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## Personalized Social Services Provided to Children Living with Disabilities: A Case Study in the North-West Region of Romania

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### Abstract

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This paper is discussing the effectiveness and efficiency of current institutional settings and practices concerning the assistance of children living with disabilities in Romania, with a specific focus on North-West Region. The main aim of the paper is to investigate the potential ways for optimizing child protection services. The research is based on a case study and semi-structured interviews with specialists involved in local social services. The case study included in our work is concerning the way in which the actors of public child protection system service work in close cooperation with each other and implement together personalized intervention strategies, grounded on specific individual needs oriented combinations of legal protection, socio-medical, school orientation and special educational services. The paper concludes that in order to be successful, the public social service system should provide personalized services and propose to each child individualized paths of development, based on professional relations and partnerships between medical, social, legal protection and educational services.

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**Keywords:** Social inclusion; children with disabilities; personalized social services; public service providers; Romania; North-West Region.



## **1. Introduction**

The social inclusion of persons with disabilities is a complex, multifaceted process influenced by several factors. One major factor is the society's development level, the way how society relates to the persons with disabilities. Research from different countries proves that the social and family-related environment exercise the most important influences on the school-related performances, being then reflected in the income levels. In fact, the influences from the inside (the cooperating conditions, the quality of the teacher-scholar interaction, the classes preparation) and from the outside of the school are decisive in the matter of social inequalities (Giddens, 2008).

At international and European level it is recognized that the disability issue should be addressed through the prism of human rights. The European Union approach to disability is based on the "social model", to ensure the rights of all persons to participate in social life equally and fully. The social pattern is promoted by the European Union, and it emphasizes the social environment that is not adapted to the people with disabilities' needs, from which result the difficulties that these people confront. As a result, the social pattern doesn't perceive disability as an individual problem, but as a social fact, generated by politics, practice, attitudes and the environment" (CNDR, 2013). „The social pattern emphasizes the way how some inadequate characteristics of the social and physical environment determine compulsions on a category of persons.” (Manea, 2006: 42).

The family represents for the child the primary environment in which he/she develops, going through the required stages of preparation for independent living. The presence of a child with disability in the family can lead to the emergence of changes in the relationships within the family, could violate its internal and external balance, potentially generating a crisis (Gherguț, 2007: 318). After 1989, in Romania fundamental changes occurred to improve the lives of children with disabilities, the intervention of NGOs with support of international organizations having a major role.

In 1998, the Department for Child Protection (DPC) launched the Government Strategy on children in need, which directed reform towards de-institutionalization and the creation of alternative services, including foster care, group homes, day centers, counseling centers, specialized centers for children with disabilities and others. In 1999, DPC was reorganized into the National Agency for Child Protection (ANPDC), and started the process of closing down large, old style institutions. In 2004, Law no. 272 was adopted, updated in 2014, on the protection and promotion of child rights, which comply closely with the Convention on the Rights of the Child and expands the scope of protection of children in difficulty to child rights protection. Among other things, the enactment prohibits placing in institutions the child under the age of three, except for children with severe disabilities "with care addiction in specialized residential services." Article 46 refers to children with disabilities "who have the right to education, rehabilitation, compensation and integration, adapted to their own opportunities, to develop their personality" actually representing the transposition of Article 23 of the Convention (Law 272/2004).

## **2. Research aims and methodology**

This paper focuses on the study of legal regulations and current institutional framework promoting social and educational inclusion of children with disabilities in Romania. The main aim is to investigate the ways to optimize services for the protection of children with disabilities. We proposed to obtain a closer picture on how the actors of public child protection system service work, what links of cooperation they establish and to what extent are the concerned institutions able to devise and implement personalized intervention strategies based on the individual situation and needs of the assisted children.

Our research is based on a qualitative type methodology. We provide a case study of a girl, born with multiple deficiencies, neglected by the family and abandoned in the hospital, who is now protected by DGASPC Bihor, and achieved significant progress in her medical condition and personal development. In addition, we conducted semi-structured interviews with specialists involved in local social services (local community social worker, the case manager, the reference person of the child) being involved in a direct support bond in order to take the most adequate measures regarding the superior interest of the child. The data collection was made in December 2015.

## **3. Public social services destined to children with disabilities in Bihor county**

According to the SWOT analysis of the NGO sector involved in providing social services (\*\*\*, 2009: 18) may be mentioned as positive factors that Bihor County is among the top 10 counties in which associations and foundations demonstrated quality in providing social services. There is a large number of partnerships between the public and nongovernmental sector, as well as between social, educational and health care institutions belonging to the public service system. As a negative factor, we can mention that there are only a few service providers in the rural areas.

Within the Directorate General of Social Assistance and Child Protection (DGASPC) Bihor there is an Complex Evaluation Service of Children (SECC), which carries out the assessment of children with disabilities. Residential type child care services for children with disabilities have the general task of providing access to housing, care, rehabilitation, education and preparation for reintegration or family integration and social inclusion with that family (order No. 27 of 2004 on mandatory minimum standards for child protection services for residential children with disabilities). In the period 01.01.2015 - 31.12.2015 the Complex Evaluation Service of Children has investigated a number of 1300 cases. They performed 1316 assessments for 16 children because some parents / legal representatives have requested to re-evaluate their children twice during 2015. All children who were enrolled in a degree of disability benefit from specific therapies included in the recovery plan of children with disabilities, through individualized plan of protection.

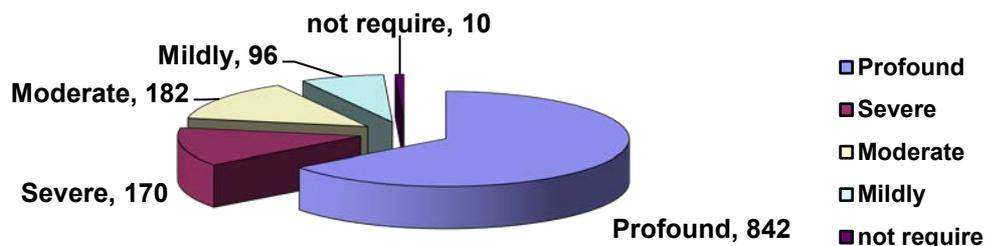


Fig . 1. Distribution of cases according to the degree of disability for 2015 *Source: DGASPC Bihor*).

#### 4. Information regarding the family structure

The child, S.N.D. was born in 11.06.2010 in Oradea, North-West Region and comes from a married couple, S.D. aged 28 and S.F. aged 27. Their residence is in Budureasa region, but now the mother is not there, she has left with the elder son to another man's residence.

Regarding the personality, the mental and physical state of the child, according to the medical certificate, she is in evidence with medium retard, behavioral disorders, IQ 45, trunk multiple afterburner scars. Two years ago, at the taking of measures of protection, it was noted cortical atrophy, according to the C.T. exam conducted in 11.04.2013. During the neurological consult there was also observed global development disorder. The child was staring at the objects but she was not following them with her sight, right stiff neck and divergent strabismus affecting both eyes were diagnosed. She was able to sit but she was not able to walk, she couldn't maintain her orthostatism, she was not communicative. It was also noticed muscular hypertonicity, especially in her legs (spasticity).

#### 5. Socio-medical and educational history

S.N.D. was prematurely born at 30/31 weeks, with an Apgar score of 5/6, she is the third child of the family. She experienced a difficult adapt to the life outside the womb. She experienced several diseases in her early childhood: pharyngitis, tracheobronchitis, HSP, deficient anemia, rickets, acute gastroenteritis, interstitial pneumonia, nappy, reactive thrombocytosis.

In 08.02.2013, S.N.D. suffered an accident due to lack of observation of a grown-up. Her father was out, collecting scrap. The mother left the two children, S.A. aged 7 and S.N.D. aged 3 unobserved in the house for several hours, leaving to Beiuş in order to get their children allocations. According to her, she had asked her mother-in-law to check the children from time to time. The dwelling, built from wooden boards and lathings caught fire, and the elder brother, S.A. aged 7, who was suspected to fire the house has evacuated himself, but S.N.D. was stuck inside, being rescued by a neighbor only when the house was all on fire, and she was having burns on over 50% of her body, affecting especially her inferior part of the body.

The child was taken by SMURD on aerial way, she needed to be intubated and ventilated, she was taken to the hospital, where there were noticed burns on over 50% of her body. Lately it was proved that S.N.D. had been massively infested with roundworms, found in her faeces, due to lack of hygiene. It is noticed the fact that S.N.D. has multiple 3<sup>rd</sup> grade afterburn scars on her face, on both her hands, on both her buttocks, on both her legs, superior respiratory tract burns, afterburner shock, global

development disorder, divergent strabismus and right side stiff neck. Her right leg phalanges and her left leg big phalange are retroverted, which in combination with other afterburning damages of her locomotor system make the walking difficult in her case. The child is ambitious, she walks, but she uses one of her legs as a support prosthesis.

After the accident from 08.02.2013, the child was nursed at the Clinical Emergency Hospital Grigore Alexandrescu. Her mother was hospitalized with the child, but she tried to leave the hospital several times. Finally, on 03.03.2013 she abandoned her child in the hospital in Bucharest, due to her husband's insinuations, affirming that she was not granted her food. Lately, the family requested for the child to be discharged from the hospital, but they haven't fulfilled her caring needs. The medical recommendations on the discharge paper were: massage, elastic strips appliance, physical therapy, but the family didn't do any of these. (In the discharge paper, at the C.T. section is noticed: brain atrophy aspect, and at the clinical exam section: she doesn't walk, follow with her sight, stand, or maintain her right position, muscular hypertonicity, she doesn't talk, and she doesn't communicate).

Since 18.06.2013, she has benefited from CPCD services in Oradea, as a result of the emergency placement. After the institutionalization, the child had a good evolution, she started to talk, to maintain her position and to walk. She was diagnosed with epilepsy (crisis being confirmed in June, 2015), usually being unleashed during an acute disorder. It was observed that in the case of acute disorder episodes, the patient quickly develops fever over 39 degrees, not responding to medication, a fact that made difficult in her case a surgery of reparatory reconstruction of her hands and legs.

Recently, the child succeeded the sitting, maintaining her position and she walks independently on short distances, in spaces where she has support, being predictable. The afterburning scars and the damages suffered are also visible. (S.N.D. walks like a pirate with a wooden leg, using one leg, the other being used just for support and rotation). She communicates using sentence-meaning words and sometimes she also formulates short sentences. In the sentences in which she refers to herself she never uses the pronoun. She quickly gets affective contact with the people from her ambient. She has preferences among persons, activities and objects.

She is a child with a strong willing, fighting for what she wants, a fact that helps her to progress even when it seems impossible. She often gets into physical conflicts even with elder children if she wants a certain toy and she doesn't back off in order to get it. She expresses her wishes and she is able to communicate her needs minimally. She has mendacity tend, making up dramatic or traumatic situations in which she affirms she was a part. She eats with difficulty, relatively clean, because of her after-burn affected hands, even if her manual function is good and she doesn't accept the helping. Her alimentation is varied, including solid food.

After the placement from 18.06.2013 at CPCD Oradea the scholar orientation was requested to the Local Centre of Resources and Educational Assistance Bihor, at the Service of Evaluation, Educational and Professional Orientation Bihor, and this institution disposed the child's orientation to special education, getting educational services and recovery therapies at the Education Centre for Inclusive Education "Cristal".

## **6. The Living and Raising Conditions of the Child**

The child grew up in her family for the first 3 years of her life. Her parents are one of the poorest families in the region. Their house is a poor wooden shelter. The parents come from a precarious cultural and socioeconomic environment, they have no education and no job. They had lost another child due to lack of observation, by drowning at the age of 5. After discharging from the hospital the family was suspected not only for lack of observation, but also for exploiting her to beg with the help of one of the child's grandmothers.

As a result of this complex of situations, in the conditions in which the mother has left her residence according to a family habit, and the father denied to adopt any protection measures, the child was taken out of the family through the emergency placement measure, through a presidential ordinance of the Bihor Court. After that, the same institution, The Bihor Court, through a civil judgment decided the change of the measure to placement in the CPCD (Placement Centre for Children with Disabilities) Oradea. Through the same judgment it is disposed that the legal parental rights of the child are delegated to the DGASPC Bihor.

In the natural family of the child there are no adequate conditions for growing, education, rehabilitation or reintegration of the child. Regarding the economic situation, they work occasionally, living by the child's grant. The family interest for their children is doubted, simply because they named three of their boys Adi and two of the girls Daniela, using the same surnames. Regarding the fact that the younger brothers of S.N.D. were prematurely born, and the reality that the family hadn't proved to have the capacity to raise them, to protect them and their rights, it was disposed the adopting of a special measure of protection.

The parents requested in writing the reintegration of S.N.D. in the family, especially the father. They have asked for telephonic conferences, but they were only once effectively present to this event. There was a trial for mistreatment.

## **7. Community Network in Assisting the Family**

On the basis of our interviewees declarations done by the social services (local social referent, Foundation's social worker) we can summarize the case management steps from the first encounter with the family to present times: while monitoring the child's development it was observed that the child was neglected by the parents following the childbirth. As the parents did not present themselves at the first medical control, medical assistance had been given to the family and nurse visited the family, and observing the living conditions and parental neglect of the child. Following this the nurse had started working with local social workers to supervise the family and child's healthy growth and to improve the situation. Family had a good relationship with the Pentecostal Church community who helped the parents with casual jobs opportunities that in many cases were refused by the family. Moreover more cases of negligence by parents against their children were reported by the neighbors. A local foundation got in touch with the family (and with the families in the community) and was helped by giving relief consisting of food, clothing, school supplies. The foundation's attention was drawn by a local social worker: "The case came to my attention in 2010-2011. I was employed at the foundation.

The problem of neglect S.N.D. It was found during the visits made by health professionals and asked for their support of our foundation, being a social issue."(Foundation's social worker)

The Foundation was in contact with a family in Belgium who sent relief for the family every third month. On a visit Belgians met the family, they helped and developed a close preoccupation concerning the situation of the child. After the accident, during hospitalization of the child to the Emergency Hospital Grigore Alexandrescu (02/08/2013 – 04/11/2013) the Belgian family offered their help and treatment abroad for the child, but the mother did not accept this. Lately, between the family and the child has developed a strong attachment consisting of visiting the child NDS in the center for disabled children and even the idea of taking in foster care the child has been suggested, or if international adoption will be possible by changing legal regulations, the family offered to adopt and raise the child in Belgium.

## **8. Conclusions**

The study of this case shows that the main problems with the assisted child occurred due to parental neglect, mistreatment and lack of early diagnostics of disability. Today it is clear, however, that after institutionalization the health of the child improved due to the existence of professional relations and partnerships between medical, social, legal protection and educational services. This fact denotes that in order to be successful, the social service system should provide personalized services and individualized development, based on complex professional relations and partnerships, with four pillars: there is effective, open, collaborative and learning communication; the roles of all the "actors" are quite specific and well defined; there is a relationship of trust between all stakeholders; there is a "leadership team" led by a case manager, the social worker who makes decisions and assumes the responsibility.

To achieve a more efficient cooperation, especially in dealing with complex socio-medical cases such as shown in this study, coagulated and functional partnerships of all social actors involved at local and regional level are needed, in order to enable the implementation of specific needs oriented combinations of legal protection, socio-medical, school orientation and special educational services in the case of each assisted child. In this regard, Social Assistance Law no. 292 / 2011 mentions the possibility of organizing social services in integrated system, next to the fields of employment, health and education (Law of Social Assistance 292/2011). Taking advantage of these regulations, local councils and regional councils should intervene by providing assistance and support to parents and by promoting the development of diversified, accessible and quality services.

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