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Services for Children with Disabilities and Their Families: The Impact on the Family's Life Quality

Tamara Džamonja Ignjatović

Abstract

Families that have children with disabilities are faced with numerous difficulties in Serbia mostly due to the prolonged effect of social and economic crises. Besides insufficient adequate and diverse community-based services, they often experience social isolation and poverty, too. During the last decades, there were efforts to improve support for parents by introducing community-based services for their children with disabilities. This chapter is based on the findings of the study that explored the effect of those services on the families' quality of life. Although the findings confirmed that the services generally improved their life quality, particularly for those who perceived the lowest quality of life before, there are some additional observations about "side effects" that should be useful guidelines for developing flexible individually tailored service that support families' needs and suit them best.

Keywords: quality of life, children with disabilities, family support services, evaluation of services

1. Introduction

Serbia has been trying to implement important reforms in the area of social welfare in the last two decades, as a part of process for integration into the European Union. One of the main courses of reforms is in the area of child protection. Therefore, it has been necessary to develop a wide range of community-based services for supporting families to improve their quality of life and provide optimal conditions for the child development. As a part of that process, different services for children with disabilities and their families have been established, in contrast to the old, mostly overcome practice to "unburden" families by an institutional placement of their children that lead to their social and educational exclusion. The main reason for that turnover from institutional care to community-based services is based on the fact that children function optimally in their families included in the community if they obtain proper support.

Families who take care of children with disabilities are exposed to challenges of intensive and demanding, sometimes lifelong, care. They could face discrimination and increased risk of socioeconomic difficulties, too [1–3]. While the children with severe difficulties were placed in institutions, the majority of families had to rely on their own resources and provide permanent care for child with (or often without)

help of other family members. It was difficult to find qualified persons for child-care, and it was too expensive for most of those families. That is, the reason why mothers often have to leave their work and stay at home to take care of their child. 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.

Another difficulty for them is very slow process of inclusion of those children in education system. Legislation rules support children with disabilities to be enrolled into public schools, but there was a lot of resistance to that processes. Teachers or even parents were not prepared for adopting such changes. Teachers who are not trained lack special skills and knowledge to deal with those children. Struggling to harmonize their needs with needs of other children and requests of educational programs, teachers experience additional burden and often feel burnout due to “useless effort” [4]. Parents are usually afraid of social rejection and failure of children compared with their peers.

In the last decades, the services have been focused on the child's needs but also were oriented to provide support to families as well [5]. The family-centered approach is based on the holistic perspective, considering families as unique. Therefore, it was important to adjust the services to the family's specific needs and unique experience of how the fact of having a child with disabilities influences the whole family. It must be carefully considered what should be the individual aims of the service, anticipating possible impact of that support. In other words, it should be considered which kind of specific activities could contribute to the optimal outcomes, reducing negative and promoting positive effects for families and children [6, 7]. The service users used to be the “objects of intervention” that assumes passive reception of services with a little control over the process. Their position slowly evolves to partnership that includes participation in the process of needs assessment, planning, and decision-making in order to individualize the content and way of service provision to the greatest possible extent [8]. Families and service providers contribute together to decisions based on information about the available services, considering the strengths and needs of all family members [9]. This approach is based on the assumption that parents are competent and eligible partners who know their children best.

All services were intended to support the children to remain within the family environment promoting their inclusion in the local community and to help the family to deal with daily difficulties intending to improve their life quality. Those services include daycare centers, “respite” care, and assistance at home. Children should be provided with a stimulating experience that is based on the individual planning with the case manager and service provider, whether services are received at home or outside in daycare centers. Daycare centers are available every day, except weekends, usually 8 h. The children spend time in small groups, engaging in different games or other stimulating activities. Home assistance provides activities with child at home 2–4 h usually 2 days per week. During that time, parents have time for other obligations at home or outside or free time to reset, which is a significant help for them. Even if these services have been focused primarily at children needs, parents could benefit from getting some useful advices and support for everyday care, but it does not include structured parent training focused on parents' skills, strengthening their coping capacities, or improving their relation with the child.

The results of different studies confirm that support programs in the community, especially the ones focused on the family, increase parental self-confidence and competence, improve parental skills, or reduce parental stress [10–13].

One of the most important measures in verifying the effectiveness of different policies, programs, and treatments is the impact of services on the quality of life of family members who are taking care of children with different types of disabilities [1, 3, 14, 15].

Quality of life is a multidimensional construct that includes objective indicators and subjective evaluation of physical, financial, social, and emotional well-being [16]. Besides the objective indicators such as material well-being, living condition, health, employment, education, social security, etc., it is important to include personal subjective perception of well-being. Cognitive evaluation of personal life and emotional experience of more positive than negative effects are the basic components of subjective well-being [17]. Although it is important to discern how a person lives and functions, it is also important to understand how somebody feels and how they perceive their own life. One of the most important components of subjective well-being is not just individual experience but also social relations and integration. It is determined by the individual's perception of the effect of the social environment to personal benefit [6, 15].

According to the concept of general life quality, the family quality of life is defined as a valuable outcome of services and policies for children with disabilities and their families. It is important to emphasize that sometimes "child" is adult person who still needs help from his/her parents.

In the last few decades, there have been many studies about conceptualization and measurement of the quality of life of people with disabilities. Schalock et al. [18] defined eight domains of their quality: emotional well-being, interpersonal relations, financial well-being, personal development, physical well-being, self-determination, social inclusion, and disability-related rights.

The comparative studies of Brown and others [14] further contributed to the development of this theoretical concepts and its measurement. They included health, financial (material) well-being, family relationships, other people's support, services and staff support, caregivers and care tools, spiritual and cultural life, free time, and community involvement as key components of life quality.

Based on a qualitative study of families, Poston defined the nine domains of life quality [15], but later analyses supported the solution of final five domains of family life quality: family interaction, parenting, emotional well-being, physical/financial well-being, and disability-related support [19, 20].

It is obvious why the focus on life quality is so important for those families who sometimes feel overwhelmed by the increased demand for care and support for their children with disabilities facing with limited financial resources and environmental support in a long term [21]. Even if they are facing specific difficulties related to certain types and levels of disability, the results of numerous studies indicate that parents and other family members have a lot of common difficulties, concerns, and needs for support that reflect their quality of life.

2. Aims and method of the study

Based on those findings, we conducted the study to analyze the effects of community-based services for children with disabilities on the quality of life of their families [22]. We were interested to find out if there is any improvement in the general perception of family life quality after 1 year of using the services and in which specific domain of life quality the changes are the most significant. Also, it was interesting to explore who has benefitted from the services the most, based upon the level of family quality of life at the beginning of receiving services as well as upon the level of the severity of disability of the child.

We examined 153 parents of children with disabilities who participated in the study at the beginning of using services and 1 year later. The services were offered to families, no matter what their socioeconomic status or child's age or type of disability is. The parents were from different regions in Serbia, from rural and urban settings where services were offered. Most families used home assistance (55.6%), some of them used a daycare center (26.1%), and some used respite care (18.3%), which was sometimes combined with the other two services.

The data were collected by the Family Quality of Life Scale (FQOL), developed by Hoffman et al. [19]. The FQOL scale consists of 25 items that are grouped in five domains: (a) *family interaction* is a subscale that describes the quality of communication in the family, mutual support of family members, and the time they spent with each other; (b) *parenting* is a subscale that assesses a parental support to their children and feeling of closeness with them; (c) *emotional well-being* is a domain intended to evaluate the availability of social support from social environment, including extended family member and other people as an important stress regulator; (d) *physical/material well-being* is a subscale that measures the availability of various community services and the general feeling of security; and (e) *disability-related support* is a domain that evaluates the provision of specific external support for educational improvement, skills' development, and inclusion in community, including contacts with the service provider.

The "family interaction" and "parenting" domains represent subjective perception of "internal" family recourses, while the other three domains are related to the perception of external support available to the family and child that contributes to their quality of life. Of course, the external support could significantly affect the first two domains.

The reliability of the subscales of the FQOL in our sample ranged from 0.81 to 0.94, which is similar compared with other results in different cultures [19].

3. Results

First of all, our findings confirmed that most of the families had been facing a lot of difficulties in everyday life. The fact that half of the families (49.7%) had no income from employment was an important indicator of their financial difficulties, so their quality of life, besides the permanent care for child, was affected by poverty, too. Most mothers (66.7%) were unemployed, due to the necessity of staying at home for childcare, but over one third of fathers (37.9%) were unemployed, too. Both parents worked only in 15.8% of cases. One third of families (32.7%) had income below 200 euros per month, including social benefits. Almost half of the mothers (42%) and a quarter of the fathers (24.2%) had a low level of education (only 4–8 years of education) which diminishes possibilities for employment or finding a well-paid job. Obviously, they cannot afford some external help, except from extended family members when it is available.

Another factor that influenced life quality is the fact that one third of mothers are a single parent (33.1%). This is higher than the average rate of divorce in Serbia, particularly in rural areas where half of the parents from the sample have lived. It is well-known that difficulties like permanent care for a child could affect partner's relationship. The poverty and increased obligations at home could contribute to the social exclusion or isolation of the parents, particularly single one, and additionally interfere with their life quality.

Another factor that contributes to the lower level of life quality is the fact that almost one third of "children" (28.5%) were over the age of 18, which indicated prolonged, persistent, and sometime exhausting care for child. Most of those children

	Pretest		Posttest		F	dfb	dfw	sig.	η^2	d _{RM}
	M	SD	M	SD						
Family interaction	23.84	7.36	26.73	5.10	23.28	1	152	0.000	0.13	0.39
Parenting	22.89	7.01	26.18	5.14	27.58	1	152	0.000	0.15	0.42
Emotional well-being	13.00	4.87	15.53	4.31	27.77	1	152	0.000	0.15	0.43
Physical/material well-being	16.11	5.73	19.01	5.40	27.87	1	152	0.000	0.16	0.43
Disability-related support	14.98	4.94	17.25	3.34	27.31	1	152	0.000	0.15	0.42
Family quality of life total score	90.82	24.07	104.71	18.83	39.70	1	152	0.000	0.21	0.51

Table 1.
Analysis of variance with repeated measures on the FQOL scale (N = 153).

(44.2%) had multiple disabilities, and according to the criteria based on the required additional support [23], 35.3% of them had severe or profound disabilities.

The family life quality was measured at the beginning and 1 year after using services for the child at home or in the daycare centers. The perception of families' life quality confirmed positive significant changes in general life quality, as well as positive changes in all domains of life quality (**Table 1**).

The association between specific services (daycare center, assistance in the home, and respite care) and changes in family's quality of life showed that there were no significant differences between the families who had been using different types of services ($F(2, 150) = 1.03, p = 0.361$). The life quality was improved after 1 year of using service regardless of the type of services ([22], p. 5).

We were interested in understanding not just *what* has been changed but also *who* has been changed the most or who has not experienced changes at all, depending on the level of family quality of life at the beginning of receiving services. Therefore, we divided sample on three groups with high (33.3%), middle (31.4%), and low (35.3%) quality of life (by LCA). Analysis of variance shows that there is a strong interaction effect between level of family quality of life at the beginning of service provision and effect of service provision to the family quality of life after 1 year ($F(2, 150) = 38.12; p < 0.000, \eta^2 = 0.34$). The perceived quality of life increased the most in the families who had the lowest scores at the FQOL scale at the beginning of using the services (**Figure 1**). On the other hand, the group that perceived the quality of their life very high at the beginning of service did not improve or in some cases even slightly decreased.

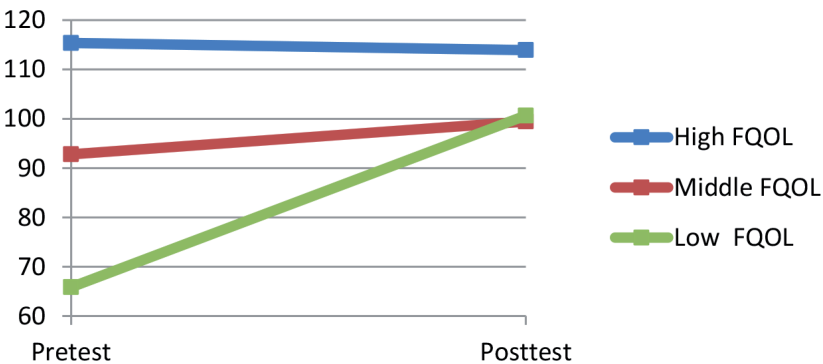


Figure 1.
Changes in the FQOL of groups based on the level of quality of life before services.

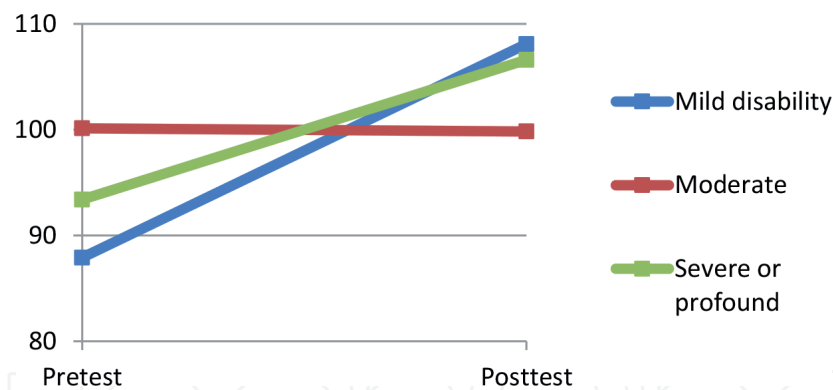


Figure 2.
Changes in the FQOL according the level of child disability.

Also, in order to understand who has been improving depending on the level of severity of child disability, we compared the three groups of families with mild, moderate, and severe disability. Analysis of variance showed that there is an interaction effect between level of severity of disability and effect of service provision regarding family quality of life ($F(2, 133) = 4.63$; $p = 0.011$, $\eta^2 = 0.07$). The most significant improvement of life quality was obtained in the families with children with mild disabilities. The families with children with severe or profound disability significantly improved, too, but for the group with the children with moderate disability, there was no evidence of positive effect of services (**Figure 2**). At the same time, they had the highest level of the FQOL at the beginning.

Although the differences of pretest level of life quality among the groups were not significantly different, it is interesting to notice that the families with children with a mild disability have the lowest quality of life before services. At the same time, there is significantly higher percentage of single-parent families (43.1%) in this group comparing to families with children with moderate (34.8%) and severe disability ((20.8%), $\chi^2(2, N = 134) = 6.32$, $p = 0.042$, Cramer's V is .22) ([22], p. 5). Also, those families mostly live in rural areas (58.6%) where external support is less available ($\chi^2(4, N = 136) = 12.67$, $p = 0.013$, Cramer's V is .22).

The results showed that there is no interaction effect between age of child and effect of service provision regarding family quality of life ($F(3, 137) = 0.37$; $p = 0.776$).

4. Discussion

According our main goals that were to explore whether there have been improvements in the perception of different aspects of family life quality, it was expected that, after a year of using services, improvement was reflected in aspects of the quality of life on which the services had direct impact. The results of the study confirmed that expectations. Besides the general improvement of life quality, the changes were evident in the domains that initially had the lowest scores—material well-being, emotional well-being, and disability-related support. Those domains are mostly dependent on the services that were designed to affect these specific aspects of the family life quality.

Although the services were not particularly focused on communication and relations among family members, nor at the parenting practices, there was improvement in these domains, too. It seems that the services affected them indirectly. When families get more external support, they could experience some relief that might contribute to the improvement of interpersonal relations between parents, as well as to their parenting. It is interesting to emphasize that *family interaction* and *parenting*

were initially rated higher. Those domains have important role as internal family strengths in dealing with the everyday problems related to childcare in the context of a lack of external support. That is supported by other authors [24] who emphasized that the quality of life is dependent on establishing and maintaining a harmonious relationship within the family members and with external environment.

Results showed that the life quality was improved regardless of the type of services. We could assume that type of service would specifically contribute to different aspects of life quality, but any kind of proper support has an impact on positive changes in general. According to the systemic approach, the family is a dynamic system, so the change in some domain influences other domains and reflects improvement of system as a whole. For example, during home assistance services, parents were usually present, and they can observe the activities and interactions between the child assistant and child. That could contribute to improvement of parenting skills (how to stimulate child, play with him/her, etc.). On the other hand, daycare service could be more useful for child socialization, where children have opportunity to play and communicate with other children or adults and spend some time out of home. Those observations were confirmed through interviews with parents. But any positive change in some aspect reflects on other aspects of family life and their perception of child improvement.

We were also interested to find out who benefited from the services the most based upon initial level of life quality and severity of child disability. The results indicated that the quality of life improved the most in the families who had the lowest scores on the FQOL at the beginning of services. It is important to notice that the effects of services are the best for the families that needed them the most. On the other hand, the changes were not significant in the group who had higher scores on the FQOL before service use. Although particular progress was not expected among those who were already satisfied with their quality of life, this does not mean that they do not face difficulties and does not imply that they do not need any services. But it is also important to notice that their level of FOQL even decreased slightly (although not significantly). These findings suggest that, when designing community-based services, it is important to respond differently to the specific needs of families and tailor service to them individually. The question is what specific service they really need and how should it be provided. If the services strongly contribute to the improvement of life quality for families who needed them the most, that means that other families need something different. The practice of social work still has a lot to learn from families how they are facing difficulties, and, in that respect, it is important to assess family strengths and ways of adaptation to those persistent difficulties. It is necessary to flexibly adapt service support to them without minimizing their personal competencies. Probably, in the cases where we noticed a slight reduction of life quality after using services, parents could experience disregard of their coping skills or homeostatic balance. If they get what they might need and do not get what they did not ask for, it could be more helpful for them and will not be wasting the time and resources of families and service providers.

Our findings confirmed that the level of disability has impact to the quality of family life. The permanent care for the child with severe disability is often additionally burdened by poverty, which is much more challenging and might lead to physical and emotional exhaustion. Those families experienced significant benefit from services regarding life quality, too, although the level of progress is limited. But, it is interesting to notice that families who have a child with mild disability and experienced a lower level of life quality at the beginning of services compared to the other families who have children with moderate or severe disability progressed the most. Needs of those families and their children could be neglected from the service providers (assessed as “easier cases” who are not the priority of system's support), so the

external support is less available to them. Also, there is significantly higher percentage of single-parent families (43.1%) among that group than the other two groups. This finding is in accordance with our previous study that confirmed higher divorce rate in families who have child with less severe disability [25]. Less possibility of sharing care and obligations could contribute more pressure and lower life quality for a single parent. In comparison with parents who share efforts together and who get more external support, it seems reasonable to expect that it contributes to their lower level of life quality. So, when they get some external help, they progress the most.

But how could we explain that the parents of a child with severe or moderate disability have fewer divorces rate and experience higher life quality? Do the difficulties of everyday life contribute to them staying together, uniting their efforts, and relying on each other, which they can appreciate as an important part of their life quality? It should be explored in future studies.

There is a lot of evidence that the age of the disabled person contributes to caregiver burden [26–28]; however, we did not confirm that prolonged and permanent care for the child contributes to lower life quality. It seems that there is a different experience of difficulties of the caregiver in parent-child (even grown-up child) relationships, than in other form of relations between caregivers (family member, but not parent) and adults with disability. Probably they develop some coping strategies and adaptation skills over time that diminishes the potentially negative effect of perennial care to their life quality. Parents with older children could be exhausted, but adapted and skillful, while families with younger children may still struggle with difficulties of acceptance of the child difficulties and the new organization of their life. It seems that each phase has specific challenges.

Besides the benefits of services, there are still a lot of problems that should be kept in mind during planning and establishing new services. First of all, there is a problem of sustainability of implemented services. That means that the service which had been provided for a while, without permanent support of local community, could be discontinued after the termination of project financial support. It may have impact to diminishing life quality, even to the lower level then before services had implemented. There were no monitoring or evaluations studies of those effects if families that faced with restriction of support on which they used on.

The other risk is that the services have been offered to all who might need them without careful assessment what exactly they need. The diversity of services had not yet been worked out or individualized according to specific family's needs, and they depended more on service providers' personal skills and resources. So, that increases the chances of imposing something that is not suitable (best fit) for service users. Anyway, the availability of support of the services contributes to positive change much more than that could damage it.

Most studies have confirmed that quality of life is a multidimensional construct [14, 15, 18, 24, 27]. Therefore, it would be useful to explore mutual influences of objective and subjective factors that play a role in life quality such as parents' age, gender, health condition, attitudes, spiritual beliefs, level of stress, coping strategies, skills, social and family networks, etc. That would be a very helpful information for creating services, as well as for creating criteria to be used for them.

The importance of service evaluation has been highlighted in the last decade in Serbia. This requires the development of standardized and reliable instruments for the evaluation of the effects of services, which can measure specific aspects of the services. This would enable researchers to explore and understand what are the most helpful or effective aspects of service provision. That could provide useful information for researchers and policy makers, as well as for practitioners and service users.

The study confirmed benefits of community-based services to the family life quality, exploring some specific aspects and range of change, as well as the influence of level of child disability and previous perception of life quality to the extent of change. Unfortunately, there are still a large number of socially excluded families who live in poor communities that had no chance to use the services and experience an improvement in their quality of life. Social workers still have difficulties in providing sustainable services, which need to be overcome in the future. Meanwhile, the results of this study might be useful for planning further steps in developing and evaluating community services for children with disabilities and their parents who should receive flexible and individually tailored service that suits their specific needs best.

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