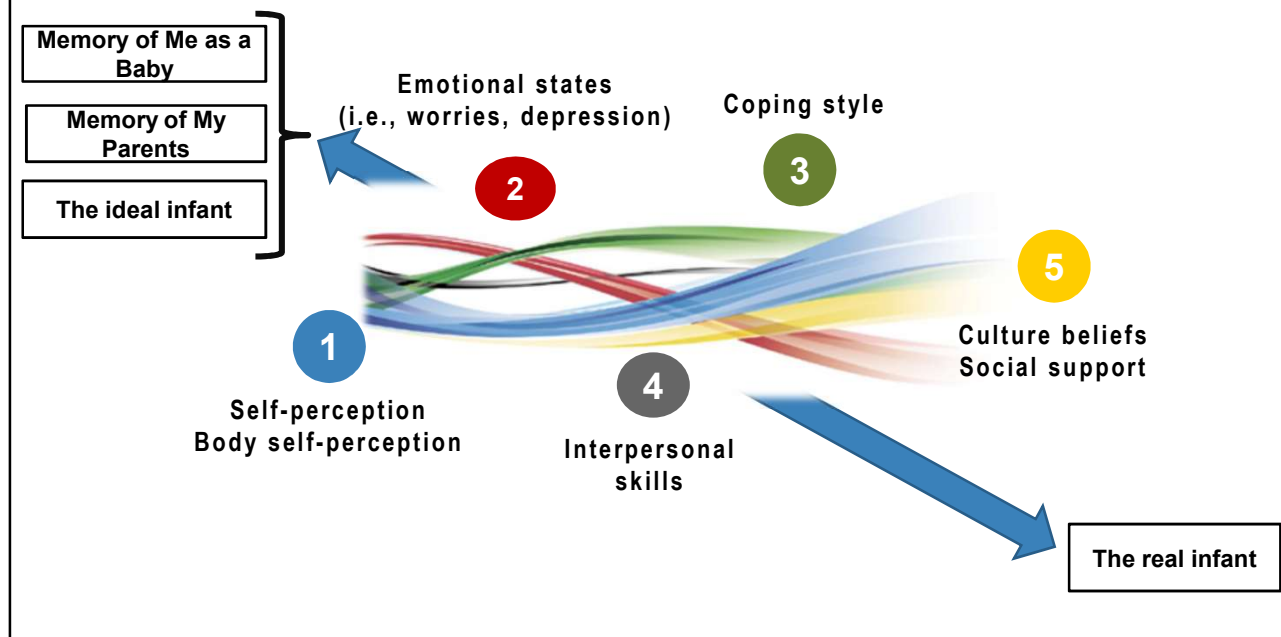
HYPOTHESIS AND THEORY  
published: 22 May 2018  
doi: 10.3389/fpsyg.2018.00789



### Attention to the felt sense of parents

*"[...] use of the felt sense is not meant to replace other techniques a consultant may have learned about watching interactions between parents and infants. The emphasis is on attending to one's felt sense as an additional resource in attending to, feeling, and understanding what is going on."* (Boukydis, 2012, page 190).

## Parenting is a complex plot



## Video-feedback intervention

□ Previous research that aimed to support parenting in families of infants with neurodevelopmental disabilities by using collaborative consultation on videotaped parent-infant interactions (Kim and Mahoney, 2005; Phaneuf and McIntyre, 2007; Lam-Cassettari et al., 2015) reported better outcomes:

- for parental sensitivity and attunement, as well as
- for infants' behavioral stability and development.

## Nicolò and his mom (1)

### MAIN CLINICAL INFORMATION

- Preterm birth
- Age at the consultation: 2yr, 5m
- DQ = 40 (Griffiths Scale)
- 3 siblings (the older one with Autism Spectrum Disorder)
- Psychomotor delay
- Brain alterations (corpus callosum and cerebellar vermis)
- Reported symptoms: psychogenic vomiting

### FELT SENSE OF MOTHER

*«It seems to me I did not know him, as if he's a stranger, I do not understand him, he is not attentive, he is unmanageable»*

*«It's difficult to think that he has only the gaze to allow me to understand his needs»*

*«Is he autistic?»*

**Nicolò's mother feels that she doesn't know Nicolò. She feels as if Nicolò were a stranger.**

**To some extent, she did not know how to be in contact with her child.**

**During the first assessment the interactive style of Nicolò's mother was mainly based on the stimulation, instead of following child's behavior.**

**But main point is that the Nicolò's mother felt she failed in trying to interact with her child.**

## Nicolò and his mom (2)

During the hospitalization, Nicolò's mother participated in 8-video-feedback sessions.

We worked with Nicolò's mother about the meaning of child behaviors and her interactive modalities in response to him.

After the video-feedback intervention the quality of interaction was better: no more than one toy, the mother and the child manage interactive turn-taking, the mother models, she also laughs and seems to get funny from the interaction.

Watching the video Nicolò's mother said, "Now, I see - it's like Nicolò is asking me to play with the ball or to do something else, such as sing a song, step by step".

Nicolò's mother said: "He needs time. I need time for myself and for him".

In one way of looking at it, her child's skill and the timing of our joint observation provided a new perspective, and our consult provided a learning space for the mother.

The message was this: *Nicolò was overloaded from too much (and too varied) sensory input, and the maternal interactive style needed to be modified to meet child's skill.*

## Changing narratives of parents means opening new opportunities of togetherness

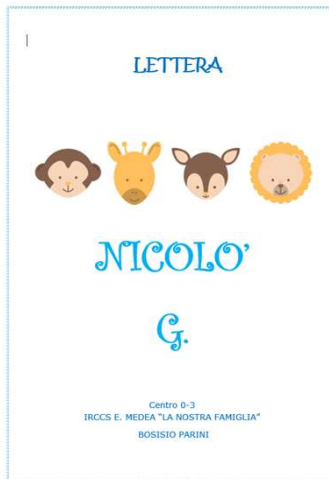


- ✓ To some extent, the initial Nicolò's mother worries were correct: "She did not know her child".
- ✓ However, the jointly reviewing mother's understanding and use reflection about how she could learn from her child help in changing the view of child.



Help parents tell a different story. Different stories have different actions and endings.

## Giving voice to speechless infants



Dear mom and dad,

This is Nicolò.

We have been together at the hospital, we met several people, I played with them and you talked a lot. I showed to them what I like, the toys I prefer and what I don't like.

I discovered that playing with cars is my top activity in the world: was it on me, I never stop doing that.

We can play together, but please consider that I am not quite ready for that, so be patient with me. When do not engage, doesn't mean I don't want to. Simply, everything new for me is hard.

[...]

Also, it seems to me that sometimes you might be sad. I am a baby, and I know that emotions are important in life. If you are, sometimes, please take time to express your feelings to each other – and consider that if I can regulate emotions with you, I can learn to regulate them better.

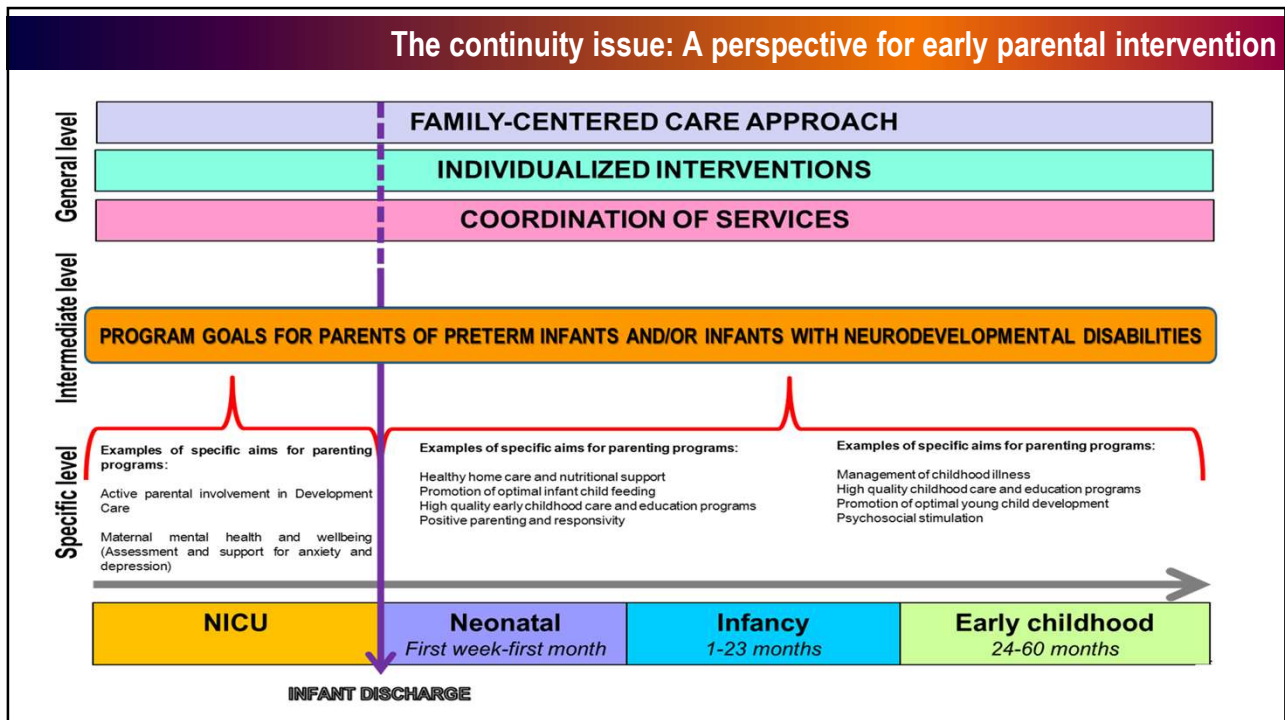
Let's go home  
Nicolò



**Charles**  
**Born at 26 weeks**

## Conclusions





### Take-home messages

#### TIMING:

- Parents of infants at high risk neurodevelopmental disabilities should **commence intervention programs as soon as possible**, to take advantage of the increased plasticity of infants developing brain.

#### BENEFITS:

- Although long-term benefits of these programs remain unclear, there is evidence that **early parental intervention programs have a positive influence on cognitive outcomes during infancy, with cognitive benefits persisting into preschool age.**

#### APPROACH:

- From a care system perspective, **family-centered care approach remains a key factor even after the NICU discharge.**

## Attention to the felt sense of parent-infant interaction

But, at the very end, the critical point is to support parents stay with their felt sense (Boukydis, 2012).

This means:

- To recognize that the felt sense underlie any parent-infant interaction.
- To help parents listen to themselves by learning the capacity to attend to their felt sense in the interaction.
- To help parents to explore their own felt sense and their felt sense of their developing relationship with their infant.

## Trying to measure what cannot be measured!

- Working with infants and parents the temptation is to set up everything by a rigorous scientific approach.
- This temptation suffers of a logical flaw: that is, to establish a strict connections between the felt sense of parent–infant interactions and some overt bids.
- However, just like “The man who measures the clouds” cannot capture the clouds complexity, it is quite possible that we cannot capture the complexity of infants and parents' subjective experience using a rigorous approach.
- We need to use our felt sense.



Jan Fabre  
*The man who measures the clouds*



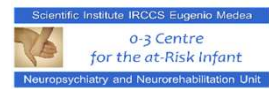
This give us a great opportunity: to be witness of “the greatest invention in the world....., the mind of a child“ (Thomas Edison).

## Acknowledgements



### Colleagues:

Renato Borgatti  
Livio Provenzi  
Lorenzo Giusti  
Anna Cavallini  
Alice Decio  
Elena Guida  
Elisa Rosa  
Eleonora Visintin



### Trainees and research assistants:

Nadia Santini  
Eleonora Raschi  
Maddalena Brambilla  
Camilla Italiano  
Silvia Fumagalli



Emily,  
born at 26 weeks



Felix, born at 23 weeks  
Alexis, born at 33 weeks

## THANK YOU FOR YOUR ATTENTION

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Tamica, born at 32 weeks (and 26 weeks pregnant at the time of the photo).