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How services for children with disabilities in Serbia affect the quality of life of their families[☆]



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ABSTRACT

Background: Families that have children with disabilities face numerous difficulties related to the lack of services support, social isolation and poverty in Serbia. Mostly due to the prolonged effect of social and economic crisis, there are insufficient adequate and diverse community-based services for those families.

Aims: The aim of the study was to examine the effect of newly introduced services on the quality of families' life.

Methods: A pretest/posttest study was conducted at the beginning of service and one year later to evaluate the effect of services measured by Family Quality of Life Scale (Hoffman et al., 2006). The sample consists of 153 families of children with disabilities from 35 different places in Serbia.

Results: The results show that the services generally improved the families' quality of life, particularly in the aspects targeted by services, but also had significant positive effect on family interaction and parenting. The services had the highest impact on the families that perceived the lowest life quality before using them. The life quality was improved, regardless of the type of services, but the effectiveness is affected by the severity of child disability.

Implications: The results might be useful for further steps in developing and evaluating individually and flexible tailored service that support families' needs and suits them the best.

What this paper adds?

- Knowledge about reforms of social protection and services for children with disabilities and their families in Serbia
- Contribution to evaluation of newly introduced services which have not been common practice in Serbia and accommodating services based on study results
- Stress the importance of family-centered services to help parents to provide the best support for their children
- Using and checking new instrument for measuring family life quality in Serbia

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1. Introduction

Serbia has implemented a series of important reforms in the area of social welfare since 2002, as a part of the European Union accession process. The main course of reforms in the area of child protection has included the development of mechanisms to protect children from abuse, neglect and exploitation, as well as the development of a range of community-based services for supporting families as the primary environment for child development. As a part of the child protection reform and deinstitutionalization, the development of services for children with disabilities and their families was supported by the project *Developing Community Based Services for Children with Disabilities and their Families* implemented by UNICEF in partnership with the Ministry of Labour, Employment and Social Policy in forty-one underdeveloped municipalities in Serbia.

Before the new services were implemented, children with severe difficulties were placed in institutions very often or the family would have to organize and provide childcare with or without help of extended family members. It was difficult to find qualified persons for childcare or it was too expensive for most of these families. That is the reason why mothers often stay at home to take care of their child and leave their work. Increased expenses for childcare and decreased income because one or even both parents are unemployed, have been keeping those families in poverty. There were some daycare centers, but only in several larger cities in Serbia.

Despite the legislation that supports children with disabilities to be enrolled into public schools, there was a lot of resistance to that processes either from teachers or even parents, because they were not trained or prepared for adopting the changes.

New services included daycare centers, “respite” care and assistance at home. All services were intended to support the children to remain within the family environment and to promote their inclusion in the local community. Children have been provided with a stimulating and constructive experience that should be based on individual planning with the case manager and service provider, whether at home or outside, in daycare centers. Although the purpose of these services is the same, they differ by the activities they involve. They generally included direct work with the child, such as the development of skills for everyday life, social skills, speech and motor skills, support for rehabilitation and creative expression. Daycare centers are available every day, except weekends, usually 8 h. Group of children spend time in different games or other activities. Home assistance is provided at home and consists of activities that are focus on child. During the time that assistant spends with child, which means 2–4 h usually 2 days per week, parents have time for other duties and activities in home or outside. That is significant help for them, but it does not include structured parent training focused to parents’ skills, strengthening their coping capacities or their relation with child. Even these services have been focused primarily at children needs, parents could benefit, too, like getting some additional information or useful advice and support for everyday care.

2. Background

Families of children with disabilities are exposed to challenges of extended, sometimes lifelong, care, but they could also be the subject of discrimination and increased risk of socioeconomic difficulties that varies in different social and cultural contexts. (Hughes, 1999; Dunst, Trivette, & Hamby, 2006; Turnbull, Turnbull, Erwin, & Soodak, 2007). In last decades, beside focus to the child needs, the services have been aimed to provide support to families, too (Turnbull, Beegle, & Stowe, 2001). The family-centered approach is based on the holistic perspective and the fact that families are unique. Therefore, it is important to adjust the services to the family’s specific needs considering how the fact of having a child with disabilities influences the whole family; what should be the specific goal or impact of the service; which kind of specific support activities lead to optimal outcomes to reduce the negative and promote positive effects for the child and the family, etc. (Summers et al., 2005; Samuel, Rillotta, & Brown, 2012). The position of service users has evolved from being the “objects of intervention” with no control over the process, to partnership in process of decision making that includes the parents’ and child’s participation in order to individualize the form and content of services to the greatest possible extent (King, Teplicky, King, & Rosenbaum, 2004). The family, together with the service provider, contributes significantly to decisions based on information about the services and support they could use, considering the strengths and needs of all family members (Law et al., 2003). The basic assumptions that underlie this approach are that parents know their children best and that children function optimally in their family and community if they obtain proper support.

The researches focused on the effects of support to family indicate that these services improve parental self-efficacy and enhance the mutual relationship between parents and professionals (Dunst, Trivette, & Hamby, 2007; Gabovitch & Curtin, 2009). The results of these studies confirm that support programs in the community, especially the ones focused on the family, increase parental self-confidence and competence.

Evaluative studies of services usually consider satisfaction with the assistants and other professionals, satisfaction with the service program, the program’s effectiveness, access to social support and resources, functioning of the parents and families, parental abilities, improvement of child behavior, etc. Most of the evaluation studies are focused on (Emerson, Fujiura, & Hatton, 2006; Emerson et al., 2012):

- 1) evaluation of training for parents, to improve their parental skills;
- 2) psychological assistance to parents, focused on diminishing parental stress, and
- 3) support focused on helping the family as a whole, including other extended family members.

The main benefit of the various programs and services does not stem just from the offered content, but also from the way in which the support is provided. The impact of services on the quality of life is one of the most important measures in verifying the effectiveness of different policies, programs and treatments (Poston et al., 2003; Brown, MacAdam-Crisp, Wang, & Iarocci, 2006; Dunst

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