

Early intervention for children with developmental disabilities: manifesto of the Eurlyaaid working party

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Eurlyaaid is a working party of the European Community (EC). It consists of experts and representatives of parents' associations from the various member states involved in early intervention for children who are disabled or at risk of developmental disabilities. Starting from the growing recognition of the importance of early identification and intervention Eurlyaaid aims to contribute to the development of a common EC policy and legislation. Here we describe a comprehensive framework for early intervention, presented as a preliminary manifesto. First of all the Manifesto gives a definition of key concepts, delineates the target group and states the rationale behind, and the content, of early intervention. Secondly, we present the conditions and demands necessary to attain the best quality early intervention, and make a number of recommendations. With an EC grant, Eurlyaaid is able to continue its activities as part of ALEFPA-Europe, a so-called non-governmental organization (NGO).

Frühe Intervention für Kinder mit Entwicklungsbehinderungen

'Eurlyaaid' ist eine Arbeitsgruppe der Europäischen Gemeinschaft (EC). Sie besteht aus Experten und Vertretern von Elternverbänden, die sich in den verschiedenen Mitgliederstaaten mit der Früherziehung von Kindern, die behindert oder von Behinderung bedroht sind, beschäftigen. Auf der Grundlage der zunehmenden Anerkennung der Bedeutung früher Identifikation und Intervention setzt sich 'Eurlyaaid' die Aufgabe, einen Beitrag zu leisten zur Entwicklung einer gemeinsamen politischen Zielentwicklung und Gesetzgebung. Dieser Artikel beschreibt einen umfassenden Rahmenplan für frühe Intervention, der als ein vorläufiges Manifest zu verstehen ist. Als erstes gibt das Manifest eine Definition von Schlüsselkonzepten, grenzt die Zielgruppe ein und beschreibt den Begründungszusammenhang, durch den der Inhalt früher Intervention konstituiert wird. Im weiteren zieht es daraus resultierende Folgerungen, indem die Bedingungen und notwendigen Forderungen zur Erreichung der besten Qualität der Früherziehung aufgezeigt und eine Reihe von Empfehlungen gemacht werden. Mit der finanziellen Förderung durch die EC ist Eurlyaaid in der Lage, seine Aktivitäten als ein Teil von ALEFPA-Europa, eine sogenannte nicht von Regierungen abhängigen Organisation (NGO), fortzuführen.

L'intervention précoce au profit d'enfants présentant des handicaps du développement

'Eurlyaaid' travaille en association avec les Communautés Européennes. Il est constitué d'experts et de représentants d'associations des différents états membres préoccupés par l'intervention précoce au profit d'enfants présentant des handicaps du développement ou se trouvant dans des situations de risque de les présenter. Partant de la reconnaissance croissante de l'importance du diagnostic et de l'intervention précoces, Eurlyaaid a pour objectif de contribuer au développement d'une politique et d'une législation communes à l'ensemble des pays de la CE. L'article décrit un vaste cadre pour l'intervention précoce, base que se veut un manifeste préliminaire. Cette proclamation donne tout d'abord la définition des mots clés, détermine le groupe cible, décrit les bases théoriques et le contenu de l'intervention précoce. Il conclut ensuite par la présentation des conditions et des exigences nécessaires à l'obtention de la meilleure qualité d'intervention précoce en dégageant un grand nombre de recommandations. Avec l'aide de la CE, Eurlyaaid pourra continuer ses activités comme membre de L'ALEFPA-Europe, une ONG ainsi dénommée.

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Intervención temprana para niños con discapacidades del desarrollo

'Eurllyaid es el nombre de un grupo de la Comunidad Europea (CE). Está compuesto por expertos y representantes de asociaciones de padres de los diferentes Estados Miembros, involucrados en la intervención temprana con los niños con discapacidad del desarrollo o en situación de riesgo de la misma. Partiendo del creciente reconocimiento de la importancia de la detección y de la intervención tempranas, Eurllyaid trata de contribuir al desarrollo de unas políticas y una legislación comunes en la CE. El artículo ofrece un marco comprehensivo para la intervención temprana, presentado como Manifiesto preliminar. En primer lugar, el manifiesto da una definición de conceptos clave, define el grupo objetivo y establece las bases que sustentan el contenido de la intervención temprana. En segundo lugar, concluye poniendo las condiciones y requisitos necesarios para alcanzar la mejor calidad en la intervención temprana, y dando una serie de recomendaciones. Con una subvención de la CE, Eurllyaid podrá continuar sus actividades como parte de ALEFPA- Europa, una organización no gubernamental (ONG).

Keywords: early intervention; developmental disability; EC working party

Introduction

Eurllyaid was founded on the initiative of Professor J. J. Detraux (Free University of Brussels) and Mr H. Heinen, director of Handicap Services for the German-speaking Community of Belgium. This happened during the international conference, 'The First Years: Children Suffering from Brain Damage', held in Rotterdam in 1989 and organized by the Dutch parent association for physically handicapped persons, BOSK. Eurllyaid is a working party consisting of experts and representatives of parents' associations from the various EC countries involved in early intervention for children at risk or with developmental disabilities. The working party hopes to stimulate the development of a common EC policy through international cooperation and the exchange of information.

Thanks to an EC subsidy, the working party met four times: in Bütgenbach (Belgium), Besançon (France), Münsbach (Luxembourg) and Marl (Germany). It emerged from these occasions that there was an increasingly urgent need for a common vision on intervention for young children who are at risk or disabled. This led to the drawing-up of a provisional manifesto, which was to constitute a first step in the direction of the harmonization of EC policy. The ultimate goal is the realization of legislation and guidelines by means of a communal action programme in order to guarantee the best possible aid to handicapped children in the respective member states. The Manifesto is based on the Convention of the Rights of the Child as agreed in the General Assembly of the United Nations on 20 November 1989 (articles 23 and 24 in particular) and the rights of the parents in accordance with articles 5 and 18. A major inspiration in the formulating of the text was US federal legislation: in particular Public Law 99-457 (1986). This law mandates that handicapped infants and toddlers are entitled to multidisciplinary assessment and intervention. It also regulated the right of the parents and the family to an 'Individualized Family Service Plan'.

The first phase of Eurllyaid's work was concluded with the presentation of the Manifesto to Mr Wehrens, the most Senior EC official in the field of care for the disabled. The continued existence of the working party is also guaranteed as Eurllyaid was able to link up with ALEFPA-Europe, a non-governmental organization (NGO) recognized by the European Community. The Manifesto gives a definition of key concepts, delineates the target group and states the rationale behind and the content of early intervention. It concludes by laying down the conditions and demands necessary to attain the best quality of early intervention, and makes a number of provisional recommendations.

Definition of the key concepts

Early intervention is intended for all children who are subject to a developmental risk or developmental disability. The aid covers the period between the moment of prenatal diagnosis and the moment that the child reaches the age at which school is compulsory. It includes the entire process from the earliest possible identification and detection up to the moment of training and guidance. Although at present we do not, strictly speaking, regard prenatal diagnosis as an integral part of early intervention, its psychosocial consequences for the parents do fall into that domain. In this Manifesto, we do not go further into this matter. Firstly, we intend to define the concepts of development, developmental risk, developmental disability and early intervention. We then propose to deal with the various phases of early intervention.

The concepts of development, developmental risk, developmental disability and early intervention

Development is a dynamic process in which both the child and its environment participate, in which both select the influence of the other and through which both evolve in a particular direction. The consequence or implication of this for assessment and intervention is that attention must not be focused exclusively on the child. The interaction between the child and his parents or caregivers must constantly be born in mind, as must factors of the family and the extended family.

Developmental risk implies that there is evidence of an increased probability that a disability may occur. Three types of risk factors can be distinguished which are not mutually exclusive: (1) established risk in specific medically diagnosed conditions or syndromes, such as Duchenne's muscular dystrophy and Down's syndrome; (2) environmental risk, such as in children in deprived environments which limit their ability to profit from important learning experiences; and (3) biological risk on grounds of prenatal, perinatal and neonatal factors, such as in cases of prematurity and dysmaturity.

Developmental disability means a significant deviation from the normally expected pattern of development, which is experienced by the person and/or by their environment as alarming. Such a disability may express itself in forms of retardation and/or dysfunction of a physical, cognitive and emotional-affective nature. As a result of our starting from the transaction model of development, a developmental disability must also be regarded as a dynamic process in which a lot of factors can play a part. Among these are differences in norms between people, genders and cultures. Retardation in development may thus occasionally be spontaneously removed or compensated for.

Early intervention can be defined as all forms of child-oriented training activities and parent-oriented guidance activities which are implemented in direct and immediate consequence of the identification of the developmental condition. Early intervention pertains to the child as well as to the parents, the family and the broader network.

Phases in the early intervention process

Early intervention for children at risk or with developmental disabilities constitutes a process and entails several phases. These phases are identification, detection, diagnosis, training and guidance. Although these phases are listed here in their logical order, in practice they intersect and merge with each other and are not clearly to be distinguished. We propose to elaborate on the phases mentioned.

Identification is the observation of the first signs or signals suggesting that the development of a child may be at risk or may be progressing atypically.

Detection is the systematic search for such signs and signals in an entire population. This includes screening programmes such as for phenylketonuria (PKU) and congenital hypothyroidism (CHT), for hearing impairments (e.g. the Ewing-test) and for developmental disorders (e.g. Denver Developmental Screening Test). The outcome is not a diagnosis. The children selected are referred for further diagnostic examination.

Diagnosis consists of finding a developmental disability, together with the suspected causes. The diagnosis takes place in consequence of the identification of signs or signals which may be considered as deviant or as a risk to development.

Training includes all goal-directed activities affecting the child and his/her environment intended to create more favourable conditions for development. It includes activities like developmental stimulation, educational practices and adjunctive services from professionals in medicine, occupational therapy, physical therapy, speech therapy and audiology, and nutrition.

Guidance consists of all specific forms of training and counselling offered to the parents, the family and the extended family. Among other things it includes: (1) help in the recognition and acceptance process and in the assistance concerning appropriate responses to the child's behaviour (parent-child interaction) (2) instruction and advice relating to developmental activities, child-rearing practices and therapy, and (3) the provision of information in general.

Target group

The target group consists of children below the age of compulsory education who are disabled or at risk for developmental disabilities. A child is disabled when we can speak of a degree of retardation and/or dysfunction in one or more of the following fields: (1) gross motor development; (2) fine motor development; (3) sensory perception; (4) cognition; (5) communication; and (6) adaptive behaviour (social and self-care skills). A development at risk occurs in:

- (a) children with specific physical disorders of an orthopaedic or neurological nature;
- (b) children suffering from a chronic illness such as heart disease, CARA, epilepsy, cystic fibrosis and rheumatism;
- (c) high-risk groups such as premature and dysmature children.

In these three categories early intervention is only necessary if the physical condition really has negative consequences for the children's development.

The rationale behind early intervention

The arguments for early intervention can relate to the child, the parents, the family and extended family, and the society. We will now discuss these aspects.

Arguments relating to the child

(1) Early intervention can prevent risk factors in the child and/or his background from leading to developmental delay and/or dysfunctions. This can be achieved by offering the child the correct stimulation and interaction with his surroundings at an early stage in his

development. Empirical research has demonstrated that this form of prevention is effective.

(2) Early intervention also fulfils a remedial function. This is the case with children who already have a degree of retardation. They can be enabled to catch up with a more normal rate of development, or the degree of retardation can be prevented from increasing.

(3) Early intervention reduces the side effects of chronic illnesses and permanent functional impairments. An increased developmental delay as well as additional handicaps can be prevented. What can also be obviated is undesirable behaviour caused by the handicap itself which can cause the handicapped child to become the cause of serious disturbances within the family.

Arguments relating to the parents

(1) Early intervention is an effective way of helping parents to deal with their handicapped children. This comes about by actively involving the parents in the intervention process so that they can discover their own possibilities and capacities. Parent involvement can be aimed at the needs of parents to become competent as quickly as possible in caring routines, in skills for positioning, handling and treatment, and in child rearing. Early intervention saves parents from the necessity of coping with the emotional problems on their own, and it makes a valuable contribution to the acceptance process. Early intervention reduces or eliminates the incapacity of many parents to manage the child's problems, improves the parent-child interaction, creates a more balanced emotional relationship, and prevents undesirable child-rearing practices.

(2) Early intervention prevents the parents from being deprived of information. This information can relate to: (a) the diagnosis, the cause of the handicap, and the prognosis; (b) knowledge about normal development and about how a retarded and/or disturbed development needs to be stimulated; and (c) the social system of provisions that are available to them.

Arguments relating to family and extended family

(1) Early intervention can prevent brothers and sisters from acquiring an unfavourable or disadvantageous position within the family as a result of which their own development may be hindered and behavioural problems may arise.

(2) Early intervention can ensure that the family as a system and the family as a network (grandparents, uncles and aunts) learn to adjust themselves to the situation of coping with a handicapped child.

(3) Alleviation of the burden to the family, among other things by offering family assistance, day care and other facilities (for instance material support, adaptive equipment and improvement of the housing conditions).

Arguments relating to society

(1) Early intervention makes society aware of the fact that there are also young children with developmental disabilities who are part of the community and have a right to support.

(2) Early intervention enhances the opportunities of the children, since they go through school more successfully. They are also less likely to draw on public funds because of delinquency, unemployment or dependence on welfare. As the child grows older, the parents will seek less guidance because they have learned early on that ways exist for them to deal with their problems.

The content of early intervention

Assessment

Assessment is a logical consequence of the recognition of signs and signals regarded as deviant or at risk in development. It is an in depth study of the child's development by one or more experts and of his/her immediate surroundings (parents and family) made on the basis of objective criteria. This implies that there must also be an analysis of the social and pedagogical situation of the child, and of the needs and strengths of the family. The assessment of the child is not made according to the medical model but according to the psychopedagogical model, in which the child's range of developmental skills and deficiencies across multiple behavioural areas are described and analysed, in addition to the relevant factors in the family and the extended family. The aims of assessment are: (1) to arrive at a broader evaluation of the child's functioning; (2) the provision of information about the examination results and a statement of expectations for the future, if possible; (3) to provide advice on the nature and form of the intervention programme, and (4) to draw up an individualized service plan.

In its most extensive form, assessment can entail the following examinations:

- (1) an inventory of the family situation;
- (2) a general medical examination and if necessary an examination by specialists, e.g. paediatrician, child neurologist, and specialists in genetics and/or rehabilitation medicine;
- (3) a paramedical examination by one or more of the following disciplines: physiotherapy, occupational therapy and speech therapy;
- (4) a psychopedagogical examination such as an investigation of the behavioural functions and the personality development of the child, observation of behaviour in free and structured situations, an analysis of the pedagogical situation, and an evaluation of the process of recognition and working through process of the parents.

Training/guidance

The purpose of the training of the child is the prevention and remediation of developmental delays and/or dysfunctions, recognition of risk factors in the immediate environment of the child, and the limiting of the consequences of illness and handicap. Treatment consists of the following.

(1) Developmental training activities. Programmes in this field can vary in intensity, the degree of structuring and the mode of execution (individually or in groups). Certain programmes restrict themselves to providing additional learning experiences (developmental enrichment programmes), while others aim at the training of selected skills (e.g. cognitive-developmental programmes and programmes for behavioural training). The setting of the programme can range from the home situation to regular or specialized day care. In addition to day care group programmes, it may be necessary for the child to receive individual therapy, for instance play therapy.

(2) Medical, paramedical and perimedical help. The medical assistance can be of a general or specialized nature. By 'paramedical help' we mean the assistance of the physiotherapist, occupational therapist and speech therapist. Perimedical help, finally, is provided by the dietician, the patient care worker or the nurse.

Guidance for parents is geared to providing information relevant to the child's problems, coming to terms with the child's disability emotionally (counselling), the

learning of skills pertaining to caring for the child, treatment, parent-child interaction and upbringing (parent instruction), and learning how to make use of the facilities available.

Guidance for families is aimed at the aggravating circumstances. These can be of both a material and an immaterial nature. Material assistance may consist of such matters as improvement of the housing conditions and the securing of adaptive equipment and providing for additional special needs. By immaterial assistance we mean, for example, general or specialized social work and all forms of home help.

Conditions and demands

Effective and efficient early intervention should fulfil a number of requirements. We will discuss these requirements based on the phases in the intervention process. A distinction is made between (1) conditions relating to identification and detection and (2) conditions relating to the process of diagnosis, training and guidance.

CONDITIONS RELATING TO IDENTIFICATION AND DETECTION

General

A programme to improve the identification attitude. This programme must target the improvement of professional skills and the enhancement of public awareness, especially that of parents and care-givers. Improvement of professional skills can be effected at the legislative and regulatory level, for instance the stipulation of appointment requirements or training requirements, and at the level of additional (in-service) training.

An adequate system of detection. The detection system must be grounded on a national policy plan. The national policy plan must be designed to enhance collaboration of the existing facilities, institutions and professional groups on a regional level and form a network for early detection of disabilities. Any gaps in the network must be filled.

Workable screening instruments like tests and observation methods. The tests need to be reliable and valid and standardized both for the native and non-native populations. The observation methods aimed at the behaviour of the child should include several strategies, such as event recording, time sampling, checklists and rating scales.

Specific

The specific conditions, aimed at the individual child and the parents, are that a conclusive and watertight system must be available for the longitudinal examination of all young children in the period before school is compulsory. This includes periodic medical examination, the execution of screening programmes and the follow up of children at risk. The medical examination involves anamnesis (aimed at, among other things, risk factors), observation and general check-up, evaluation of growth curves, an examination of congenital malformations and of psychomotor development, advising and registration. Examples of screening are PKU and CHT examination, an auditory examination along the lines of Ewing and the completion of the Denver Developmental Screening Test. Three categories of children at risk should be followed longitudinally: those with an established risk, those with an environmental risk, and those with a biological risk.

In addition, there must be procedures for swift referral. This involves close cooperation between institutions and professional groups engaged in identification and detection and the groups conducting diagnosis and treatment.

Conditions relating to diagnosis, training and guidance

General

Provisions must be available for early diagnosis and corresponding treatment. These provisions need to be within easy geographical reach, need to comply with the various demands made upon them, and need to have access to teams of sufficient professional expertise. Since the requirements of child and parents may differ greatly, a degree of variation in the mode of intervention is necessary: home help, ambulant help, all sorts of day care and intramural care, including admission to a general hospital or a specialised institute.

The financing of assessment, training and guidance must be regulated by law, so that financial considerations can never be an obstacle to securing adequate assistance.

Trained staff. The demands made of staff include the following: (1) they must have knowledge in normal and atypical development and understand how developmental processes in young children proceed and can be accounted for; (2) they must have experience in carrying out specific training programmes (like educational and therapeutic programmes); (3) they must be prepared to work with other professionals in teams; and (4) they must possess expertise in the guidance of parents (giving advice and instruction and counselling).

Curricula for the various target groups must be available. A curriculum functions in the first place as a guide for the person directly engaged in the treatment. It contains a systematic whole of objectives and concrete activities. Depending on the vision on how children learn and develop, a curriculum can be based on the milestones of normal development, the cognitive development theory and the applied behavioural analysis.

Parent participation. Parents should be involved as partners in decision-making concerning their child. For this it is essential that they receive the necessary information and skills.

Specific

For each child the intervention activities must always consist of three stages: the assessment of the child and the family, the construction of an individual plan of action, and the evaluation of the plan of action after a certain period of time:

Assessment is directed towards both the child and the family. The assessment of the child is a total evaluation of the unique developmental needs and strengths. The assessment of the family involves mapping out (1) the needs and the concerns of the parents, (2) the emotional strengths of the family, (3) family characteristics, and (4) critical events;

An individual plan of action for the child and the family must be drawn up as soon as possible and carried out following the results of the assessment;

Evaluation is carried out after a predetermined period of training the effects of the individual plan of action must be assessed. The data provided by this assessment constitute the necessary feedback for the revision of the individualized service plan.

Recommendations

General

(1) It is essential that children with developmental disabilities receive help at an early stage. This has an important preventive value for the child himself, for the parents and for

the family. At all times parents have the right to decide whether or not they will accept the help that is offered.

(2) It is therefore of great importance that in consequence to this preliminary EC Manifesto a more definitive Manifesto be drawn up for all Member States which lays down the minimum conditions to be satisfied by early intervention. This definitive Manifesto must also be based on the Convention of the Rights of the Child which was decreed in the General Assembly of the United Nations on 20 November 1989 and in which the rights of the parents are also stipulated.

Per member state

(3) It is desirable that the government of each Member State draw up its own policy plan for early intervention and put it into effect by means of legislative and regulatory measures.

(4) It is therefore also that each Member State provides the financial means required to carry out this policy plan.

(5) Early recognition of developmental disabilities requires an adequate system of detection.

(6) This system can only function efficiently if the facilities, professional organizations and individual practitioners co-operate and form a network at regional or local levels.

(7) Specific conditions for early recognition are: a programme aimed at stimulating and improving the attitude to early identification, adequate assessment strategies and techniques, procedures for swift referral and consultation possibilities.

(8) The diagnostic assessment must be aimed at the entire child in all his aspects, including his family and extended family.

(9) 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 the parents, the family and the broader network.

(10) Parents must be actively involved in all phases of the intervention process.

(11) The authorities must provide the financial resources needed for scientific research for the advancement and development of early intervention.

(12) It is advisable to make a study of the ethical aspects of early intervention in relation to the rights of the child, the parents and those who are professionally involved.

(13) There should be one single information and documentation centre for all EC countries so that knowledge, expertise and experience can be collected in and disseminated from one central point.

(14) A commission of experts must be appointed to further promote the interest of early intervention in all the Member States. This commission may also serve as think tank for the authorities.

(15) The harmonisation throughout the EC of training requirements for those engaged in early intervention is necessary.

(16) Possibilities must be created within an EC framework for the exchange of professional expertise.