

Report about answers to an EURLYAID Questionnaire

The Implementation of Early Childhood Intervention (ECI) in 15 European Countries



1989 to 2014



Eurlyaid, der europäische heilpädagogische Frühförderungsdienst tagte in Münsbach

Wichtige Erkenntnisse über die Frühförderung von Behinderten ausgetauscht

In den ersten Lebensjahren werden entscheidende Erziehungsmuster geprägt. Bei Kindern bieten sich in diesen Jahren die größten Entwicklungsmöglichkeiten. Aus diesen Erkenntnissen müssen Behinderungen frühzeitig erkannt werden, damit die Fähigkeiten der

Behinderten entsprechend gefördert werden.

Nach deutschen und schweizerischen Vorbildern begannen vor mehr als zehn Jahren Heilpädagogen in einzelnen Familien geistig behinderte Kinder zu fördern. Dar-

aus entstand der heilpädagogische Frühförderungsdienst, „Service d'intervention précoce orthopédagogique“, dessen Präsidentin heute Marie-Thérèse Probst-Mousset ist, der von Lisy Krieps verwaltet wird und zahlreiche Fachkräfte als Mitarbeiter zählt.

Auf Initiative der Verantwortlichen der „Frühhilfe Ostbelgien“ aus Neubelgien wurde 1988 „Eurlyaid“ geschaffen, um unter Leitung von Helmut Heinen (B) eine grenzüberschreitende Zusammenarbeit der Heilpädagogen aus den Niederlanden, Belgien, Deutschland, Frankreich, Spanien und Luxemburg zu ermöglichen.

Seit 1990 gehört Lisy Krieps „Eurlyaid“ an, und zusammen mit Jan de Moor und Monika Engfer hat sie die diesjährige Tagung der Heilpädagogen, die regelmäßig ihre Erfahrungen über die Frühförderung Behinderter austauschen, in Münsbach organisiert.

So wurden am vergangenen Donnerstag die Fachleute aus den verschiedenen Ländern von Marie-Thérèse Probst-Mousset und Alain Tandel, Verwalter des „Institut d'Europe“ in Münsbach, empfangen.

An drei Tagen tauschten die Pädagogen ihre Erfahrungen aus, stellten ihre Arbeitsmethoden und ihr Hilfsmaterial vor, beleuchteten die ethischen Aspekte der Frühziehung und bereiteten das Symposium über Frühziehung, das 1993 in Butgenbach (B) stattfinden wird, vor.

Hauptziel der Tagung in Münsbach waren dazu die Ausarbeitung eines Grundkonzeptes über die heilpädagogische Frühförderung Behinderter und das Aufsetzen eines Dokumentes, das im November an H. Wehrns, „Chef de division des actions en faveur des personnes handicapées“ bei der Europäischen Gemeinschaft überreicht wird.

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Luxemburg, 1991

INTRODUCTION

EURLY AID was started in 1988 at a conference in Rotterdam by a small and honorary group of scientists, parents and professionals. During the past 25 years the engagement of EURLY AID focused on the development and qualification of the professional work of Early Childhood Intervention (ECI) in Europe and neighboring countries. The “Manifesto” was the first and most important document to define a standard and was published by the group, as it existed in those days.*

This article will present an overview of the conditions for the establishment of Early Childhood Intervention in 15 European countries based on the answers to a questionnaire. The background of the questions are recommendations our former colleagues presented in 1993 within the Manifesto. We used seven of those recommendations to get answers about the actual situation in the different countries. (*Belgium, Bulgaria, Croatia, Cyprus, Denmark, France, Great Britain, Germany, Greece, Holland, Norway, Portugal, Romania, Spain, Sweden, Parents' associations: BOSK, Holland, BVKM, Germany*) We sent them to key respondents in the field of ECI such as Parents' associations, professionals and academics. These persons have a critical insight concerning the conditions of their work. The collection of answers dates from 2014, about 20 years after the publication of the Manifesto. We received answers to the following seven questions together with some additional statements.

1. “It is essential that children with disabilities receive help at an early stage. (...) At all times parents have the right to decide whether or not they will accept the help that is offered.”
2. “It is recommended that the government of each Member Country draw up its own policy plan for early intervention and put it into action by means of legislative and regulatory measures.”
3. “It is therefore (required) that each Member State provides the financial means required to carry out this policy plan.”
4. “Early recognition of developmental disabilities requires an adequate system of detection.”
5. “The diagnostic assessment must be aimed at the entire child in all (...) aspects, including his/her family and extended family.”
6. “A plan of action must be set up for each child individually and subsequently evaluated at fixed times. This plan of action is also geared to parents, the family and the broader network.”
7. “Parents must be actively involved in all phases of the intervention process.”

Survey of the Answers to the Questionnaire

Our survey, of course, does not present statistical results or official statements. The majority of the answers came from colleagues working in the field of Early Intervention. Its value is their professional knowledge and experience. - Our report concentrates on three fields in order to summarize the implementation of ECI and the quality of professional work with children and their families. At the same time, it will indicate challenges for the future.

1. Policy and financial resources

1.1 Does the country have a policy plan for early intervention and will put it into effect by means of legislative and regulatory measures?

1.2 Does the country provide the financial means required to carry out this policy plan?

2. Early detection and early support

2.1 Does there exist an adequate system of early detection?

2.2 Do children with disabilities receive appropriate help at an early stage?

3. Individualization of the intervention and inclusion of the Family

3.1 Is an individual plan of action a precondition as a distinctive mark of ECI?

3.2 Are parents or families actively involved in the plan of action and in all phases of the intervention process?

Each of the 15 countries country established a system to develop ECI under quite different conditions and as a specific system. Each country has its own cultural and social history to deal with the support of babies and young children with developmental problems, and their families.

The awareness of the importance of ECI is obvious in all the answers we received from our colleagues in the 15 European countries. Of course, the conceptions of working in ECI are quite diverse, but in general, human rights are considered as a standard. The implementation of ECI is an on-going process, and we understand this report to be a reflection of the present situation that gives us reasons to improve the quality of ECI in favor of very young children and their families in the future.

1. POLICY AND FINANCIAL RESOURCES

1.1 DOES THE COUNTRY HAVE A POLICY PLAN FOR EARLY INTERVENTION AND WILL PUT IT INTO EFFECT BY MEANS OF LEGISLATIVE AND REGULATORY MEASURES?

In 8 of the 15 countries a special law covers the right of Early Childhood Intervention (ECI) which guarantees the access, especially for children of less than 6 years of age, or it is focused on support for all children with special needs. In some countries, a law does not specifically recognize ECI, but the system of social welfare covers the very different special needs of young children and their families by local authorities and at a good quality level. A few examples exist where the law integrates educational, health, and social care for a child and its family as an inclusive approach. Such a policy plan develops, and continues to develop, its quality in several steps of cooperation.

A plan to put into effect the law by means of regulatory measures is generally insufficient. A country's control over the quality and effectiveness of ECI is lacking in almost all of the countries. Even if a general law exists, in most of the countries regional authorities or communal authorities create their own guidelines (often in their financial interest to decrease the costs) which results in an extremely diverse quality of support, and the support of the families is often considered to be less important.

1.2 DOES THE COUNTRY PROVIDE THE FINANCIAL MEANS REQUIRED TO CARRY OUT THIS POLICY PLAN?

Big differences exist between the 15 countries. The financial resources differ from sufficient regulations to nearly zero. – The distribution of the resources allotted by the country for dispersal by political units and local communities results in different budgets and very different quality standards for ECI.

If financial support does exist, it often comes from different resources and very often without coordination. This leads to big differences between „poor“ and „rich“ communities. In some countries and in some cases, parents still have to pay for ECI.

The amount of financial resources restricts home-based work, interdisciplinary work and coordination, and the number of children getting support.

A well-organized interdisciplinary network or institution requires less financial support than the coordination of different special services at different locations.

2. EARLY DETECTION AND EARLY SUPPORT

2.1 DOES AN ADEQUATE SYSTEM EXIST FOR EARLY DETECTION?

Public awareness and the knowledge about ECI, “well baby clinics”, or maternal and child health care centers is not well developed. In almost all countries, there exist activities to develop or increase the information systems. – The lack of cooperation between the different government or administrative departments and different welfare organizations complicates early detection.

The basis for early detection of very young children is the medical system. There are programs developed especially for some groups of children such as for children with hearing impairments and premature babies. The chance to detect developmental problems is high, when the educators in a nursery or kindergarten are informed. - Professionals working with children have increasingly more responsibility for early identification of children’s needs. This awareness is a very important challenge during professional training. There is a lack for professionals educated especially in child development.

Services outside the Early Intervention system often are not open-minded to ECI. They do not consider that ECI offers help and argue a system of control. - In most countries, there exists a gap between very early detection within the medical system and the later detection when children are in a kindergarten setting, where there may be increased professional awareness. - Early detection is lacking for children at risk, for children with no obvious pathology. Access is especially difficult for families living in poverty or who experience social problems.

2.2 DO CHILDREN WITH DISABILITIES RECEIVE APPROPRIATE HELP AT AN EARLY STAGE?

In all European countries, early support exists in a great variety of concepts, organizations and accessibility. The systems vary from home-based, to center-based, to specialized centers and to institutional care. In the majority of the countries, the services are free of charge and the access is easy. In some regions within several countries, ECI services are still lacking.

The variety of the different special needs of children and the availability of help from different disciplines very often is not coordinated and difficult for the parents to obtain.

Since early support is depending on early detection of developmental problems there exists a functioning system for babies and very young children in most countries based on the medical system. - In some countries, a pediatric nurse or midwife regularly visits the family. The chance to detect developmental problems is high when the child is in a nursery or kindergarten setting and the educators are informed.

The choice to decide between different services exists only sporadically. Generally, there is only one ECI service in a (rural) community.

In several countries, parents seem to be misinformed about existing resources, where to address their problems, or they do not even ask for help. - Child neglect and abuse often correlate when parents do not have access to the appropriate information. - In such situations of lacking information about existing resources, parents are not in a situation to make the right choices.

Remarks of several countries stress the fact that parents can choose (if they have the choice) as long as their decision does not have a serious impact on the child's well-being.

3. INDIVIDUALIZATION OF THE INTERVENTION AND INCLUSION OF THE FAMILY

3.1 IS AN INDIVIDUAL PLAN OF ACTION A PRECONDITION FOR A DISTINCTIVE MARK OF ECI?

In some countries, the plan of action is “tailored” to the needs of the child including the family. The plan has to be discussed together with the parents and signed. The regular assessment needs time. The proposal for the frequency of new assessments is 6 months, 1 year, or following an actual situation.

There are complaints about a considerable gap between the plan of action and its implementation in order to ensure a coherence because of the difficulties in cooperation between the different services and even the different professionals. - An inclusive approach prevents labeling on the one hand, but children's special needs could be in danger of being underestimated on the other hand. Standards of quality should be established and be compulsory for inclusive settings.

3.2 ARE PARENTS OR FAMILIES ACTIVELY INVOLVED IN THE PLAN OF ACTION AND IN ALL PHASES OF THE INTERVENTION PROCESS?

It is the right of the parents to be involved. There has to be respect for the level to which they want to be involved, together with the right to deny strategies of support that they do not consider being helpful.

The child, its family and its environment are the initial point for a

holistic intervention, based on a prior interdisciplinary assessment. (Environmental factors can be resources or barriers as well.) Families should participate in the identification of strengths, needs, and priorities. (Some systems involve them more than others.) Home visits are a very helpful opportunity to detect resources. The satisfaction of the parents is a decisive factor influencing the development of the child.

Therapy and education cannot be efficient without the involvement of parents and adult persons living together with the child.

There are big differences between the cultures in the European countries. There are traditional and more restrictive views of support, for instance institutional care on the one hand, and quite open family structures, which allow the discharge of responsibilities to different caregivers for the child on the other hand.

Stress within the family often prevents parents from involvement. The necessary training to deal with difficult problems in the family is often lacking in professionals.

The medical system is often predominant - Medical doctors and therapists continually have to be sensitized to interdisciplinary cooperation.

The synthesis of different specialist is often difficult for a family to organize.

Summary of the above collected Statements

We respected each actually working single system with deference to the above-mentioned historical conditions. We considered as being a wealth but at the same time a work in progress. Therefore, we dare to emphasize that in all of the countries the improvement of the organization and the quality is an on-going process of discussions and negotiations. This is the viewpoint we choose for the summation of the experiences in the 15 countries and for looking at how to implement appropriate conditions of ECI.

1. LEGISLATION

The fact that in half of the countries the regulation of ECI has its basis in legislation is obviously a considerable step forward within the past 20 years, in allowing children the right to live and participate in their natural environment. At the same time, it stresses the necessity for the other countries to engage themselves in opening up the same rights for their children.

A general countrywide control over the quality and effectiveness of ECI is lacking in almost all of the countries. The legal right of families to have access to ECI stimulates the experts working in this field to consider how to translate these rights into action. – This is a crucial situation for the quality of the provided support as no compulsory regulations guarantee the financial requirements. This concerns the access for every family to at least the minimum of provided support.

The qualification of the experts and the equipment of services are very different even in those countries where the general economic situation is

favorable. All of it depends on provided, or lacking financial resources and their distribution; depends on a region with sufficient and qualified services or services that exist only at great distances; depends on the level of expertise by the different professionals or on insufficient qualifications of the professionals.

Even if a general law exists, in most of the countries regional authorities or communal authorities create their own guidelines, often in their own financial interest to decrease the costs. This is in contradiction to the equal rights of every European citizen that have to be respected in all 15 countries and in the other European countries as well.

2. INTERDISCIPLINARY APPROACH

A second step forward is the interdisciplinary approach of ECI. There exist examples of how the law integrates educational, health, psychological and social care for a child and its family. Such a policy plan has to develop its quality in several steps of cooperation and with the understanding that this is a work in progress, too.

At the beginning services with the aim to support children with developmental problems were specialized services - specialized in the sense of classifying disabilities by diagnostics comparable to adult persons. Therefore, the authorities in charge of the different legal responsibilities independently from each other established different special medical services, different special educational services, and other services for young children with developmental problems.

Investigations proved that therapy or stimulation based only on a biological diagnosis ignore the complexity of development. Experts planned ECI increasingly as a holistic approach for so-called “children with special needs”. Such an approach only works with the cooperation of

experts from the medical, educational and psychosocial fields.

We have to state that there exist many ECI services where interdisciplinary work is compulsory. By contrast, there exist services in several countries where specialization excludes interdisciplinary work. There the basis of the support is a medical view of the developmental needs of a child.

The concept of prevention concerning children at risk or children with no obvious developmental problems is not in the focus of many services. Institutions outside the Early Intervention system often do not consider that ECI offers help and argue a system of control.

The gap between specialized services in the medical field and the interdisciplinary services offered by ECI has to be an important issue in establishing cooperation for the future and promote the ECI work as an interdisciplinary necessity.

3. FAMILY-CENTERED PRACTICE

Finally, we can emphasize that the importance of the family in the course of the differentiation of ECI during the last 20 years is increasingly accepted as fundamental. The opening of the mind towards a holistic view of disability, considering more than the biological factors, embraces the embedding of the child in its family as being crucial. Professionals working in ECI generally acknowledge the right of the parents to be involved in the process of planning the support and translating it into action – often together with the whole family.

Nevertheless, the quality of cooperation with the family is an issue of time and financial resources. There exists a general acceptance that the family must be involved.

At this time, empowering the family is not always part of the program of support because administrators and parents regard early intervention as



focused on the child. This field needs to be “enlightened”.

There are big differences in the existing cultures of the European countries, as a traditional context leads to institutional care on the one hand, and very open structures where the charge of responsibilities towards children changes within families, caregivers or one-parent-families on the other hand.

Including families in the support for children with developmental problems is irrefutable as a basis of ECI work in the 21st century. The flexibility of the ECI concepts should be open in financial and intercultural respects to provide the right kind of support even while considering the different necessities and circumstances.

Conclusion

“States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education ... with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas.”

This could be a part of the statutes of EURLYAID, but it is the Article 23 from the “Convention on the Rights of the Child” from 1989.

The presented EURLYAID survey of the answers to our questionnaire demonstrates the importance of exchange of even basic information that can be helpful to describe the necessities for the improvement of Early Childhood Intervention systems in all of the countries.

We can summarize that since the EURLYAID-MANIFESTO from about 20 years ago; there has been a considerable development to cover the right and access to ECI by law and administrative authorities. There is a significant shift to install cooperation between different professionals and different disciplines. In addition, there is a meaningful paradigm shift towards family-centered practices. – We described in detail that in spite of many insufficiencies we look at the improvement as an on-going process.

The requirement to improve the ECI systems in each of the countries has to be based on fundamental statements in the ICF-CY by the WHO, in the

“Convention on the Rights of the Child” from 1989 and the “Convention on the Rights of Persons with Disabilities” from 2006 by the United Nations.

There we found guidelines to substantiate our actual conception of Early Childhood Intervention.

1. POLITICAL CHALLENGES TO GUARANTEE HUMAN RIGHTS

Even if in several countries laws exist which are the basis for the ECI organization, the reality, however, shows that the translation into action is still far away from the described necessities in the conventions.

The Convention on the Rights of Persons with Disabilities” from 2006 refers to the former convention on Children’s rights. *“Recognizing that children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end undertaken by States Parties to the Convention on the Rights of the Child”* (Preamble >r<).

Article 23(2) of this convention describes precisely the preconditions to guarantee the necessary support. *“States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child’s condition and to the circumstances of the parents or others caring for the child.”* Therefore it has to be ensured (23>3<) *“that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child’s achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.”*

2. DISABILITY IN A SYSTEMIC PERSPECTIVE AND INTERDISCIPLINARY

APPROACH

There has to be awareness of the considerable progress in the conception of a disability, which is not interpreted only as an impairment by a medical diagnosis anymore.

The interpretation of a “Disability” in the “Convention on the Rights of Persons with Disabilities” introduces a systemic view. *“Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”.* (Preamble >e<) This conception opens the work with children with developmental problems of different origins to a more holistic view including the family and their environment (community).

The ICF-CY (International Classification of Functioning, Disability and Health for Children and Youth) covers *“the body functions and structures, activities and participation, and environments of particular relevance to infants, toddlers, children and adolescents. With its functional emphasis, the ICF-CY uses a common language that can be applied across disciplines as well as national boundaries to advance services, policy and research on behalf of children and youth.”* (Preface page VIII) This precisely is the aim of EURLY AID to foster interdisciplinary cooperation and research. ECI demands an interdisciplinary/transdisciplinary approach wherever professionals work together with young children and their families.

3. FAMILY CENTERED PRACTICE

As children are dependent on their parents and families, ECI is not only focused on the child but on its family as well, which is generally accepted as “Family-Centered Practice”. The “Convention on the Rights of Persons with Disabilities” stresses the necessity to include the family in the system of support: *“Convinced that the family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities.”* (Preamble >x<) This, of course, has to be balanced between the rights of the parents to choose whether they accept the Early Intervention with the rights and the well-being of the child.

4. OUR VISION

We are convinced that the three topics based on the ICF and the UN Conventions describe necessary conditions to develop a “good practice” by ECI that result in the full acceptance of a child in its environment and its participation in daily life. This is a situation we can observe and, to a certain degree, objectify. - But there may be more which is desirable. The “Convention on the Rights of Persons with Disabilities” (Preamble >m<) describes for everybody as a final result of the support *“their enhanced sense of belonging”* which is the deeply human need for the feeling of being important and being part of a family, a group, a society. That is the real significance of Inclusion.

Final Statement

The engagement of EURLY AID from the beginning and during the last 25 years was developing and qualifying the professional work of Early Childhood Intervention (ECI) in Europe and neighboring countries. In addition, over the years, important other elements concerning Early Childhood Intervention in general and ECI-systems in particular, were the exchange between the different involved countries, the study of evaluation methods for services to define their quality, the study and development of a curriculum for professional training and quality standards. We were engaged in different EU projects. This led to further development of professional training in some countries in Europe, to improve the quality of ECI, for instance by using the ICF (and more recently by using ICT devices) as common language involving parents in the process of support and to widen this network and the awareness of the importance of professional training in Early Childhood Intervention.

We organized meetings, conferences and we were partners in many conferences in different countries improving the opportunities for the exchange of information and the cooperation for developing professional knowledge, publishing articles and presenting an e-book about ECI research and practice in European countries. **

For the years to come:

1. Eurlyaid will continue with this work, maintaining and widening our network, continuing existing cooperation, organizing meetings and conferences.

2. Because of the current economic situation all over Europe, we will actively seek and maintain contact and cooperation with “colleague” networks that will benefit all parties involved in mutual exchange of their expertise and our special expertise in ECI.
3. Eurlayaid will actively research possibilities to find more structural financial means that will enable us to continue the work by considering the opportunity to cooperate more closely with other NGO's in the field of ECI
4. Eurlayaid will continue its advocacy for professional training (standards): Working with very young children with developmental problems and their families is a highly sophisticated challenge that needs profound professional training on university or applied science level. At the same time, it can be regarded as a preventive work with vulnerable children with a view towards their individual future in the sense of their inclusion.

It is obvious that there has been an important development in the implementation of Early Intervention services and an improvement in quality and interdisciplinary cooperation. However, as we described in our survey there exist big differences between the European countries and within the countries themselves. There is still lot of work to do.

The board members of EURLY AID express - in the light of the economic crisis all over Europe during the last years - our worries about the risk that especially the target group of Early Childhood Intervention (ECI) will suffer from the consequences of austerity politics: **the very young and vulnerable children and their parents.**

The actual state of development in ECI is a challenge for all professionals and stakeholders to engage themselves in further improvements in the context of the above-cited UN Conventions which were ratified in most of the countries.

(Report: Juergen Kuehl, member of the Eurllyaid board)

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**Early Intervention for Children with Developmental Disabilities:
Manifesto of the Eurllyaid Working Party**

J. M. H. DE MOOR*, B. T. M. VAN WAESBERGHE, J. B. L. HOSMAN, D. JAEKEN and S. MIEDEMA,
International Journal of Rehabilitation Research 16, 23-31 (1993)

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European Developments in Early Childhood Intervention
edited by Barry Carpenter, Jacques Schloesser and Jo Egerton
published by Eurllyaid / EAECI (2009)

* and **

Download as „Key Documents“: <http://www.eurllyaid.eu/index.php?menupos=4>

In conclusion, we would like to express our gratitude to all those colleagues who helped us – spending their precious time to respond to the questionnaire – in order to produce this report reflecting the development of Early Childhood Intervention in European countries during the last two decades.

Thank You! – Merci! – Danke!



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1989 to 2014

