

MINISTERUL SĂNĂTĂȚII Al republicii moldova







Quality in Early childhood Intervention

The importance of prevention, cooperation with parents, evidence orientation and transdisciplinary professional training

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KEY NOTE within the Moldova Conference 30.11.2023



- 1) What are we talking about (numbers and their contexts)
- 2) Current theoretical model approaches (Guralnicks Developmental Systems Approach and Sammeroffs transactional approach)
- 3) Quality criteria in ECI
- 4) Indicator questions for continuos training and QM processes
- 5) Key messages



1) What are we talking about?

We are talking ABOUT ALL children and FAMILIES BUT: Not every family needs the same! - Early Childhood Intervention in general is an integrative part of broader services for children and families.

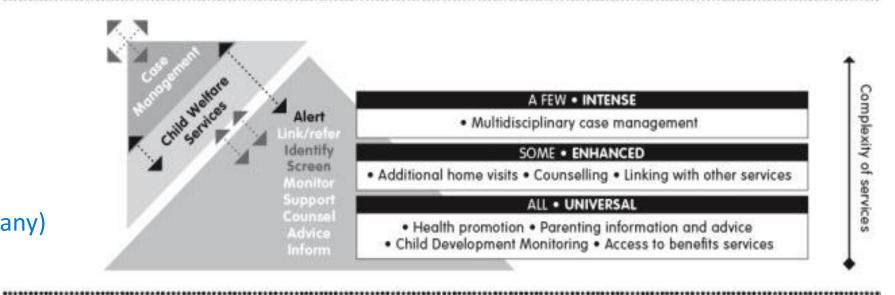
Unicef framework for home visits (amended by the author)

5-6%

Severe to moderate disability e.g. WHO/Worldbank, 2011

Up to 22%

Psychosocial risk-factors (e.g. Eickhorst et al. 2015 for Germany) **ALL Children**



Source: UNICEF CEE/CIS

Early Intervention as secondary and tertiary prevention: Usually Early Intervention services are understood as highly specific inclusive programs for a dedicated number of families (in high need for support)

WHO: Families of CwD**

<u>WHAT:</u> Specific inclusive programs in transdisciplinary teams around the child <u>HOW:</u> Easy accessible, affortable, divers, interdisciplinar, team-oriented

<u>WHO:</u> Families with endangered resilience factors (SOME)
<u>WHAT:</u> Extended offers (intensivied homevisits, Parenting programs)
<u>HOW:</u> Use synergies, empower exisiting services (Patronage nurses, midwifes, Family Doctors, Social Workers, Parent Initatives...)

<u>WHO:</u> Children/Families of newborn (ALL) <u>WHAT:</u> Screening/Monitoring HOW: Increased use of ICT When using ICF as a Common Language the term "developmental difficulty" does not only refer to Children with Disabilities. But to all children/ Families in need for Different degrees Of support

*"Screening" as well established term to look for developmental difficulties or "monitoring" as a term currently under discussion

**CWD Children with Disabilities

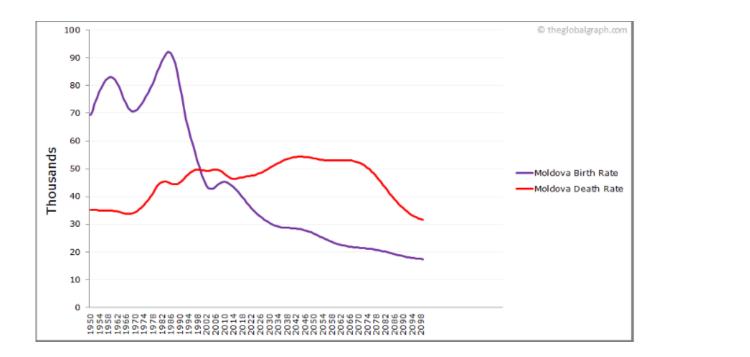
What are we talking about (2)

Specifically for children with developmental difficulties:

Birth rate per year in MD: average 36,263 annually (during the last 10 years): Possible target group for ECI (0-6 years): 10878 children.

At the moment 11,700 children aged 0-17 years are considered disabled.

at least half of the potential target group (0-6 years) might be excluded from the preventive service of ECI (in concordance with other countries(Pretis 2016)





www.worldpopulation.theglobalgraph.com/p/moldova-population.html

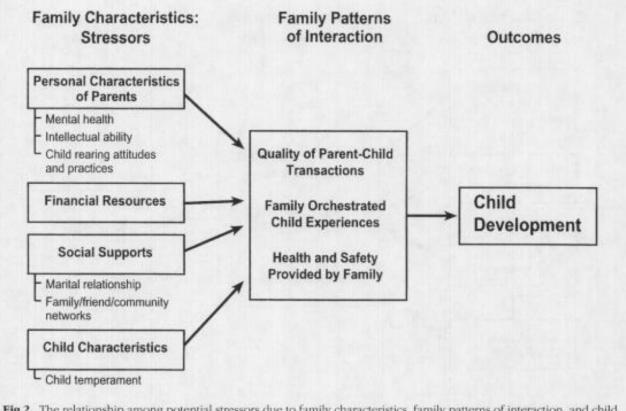
What are the (most common) developmental difficulties?

	0-17	Children 3-5 years
Any developmental disability	16,93%	10,55 %
ADHD	9,04 %	2,13 %
Learning disability	7,74 %	3,30 %
ASD	1,74 %	1,68 %
Intellectual disability	1,10 %	0,63 %
Moderate to profound hearing loss	0,63 %	0,45 %
Cerebral Palsy	0,31 %	0,28 %
Blindness	0,16 %	0,10 %

www.ncbi.nlm.nih.gov/pmc/articles/PMC7076808/

In most western countries children with **unspecified developmental** difficulties are the main target group (R62, F83...) of ECI.

How do we theoretically address these families in ECI? Guralnicks "Developmental systems model"



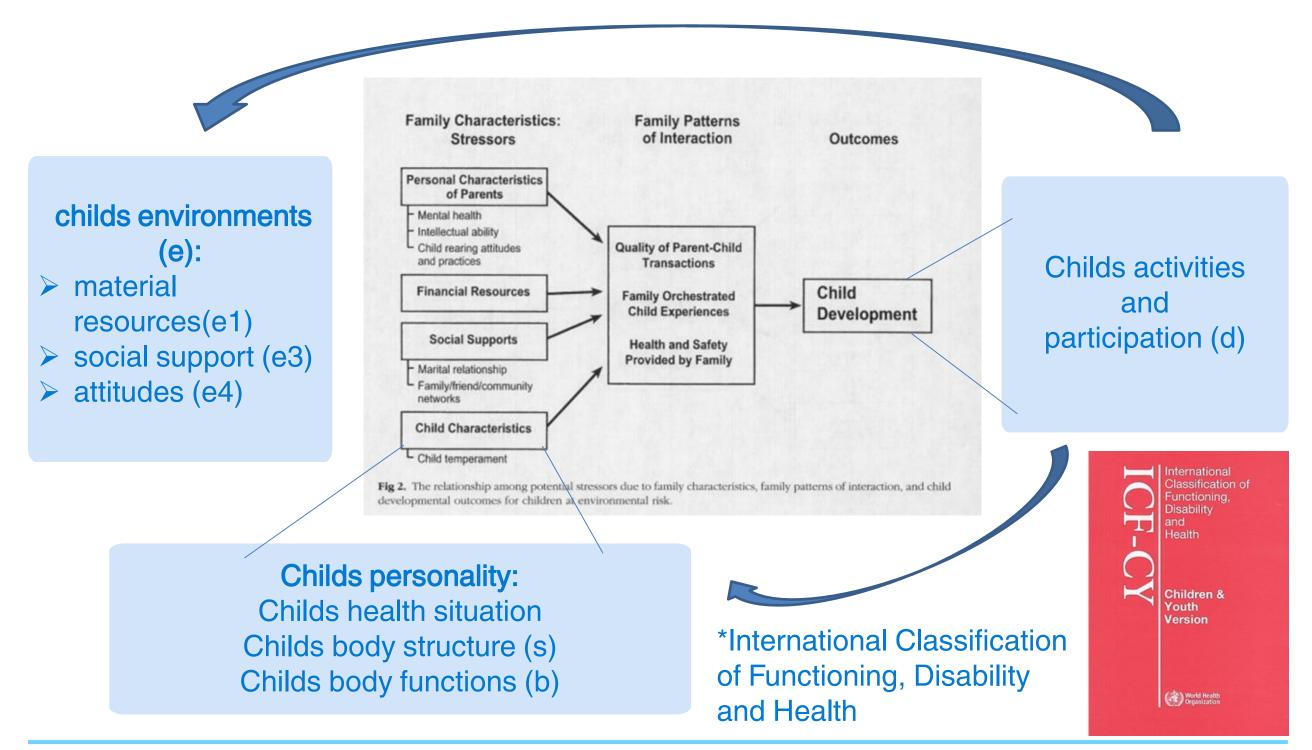
Michael J Guralnick (2001). A developmental systems model for early intervention

Infants and Young Children; Oct 2001; 14, 2; Research Library

Fig 2. The relationship among potential stressors due to family characteristics, family patterns of interaction, and child developmental outcomes for children at environmental risk.

+ Sammeroffs transactional model

Let us put Guralnicks model in another light using ICF* in Early Childhood Intervention and how this is connected with QM?



What does it mean to use an ICF focus on Early Childhood?

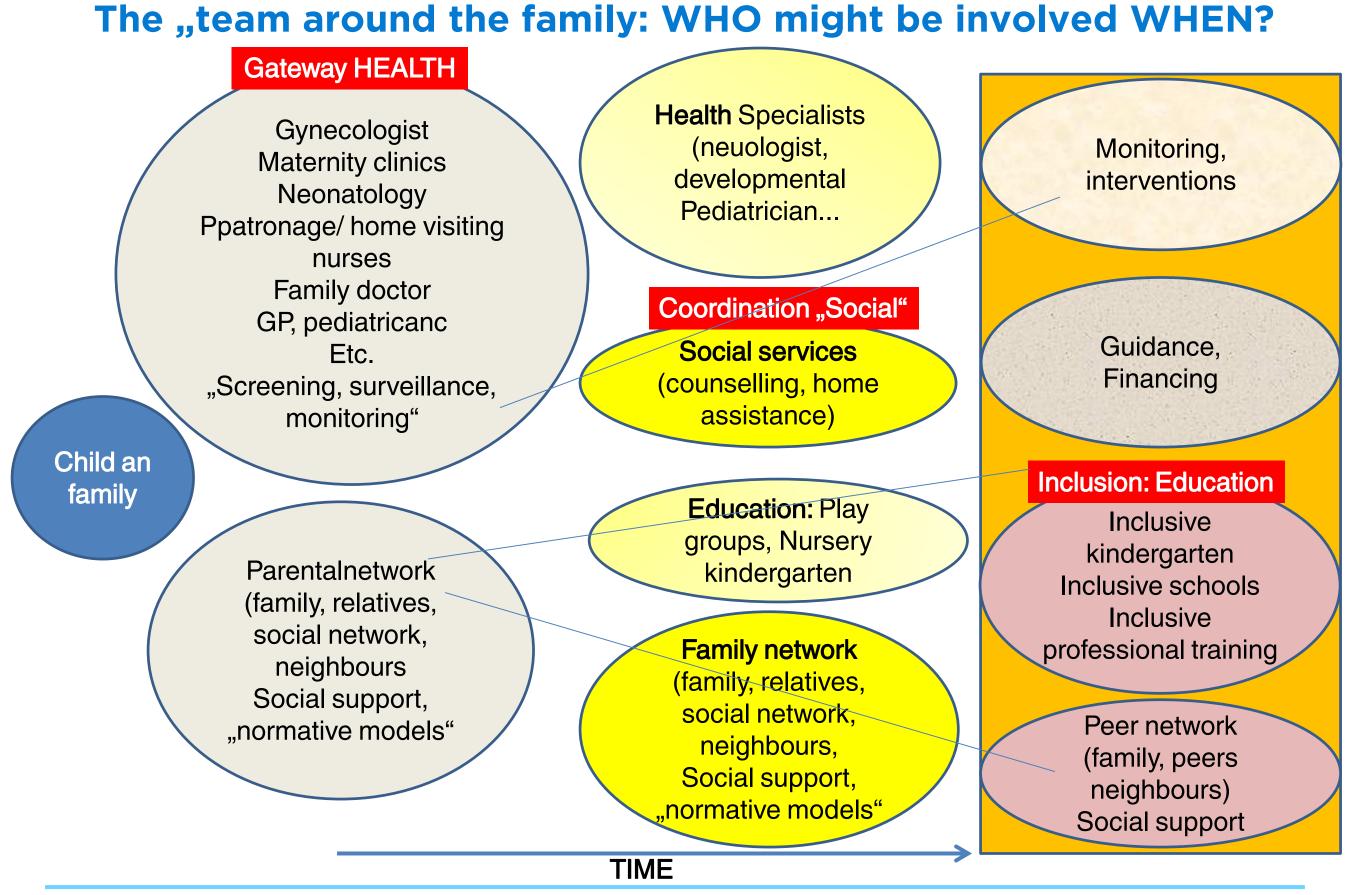
The context (the <u>environments</u> in terms of ICF) usually play a <u>bigger role</u> than in other vulnerable age groups

- The environments of small children usually address <u>parents/primary care</u> <u>givers</u>
- Body structures and body functions usually show more plasticity in young age
- Each child usually wishes to participate in a meaningful child centered way.
- Many professionals might be involved if developmental concerns appear. The <u>team around the family</u> might play different roles within the childs life-chart.

What are the professional challenges in ECI?

Due to its complexity and interacting agents Early Childhood Intervention can be understood as one of the most difficult biopsycho-social interventions:

- > The primary beneficiaries (children) usually do not have an explicit SAY
- > The primary "contractors (of services)" are the parents
- Developmental difficulties/disability usually cannot be "healed/cured" (They represent a "state of being")
- Each adult seems to have a "say on education" (models and theories might be diverse and mostly anecdotical)
- Developmental difficulties (neurodiversity) usually trigger distress, anxiety, hopes... Usually all parents which to have a healthy (full functioning) child.



3) Four important professional quality criteria for ECI

- > As early and as parent friendly as possible
- > As activity/ learning focused as possible
- > As evidence based/ oriented as possible
- > As coordinated as possible



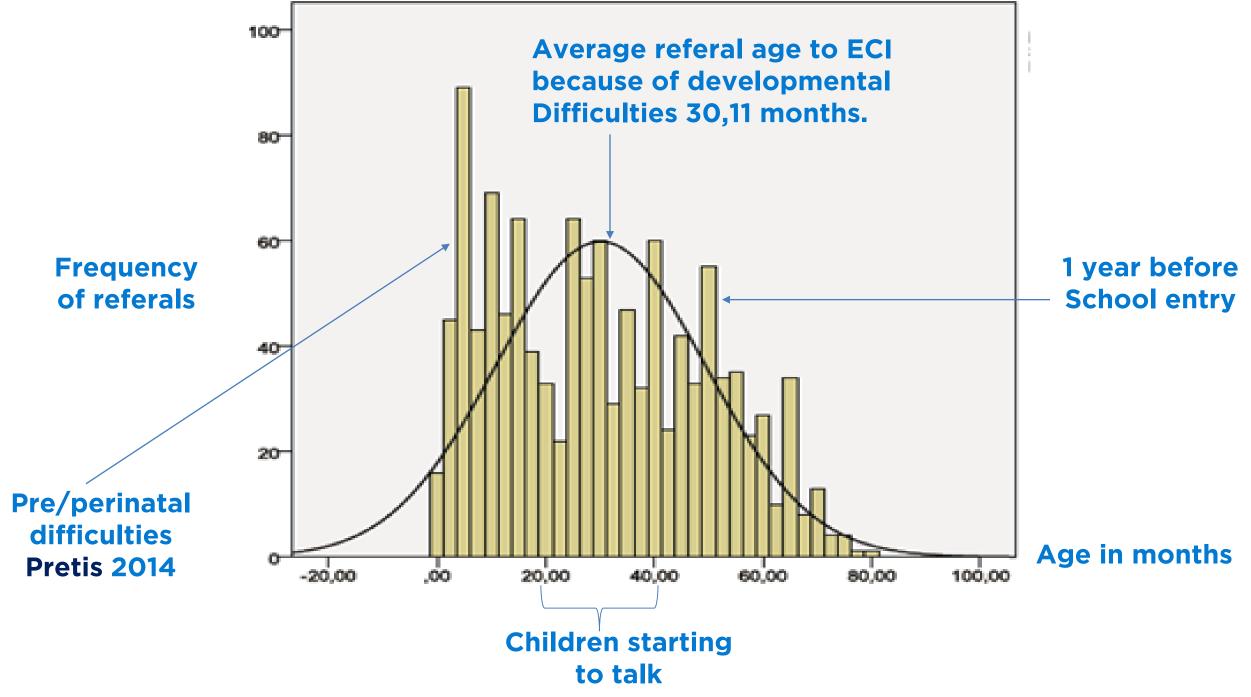
ECI

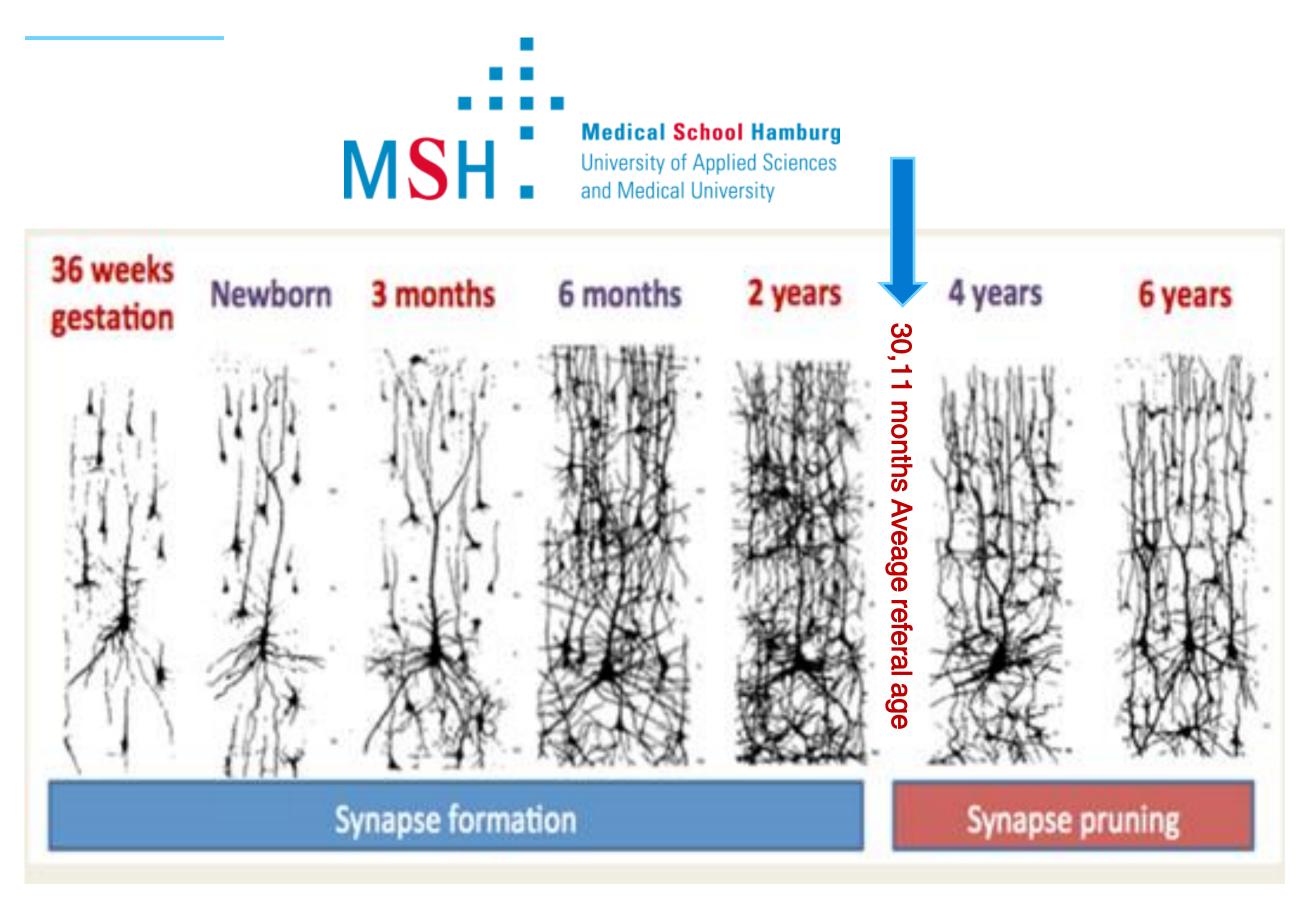
EarlY

As EARLY as possible?



Medical School Hamburg University of Applied Sciences and Medical University





http://blog.tinkergarten.com/blog/2017/4/27/whats-really-happening-in-your-childs-brain

1st AXIOM of Early Childhood Intervention:

> Use the earliest possible gateway!

In most of the countries, this is the "Health- system"



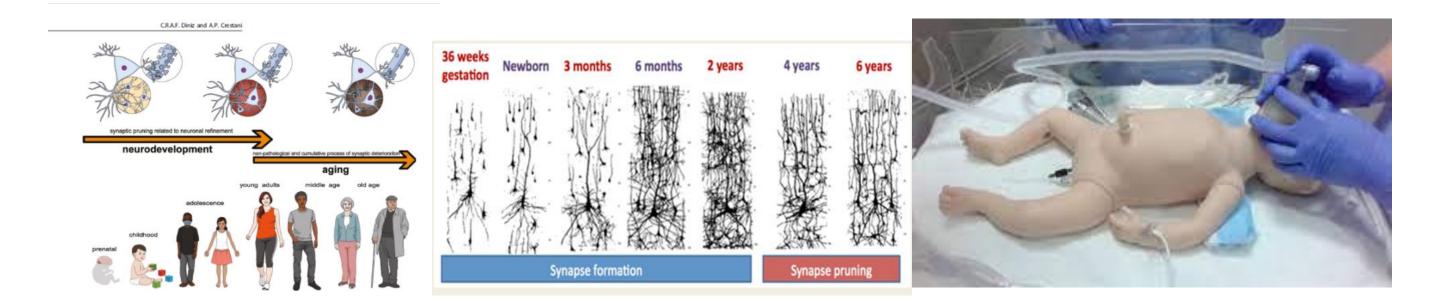


WHY?

In most countries medical facilities (beside close family members) are the first agents to have professional contact to families

They address body structural and body functional aspects

Their expertise focuses on experience-dependent plasticity of the BRAIN and on evidence based body structural/functional aspects interventions



Quality criterium 1 "Gateway health"

1a: As <u>early</u> as possible

Profesionals use developmental screening/ surveillance (e.g. "Learn the signs, act early", ASQ, GMCD..)

1b: As child and <u>family friendly</u> as possible

- > Professionals take their our time (in primary care)
- Professionals communicate with parents in a "parental language"
- Professionals increase PARTICIAPTION of the parents (providing concrete ideas WHAT parents/care givers CAN DO AT HOME

1c: As transdisciplinary as possible

Professionals involve the community (who is important, who can support?)

Indicator questions

In our ECI center:

- What is the average intake age (when developmental concerns are addressed?)
- How much time (in primary care) is foreseen addressing developmental concerns?
- > How do we talk as professionals to parents?
- How do parents feel about these situations?
- > Which concrete ideas (what they can do at home)
- b do parents get from professionals?
- > How do we guarantee that relevant others are involved?

2nd axiom: ENRICH ENVIRONMENTS for the CHILDREN!

Enriched environments (mainly provided in the context of primary caregivers) – at the moment – are understood as most promising agents in supporting/promoting the development of a child (despite the need of methodological clarifications). (See outcomes of Head Start - Programs)

IMPACT on ECI: create environments where the child is motivated to be active and where learning activities of a child are triggered

Ball/Ill/Orduna (2019). Enriched Environments as a Potential Treatment for Developmental Disorders: A Critical Assessment

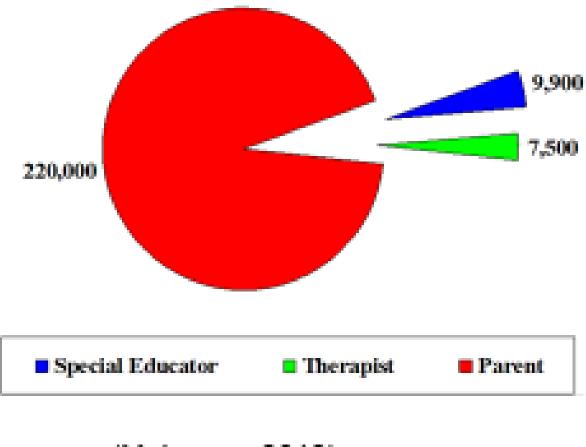
WHY?

- Enriched environments trigger/stimulate/facilitate
- LEARNING ACTIVITIES
 - of the child and
 - the family (care givers)
- The child is able to DO something
- The parents are able to DO something



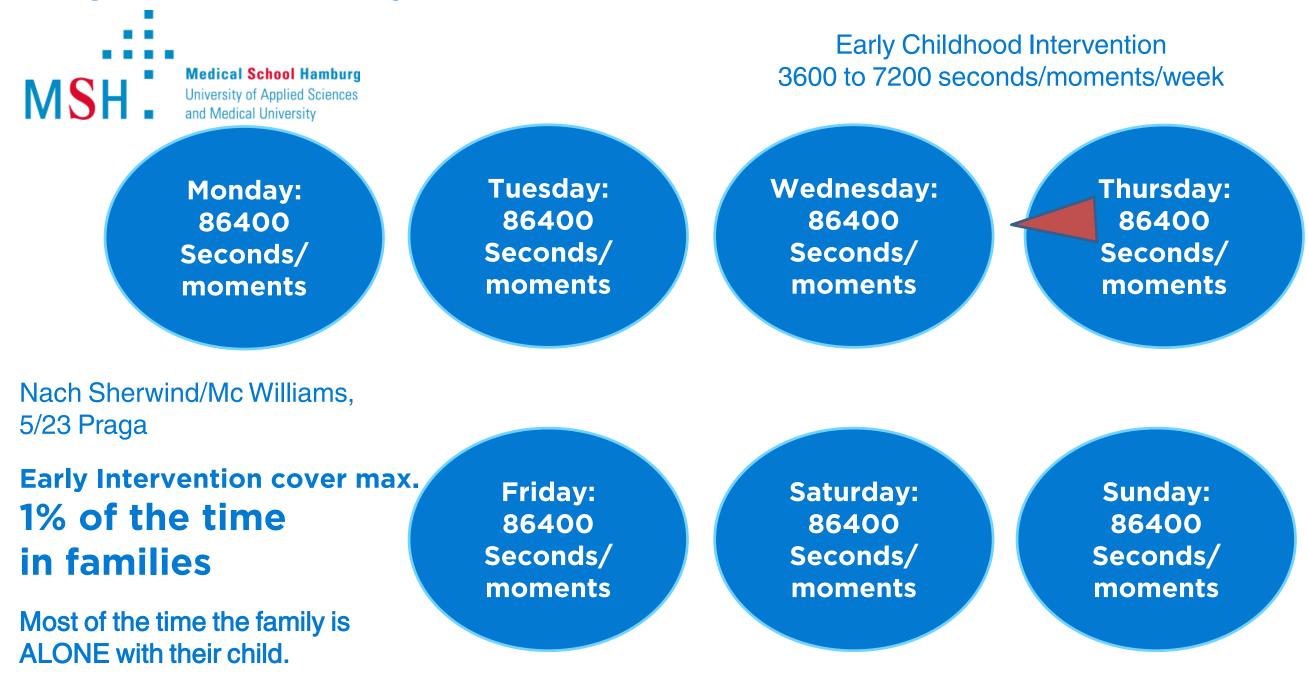
When and HOW?

PARENTS are seen as main "change agents" toward developmental potentials and situations which enable LEARNING activities



(Mahoney, 2012)

Primarily, parents have to be supported to translate professional expertise into daily life



Quality criterium 2 for ECI

2a) Nothing without parents

> How much time are parents involved in our (professional) ECI activities?

2b) Nothing <u>about</u> parents. Parents are equal partners in ECI (they (co)decide; professionals provide suggestions (except in cases of endangered child welfare)

- How is it guaranteed in our ECI center that parents are the decision makers?
- **2c)** Parents <u>understand</u> everything when they professionals

2d) Parents can do what they are able to do

Indicator questions

How do we assure and proof that parents are the <u>main agents</u> in this process?

- Who is making decisions and how? Are parents able to discuss with the professionals
- > How is guaranteed that their arguments heard and acknowledged?
- > To which extent parents report any type of pressure?
- > How high are drop-out rates of parents? What are the reasons?
- How much effort it is for the parents to obtain ECI services (transport, schedule..)

How do we talk to parents?

- How much time parents can talk
- > How are the professionals talking **about** families?

How do we assure that parents <u>understand</u> everything we are talking about?

- Do we foresee summaries of exchange processes?
- > Are the relevant documents/information available in EASY LANGUAGE

3rd axiom: As evidence oriented as possible

Evidence orientation is a DIFFICULT ISSUE in ECI

- No Randomized Control Studies
- Ethical questions concerning "WAITING GROUPS"
- Difficulties concerning "clinical designs" (each family/each child might be different)

Solution:

Use the highest available level of evidence - in exchange with the parents

WHY?

A) Families, evidence and "laboratory situations"

It is obvious that ECI faces some challenges to "proof" its efficacy and efficiency. As it is embedded in real life situation with complex interaction/ transaction systems.

We do not even have the ONE AND ONLY model of child development



https://www.google.com/imgres?imgurl=https%3A%2F%2Fwww.starrlifesciences.com%2Fwp-content%2Fuploads%2F2019%2F09%2F201909-SLS-Running-Wheels.jpg&tbnid=eQTE9FEN1xc66M&vet=12ahUKEwj7sb_kjfqBAxUEs6QKHQdBAccQMygAegQIARBP.i&imgrefurl=https%3A%2F%2Fwww.starrlifesciences.com%2Factivity %2F&docid=r7YDF5xqs0SCjM&w=432&h=284&q=laboratory%20rat%20wheel&ved=2ahUKEwj7sb_kjfqBAxUEs6QKHQdBAccQMygAegQIARBP

B) Families, causality and ECI designs

ECI centers usually are no experimental university clinics

It is highly **ethically question**able to apply classical experimental designs (control groups without treatment, waiting groups taking into account developmental pathways..)

Most of parameters in ECI cannot be controlled (because they occur in natural settings)

Empirical evidence in ECI therefore is mostly WEAK (beside anecdotical evidence)

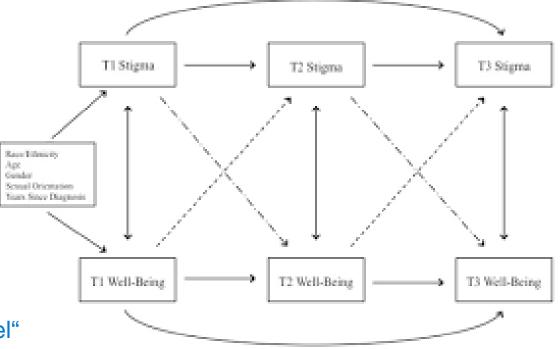
Most prevention effects also **depend on environmental aspects** (whether there is an inclusive School etc..)

Many intervention methods rather rely on personal expertise than on empirical proof.

ECI professionals are "professionals in the field" not researchers (no time for research)

Research usually has to be "translated" into practice.





Sameroff (2007) "Transactional model"

C) What can we do to increase evidence orientation?

- a) Validate effects with the parents or relevant others (talking to them!)
- b) Enable expertise exchange and **hypothesis** generating processes in the Center (e.g. Common time for reflection, preparation, intervision)
- c) Guarantee **individual hypothesis** (what would be helpful in a certain family and why do we think it would work) and apply **single case designs**
- d) Focus on (smart) participation goals.

How to check evidence aspects with the parents/ primary care givers (and within teams)

a) Look back

- > What was the reason for ECI?
- > Who referred why?
- > How was the situation at the beginning (e.g. Using ICF domains)
- > Which (participation) goals did we co-develop?
- b) What happened during our joint process (how many "units" were performed with whom?)
- c) What turned out to be successful? (what not)
- d) Which (smart) participation goals could we reach?
- e) Which aspects remained open (and why)?
- f) How shall we proceed?

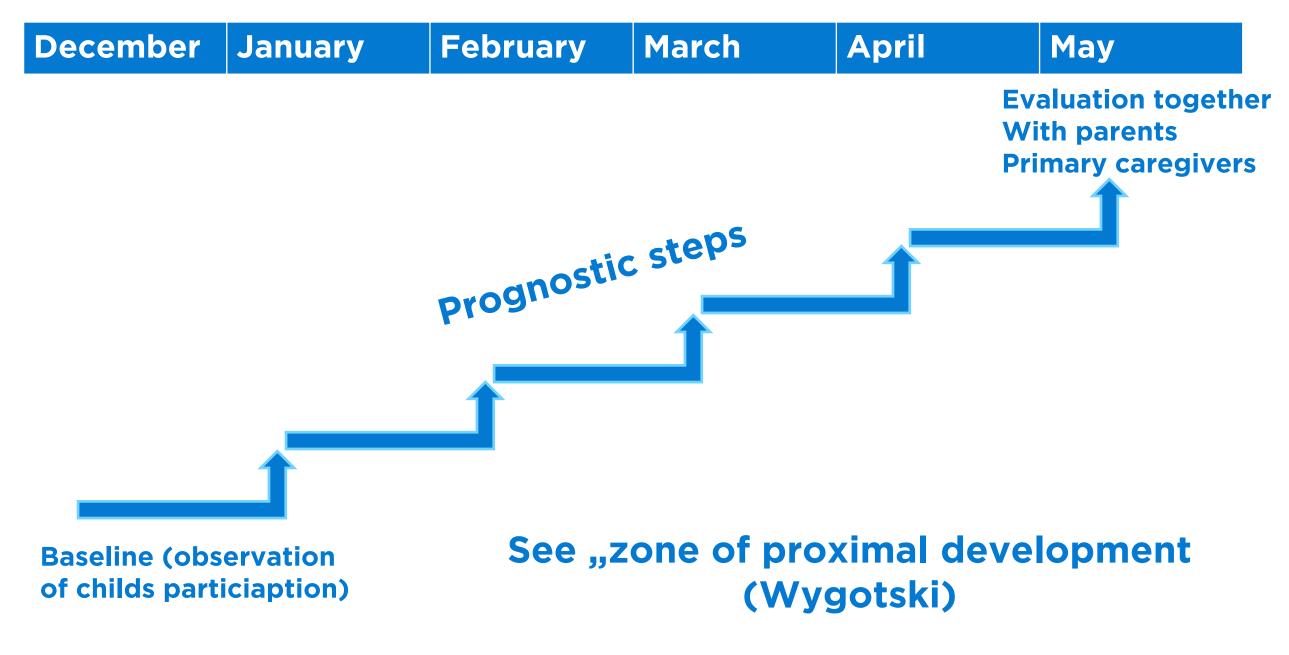
g) As a professional: What was I able to learn from you as a family

Think and act in terms of hypothesis

Status quo	if	We can expect
Daniela (F81, 4 years) expresses herself with single utterances and pointing	If "HOW and WHAT" questions are used by the parents in daily life	We expect that Daniela will use first "single (important") words "this" "open" "Other" "again"

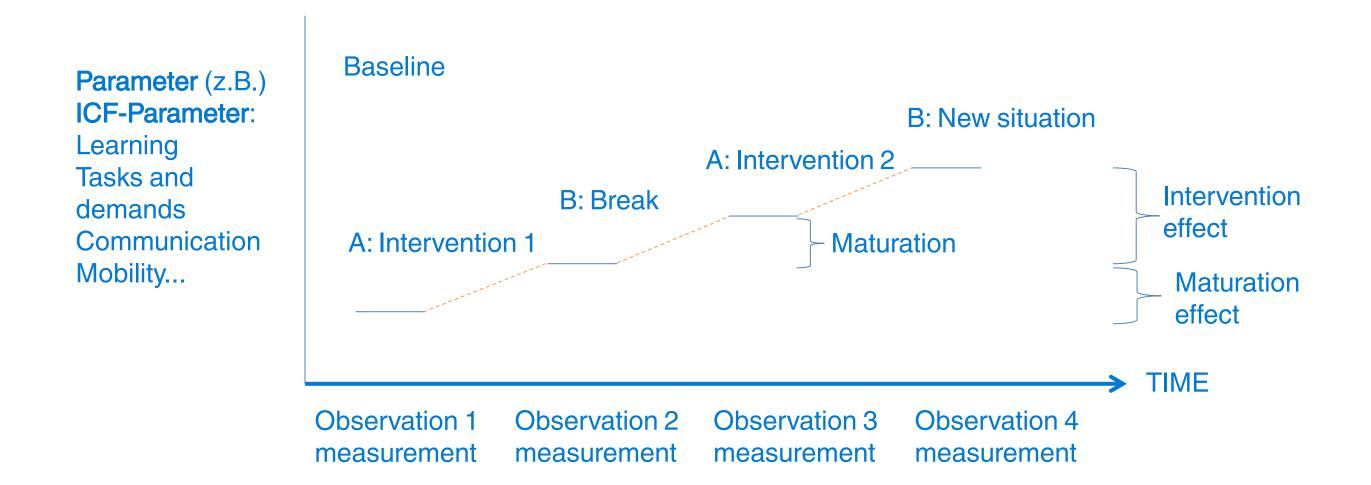
What do we need for this?

Prognostic models of child development, family dynamics...



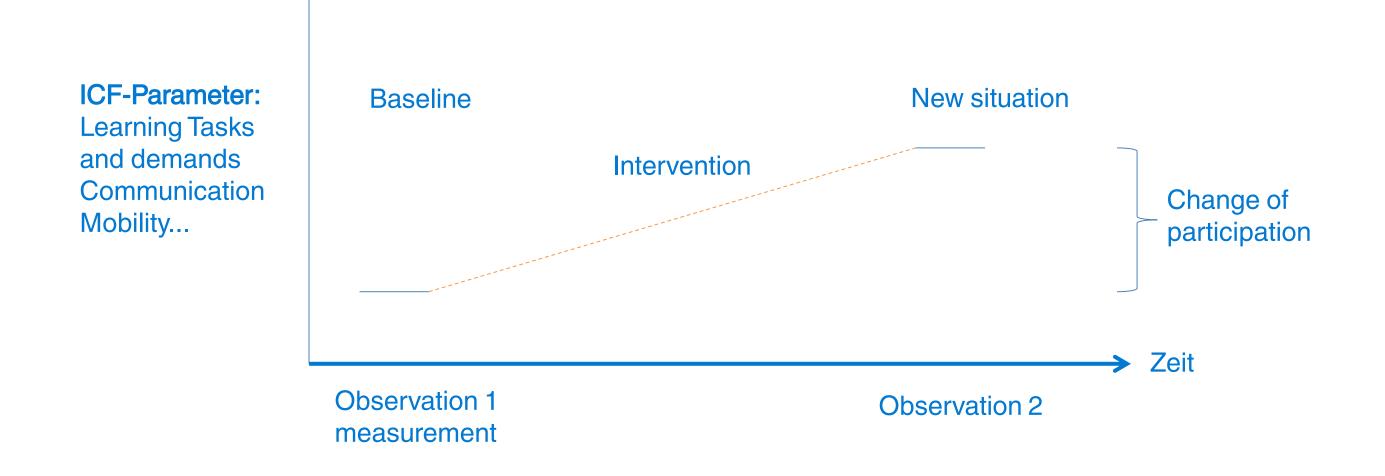
In a perfect ECI-world

Single case-based designs (A – B – A – B design)



The realistic scenario

(challenge: "natural maturation processes)



Focus on (smart) participation goals

The new understanding of disability (UN CRPwD, ICF) focuses on the interaction between the functionality of a persons and his/her environments.

- Participation (= involvement/ engagement in real life situations) is one main category.
- PARTICIPATION GOALS are one-person centered goals based on the inherent tendency of each person to participate in a meaning full way in relevant contexts.

Quality criterium 3 for ECI

3a) Guarantee evidence (orientation) on a highest possible level

3b) **Exchange** about obvious evidence (e.g. Based on observable participation goals) – with the parents/primary care giver and within the team

3c) Focus on participation (goals)

- From the point of view of the beneficiary (as an agent)
- Focusing on activities and

Contexts (how and where)

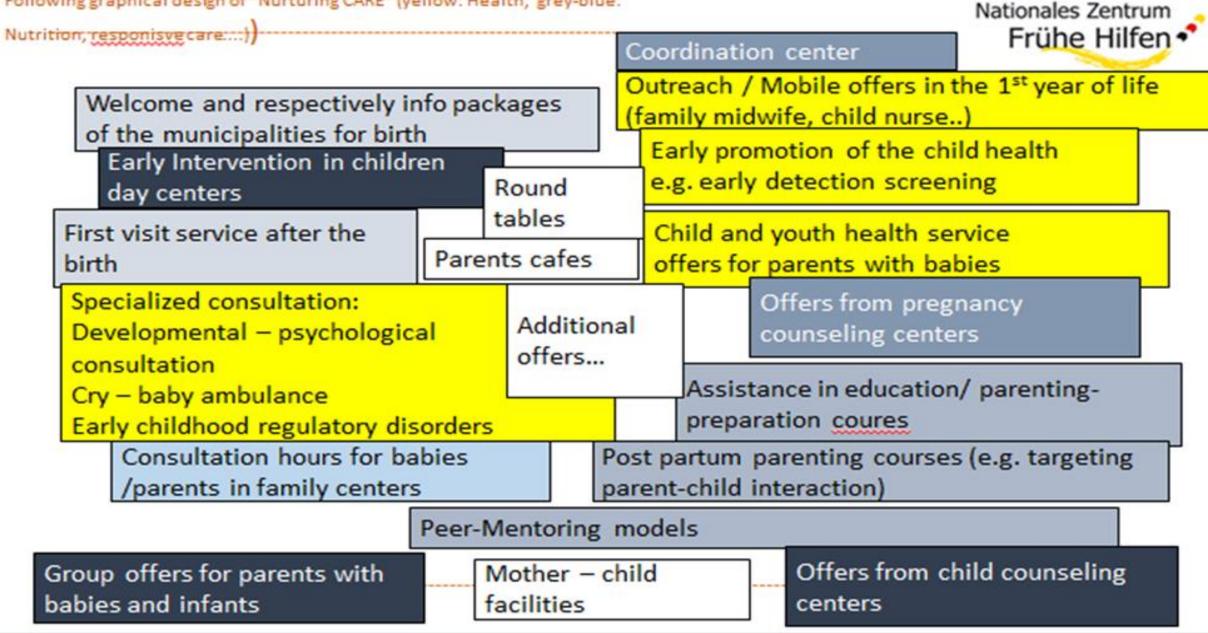
Indicator questions

- > How do we guarantee highest possible levels of evidenceorientation?
- > Which tools do we use?
- > How do we define hypothesis and goals?
- > How do we measure outcomes (in terms of efficacy and efficiency)?

4th axiom: As coordinated as possible

The landscape of multidisciplinary services

(conceptual view, of German model of "Frühe Hilfen" adapted by the presenter) Following graphical design of "Nurturing CARE" (yellow: Health, grey-blue:



The challengeing landscape of German early support services

Quality criteria

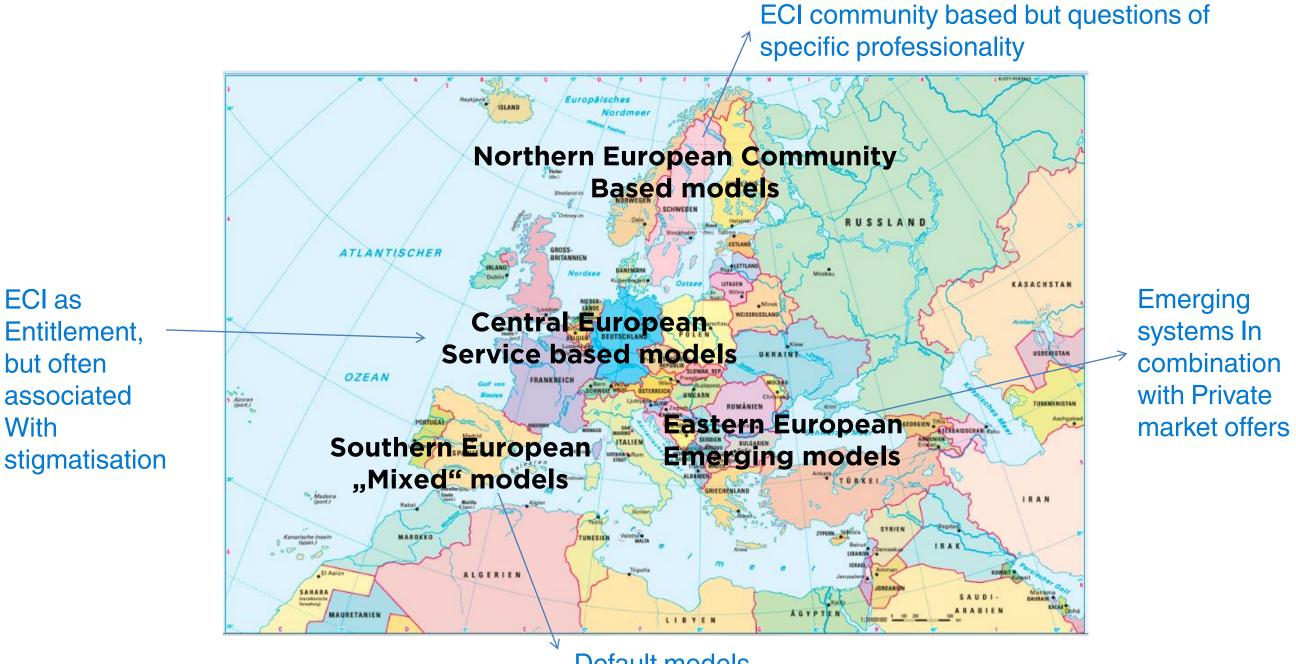
4a How does your institution guarantee that processes are well coordinated for the family (e.g. In transdisciplinary team)?

4b) How do we communicate (in a coordinated way within interagency contexts?

Indicator questions

- How do parents/care giver percieve that the whole team is following coordinated goals (e.g. By means of shared documentation)?
- > What are all agencies doing to empower parents?
- > When do agencies percieve that parents are able to cope in the best possible way with the health situation of their child?

How do European countries address these QM challenges?



Default models With high diversity and question of cooperation/coordination

Towards "optimal" system(s) (1)

There is no "optimal" system (there are only attemps to match the existing systems to the needs of families and enable synergies)

1st key message:

Need for "CONFLUENCE & COORDINATION of the sectors: **Professionals WORK in teams**



Rio Negro/Branco, Amazonia

Belgrade

Key message 2: It is about the PARENTS

Professionals need to know how to communicate with parents as PARTNERS

- 1) Parents wish to know about concerns as EARLY as possible -> detection/identification;
- 2) They wish to be **able to do something** about it -> empowerment/ parenting activities should focus on **PLAY**:

PARTICIPATION of the young child in all LIFE domains in an Activating way as earlY as possible

- 3) In case of more severe concerns parents might need coordinated support and
- 4) high-quality services.

Key message 3: "Systems will have to invest"

There is a GAP between officially "detected children with disabilities/ developmental difficulties" and expected target numbers. In terms of prevention this gap will have to be addressed.



The Return on Investment (Karoly et al. 2010) is higher in (social) high risk-families (1: 17) than in lower risks families (1:1,26)

Investing where?

- > Within the first 18 months to 2 years in parenting (Dolye, Harmon & Heckman, 2013);
- Afterwards, longterm (inclusive) education-based interventions with small child to staff ratios (Caution: wash-out effects!);
- Investing in training (better-trained caregivers appear to be more effective); Caution: necessary model-approach in terms of partnership models with parents (Kim & Mahoney, 2004): "Let parents do something with their children -> PLAY.

Lancet 2017: Investment-needs 2015-2030: for lower-income countries to upper mid-income countries: **50c per capita/year.**

Key message 4: Sectors will have to cooperate

There is no:

- Primary MEDICAL-SECTOR-CHILD
- Secondary SOCIAL SECTOR CHILD and then
- Tertiary EDUCATIONAL SECTOR child

There is ONLY 1 child in diverse contexts



Thank you for your attention.

Please visit our related European Erasmus+ projects

<u>www.icf-inclusion.net</u> (participation - checklist and participation goal incubator: how to create participation goals)

<u>www.icf-plan.eu</u> (best practice examples, training materials and FAQs on ICF)

www.icf-implement.net

<u>www.naturalisticteaching.com</u> (training materials on responive teaching and playing)

For further information:

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References

- Britto, R. (2017). Advancing Early Childhood Development: from Science to Scale 2. Nurturing care: promoting early childhood development. Thelancet, 389 January 7, 91-102
- Deepa Grover, D., Schwethelm, B. (without year) Partnering with families: improving home visits in Europe and Central Asia http://earlychildhoodmagazine.org/partnering-with-families-improving-home-visits-in-europe-and-central-asia/
- Doyle, O., Harmon, C., Heckman, J., Moon, C. (2013). MEASURING INVESTMENT IN HUMAN CAPITAL FORMATION: AN EXPERIMENTAL ANALYSIS OF EARLY LIFE OUTCOMES. Working Paper 19316 http://www.nber.org/papers/w19316
- European Agency (2005/2010).Early Childhood Intervention. Analysis of Situations in Europe. Key Aspects and Recommendations. Middelfart/Brussels: European Agency for Development in Special Needs Education.
- Suralnick, M.J. (1997). The Effectiveness of Early Intervention. Baltimore: Brookes.
- > Karoly, L.A. Karoly, Kilburn, R., Jill S. Cannon, J.S (2010). Early Childhood Interventions. Proven Results, Future Promise. Rand.
- Lancet Series (2007). Child development in developing countries.
- Kim, J-M., Mahoney, G., (2004) The Effects of Mother's Style of Interaction on Children's Engagement: Implications for Using Responsive Interventions with Parents Topics in Early Childhood Special Education, 24 (1), 31-38
- Pretis. M. (Ed). (2010). Early Intervention across Europe. Ankara: Maya.
- Pretis, M. (2018). Let us be prepared, but wait and see": the use of ICF-CY in early childhood intervention and peadiatric social care in Germany and neighbouring countries. In: Castro & Palikara (Eds), An emergeing approach for education and care. Implementing a worldwide classification of functioning and disability, (165-178). Lonodn: Routlegde
- > Pretis, M. (2016). Early Childhood Intervention and Inclusion in Austria-. Infants and Young Childern
- Renner, I. (2011) Frühe Hilfen in Deutschland Erreichtes und Ausblick. Frühe Hilfen und Wirkungsorientierung, Fachtagung im Forum
- > Offenburg