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Early intervention as a dynamic process

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Abstract
Early intervention programs in Russia have spanned a short 25-year history. Serving as active participants in the development of Early Intervention programs in various regions of Russia and post-soviet countries and training of professionals has provided us the ability to oversee the progress of the Early Intervention system. This article will go on to present the process through which Early Intervention services have been established and developed. Development of early intervention programs can be considered as a dynamic process, which on the one hand, changes the lives of the families of young children with disabilities, and on another hand, alters the system of support and concrete early intervention services. The development of an early intervention service as a new model of family support is also a dynamic process and these processes mutually influence one another. The article analyzes the process of development on the example of the core principles of early intervention such as: interdisciplinary teamwork, family centered approach, normalization of life, and principle of scientifically reasonable and evidence based practice. Ours observations show that adherence to the principles of early intervention allows for the development of professional teams, thereby providing improvement of quality of the support programs created for children and their families

Resumen
Los programas de la intervención temprana en Rusia solo tienen 25 años de historia. Servir como participantes activos en el desarrollo de programas de intervención temprana y en la formación de profesionales en varias regiones de Rusia y países postsoviéticos, nos ha brindado la oportunidad de supervisar el progreso del sistema de intervención temprana. Este artículo presentará el proceso a través del cual se han establecido y desarrollado los servicios de intervención temprana. El desarrollo de programas de intervención temprana puede considerarse como un proceso dinámico que, por un lado, cambia la vida de las familias que tienen niños pequeños con discapacidades y, por otro lado, altera el sistema de apoyo y los servicios concretos de intervención temprana. El desarrollo de un servicio de intervención temprana como un nuevo modelo de apoyo familiar también es un proceso dinámico y estos procesos se influyen mutuamente. El artículo analiza el proceso de desarrollo sobre el ejemplo de los principios básicos de intervención temprana, tales como: trabajo en equipo interdisciplinario, enfoque centrado en la familia, normalización de la vida y principio de práctica científicamente razonable y basada en evidencia. Nuestras observaciones muestran que el cumplimiento de los principios de intervención temprana permite el desarrollo de equipos profesionales, proporcionando así una mejora de la calidad de los programas de apoyo creados para los niños y sus familias

Keywords
Early intervention; Early Intervention services; Family; Support programs

Palabras clave
Intervención temprana; Servicios de intervención temprana; Familias; Programas de apoyo

1. Introduction

Early intervention programs in Russia have spanned a short 25-year history. Serving as active participants in the development of Early Intervention programs in various regions of Russia and the post-soviet countries has provided us the ability to oversee the progress of the Early Intervention system. This article will go on to present the process through which Early Intervention services have been established and developed.

The first early intervention programs were provided by the NGO St. Petersburg Early Intervention Institute and initiated the development of this field in Russia in the early 1990-es. (Alwal, 2008) At that time early intervention programs filled an empty niche as no programs existed for young children with disabilities. Children with disabilities could receive medical support, but those who stayed in their families were not provided with professional assistance. Most children with disabilities were placed into governmental institutions (Sundh, Kozhevnikova & Alwall, 2014). Those parents who kept their children had to cope with their personal grief and try to raise them the best they could. They had to play the role of a therapist for both themselves and their child. While Early Intervention programs were developing, defectological ("*correctional education*") organizations had already existed. However, these organizations only assisted in the rehabilitation and education of children older than 3-4 years of age. In this system the role of the professional who tried to "*correct the defects*" was primary and the role of the parents became secondary. It is also important to note that all children with disabilities were divided into two groups, "*educatable*" and "*non-educatable*", and the system of support was geared toward children with very mild disorders. On the other hand, "*non-educable*" children were placed in institutions where their basic needs were met. (Sundh, Kozhevnikova & Alwall, 2014).

Early intervention programs not only became the first programs for younger children, but the programs also aim to provide professional support to the entire family, because a young child is inseparable from his/her family. Presenting parents with direct support allows the family to keep a child with disabilities at home instead of placing him/her into an institution and also provides the child with an environment for optimal development and normalization of life (Kozhevnikova & Sundh, 2009).

Development of Early Intervention programs seems to be a dynamic process that works to change the functionality of the system, in this case to directly support families of young children with disabilities.

Practically from the start, development of Early Intervention programs in Russia was built on several basic principles that in fact define the core of early intervention programs and their characteristics. Among them are such principles which state that Early Intervention programs should be family centered; should provide services in natural environment by an interdisciplinary team; and should focus on the strengths of family and child, etc. (Guralnick, 1997). Compliance with these principles has shifted Early Intervention programs from a "*medical model*" to a "*medical-social model*" of rehabilitation, changing attitudes and methods that specialists use in the practice of Early Intervention programs.

It should also be noted that in practice, in the early stages of establishing an early intervention services none of them correspond with the principles mentioned above. It takes time and effort on the part of the specialists to achieve compliance regarding the principles of Early Intervention. Only during the gradual development of services do the principles become real characteristics of the program's activity. When initiating an early intervention program, the ultimate goal is to make sure these principles are observed.

Let's consider these principles in more detail.

2. Interdisciplinary teamwork

The interdisciplinary principle of early intervention services assumes that a cohesive team of specialists from various disciplines work together. This principle is very important because it allows for a holistic approach towards a child's development (Peterander, 2003).

It is considered that children with developmental disabilities have various needs (e.g. cognitive, language, motor, etc.) that are intricately interconnected. In order to provide the most optimum services for this population, it is necessary to develop a team of specialists including: doctors, teachers, psychologists, speech and physical therapists, etc.

In Russia the interdisciplinary approach is still one of the most problematic questions from an organizational point of view. Doctors, teachers, psychologists and speech therapists belong to different agencies such as health care, education or social protection services. None of these separate organizations have found a way to collaborate in an early intervention setting. For example, teachers cannot work in the health care system, because there are no such positions established in the medical organization and doctors cannot work within the system of social protection and education, because they can lose their medical status. There are few organizations such as non-governmental entities that include an interdisciplinary team of specialists; however, these organizations lack financial support. Luckily early intervention programs got recognition at the governmental level during the last year that hopefully can solve this problem at the legislative level.

However even if we assume that a team of specialist works in the same center it does not mean that they automatically provide collaborative services (i.e. become an interdisciplinary team). Quite often specialists declare "*we work as a team*", but in practice this statement means that different specialists work in one center, but each of them only carries out their narrow scope of practice. First off, an interdisciplinary approach demands a high level of interaction among specialists. An interdisciplinary approach means that each specialist is an expert in his/her professional field, but they unite their knowledge in order to achieve a common goal. This means that they should first, put these tasks together, and then define actions that are necessary to achieve these goals next allocate the roles to carry out these actions, and lastly, fulfill these actions in coordination with one another.

It is difficult to imagine that such a diverse group of professionals of different ages, having professional knowledge in various fields, a variety of experiences and different ideologies will come together to work as one team. To become a real team, this group of professionals needs time, daily hands on experience with children and families and the strong desire to collaborate as a team. A team becomes a real team in a result of permanent development and interaction. There are several factors that influence this process, and a team of professionals does not always succeed in achieving consistent goals. On the one hand, the dynamic processes, characteristic for development of any small group, play a role. On the other hand, it is very important that a team is created not only with the simple aim to unite the specialists, but with the goal to satisfy the needs of the child with disabilities and his/her family most effectively, giving them full support.

Our experience in observing the development of teamwork in early intervention services shows, that in the beginning it is difficult for specialists to work together as they may disrupt each other rather than feel the need for mutual support. Only successful interactions gradually give the specialists an understanding of the importance and efficiency of collaboration.

The development of an interdisciplinary approach requires the observance of several conditions which promote the formation of a team. First, it is important for the therapists to engage in a maximum amount of collaborative therapy and allocate time to group discussions/meetings. It is important for specialists not only to carry out the treatment together, but also to present their clinical cases, to discuss the complexities and successes, and to exchange professional knowledge between team members. Joint educational activities are the second condition. Participation in the same seminars and other educational events lets specialists form common

ideologies and terminology, to gain novel knowledge about approaches and methods, which are used in adjacent specialties. The third important factor is to create possibilities for open communication among other early intervention professional across the field. The professional supervisions can be a very useful and effective tool. Usually supervisions are provided by external professionals who help a team solve problems that may arise in their clinical practice. Developing early intervention programs in St. Petersburg, we created a new model of supervision. Early intervention departments were opened in several pediatric policlinics in the city. Therefore, several teams received educational courses at the Institute, together. The main questions arose after the course ended, when specialists in newly opened centers started their practical work. We got the idea to organize regular supervisions for all these Early Intervention teams to serve as continued practical education. Several teams come together to attend the supervision, where one team presented their practical case that was then discussed among the professionals from other centers. Every team received the chance to present their most complicated case as well as their most successful one. Specialists from the Institute provided advice and shared some additional knowledge where necessary. This form of education and interaction between specialists became very popular among practitioners and still is very highly demanded.

Thus, development of a team of professionals is a process which is necessary for ensuring the principle of interdisciplinary work.

3. Family centered programs

Family centered programs are another basic principle of early intervention and can be looked at in two ways. On the one hand, this principle tells us that the focus of early intervention programs is the child in the context of his/her family. The main task of professionals is to support parents or caregivers in order to promote the child's development. In the absence of timely professional support to parents and other family members may lead to situations where the family refuses their child and places them in an institution. Quite often assistance must first begin with the support of the child's family as they have the most stress and often feel shocked after receiving their child's diagnoses from the doctor. Development of a young child depends on his/her environment in a critical way. This is why the psychological condition of a child's parent, their ability to promote a thriving environment and good care is so important for the optimal development and wellbeing of the child.

From another side, this principle means a change of roles for parents that seek support programs for their child. In the medical (defectological) model, parents are passive members and their role is limited to delivering their child to a specialist. But in early intervention programs, the parents have an equal partnership and are a part of the interdisciplinary team. That means that parents contribute to the assessment process of their child, in the creation of an intervention program, as well as in the progress of the goals and treatment plan in place. This should not be a surprise that parents are often experts in their child's development. Further, this principle also means that parents' opinions and needs should be respected when designating intervention goals.

Two important questions arise when building an early intervention program that should be considered: 1) Are parents prepared to engage in an equal relationship with that of the interventionist team; 2) Do specialists always answer parents' questions and requests about their child. In responding to these concerns sincerely, the answer may not always be positive for various reasons.

First, as mentioned above, intervention must take place as early as possible, for instance where a child's symptoms or diagnosis conclusively establish that treatment is necessary. Often after receiving their child's diagnosis parents feel devastated and need personal support first of all. In the early stages of grief, they are not prepared to accept their child's diagnosis and are therefore not ready to take on the partnership role with the interventionists. Parents need professional support, as well as psychological and informational assistance, but often cannot

formulate their request for help to their child as they don't understand the specific needs of their child.

In other instances, a child's developmental problems might be influenced by the parents. There are various examples of such instances socially disadvantaged parents neglecting the needs of their child; parents with mental health problems; parents who have overestimate demands to their child's developmental abilities; or simply for lack of understanding child's basic needs. Such families might not approach a specialist with specific requests, or the requests may not be realistic regarding their child's needs. In such cases, therapists are inclined to implement specific therapy treatment with parents or to train them to implement a specific treatment, rather than involve them as partners in the care of their child.

Does it mean that this principle is inappropriate? No, this just means that in the beginning not every parent can become a partner but one of the goals of early intervention is to eventually include the parents in all aspects of their child's therapy and development to make them a partner. This can only be achieved if the specialists are socially and culturally sensitive toward the parents.

A family's request for services is a very important aspect that should be mentioned. Parent's request, as a rule, reflects their ideas about the overall social and health care system. Quite often parents formulate the request for help due to their knowledge of how the support system functions opposed to the understanding of the child's direct needs. They say, "*we need a speech therapist, massage and psychologist*" and they know they can receive these services, but they don't understand what concrete needs their child has. Families became accustomed to being passive consumers of services and only choose experts they trust or that have been "*prescribed*" to them. The active role that early intervention places on parents is new and unclear. Some parents are not ready to accept this responsibility, believing that only specialists can do something for their child, and that it is better not to disturb his/her work.

Implementation the principle of family-centered programs requires both the parents and the specialists to change their mentality. Some early intervention services specifically treat this principle as "*work with parents*". Often, we observe that early intervention services for the child and parent are provided simultaneously (e.g. parents can take educational seminars while their child is receiving therapy) as opposed to having the parent in the therapy session with their child. In fact, it is the same correctional model: the expert trains the child without allowing the parent to participate in the process and organizes lectures and seminars to educate them. Parent education in itself is certainly an important element of early intervention programs; however, it shouldn't exclude the parent direct participation in their child's sessions. A therapy structure, when the specialist works, and the parent observes from the outside does not respect the early intervention principle. A parent can only be an equal participant of the therapy process only if the specialist is ready to accept this collaborative role. Inclusion of parents as equal partners is a mutual process.

Early intervention program for a concrete family itself is a dynamic process, the implementation of which leads to qualitative changes. On the one hand, the small child grows quickly, his skills and needs change and this demands regular modification of the goals and intervention methods. The early intervention program must react sensitively to the changing needs of the child in order to promote maximum development and to cope with arising difficulties. Dynamic processes also lead to quality changes that happen in a family as a result of the early intervention program. Parents also change as they become more competent in understanding their child and his/her special needs, and they cope with the parental functions more assertively. They learn how to interact with their child and have a better understanding of the methods used to support their child's learning and development. The successful program of early intervention helps to normalize family life. There is also a change in the parents' social status. Parents transition from being passive recipients of treatment to the role of advocates for the rights of their children and, therefore, begin to change the treatment process as a whole.

In order to achieve this goal, specialists need to see the parents as equal partners by learning to respect their opinion and point of view, not to accuse them, but rather to support and empathize with them. The best approach to reaching the parents is to understand that they are an integral part of a young child's life and that only through them it is possible to influence child development in an optimal way. Within the early intervention program specialists and parents must find a model for mutual interaction between themselves and the child and develop a strategy that will help carry out this program.

3.1. Principle of normalization of life

The principle of normalization of life in fact is the principle which led to the transition from the medical (biological) model to the medico-social model. Only recently we have used the term "*social model*" to describe early intervention programs. Many specialists use the social model opposed to the medical model, which rejects medical components of the rehabilitation programs, including early intervention. Many psychological-pedagogical early intervention services were opened (in Russia they are usually referred to as early support programs), which do not include doctors in a team and consequently, the medical aspects are not part of the treatment. It is rather difficult for us now to imagine the high-grade early intervention program without physical therapists or developmental pediatricians, because many questions concerning the development of children with disabilities can only be solved in close cooperation with doctors. This situation might be explained by the organizational difficulties as mentioned above but also by misuses of the meaning of the term "*social model*". Therefore, we prefer to use the term "*medico-social model*" concerning programs of early intervention.

Revisiting the principle of normalization of life, it should be noted that early intervention programs (as well as in rehabilitation programs) allow the focus to shift from separate disorders (defects) and attempts to correct them, to more global concepts, such as the wellbeing of the child and their family and their quality of life. For example, when treatment is conducted in a disconnected manner, a family's life may turn into an infinite train of visits to numerous specialists. A child may receive a huge number of services aimed at treatment, education and training of different skills, but he/she loses the – opportunity to live a normal life: to communicate with close people and peers, to play and to enjoy life. There is a certain polemic concerning the concept of a "*normal life*", however the concept "*normalization of life*" is rather unambiguously perceived as a process and the result should be that family life with a child with disabilities be approached the same as family life with a typically developing child. At the same time this means providing the child with disabilities the opportunity to have a life typical for peers without disabilities.

From the point of view of dynamic processes, observance of the principle of normalization demands the change in its approach by setting intervention goals. The aims and tasks must be based not only on the developmental level of the child in specific areas, but also on the needs of the child and his/her family from the point of view of such aspects as: psychological climate, maintenance of daily routines and the participation of both family and child in social and cultural aspects of life.

When beginning to work with young children many specialists use step-by-step guidelines and curriculums based on the sequence of skills that should be developed in various areas. Such curriculums (as the Portage program, Carolina curriculum, etc.) allow for the assessment of skills as well as define the zone of proximal development proceeding from the typical sequence of the development of skills. In our practice we also use the KID and RCDI scales. These scales allow us to assess a child's developmental level in each area and create appropriate goals based on the results of the assessment. However, this approach is not appropriate for all children including those with multiple disabilities or progressive genetic diseases. Specialists have to think how to estimate the efficiency of Early Intervention programs in a case, when a child makes little or no developmental progress. In such cases the issues of improving a child's quality of life and his/her environment come to the forefront.

Following the principle of "*normalization of life*" a transition was made from training of separate motor and speech skills to the development of functional movements and alternative and augmentative communication. More attention was given to the development of integrative groups and parental clubs and the cultural and social lives of families of children with disabilities. It doesn't mean that programs began to have purely social character, but it forced specialists to reflect directly on the family's and the child's needs.

3.2. Principle of scientifically reasonable and evidence-based practice

The principles of scientific character and evidence-based practice in early intervention are in many respects similar to scientifically reasonable approaches in evidence-based medicine. Evidence based practice in medicine is defined as the integration of an individual clinical experience with the best available external clinical proof based on regular research. Scientifically reasonable practice of early intervention must build on integration of modern research and scientifically reasonable methods by taking into account the expert opinion of specialists and families.

At first glance, people tend to look at early intervention programs and often expect to see unique equipment and modern high technologies as proof of scientific character of this area. Many parents note with surprise that "*specialists simply play with the child*" during sessions, but parents really see results and the changes happening to their child. Importance of early experiences, development of attachment and interaction, education and training in a natural environment and many other theories all confirm and are supported by research and underlie programs of early intervention as well as provide efficiency of these programs.

In their clinical practice beginning specialists are first guided by experience already available in the field, results from research and, best practice described by other professionals in the field. For practitioners who provide early intervention programs it is important to know that their professional activity is safe and effective. The choice of methods must meet these requirements whether specialists choose methods and techniques already developed and described by someone in the field or use the integrated knowledge and development of their own methods of work.

Assessment of the efficiency of programs must be the integral element of early intervention programs. But only having a certain amount of experience, specialists start reflecting on the assessment of their personal efficiency, what results they managed to achieve, whether the program was effective and so on. Efficiency can be calculated from different positions, but the opinion of direct recipients of services undoubtedly is one of the most important aspects.

In the beginning specialists are afraid to ask questions about their own efficiency. Some specialists consider that their professional activity cannot be evaluated by the parents of children receiving services because they do not possess the appropriate knowledge to make such judgments. Others are simply afraid to hear that they need to improve upon certain areas of their therapy skills as they are not yet confident in their own work. Only after getting some experience specialists start to understand that parent's opinions about the program can be invaluable. When some years ago we started to conduct focus-groups for parents we were surprised to find how accurately parents recollected what occurs during the program and how kindly and positively a dialogue between specialists and parents can be regarding necessary changes that can be put into place to make the program better.

The scientific approach and evidence-based practice has changed the role of specialists/practitioners. Their role in many respects becomes similar to that of researchers who, upon assessment define a hypothesis and during implementation of intervention regularly record what they observe. In addition to conducting research on an initial assessment of the program, monitoring changes, achieving results, documenting results and recording methods of efficiency are targeted. Understanding of importance for specialists to be aware of their efficiency can be achieved through experience working in early intervention programs. As aforementioned, in order to create an effective program of intervention – many aspects should

be considered. In practice, early intervention specialists face higher (or supervising) organizations that look at services unilaterally and do not use the adequate indicators for assessments. For example, the authority often defines early intervention programs as programs that help prevent disabilities in children, many such services are required to quantify their reports of how much of the "*disability was removed*" as a result of their therapeutic work. In other cases, to prove effectiveness a service must report that they included a specific percentage of their district's population of children. Thus, there is a need for specialists to develop methods which could help to estimate the efficiency of programs they provide more adequately.

In conclusion, we have discussed that the development of early intervention programs is a dynamic process, which on the one hand, changes the lives of the families of children with disabilities, and on another hand, alters the system of support and concrete early intervention service. The development of an early intervention service as a new model of support is also a dynamic process and these processes mutually influence one another. Adherence to the principles of early intervention allows for the development of professional teams, thereby providing improvement of quality of the support programs created for children and their families.

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