

Compilation of Best Practices

***ON TRAINING PROGRAMS
FOR CHILDREN WITH
DEVELOPMENTAL DISORDERS***





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Introduction

The EarlyBrain project, titled "Empowering Families in Early Childhood Intervention," is dedicated to supporting parents and relatives of children with developmental disorders by equipping them with the knowledge and skills necessary to foster their children's development.

Recognizing the crucial role that families play in the growth and well-being of these children, the project adopts a holistic approach that addresses the needs of both the children and their caregivers.

This document brings together a collection of best practices from various regions and contexts, each offering unique insights and methodologies to empower families and caregivers. These practices illustrate a range of innovative interventions designed to tackle the diverse challenges faced by families of children with developmental disorders, from rural Ireland to urban Bulgaria, and from low-resource settings to specialized training programs.

By sharing these exemplary approaches, the EarlyBrain project aims to inspire and guide practitioners, policymakers, and families in their efforts to enhance early childhood intervention and support.

Here below is a short introduction to each of the best practices collected in this document.

Best Practices

1. Development of the WHO Caregiver Skills Training Program for Developmental Disorders or Delays

The CST program, developed by the World Health Organization, aims to teach caregivers skills to support their children's social communication and adaptive behavior in low-resource settings. The program is adaptable and designed to be implemented by non-specialists, ensuring it is feasible and relevant in diverse cultural and socioeconomic contexts.

2. The “Dance Steps” of Reciprocity between Caregivers and Infants/Children: A Pilot Validity Study

This study introduces an observational tool to assess the reciprocity between caregivers and infants/children, focusing on the co-creation of meaningful experiences. It applies Gestalt psychotherapy principles and was tested with caregiver-preterm infant dyads, providing insights into the dynamics of caregiver-child interactions.

3. European Child Guarantee in Bulgaria: System Approach to Early Childhood Intervention

This pilot project supports the development of a system approach to early intervention for children with developmental difficulties, emphasizing a holistic support system for families with young children. It focuses on children from 0 to 7 years old, addressing both social and biological risk factors.

4. The Impact of a Family-Centred Intervention for Parents of Children with Developmental Disabilities: A Model Project in Rural Ireland

This practice addresses the compounded challenges faced by parents in rural settings, including poor mental health and social isolation. The family-centred intervention involves monthly home visits and regular phone check-ins to set developmental goals for the child and address the needs of the parents and siblings. Community activities are also identified to promote social inclusion.

5. A Training Program to Improve IFSP/IEP Goals and Objectives through the Routines-Based Interview

This training program bridges the gap between family-centered philosophies and actual practices in early childhood intervention. It focuses on routines-based interviews to help families identify their priorities for child and family goals, thereby enhancing the functionality and family-centeredness of intervention plans.

6. Management of Autism in Children and Young People: A Good Clinical Practice Guideline

This guideline highlights the limitations of standardized assessments and proposes the use of curriculum-based assessments to better measure child progress and

individualize treatment plans. The adapted student learning profile (aSLP) is presented as a tool to systematically track progress in early intervention programs.

7. Helping Young Children Understand Inherited Cancer Predisposition Syndromes Using Bibliotherapy

This practice employs a bibliotherapeutic framework to help families communicate with children about hereditary conditions and cancer predisposition syndromes. Illustrated stories are used to support children aged 5 to 10 at risk of developing these conditions, facilitating informed decision-making and reducing emotional distress.

8. The TEAVIAL Project: Enhancing Cognitive Accessibility for Individuals with Autism

The TEAVIAL project aims to improve cognitive accessibility for individuals with Autism Spectrum Disorder (ASD) through the use of pictograms. A participatory action research methodology was used to design and evaluate sequences with pictograms for better comprehension, promoting autonomy and social participation.

9. Theoretical Guide on Play: The Role of Play in Facilitating Inclusion

This guide emphasizes the importance of inclusive play in preventing social exclusion and promoting natural learning. It proposes transforming school recess into inclusive environments to enhance children's experiences and prevent bullying, thereby fostering social inclusion and conflict resolution.



Criteria for the selection of Best Practices

The best practices shown in this document have been selected based on a set of criteria and sub-criteria, some of which are mandatory while others are optional, as outlined below.

1) Criterion n. 1: Conceptual approach

- a. Concept (mandatory)
 - ☐ There are (written) definitions/guidelines/protocols.
 - ☐ The practice/experience contains the objectives of the program.
 - ☐ There is available information about the methodology and activities/ tools.
- b. Target Group (mandatory)
 - ☐ The target group (children & caregivers) is clearly identified and fits with Earlybrain objective (age covered from 0 to 6 years old)
- c. Innovation
 - ☐ The programs/practices have an innovative character or implies innovative aspects (e.g. actual knowledge on infant suffering and disorders, new ideas or methodology, etc.).
- d. Formal networking/complementary links with relevant institutions
 - ☐ The practice implies networking and cooperation with other Institutions.

2) Criterion n. 2: Orientation at the target group

- a. Active Participation: the target group can participate in an active way (e.g. express ideas, wishes, and suggestions for planning, implementing, and realizing).
- b. Empowerment: in developing skills, the target group (caregivers and children) becomes self-acting and self-determined.

3) Criterion n. 3: Relational Approach (mandatory)

- a. Best practice should be relational carrying on caregiver/child alliance: applicable on dyadic/triadic interactions

4) Criterion n. 4: Quantitative criteria

- a. Best practice should be selected from validated research with sizable sample size. Sample should be representative and selected using probabilistic techniques.

5) Criterion n. 5: Quality Control: documentation and evaluation (mandatory)

- a. Documentation shows the content of the working process.

-
- b. Evaluation is documented and it covers the analysis of the processes and the results.
 - c. There is a good impact reported on the target group.

6) Criterion n. 6: Transferability / Replicability (mandatory)

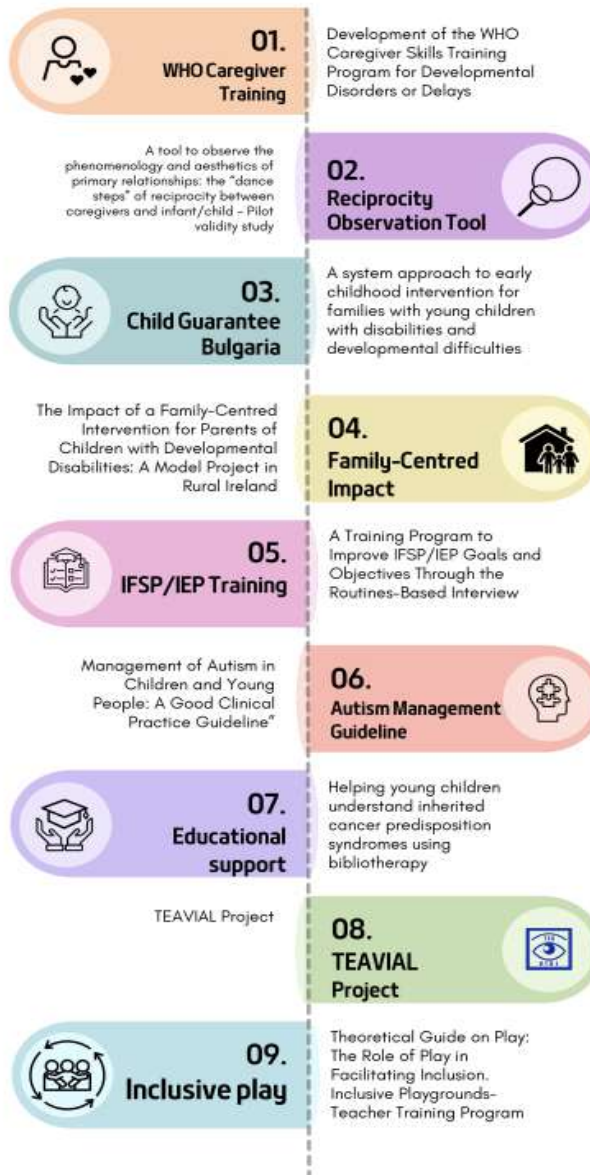
- a. There is access to the methodology and how the practice/program is realized (e. g. process description, guidelines, manual etc.)
- b. The program/practice can successfully be transferred/replicated to different conditions of neurodevelopment, as:
 - Sensory hypersensitivity/hyposensitivity
 - cognitive inflexibility
 - Dyspraxia
 - Difficulties in adaptive behaviors
 - Low impulse control inhibition
 - tone changes
 - attention difficulties
 - Alterations in the ideation, planning and execution of tasks
 - Low emotional intelligence
 - Lack of social skills

7) Criterion n. 7: Time Frame (mandatory)

- a. Best practice should be recent, created not earlier than 2010

9 BEST PRACTICES

ON TRAINING PROGRAMS FOR CHILDREN WITH DEVELOPMENTAL DISORDERS



BPI: Development of the WHO Caregiver Skills Training Program for Developmental Disorders or Delays

Info (link)

<https://www.frontiersin.org/articles/10.3389/fpsy.2019.00769/full>

Front. Psychiatry, 11 November 2019

Sec. Child and Adolescent Psychiatry

Volume 10 - 2019 <https://doi.org/10.3389/fpsy.2019.00769>

1) Conceptual Approach

a) Concept

Globally, 52.9 million children under the age of 5 experience a developmental disability, such as sensory impairment, intellectual disability, and autism spectrum disorders. Of these 95% live in low-and-middle-income countries. Most of these children lack access to care. In light of the growing evidence that caregivers can learn skills to support their children's social communication and adaptive behavior and to reduce their challenging behavior, the World Health Organization developed a novel Caregiver Skills Training Program (CST) for families of children with developmental disorders or delay to address such treatment gaps.

The CST program is designed to be feasible, scalable, and adaptable and appropriate for implementation in low-resource settings by non-specialists. The program was informed by an evidence review utilizing a common elements approach and was developed through extensive stakeholder consultation and an iterative revision process. The program is intended for a global audience and was designed to be adapted to the cultural, socioeconomic, geographic, and resource context in which it is used to ensure that it is comprehensible, acceptable, feasible, and relevant to target users. Caregivers are encouraged to practice interacting with their child within both "home routines" (setup within activities done regularly, such as eating, dressing, caring for animals, tidying and going into the community to run errands, pick up siblings, or enjoying being outside) and "play routines" with toys and recycled materials (e.g., cups or cardboard boxes) that are easily available to the family.

b) Target Group

The target group is represented by children younger than 5 years.

c) Innovation

N/A



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d) Formal networking / complementary links with relevant institutions

The impetus for the development of the CST program lies within the WHO's mhGAP Intervention Guide for mental, neurological, and substance use disorders in non specialized health settings, which since 2010 recommends parent skills training for developmental disorders or delays.

2) Orientation at the target group

As a starting point for the development of CST, the results of the systematic review and meta-analysis were examined and discussed by global leaders with experience in parent-mediated interventions from diverse professional, geographic, and cultural backgrounds at a meeting at WHO Headquarters. The meeting included representatives from 21 countries across all six populated continents with a majority of representatives from LMICs, according to World Bank Classification.

Representatives included academic leaders, clinicians, foundation leadership, practitioners, and caregivers (beneficiaries). These representatives were asked to advise on content and structure of the intervention, help address acceptability and feasibility concerns, and identify capacity building strategies.

3) Relational Approach (mandatory)

Central to the development of caregiver skills training (CST) was the requirement that the target beneficiaries of the intervention were children with heterogeneous developmental difficulties and there was a need to promote scale-up in LMICs with the use of briefly trained non-specialists. The program was designed to adopt a family-centered approach that fit within a stepped-care model, where CST is to be integrated into existing maternal, child, and family health and social services.

The program was designed to include a combination of group sessions in community centers, health centers or schools and individual sessions in caregivers' homes.

4) Quantitative Criteria

To date, there are 30 active field-testing sites, representing all WHO world regions, African (n = 4), Americas (n = 9), Eastern Mediterranean (n = 6), European (n = 4), Southeast Asia (n = 2), and Western Pacific (n = 5). Official field-test versions of the package are now also available in Spanish, and translations are in process in multiple other languages.

5) Quality Control: Documentation and evaluation (mandatory)

The datasets generated for this study are available on request to the corresponding author.

6) Transferability / Replicability (mandatory)

Central to the development of caregiver skills training (CST) was the requirement that the target beneficiaries of the intervention were children with heterogeneous

developmental difficulties and there was a need to promote scale-up in LMICs with the use of briefly trained non-specialists. The program was designed to adopt a family-centered approach that fit within a stepped-care model, where CST is to be integrated into existing maternal, child, and family health and social services

7) Time Frame (mandatory)

2019

8) Best practices should be enclosed in childhood (0-6 years old) (mandatory)

The best practice is specifically tailored to early childhood with a focus on age between 0 and 5 years old.



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BP2: A tool to observe the phenomenology and aesthetics of primary relationships: the “dance steps” of reciprocity between caregivers and infant/child – Pilot validity study

Info (link)

<https://jpnim.com/index.php/jpnim/article/view/e120125>

Journal of Pediatric and Neonatal Individualized Medicine (JPNIM)

Vol. 12 No. 1 (2023)

<https://doi.org/10.7363/120125>

1) Conceptual Approach

a) Concept

This study addresses the complexity of caregiver-infant/child interactions from the theoretical frame of Gestalt psychotherapy and the field of application of Pediatric Psychology. Based on a previous empirical study on the process of reciprocity in caregiver-infant/child interactions (Spagnuolo Lobb, 2016), the authors have worked on the construction of an observational tool to look at the co-creation of meaningful experiences, switching the focus from the child to the “dance” of reciprocity between caregiver and infant/child. Considering the contextualization in the field of Pediatric Psychology, this pilot study aimed to test the tool's application with caregiver-preterm infant dyads, but exclusively referring to moderately preterm birth conditions and with lack of disability or in any case serious evolutionary compromises.

b) Target Group

Children aged 6-9-12 months and their mothers.

c) Innovation

The study can be considered innovative as it wants to produce a tool that takes into account the idea of co-creation of the actual contact experience between infant and caregiver. The co-creation is based on the study of the movements or dance between the child and the caregiver.

In other words, we can see infant-caregiver interactions as a complex system of perceptions and movements in their phenomenological field. Therefore, to observe their interactions, we need to orient ourselves in a complex situation, where it is essential to look at reciprocity, the mutual act of moving towards the other in a reciprocal “dance”.

Also, the concept of reciprocity is important: when we focus on the co-creation, we are interested in the “dance” between caregivers and infants, which includes the notion of synchronicity.

d) Formal networking / complementary links with relevant institutions

N/A.



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2) Orientation at the target group

The study measured: 1. the content/construct validity of the tool, 2. its internal reliability, 3. Its “sensitivity” to grasp the changing of the relational “dance” in the transition from one developmental step of the infant to another, regarding the times considered (between 6-9-12 months of corrected age), 4. co-occurrences between the behavioral flows of the infant-caregiver dyad in the 3 developmental stages considered. 32 expert psychotherapists were involved in measuring the instrument’s validity, and 13 caregiver-infant dyads were observed in their interactions at 6-9-12 months of corrected age of the infant.

3) Relational Approach (mandatory)

The approach is configured as relational as it is based directly on the “dance” between child and mother.

4) Quantitative Criteria

32 expert psychotherapists, all licensed and post-graduated in the clinical approach of Gestalt therapy, with at least 8 years of Gestalt psychotherapy training and 8 years of private practice, who measured the content validity of the instrument.

The group on which the relational “dance” observation was conducted consisted of 13 caregiver-infant dyads (all mothers) (please note that in the text we will continue to use the term “caregiver” because the tool can be used with any significant caregiver figure of the infant/child (mother, father, or other substitute caregiver in the absence of parents)).

5) Quality Control: Documentation and evaluation (mandatory)

The documentation provides a clear representation of the working process, and a positive impact on the target group has been effectively demonstrated.

6) Transferability / Replicability (mandatory)

The program sets learning targets for both children with disabilities and parents based on daily life activities that are common and replicable for families to develop more confidence and social skills, providing emotional support and social inclusion.

7) Time Frame (mandatory)

The best practice is recent, having been initiated in 2022, ensuring it aligns with the requirement.

8) Best practices should be enclosed in childhood (0-6 years old) (mandatory)

The best practice is specifically tailored to early childhood with a focus on age groups including 6, 9, and 12 months.

BP3: European Child Guarantee in Bulgaria – Phase III of the Preparatory Action of the European Commission – Component 2: system approach to early childhood intervention for families with young children with disabilities and developmental difficulties

Info (link)

<https://www.unicef.org/bulgaria/en/press-releases/european-commission-and-unicef-include-three-year-pilot-scheme-address-child>

UNICEF - Bulgarian agency

1) Conceptual Approach

a) Concept

The pilot project supports the development of a system approach to early intervention for children with developmental difficulties or children at risk of developmental difficulties due to social or biological factors, with focus on children from 0 to 7 years old.

b) Target Group

The pilot programme helped reach more than 30,000 children and young adults, and 16,000 caregivers dealing with vulnerable groups, such as children with disabilities, children living in precarious family situations, children residing in institutions, and refugee and migrant children.

c) Innovation

The staff of Community Centres went through 75 hours of basic training on contemporary approaches for the provision of family-centered early intervention in the child natural environment which covered the following topics: “Early intervention” (Eurlaid), “Early childhood intervention, needs assessment, drafting of individualized plan and engagement in the family environment” (Karin Dom Foundation), “Specifics in the delivery of ECI services for preterm children and their families” (“Our Premature Children” Foundation), application of the ASQ-3 screening tool. Methodological Guidelines have been developed for the application of the system approach for ECI, and the latter is already operational in the Community Centres.

d) Formal networking / complementary links with relevant institutions

N/A.

2) *Orientation at the target group*

Between June 2021 and March 2022, the newly established ECI teams reached out to 119 families, 33 of which received continuing intensive support. The teams worked actively to raise the awareness about the benefits of involvement of the family and the importance of working in the natural environment.

3) Relational Approach (mandatory)

This Best practice is relational. The approach foresees the interaction between children and their family with caregivers.

4) Quantitative Criteria

- 9 additional specialists were hired and 3 mobile teams for ECI were established.
- 31 specialists from 3 Community Centres received 84-hour intensive training in ECI.
- 196 parents and 186 children were covered by the Early Childhood Intervention teams, and 33 of those families received intensive support.
- 99 specialists in the area of ECI, including general practitioners, home visiting nurses, healthcare professionals trained to conduct development screening.
- 150 people participated in workshops for parents on ECI, including specialists, healthcare professionals and parents of young children.

5) Quality Control: Documentation and evaluation (mandatory)

As for the impact and the content of the working process, these are both documented by the results indicated in the relative section.

6) Transferability / Replicability (mandatory)

There is access to the methodology and how the practice/program is realized. The program/practice can successfully be transferred/replicated to different conditions of neurodevelopment.

7) Time Frame (mandatory)

The best practice is recent, having been initiated in 2020, ensuring it aligns with the requirement.

8) Best practices should be enclosed in childhood (0-6 years old) (mandatory)

The best practice is specifically tailored to early childhood with a focus on age between 0 and 7 years old.

BP4: The impact of a Family-Centred Intervention for Parents of children with Developmental Disabilities: a Model Project in Rural Ireland

Info (link)

<https://www.mdpi.com/2227-9067/10/2/175>

Children 2023, 10(2), 175.

<https://doi.org/10.3390/children10020175>

1) Conceptual Approach

a) Concept

The greater risk of poor mental health and social isolation, experienced by parents of children with developmental disabilities, is compounded by family circumstances and living in rural settings. Often parents receive little personal support. Family-centred interventions have been recommended internationally for promoting children's development, as well as boosting parental well being. Yet, in many countries, current service provision is predominantly child-focused and clinic-centred. An innovative, family-centred support service was designed and evaluated in a rural county of Ireland. Support staff visit the family home every month for around one year with regular check-ins by phone. The service aims included setting developmental goals for the child that were agreed with parents, alongside actions to address the personal needs of parents and siblings. In addition, community activities are identified or created to promote the social inclusion of the child and family in local communities, as well as locating opportunities for social activities for mothers.

b) Target Group

Children with disabilities between 9 months and 13 years old and their families/parents.

c) Innovation

The value of innovative projects, such as this one, goes beyond the outcomes they provide to families and children. In particular, they demonstrate how new models of social support services in rural communities can provide cost-effective, emotional and practical support to families who are raising a child with developmental disabilities.

d) Formal networking / complementary links with relevant institutions

N/A

2) Orientation at the target group

In all, 110 children from 96 families have participated in the project thus far, representing 91% of families referred to the project.

The majority of children had a statement of special educational needs ($n = 68$: 62%), but this was higher for those with a learning disability (90%), compared to autism (75%) and developmental disabilities (78%).

3) Relational Approach (mandatory)

This Best practice is relational. The project set objectives for both children with disabilities and their parents/family.

4) Quantitative Criteria

110 children from 96 families participated in the project, mostly located in rural areas and encompassing different family models (parents together, single parents, etc.).

5) Quality Control: Documentation and evaluation (mandatory)

Individual learning targets were set for each child according to their development levels and agreed with each family; these targets were reviewed at six, nine and 12 months. For each target, a judgment on the child's progress was made by the parents and project staff using a five-point scale from 'much better'; 'better'; 'the same'; 'worse' and 'much worse'. In order to condense the information relating to the 110 children, the chosen targets were grouped into six domains and within each domain, the number of children whose progress was assessed as 'much better' could be ascertained. Overall, the results report that the parents expressed a very positive progress on their children.

6) Transferability / Replicability (mandatory)

The program sets learning targets for both children with disabilities and parents based on daily life activities that are common and replicable for families to develop more confidence and social skills, providing emotional support and social inclusion.

7) Time Frame (mandatory)

The project has been operational for five years (2018-2023).

8) Best practices should be enclosed in childhood (0-6 years old) (mandatory)

The project includes children with disabilities between 9 months and 13 years old.

BP5: A Training Program to improve IFSP/IEP Goals and objectives through the Routines-based interview

Info (link)

<https://journals.sagepub.com/doi/abs/10.1177/0271121413494416?journalCode=teca>

Tânia Boavida, MPsy, Cecília Aguiar, PhD, and R. A. McWilliam, PhD View all authors and affiliations

Volume 33, Issue 4

<https://doi.org/10.1177/0271121413494416>

1) Conceptual Approach

a) Concept

Practices often do not match philosophies about family centeredness and functionality in early childhood intervention (ECI; Campbell & Halbert, 2002).

We propose a training program as a promising solution for bridging the gap between philosophy and practice. ECI has come to be defined as a family-centered endeavor, which means practitioners are expected to interact with families in a friendly and supportive manner, are expected to give families opportunities to make meaningful decisions about how ECI helps them, and are expected to address family-level needs.

The training program described here was aimed at promoting these concepts of family centeredness and functionality among early childhood interventionists in the Lisbon area. Specifically, the participants were trained for routines-based interviews (RBI), which is designed to help families identify their own priorities for child and family goals. The contextual basis of this needs assessment encourages families to think about the details of their everyday lives, thus promoting their ability to specify what they want to change.

b) Target Group

This program is intended to provide Earlychild intervention.

c) Innovation

Person-centered assessment of objectives and goals, individualized training and regular follow-up.

d) Formal networking / complementary links with relevant institutions

N/A

2) Orientation at the target group

The target of this training are early childhood intervention (ECI) and early childhood special education (ECSE) professionals.



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3) Relational Approach (mandatory)

Participants were trained to use the routines-based interviews (RBI), which is designed to help families identify their own priorities for child and family goals. The ultimate beneficiaries of the training are the children and their families.

4) Quantitative Criteria

The training was carried out as a pilot project with 80 professionals of ECI and ECSE of different localities, ages and years of experience.

5) Quality Control: Documentation and evaluation (mandatory)

The training was evaluated positively by the participants. According to the document, after the training, the EIP/IFSP developed contained fewer goals/objectives and more functional ones.

6) Transferability / Replicability (mandatory)

The document describes all the methodology and process of the training. Starting from the conceptual development of the training to the final feedback and evaluation by the participants.

7) Time Frame (mandatory)

The best practice is recent, having been initiated in 2015, ensuring it aligns with the requirement.

8) Best practices should be enclosed in childhood (0-6 years old) (mandatory)

Ultimate beneficiaries professionals of ECI and ECSE for families and children with disabilities between 0-6 years old.

BP6: Management of Autism in Children and young People: a Good Clinical Practice Guideline

Info (link)

[964704.pdf \(hindawi.com\)](https://www.hindawi.com/964704.pdf)

Hindawi Publishing Corporation

Autism Research and Treatment

Volume 2014, Article ID 964704, 9 pages

<http://dx.doi.org/10.1155/2014/964704>

1) Conceptual Approach

a) Concept

Advancements in the identification, diagnosis, and treatment of very young children with autism spectrum disorder (ASD) have challenged researchers and clinicians to examine alternative assessments of child progress and outcome in early intervention programs. The most common assessments evaluating change across developmental domains (i.e., cognition, communication, social skills, adaptive behaviour, and behaviour challenges) are standardized assessments. However, several limitations to this type of measurement approach have been noted in the literature, including lack of sensitivity, testing constraints, and contextual issues.

Standardized testing be supplemented with the use of curriculum-based assessments to provide finer detail on child progress and to assist with treatment individualization and planning. This paper presents the results of an evaluation of the utility of the adapted student learning profile (aSLP) to measure progress of children in an early intervention program specific to the aSLP curriculum. The aSLP is a curriculum-based measure that assesses mastery of targeted skills to measure a child's progress during, and outcome after, an intervention program. The aSLP has the potential to measure child progress throughout ongoing intervention in a systematic way that better allows comparison of child progress and rate of learning in intervention within and across programs.

b) Target Group

This guideline is intended to be used by all care providers involved in the management of children and adolescents (until their 19th birthday) with autism in the primary health care sector (including general practitioners), in the secondary and tertiary health care sector (including medical specialists), in social care services, in disability services and in the educational sector.



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c) Innovation

This paper presents the results of an evaluation of the utility of the adapted student learning profile (aSLP) to measure progress of children in an early intervention program specific to the aSLP curriculum.

d) Formal networking / complementary links with relevant institutions

N/A

2) Orientation at the target group

N/A

3) Relational Approach (mandatory)

This guide shows a method for analyzing results by introducing new assessment methods that show progress in learning and intervention, looking at it from a global perspective, including the academic context.

4) Quantitative Criteria

Of the 49 children who received treatment from the program, 45 of the children (mean age = 22.67 months) were included in the analyses.

5) Quality Control: Documentation and evaluation (mandatory)

The results of this study provide support for the supplemental use of a curriculum-based assessment, the aSLP, for determining the benefits of an early intervention program for children with ASD.

High variability in scores among participants was seen across all assessments. Assessments were highly correlated, likely indicating that children who had higher overall cognitive and adaptive functioning were more likely to have mastered more skills, which is not surprising but may support the validity of a curriculum-based assessment.

6) Transferability / Replicability (mandatory)

Standardized testing can be implemented with the use of curriculum-based education.

7) Time Frame (mandatory)

The best practice is recent, having been initiated in 2014, ensuring it aligns with the requirement.

8) Best practices should be enclosed in childhood (0-6 years old) (mandatory)

The project includes children with disabilities between 1 and 3 years old.

BP7: Helping young children understand inherited cancer predisposition syndromes using bibliotherapy

Info (link)

<https://pubmed.ncbi.nlm.nih.gov/33788335/>

PMID: 33788335

DOI: [10.1002/jgc4.1396](https://doi.org/10.1002/jgc4.1396)

1) Conceptual Approach

a) Concept

Communicating with minors about hereditary conditions and cancer predisposition syndromes can be challenging for family members and have an impact on the minors, as well as genetic testing and timely surveillance. Given that testing often begins early, it is crucial to provide families and the minor with appropriate communication strategies and counseling for informed decision-making. To inform such communication strategies, a bibliotherapeutic framework was employed, where stories are delivered in a prescriptive manner, to develop a psychoeducational resource for children aged 5 to 10 at risk of developing Li-Fraumeni syndrome (LFS) and hereditary pheochromocytoma and paraganglioma syndrome (HPPS). Illustrated stories based on developmental understanding models of children were created for this purpose.

Families were invited to read a storybook to their sons and daughters, followed by semi-structured qualitative interviews. According to the reports, the bibliotherapeutic resource provided support to families in communicating about these topics, without generating emotional distress in either the family or the minors. All family members reported that it would have been useful when their sons and daughters were first evaluated and/or diagnosed.

b) Target Group

It was developed for children between the ages of five and ten.

c) Innovation

This program is innovative as it uses storytelling to inform about typically distressing processes. Additionally, the stories are tailored to enhance understanding among children based on their developmental age, following Piaget's stages of cognitive development.

d) Formal networking / complementary links with relevant institutions

It's inspired by the Constitution of the WHO

In this Constitution health is defined as 'a state of complete physical, mental, and social well-being and not merely the absence of disease or disorder. The enjoyment of the

highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic, or social condition.

2) Orientation at the target group

Family members who are minors with a risk of LFS

3) Relational Approach (mandatory)

The program employed in-depth, semi-structured telephone interviews with families to gain insight into their experience of reading the book with their children.

4) Quantitative Criteria

Interviews were conducted with 12 relatives who had a total of 29 children aged between 2 and 18 years old.

5) Quality Control: Documentation and evaluation (mandatory)

The good practice achieves the stated objective of making health-related information understandable and accessible to all individuals, using stories as an entry point, one of the main sources of learning for children, and language that is appropriate and adapted to their developmental age.

The results support the benefits of using stories as a tool in the communication process between family members and children who are undergoing genetic testing and ongoing cancer screening for hereditary conditions. This communicative process becomes intimate and enjoyable, providing support to families in addressing misconceptions and fears held by the children. Lastly, it was also demonstrated that the shared ritual of reading a book between family members and children is beneficial for family communication.

6) Transferability / Replicability (mandatory)

Throughout the study, the methodology used for implementing the program is described, including the inclusion criteria used for selecting the population, the criteria for adapting the stories, and the procedure conducted for data collection.

The stories are not provided, although due to their adaptability and themes, it would be important to use different stories according to the age and circumstances of the participants.

From this study, we can infer that an intervention such as bibliotherapy would be an economical, accessible, and convenient approach for genetic health professionals to use in counseling and meeting the needs of families.

7) Time Frame (mandatory)

2020. Published on January 2021

8) Best practices should be enclosed in childhood (0-6 years old) (mandatory)

A total of 29 children, aged between 2 and 10 years, at risk of developing Li-Fraumeni syndrome (LFS) and hereditary pheochromocytoma and paraganglioma syndrome (HPPS), participated in this project.



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BP8: TEAVIAL PROJECT

<https://Miteco - TEAVIAL>

1) Conceptual Approach

a) Concept

The TEAVIAL project was motivated by the need to improve cognitive accessibility for individuals with Autism Spectrum Disorder (ASD) or other cognitive difficulties, thereby promoting their autonomy and social participation.

In order to initiate this project, a preliminary study was conducted using a Participatory Action Research (PAR) methodology, involving 1,786 students from Early Childhood and Primary Education Centers in the province of Seville (Spain).

Sequences with pictograms were designed and evaluated in order to find the one that facilitated better comprehension by the children regarding the guidelines to follow at pedestrian crossings. As a result of this study, it was agreed to use two sequences with four pictograms, depending on whether there was a traffic light or not. The agreed colors to depict these pictograms were blue and white.

The dissemination and implementation of these sequences in different cities and municipalities, both in Spain and internationally, will allow the achievement of the proposed goal of social inclusion and contribute to raising awareness of the autism community.

b) Target Group

The study specifically targeted students in the Early Childhood Education (ages 3 to 6) and Primary Education (ages 6 to 12) levels.

c) Innovation

The TEAVIAL project encompasses innovative aspects by shedding light on the insufficient adaptations in traffic infrastructure that facilitate the autonomy of individuals with Autism Spectrum Disorder (ASD) or other cognitive difficulties. It underscores the challenges they face when navigating as pedestrians in public settings, particularly at pedestrian crossings, irrespective of the presence or absence of traffic signals.

d) Formal networking / complementary links with relevant institutions

The motivation for the TEAVIAL project is in line with the third target of Sustainable Development Goal 11, which focuses on "Sustainable Cities and Communities." This target is part of the United Nations' 2030 Agenda for Sustainable Development, which was approved in 2015.

2) Orientation at the target group

As a foundation for the development of the TEAVIAL project, a Participatory Action Research (PAR) study was carried out, engaging 1,786 students from Early Childhood and Primary Education Centers in the province of Seville, Spain. This study featured a multidisciplinary team comprising:

- Doctors affiliated with the University of Seville.
- Educators: school principals, educational psychologists, specialized teachers in Therapeutic Pedagogy and Physical Education, teachers from early childhood, primary, secondary, and university levels, and technical personnel in early childhood education.
- Police officers: local police chiefs, school resource officers, and specialists in traffic education.
- Healthcare professionals.
- Local Administration Technician: Civil Engineer.
- Students from the Faculty of Education Sciences at the University of Seville.
- Family members of children with Autism Spectrum Disorder (ASD).

3) Relational Approach (mandatory)

The best practice is relational: implementing new measures that ensure the right to inclusion of all individuals in society.

4) Quantitative Criteria

The TEAVIAL project was initiated in 2016. The City Council of Mairena del Aljarafe (Seville) was a pioneer in implementing the sequences at pedestrian crossings. Since then, numerous municipalities have collaborated with the TEAVIAL project, including: El Guijo (Córdoba), Brenes (Seville), San Martín de la Vega (Madrid), Amposta (Tarragona), Los Llanos de Aridane (La Palma Island), Castrillón (Asturias), Castilleja de la Cuesta (Seville), Fuenlabrada (Madrid), etc.

5) Quality Control: Documentation and evaluation (mandatory)

The good practice successfully accomplishes the intended goal of promoting social inclusion for individuals with Autism Spectrum Disorder (ASD) or other cognitive difficulties.

In the preliminary study titled "Cognitive accessibility in crosswalks to facilitate inclusion: design, development, and evaluation of a sequence of pictograms," the process leading to the creation of two pictogram sequences adapted for pedestrian crossings is outlined.

The impact can be observed through the increasing number of municipalities that are joining the project by signing an agreement to adopt the pictogram sequences."

6) Transferability / Replicability (mandatory)

Both from the preliminary study of the project and on the TEAVIAL website, the methodology used, the rationale behind each decision, and the necessary documentation can be found.

The sequences have been used in numerous Spanish municipalities, facilitating the mobility and autonomy of individuals with Autism Spectrum Disorder (ASD) or other cognitive difficulties. The sequences cannot be modified to ensure universal understanding.

7) Time Frame (mandatory)

The TEAVIAL project was initiated in 2016 and is currently ongoing.

8) Best practices should be enclosed in childhood (0-6 years old) (mandatory)

In the preliminary study of the TEAVIAL project, 1,786 students participated. The selected stages included Early Childhood Education Centers (ECE) with students aged 3 to 6 years old, Primary Education Centers (PEC) with students aged 6 to 12 years old, or combined centers encompassing both stages (Early Childhood and Primary Education, ECE).



BP9: Theoretical Guide on Play: The Role of Play in facilitating Inclusion. Inclusive playgrounds -Teacher Training Program

Info (link)

<https://inclusiveplaygrounds.eu/media/pinc-io5-roadmap-es.pdf>

Inclusive Playgrounds

Teacher Training Programme - PINC

1) Conceptual Approach

a) Concept

The Way of Learning During Childhood is Through Play, where learning and fun go hand in hand. However, there are often situations of exclusion that arise. These situations may not pose a danger as long as they are occasional, but if they persist over time, there is a risk of enduring social exclusion.

Such situations are detrimental to the education of children who exclude or ignore their peers, as certain attitudes that promote this kind of exclusion become normalized, especially when reinforced and approved by adults.

During school recess, it is often observed that some students do not interact with others or participate in games, placing themselves in a vulnerable position that can lead to bullying. Therefore, it is important to promote inclusive play in real environments to facilitate natural learning and prevent bullying.

In light of all this, it becomes evident that there is a need to create a project that prevents any form of social exclusion, transforming recess into inclusive and enjoyable environments that promote learning, including conflict resolution techniques.

The main objective of this guide is to enhance the enjoyment of free play and improve children's experiences.

b) Target Group

This guide is aimed at children between the ages of 3 and 12 who are in early childhood education or primary education. However, it is applicable to any child population as it has a positive impact globally.

c) Innovation

This guide is considered innovative and significant as it theoretically captures inclusive play in childhood, focusing on free play during children's leisure time. In this regard, it will provide knowledge related to teaching methodologies and thereby promote accessibility to free play in childhood.

d) Formal networking / complementary links with relevant institutions

The game and its benefits are recognized by scientific literature and international conventions as a child's right, subscribed to by all member countries of the United Nations (UN). In this sense, the importance of play and recreation in the lives of children was recognized in 1948 by the Universal Declaration of Human Rights, which acknowledged that "everyone has the right to rest and leisure." Years later, in 1989, the Declaration of the Rights of the Child affirmed that "the child shall have the right to engage in play and recreational activities, which should be directed to the same purposes as education. The society and the public authorities shall endeavor to promote the enjoyment of this right."

These texts implicitly state that the right belongs to all boys and girls without distinction. However, in 2006, the Convention on the Rights of Persons with Disabilities explicitly protected the participation in recreational, leisure, and sports activities for all, ensuring that children with disabilities have equal access, along with their peers, to participate in and enjoy games and/or recreational, leisure, or sports activities, including those taking place within the education system.

2) Orientation at the target group

This guide is aimed at children between the ages of 3 and 12 who are in early childhood education or primary education. However, it is applicable to any child population as it has a positive impact globally.

3) Relational Approach (mandatory)

The interactions between caregivers/teachers and students are facilitated by specific support materials.

Some of the resources used or characteristics of the elements to be considered were:

- Noise-canceling headphones.
- Switches.
- Easy-to-read materials.
- Accessible font type.
- Pictograms.
- Videotutorials.
- Photographs.
- Communication technology.
- Support apps: Tempus, DictaPicto, TEAyudo a Jugar.
- Technology: ARASAAC, ARAWORD, PICTOSELECTOR.

- Sensory elements such as role-play markers (jingle bell bracelets, tactile team markers, tactile zone markers).
- Student agenda.
- Communication board.

4) Quantitative Criteria

This project started in October 2020, being the main entity the University of Murcia, with Olga Rodríguez Ferrán as coordinator. The project is aimed at teachers to facilitate children inclusion, as well as in class, during breaks. Guides and recommendations are created related to: inclusive processes in education, theoretical guide on play (play as a facilitator of inclusion), practical guide to play and guide to lead an educational community (strategies for raising awareness towards inclusion) and roadmaps for teachers (resources and didactics of PINC training).

5) Quality Control: Documentation and evaluation (mandatory)

The report shows the methodology of the project into different steps:

- **Step 1**
 - Active observation.
 - Recording.
 - Analysis.
 - Identification of target students and decision-making regarding them.
- **Step 2**
 - Organizing play areas.
 - The accessibility chain.
 - The play mediators team.
 - Frequency.
- **Step 3**
 - Creation and selection of engaging games.
- **Step 4**
 - Play and accompaniment.

To evaluate the effectiveness of the guide and determine the achieved outcomes and progress, it is suggested to collect the following information:

- Degree of student participation and enjoyment.

- Effectiveness of game zoning.
- Appropriateness of material and human resources.
- Effectiveness of the accessibility chain.
- Effectiveness of the provided support.
- Summary of the most notable aspects occurring during the breaks.

Collecting this information also helps identify potential needs for modifications in the proposed games and activities.

6) Transferability / Replicability (mandatory)

Access to the methodology and the practice/program implementation process is available (e.g., process description, guidelines, manual, etc.).

The methodology employed is reflected in the program implementation process, which consists of the following steps:

- Observation: Observational analysis of play in a recreational context, student participation, game accessibility, environmental analysis.
- Team organization, data collection, and schedule.
- Game selection and creation: Selecting or creating motivating games.
- The game itself: Daily intervention process or intervention process for a specific game.
- Evaluation.

The program takes into account the elimination of physical, sensory, cognitive, communicative, attitudinal, or training barriers. Therefore, the game is adapted to the participation of all children, regardless of their neurodevelopmental conditions.

It is based on inclusive play, guided by the principles of equitable and flexible use of materials, intuitive and easy-to-use gameplay, and access to perceptible information. It allows for tolerance of errors, demands adjusted physical effort, and considers appropriate sizes and spaces, benefiting individuals with the aforementioned conditions and the overall child population.

7) Time Frame (mandatory)

The project took place from October 2020 to March 2023 (30 months).

8) Best practices should be enclosed in childhood (0-6 years old) (mandatory)

The guide focused on students in Early Childhood Education (ages 3 to 6) and Primary Education (ages 6 to 12). However, its practical implementation has a positive impact on the entire child population.

Conclusion

The compilation of these best practices highlights the diversity and innovation in approaches to supporting families and caregivers of children with developmental disorders. Each practice offers valuable lessons and methodologies that can be adapted and applied in various contexts to enhance early childhood intervention. For instance, the family-centred intervention in rural Ireland not only addresses the developmental goals of the child but also considers the well-being of parents and siblings, promoting a holistic approach to support. Similarly, the training program in Lisbon bridges the gap between family-centered philosophies and actual practices, empowering practitioners to better support families.

Other notable practices include the WHO Caregiver Skills Training Program, which exemplifies the potential for scalable and adaptable interventions in low-resource settings, and the TEAVIAL project, which focuses on improving cognitive accessibility for individuals with Autism Spectrum Disorder. The bibliotherapeutic framework demonstrates an innovative approach to communicating with children about hereditary conditions, facilitating informed decision-making and reducing emotional distress.

By focusing on the holistic needs of both children and their families, these interventions not only promote developmental progress but also foster a supportive and inclusive environment for all involved. The EarlyBrain project is committed to disseminating these practices to inspire and guide ongoing efforts to empower families and improve outcomes for children with developmental disorders across Europe and beyond.







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