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Early Childhood Intervention in Belgium (French Speaking Community): Family needs, standards and challenges

Abstract

The services are provided mainly at home. This situation seems to meet the needs of the parents as a recent survey shows. Accessibility to the services is quite good although some parents with a disabled baby report that they did not receive adequate information. ECI services in Belgium do not provide therapies or medical care. They act as a mediator to empower the families as a whole. The use of existing regular services in hospitals, in specific rehabilitation centres or delivered by private therapists is encouraged. Various challenges are presented. Among others, we wonder how the ECI services will be able in a next future to cope with the increasing demands. Further, for the parents, a balance is to be found between the need for appropriate support and the need to assimilate the elements of the situation, find some landmarks and become able to take their own decisions. The networking with various regular services is another important challenge. Finally we explore the question of training and the necessary links to be maintained between in-service training and research

Key words: Early intervention, policy, practice, Belgium, children, work with parents

Introduction

Belgium is generally considered as having quite a complex structure. There are three communities (Flemish, French and German speaking) that are responsible for Education. In the French Community, there are two regions: the Brussels Region and the Walloon Region. Regions are responsible for Social services (among them, the early childhood

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intervention services (=ECI) and also some vocational training. Each community and region has its own government (Ministers and Parliament).

Improved coordination can now be observed between regions and communities and some agreements are signed to facilitate cooperation. However, some parents are faced with different provisions from one region to another when they have to move. The following considerations refer mainly to the organization of the French Community of Belgium.

How do parents access the ECI system?

The majority of parents hear about the existence of ECI services through a pediatrician (for instance, in a neonatology service in hospital), a therapist, or a nurse from the Office for Birth and Child. The Office for Birth and Child (ONE) organizes pre and post-natal consultations. Further, when the parents return home after a stay in a maternity hospital, a social nurse is visiting the family, gives information to the parents if requested and presents the services the parents could need. The role of parent's associations is also important to consider when parents are searching for support. Generally, they will find the references on a website or by exchanging information with other parents. In some cases, family cohesion works as such that resources are identified by grandparents, siblings, etc. Furthermore, due to the development of antenatal fetal abnormality detection and diagnosis, ECI services could intervene before birth and support the parents in making decisions regarding the follow up of the pregnancy. Ethical aspects are of course a major issue in those cases.

Some parent's associations have trained parent volunteers to become "support-parents" who can visit the mother when she is still staying in the maternity hospital. Those support-parents have experienced the birth of a disabled child themselves. They intervene after the "official" announcement has been made by the pediatrician and share the parent's sorrow. Information regarding possible resources such as ECI services and parents associations are also given.

Parents report that they do not know exactly what the ECI service can offer and how it can be a support for their child. When they have first contact with the service, they generally receive relevant information through flyers and/or booklets. A recent survey (Flies, 2010) shows that parents that have no clear guidance on what they have to do, consider ECI service as mainly concerned with the disabled child and not focusing on the family as a whole. When asked, parents report that the ECI service will enlarge the possibilities for intervention and give useful information on the disability. The service will act as a referent and gather all the information from various professionals. It also represents the opportunity to share their experiences and questions. Parents are looking for very practical answers relating to daily life with their child. They also expect to learn how to react when facing the family circle and neighbors. ECI service is perceived as a mediator when the parents have to communicate with them. Of course, ECI service is also an important resource when parents are demoralized and need emotional support.

Time is an important issue to be considered. The fact of giving information to parents does not mean that they will use it immediately. The individual development of each parent and the necessity for time to “digest” information could lead to postponing the first effective contacts with the ECI service. In all cases, a clear request from the parents is needed for the ECI service to intervene. Very often the request relates to support in daily life and not therapy or reeducation. Parents want to know “what to do”, and they need information about the development of the disabled child. Professionals will also suggest considering the situation of the siblings, and provide information on available resources, persons or services.

How does the system of ECI address the needs of families with vulnerable children?

We have asked parents to outline how they perceive the intervention of an ECI service. The following are examples of answers:

“I take a hand (parents) that holds another hand (the service). It is a relationship. A link. The service will lead parents in a good direction.”

“The service is like the wind. The announcement of the disability is like big dark clouds. Thanks to the wind that blows on the dark clouds, we can see some sunny spell (the future: that’s a bit of a boost. Nobody is prepared to face disability and there are a lot of questions about the future. Now we are able to talk about the future. The question does not frighten us any longer [...])”

“Early intervention is like a support for education. It’s like a motor, a small motor that parents sometimes want to stop. It’s also a motor to push the child and show us how he/she will be in the coming future [...])”

“For us, ECI is like a present [...])”

ECI services have to be solicited explicitly by parents or representatives of the parents to intervene. A diagnosis has to be made in order to be eligible for ECI support. A medical report must be registered by the authorities in order to benefit from the ECI. As we can imagine, in some cases this requirement can represent a problem in the case of at-risk children. The label “developmental delay” or “suspicion of intellectual disability” is therefore used. Once approved by the authorities, there is no further re-evaluation except if the diagnosis is not precise enough.

The ECI service supports both the child and the family. The support consists of an active participation in following up the child and his/her family’s individual plan. Professionals have to respect the socio-cultural habits and beliefs of the parents. They have to promote the use of regular services as far as possible. Four main missions are devoted to those services:

- Individual support for the education of children with intellectual, neuro-motor or sensorial disabilities within the regular environment.

- Educational and social support for parents in order to empower them in coping with the daily difficulties related to the disability and ensures the best development for the child.
- Promotion of prevention and recognition of disabilities before, during and after the pregnancy and joined up working with any related initiatives.
- Development of collective action and a community-based approach, aiming to provide information and training for professionals and the general population.

The ECI service can achieve cumulative work with other services such as family placement services or centers for functional rehabilitation. The ECI team generally includes a psychologist, a social worker, a physiotherapist, a speech therapist, an occupational therapist and an educator. There is also a referent physician (usually a pediatrician).

It is important to note that the services cannot directly provide medical care or therapy. This specific activity is the responsibility of practitioners in hospitals or in rehabilitation centers or private therapists. As a consequence, ECI services have to work in terms of networks and very often play the role of mediator.

The ECI services operate from birth to the age of 8 yrs. As already mentioned the service also has to promote prevention before birth during pregnancy and can support parents when a fetal abnormality is discovered. The ways in which it works are as follows:

A bilateral contract is established with the parents and includes: the identity of the contracting parties; general objectives to be reached by the support of ECI; the establishment of an individualized support plan; date of the beginning and the end of the contract; information about the family's involvement in an evaluation process of the support provided by the service; the amount of the parent's contribution; the person or legal entity responsible for payment; ways of cancellation and address of the administration where to send a complaint.

An individual plan for the support is established within the first three months and has to mention at least the following items: information about the situation of the child and family; specifics regarding how to achieve the support tasks related to the expectations and identified needs of the family and child; the services that will be solicited; the nature and number of actual services to be delivered and finally the way of evaluating and updating the support process. This document is signed by the legal representative and is joined to the child's file.

Parents have the choice to accept or not to accept interventions at home. Most parents accept that professionals intervene at home even if they are able to come to the center themselves. Parents consider at-home intervention to allow them a better organization of daily life where they can stay busy with domestic tasks while benefiting from professional support. Parents can also care for their other children themselves without

having to call for a babysitter (Flies, 2010). In any case, when professionals make an intervention at home, the presence of at least one parent is required!

Generally parents will regularly receive written reports on those visits as well as on the achieved assessment sessions each semester. Parents are always asked if the reports can eventually be sent to other networking professionals.

Interventions take place once every fifteen days, or even once a week at the beginning. After this, the rhythm of the visits can decrease to once a month. Professionals of two or three different disciplines can alternate for those visits.

Assessment is always achieved using a multidisciplinary approach and the support given to the family is transdisciplinary. When visiting the family, any professional whatever his/her own discipline is, has to have a look at various aspects of the child's development as well as at the environmental factors that influence the development.

A financial contribution from the parents is asked for. The amount is about 80 Euros a year and calculated according to the number of effective interventions. It never exceeds 25 Euros a month (index-linked). Some additional contribution for specific activities can be asked for but parents have to agree explicitly to this.

Background to the system

The first ECI services were created in the early eighties and the first provision appeared in 1990. The more recent Act has been promulgated in 2004 by the Walloon Region. It has been created in collaboration with professionals and also concerns services for adults. In the Brussels Region, there are 5 services (for 1 million inhabitants) supporting young disabled children and their families. In the Walloon Region, there are 18 ECI services (for 3.5 million inhabitants). The organization of the services differs from one Region to the other (AWIPH; Arrêté du Gouvernement wallon; Portail de la Communauté française). In Brussels, some services are also dealing with children at school age and with adults. In the Walloon Region, the services for young children (0-8 years) are separated from the services for children at school age (6-18 years) and from the services for adults (up to 18 years). Each service is created and managed by a non-profit organization that gets a subsidy from the government. The service can find (and generally has to!) additional funds from other sources (private, charity...).

Legislation allows one ECI service within an area covering at least 8000 children under 8yrs. In reality, most services are dealing with a number of cases which is higher than the officially approved number by authorities. During the last decade no new services were created.

The service can be approved as multi-purpose or specialized. The multi-purpose services support children whatever the child's disability. The specialized services support children with one specific disability (for instance: Autism, Down Syndrome, Cerebral Palsy) and also provide information and training for every service that needs it. Those

specialized services contribute to research programs in the field of ECI. The service is approved by authorities for a period of 3 months to 3 years (and has to be renewed after that) and for a fixed amount of hours to support children and families.

The service has to create a plan describing the history of the service, the aims and objectives, the characteristics of the target population (disabilities, age,..), the geographical area covered by interventions, the amount of parental financial contribution, the practical organization of the service (how the work is organized, type and number of meetings, schedules, opening hours,..), the strategies used to communicate with the target population, the methodology used to assess the needs, the methods of interventions in various domains, how the service evaluates the quality of interventions regarding wider aims and regarding individual intervention plans, human resources and how training opportunities are provided.

Furthermore, every two years the service has to establish a plan for training related to the objectives, the global environment in which the service is implemented and the dynamics of the service's wider plan as well as to the current competencies of each staff member. Daily activities of the workers are written down in a diary.

The service gets an annual subsidy from the government for salaries (including a bonus for length of service) and functioning costs. It covers the equivalent of at least 2.5 full time staff (EFT). The specialized services for children with visual or hearing impairment get 0.5 EFT more. The service has to establish a team with at least one part time psychologist, social worker, therapist, and educator. The enrolment of administrative workers is limited. This subsidy is a basis to determine the theoretical amount of time units for support and the minimal number of individual files the center has to manage to be approved by authorities. Calculation of the final subsidy a center will receive is a very technical one.

The service is regularly inspected in relation on the one hand to the pedagogical activities (respect for the conditions of the agreement, effectiveness of the service plan, effectiveness of collaboration between workers, quality of interventions, existence of updating activities and in-service training,...) and on the other hand regarding the financial management (respect of rules in using subsidies). Inspectors can also act as advisors for the team.

Current evaluation of the system

As a matter of fact, the ECI services in Belgium have succeeded in approaching the child holistically in his/her family and in various life environments (nursery, school, leisure activities...). However, this way of functioning is time consuming and the means allocated to the services are not covered entirely by subsidies. Furthermore, the number of parents applying to benefit from ECI is increasing and the question arises over to what extent the services can take proper care of all the children and families. In some cases, registration on a waiting list is suggested, although it is evident that the lack of

adequate and “timely” intervention could represent a serious injury to the child’s development.

The accessibility of ECI services seems to be quite good. A lot of information is displayed through various means and channels. However, parents report quite constantly their difficulty in finding the adequate information quickly. Empirical observations reveal that there must be a correlation between the perception pediatricians has about a disabled child and his/her developmental capacities on the one hand and the involvement of those professionals in guiding parents towards ECI services on the other hand. Moreover, where the perception about the disabled child is a positive one: it is more likely that the professional will inform parents about actual possibilities for support.

As we know, the period following the announcement of a disability is a very chaotic one. Parents need time to cope with this unexpected and completely unknown situation, while professionals with a rational attitude prompt parents to engage themselves in “useful” interventions. For the parents, a balance must be found between the need for appropriate support and the need to assimilate the elements of the situation, find some landmarks and become able to take their own decisions. The philosophy and provisions of ECI services in Belgium are clearly oriented towards a support that leaves time for the parents. The aim is not to provide therapies immediately, but to help parents to mobilize existing resources in the nearby environment. This position, excluding pre-defined programs of intervention, raises a problem: the therapeutic interventions to be found in hospitals or by freelance workers are in some cases not sufficiently applicable and of good quality. The ECI service has no real ability to directly control those interventions.

Furthermore, networking with various services is another challenge. Many questions arise: which service can be considered as the preferable one for the parents? How should information be shared between the services (very often parents take responsibility for passing on the information to the various professionals)? Is there a possibility to control the coherence of the activities around the child and the family? How can an unproductive competition between the interveners be avoided? How can the transitions between the services at successive stages of the child’s development be managed? Many risks do exist, among others:

- Experiencing an illusory partnership without effective sharing of knowledge and co-construction of a plan, without the possibility for parents to adopt another way or take a contradictory position
- Prompting parents to consume more and more services, fostering a need to be a “good” parent who attempts to achieve the best for the child.
- Using up all the energy to manage the network to the detriment of the child’s and his/her family’s basic needs.

Evaluation of the quality of the service as well as professional networking also needs to improve. The work done by EURLYAID (www.eulyaid.net), which suggests the use of a scale exploring parental satisfaction, represents one aspect of quality measurement. However, some tools and methodologies have to be developed in order to ensure a

holistic approach to the service quality. We could imagine that a European panel of experts can help the services to achieve an evaluation as achieved by universities, secondary education, etc.

Finally, the question of training as well as the link between research/training has to be highlighted Professionals working in the field of early intervention generally have the following qualifications:

- Master's degree (5 years after secondary education): psychologists, some speech therapists, some physiotherapists; physicians (7 years and more)
- High School degree (3 years after Secondary Education): the majority of therapists (speech therapists, physiotherapists, occupational therapists, others), nurses, social workers, educators.

All those professional qualifications are not specific for the field of ECI. No specific/complementary requirements are necessary to get a job in the field of ECI. Furthermore, it has to be highlighted that in some ECI services, parents are members of the professional team.

There are a lot of opportunities for in-service training. In the Brussels Region, 1% of the total amounts of salaries are given to services in order to organize in-service training (those activities are either achieved by the service with a resource expert, or organized by schools, private associations or individual experts that bring together a small group of professionals for one or more session). In the Walloon Region, a specific budget is allocated to organize "tailor-made" training. Furthermore, some services are commissioned to inform and to train professionals from other services (for instance, in the fields of Down syndrome, Autism, Cerebral Palsy). Parent's associations also offer some specific modules for professionals.

To improve this situation, we could implement some specific training after the initial general bachelor/master's degree. This approach is difficult due to various issues: funding difficulties, poor recruitment (the French Community is a small one and registration fees are often a real obstacle), duration of training (usually only one year). We should probably improve existing programs in initial training to reinforce the content by focusing more explicitly on development and disabilities in infancy and by promoting cooperation between teachers of different disciplines or sub-disciplines. This way is probably more appropriate for training people to become able to cope with the large variety of problems encountered in the field of ECI. A certain degree of adaptability is indeed necessary. Furthermore, this way is likely to fit better with the promotion of an inclusive education. It supposes also that we reflect more widely on the organization of initial, complementary and in-service training in order to allow progressive advancing of knowledge and to allow possibilities for change and new career directions.

Finally, improved cooperation with researchers in the field of early development and learning would be profitable for both parties. It is important to conduct research work on

questions arising from the practice and we need to regularly give feedback from the research results to the practitioners. In the future it will be a real challenge to feed both research and practice mutually with respect for the families (no over solicitation)!

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