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# Supporting Families with Children with Disability — Evaluating the Impact on Family and Child Wellbeing

## Executive Summary

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# SUPPORTING FAMILIES WITH CHILDREN WITH DISABILITY — EVALUATING THE IMPACT ON FAMILY AND CHILD WELLBEING

## EXECUTIVE SUMMARY

## Background

The "*Monitoring of Outcomes of the Community Services for Vulnerable Families with Children and Juvenile Offenders* research project, implemented by the Research Center for Social Work and Social Policy of the Faculty of Political Sciences of the University of Belgrade (FPN UB) is an integral part of the multi-component project entitled *Strengthening the Justice and Social Welfare Systems to Advance the Protection of Children in Serbia*, which is supported by the European Union, within IPA 2013 for social development, implemented by the UNICEF in cooperation with the Ministry of Justice and Ministry of Labor, Employment, Veteran and Social Affairs.

The results of the two studies will be presented in the Summary: "Outcomes of the Family Outreach Service for Families with Children with Disability" followed by those of the study entitled "Outcomes of the Temporary Fostering for Families with Children with Disability", with an overview of goals and applied research methodologies, process of data gathering and processing, research results, conclusions and recommendations.

## Outcomes of the Family Outreach Service for Families with Children with Disability

### Purpose and Goals of the Research

The improvement of the social inclusion practice requires understanding outcomes, arising as a result of different initiatives and activities. Reviewing outcomes of the Family Outreach Service for families with children with disability aimed at determining the

outcomes that this service delivered from the perspective of the service users, in this case parents and other adult family members.

Thus, we looked into the parents' perceptions, but also gathered data from the family outreach workers on service referral, child and family expectations and needs, experiences, relationships with case managers, adequacy and intensity of the service use, effects, participation and satisfaction with the process and outcomes.

## Methodology

Evaluative and exploratory design was developed based on a logical framework created in the consulting process with the organizers and service providers before piloting the service. Research was organized as a mixed qualitative and quantitative test-retest study, which gathered various data from parents with children with disabilities and family outreach workers.

**The sample** of families who participated in survey is sutable **convinient** because it included solely families about whom the service organizers notified the researchers. The survey included 30 to 189 families which used the family outreach service for families with children with disability, which is 15.87% of the population of service users.

Out of 30 families under survey, 14 were interviewed early in the process of using the service (during the first month) and later 7–9 months into the service use, within one month following the service termination. A total of 16 families which had just stopped using the Family Outreach Service (within 2 to 4 weeks) were also interviewed and with these families interviews were repeated after 9 months in order to monitor the sustainability of the effects of the service. A total of 24 families took part, in the second, last round of research, 7–9 months since the beginning of its use, and/or termination of using the service, namely, 10 to 14 families interviewed in the first round of research at the beginning of the service use and 14 to 16 families which were monitored for sustainability of the effects of the service.

Out of 30 interviewed families, more that half (18) were families with both parents living in the household, while in the case of single-parent families, eight families were with single mothers and four with single fathers. In 8 families, in addition to a mother or a father, a grandmother, grandfather or uncle lives in the family. In the interviewed families, there were a total of 64 children up to 18 years of age, 34 of whom were children with disabilities. Two interviewed families had two children with disabilities. Out of 34 children with disabilities in the interviewed families, there were 25 boys and 9 girls. Regarding disabilities, that is, the type of a child's impairment or disability, 6 of them have multiple problems and conditions. Intellectual disabilities

are dominant (12), followed by autism spectrum disorder (5) and physical disabilities (4). Two children were affected by both a mental illness and a hearing impairment, while other children had other specific syndromes, disabilities or conditions. At least 9 children above the age of three have not developed speaking skills.

## Characteristics of the Family Outreach Service for Families with Children with Disability

To understand findings, it is important to bear in mind that the received data show that the service was piloted in families which, in addition to having children with disabilities, also have other difficulties not directly related to the child's disorders. According to the data, provided by the family outreach workers in the entry and exit questionnaire, in order to pilot this service families were selected in which moderate problems were detected regarding physical and mental health of parents (around 1/3 of families), families with moderate difficulties regarding parental, communication and living skills (around 1/2 of families), in 1/3 of families relationships were described as 'temporarily problematic', between 1/3 and 1/2 of interviewed families had a 'limited support network', and there were also difficulties in requesting and using community resources. At the family level, almost all interviewed families are affected by moderate or severe problems caused by poverty and inadequate income, and approximately 1/3 of families are affected by problems connected to family violence. There are also various problems regarding behavior of children and school- attendance.

Those are families experiencing **difficulties in inclusion in the community and in the use of existing resources due to multiple and complex problems** some of which are becoming or have become chronic and multiplied in time. In these families, development and safety of children with disabilities are at risk, despite great efforts by parents, due to multiplied internal and external difficulties caused by unavailable resources and social exclusion. Such situation puts the children from these families in the high-risk zone of removal from the family.

We have tried to understand the expectations and needs of the families at the beginning of using the service and then later to see to what extent such expectations have been met and what has changed in that regard. In initial expectations, several topics emerged:

➤ **Assistance with a complex family situation** (which is particularly emphasized by single-parent families, followed by families in which a parent has become ill);

➤ **Parental skills' training was** an initial expectation of families with adolescents who developed behavior problems and school attendance problems, and with families with younger children whose disabilities are related to challenging behaviors.

- **Material support** is stated as the initial expectation of almost 1/3 of families.
- Families also emphasized the importance of receiving **information, overcoming social isolation and assistance in exercising rights and organizing mutual relationships within the family.**

Since complex family situation requires complex and tailored interventions, interviewed family members stated that they had worked with family outreach workers in the following areas:

- **Development, behavior and abilities of the child** (stimulating development and inclusion of the child in rehabilitation processes, recreation and education system, improvement of parental skills, modeling and modifying challenging behavior in children and adolescents).
- **Children's health condition and health care** (making an examination appointment, referrals, getting the required interventions and medications, transport to a health care institution, preparing a child for dental interventions).
- **Resolving the family relationships and problems with the ex-spouse.**
- **Material assistance to improve the household conditions** was the most 'tangible'area, where many of the interviewed families saw a specific improvement in their lives (for instance, bathroom renovation, buying a stove or a washing machine, appropriate bed, aids etc.)

**The discretionary fund** turned out to be a powerful intervention tool, which was more than welcome for the deprived families. This fund was used to resolve issues that families find to be the most important, and which may produce a significant positive change; for instance: bathroom renovation, kitchen floor repair, fitting new windows, paying a professional development course for parents, buying major household items (for instance, a bed, a special pillow, a vacuum cleaner, shutters, a wood stove, firewood etc.).

Almost all families said that the **intensity of contacts** with outreach worker was appropriate, and they found **reliability and regularity of contacts** very important, as well as timely cancellation. For the interviewed families, the service **lasted** between 6 and 9 months, which most of the families (around 2/3) found "sufficient".

In the early stage of the service, parents and other adult family members mostly recognized the significance of assessment and service planning, and that they were important in order to **understand family needs well**, and in order to reach an **agreement regarding what was in the child's interest**.

These findings are fully in compliance with numerous other international surveys, based on which relevant intervention factors emerged regarding working with family:

- Dedicated worker, attached to family.
- Practical support (material and non-material).
- Persistent, challenging and assertive approach of the workers. The family feels encouraged when it sees that the worker "does no give up on them".
- A family-centred approach and perceiving the family "from within", in order to understand what it needs.
- The common purpose of the work and agreed activities. Coordination and consistence of activities are ensured by one professional well acquainted with the family and its circumstances.

## Main Findings

- **POSITIVE AND SUSTAINABLE EFFECTS OF THE SERVICE HAVE BEEN RECORDED IN 2/3 OF INTERVIEWED FAMILIES**

In the interviewed families, there have been changes at numerous levels. Approximately 2/3 of interviewed families stated that "things took a turn for the better" and that contribution of family outreach worker was considerable, through the following:

- Improvingthe living space or living conditions of family (renovation of the child's room, reconstructed floor, reconstructed bathroom, new windows fitted, moving to a more appropriate apartment etc.),
- the child has been included in appropriate education institutions,
- the child has overcome behavioral problems, parents are becoming more successful in disciplining or better understanding the child's behavior and responding to it more appropriately,
- the child's health condition has improved, the child undergoes treatments, rehabilitation, receives appropriate therapy,
- there has ben an improvement in chid's development,
- problems with the child's other parent and those of the child living with other parent have been overcome,
- family members have been able to claim the rights of which they had not been informed earlier,
- family members had the opportunity for socializing, new experiences and community participation.

In fact, the listed outcomes point to the fact that family outreach worker interventions were aimed at overcoming environmental risks that endanger children's development,

and that there has been an improvement of the family environment which was supported in order to ensure a caring environment for the child with disabilities and for other family members.

These changes turned out to be **sustainable** in 3/4 of families interviewed 9 months after the termination of the service. Similar to statements of the interviewed family members, family outreach workers mostly highlighted the **developmental progress and improvement in the children's condition**, which were included in health, rehabilitation and recreational treatments during the service or in an appropriate educational process, moderate or considerable progress in **parental skills and use of community resources**, and they assessed that the determined **service goals** had been fully or partially achieved in 4/5 of families. Families **requiring more assistance** are the ones affected by chronic poverty and the ones facing serious social isolation.

### ► COMPLEX FAMILY SITUATION REQUIRES COMPLEX AND TAILORED INTERVENTIONS

Interviewed parents describe this service as "**a person who professionally assists the family to overcome problems, in the family home**". Interviewed persons stressed in many instances that the fact that most of the service was provided at the place where the family lived was a **new and an empowering experience** for them. Also, having a **choice and voluntary** participation had an important role for the parents.

The service responded to the complex needs of these families, because the interventions were:

- ► **tailored to the needs of the specific family** and its specific situation;
- ► **agreed with the family** (evidently, larger degree of activation and participation of the family in setting goals and in implementing activities has led to better results as well);
- ► **comprehensive,** so that they respond to various aspects of the family life and respond to difficulties connected to parenting children with disabilities, so that practical support includes psycho-social support as well;
- ► based on a **collaborative relationship**, where dedication, honesty, expertise, assertiveness, perseverance and optimism of the family outreach worker encourage and strengthen family members;
- ► **child-centered and family-focused**, which supports the development of a child with disabilities in the family and community environment.

## ► RELATIONSHIP WITH THE HELPER — FAMILY OUTREACH WORKER IS THE CENTRAL COMPONENT OF THE SERVICE

This relationship **is not inherent, but carefully built** based on a well prepared introduction, sincere but professional behavior, openness to family needs and demonstration of genuine respect. Families interviewed immediately after the termination of the service and 9 months afterwards, listed **trust** as a central characteristic of the relationship:

- ► Trust is the result of **fairness** (fulfillment of what was planned and agreed) and it has yielded **results in the children's behavior**;
- ► Trust is the result of **engagement** and **joining** the family, and also of **providing complete information** to the family;
- ► Trust has emerged based on belief that the relationship is truly **confidential**. Many parents stressed that they particularly appreciated the confidentiality of the relationship.
- ► Trust is built and **gained over time, by investing efforts and showing sincere interest** in being part of resolving family problems.

**Adequate access to various family members** is also important, whereby parents have particularly appreciated the ability of the family outreach worker to communicate with children. Interviewed family members felt the need to highlight **personal features** of family outreach workers : **optimism, composure, openness, kindness, sincerity, combative spirit and perseverance.** The fact that family outreach workers are persons who are considered **young** in the Serbian society (which usually means insufficient competence and maturity) has paradoxically become **an advantage rather than a disadvantage** in the eyes of family members. Although they were initially scared by the family outreach workers' young age, the family members gained trust in their expertise **and dedication** over time and they highlighted all the advantages of their young age. According to them, those advantages are cheerfulness, energy, readiness and ability to communicate with children with disabilities, particularly with adolescents with whom communication may be challenging.

## ► THE QUALITY OF THE RELATIONSHIPS WITH SOCIAL WORKERS FROM THE CENTER FOR SOCIAL WORK HAS IMPROVED IN A NUMBER OF FAMILIES DURING THE SERVICE USE

The offer of the Center for Social Work was understood by the parents as **unexpected**, **surprising** and was often taken with **disbelief and apprehension.** Where earlier good cooperative relationships were established with the case manager or the social worker from the Office for Providing Material Assistance, parents expressed satisfaction for being — 'privileged' to be selected or happy to be able to participate in something new.

Disbelief emerged as a result of seeing community and social services as disinterested in real family problems, while distrust and apprehension (that the children would be 'taken away from them', that their parent competences would be undermined etc.) resulted from previous conflicting or antagonistic experiences with the center for social work. Crucial factors for accepting the service may be summarized as the following:

- the parents' and family members' eagerness **to do what is best for their child**, and/or children with developmental disabilities,
- readiness to work and improve their own situation ('**effort**'),
- **avoiding problems** with the center for social work,
- **positive reaction of the child** with disabilities and other children in the family.

The manner in which the service was offered has, along with initial distrust, provided **hope** to parents and space for accepting assistance.

All interviewed families had experiences and contacts with the center for social work prior to inclusion in piloting of the service, namely almost all families had such contacts due to the fact that the child was using basic or, more often, increased allowance for the assistance and care of child with disability, and, in some cases, other forms of material assistance as well. Several families highlight good relationship with the case manager or social worker in charge of material assistance, particularly where there were regular contacts, talks and support. They particularly **appreciate** respecting and stressing their parental competences, and they **are bothered about** "too much administration", over-burdened staff, not going deeper into family problems and lack of interest by certain social workers whom they have contacted. The Family Outreach Service was an opportunity to change the perception of the work of centers for social work and to consider the complexity of work that such an institution deals with.

During the exit interviews, respondents from slightly over 1/2 of families stated that after using the Family Outreach Service, the relationship with the case manager and other professional staff from the Center for Social Work remained the same — good and fair, as it was before. Mutual relationship improved during the time Family Outreach Service was used in almost all other families. These respondents stated that they believed that the Family Outreach Worker 'improved the perception' held by professional social workers of CSW on them. Other respondents make a big difference, holding Family Outreach Workers in higher esteem than these professional experts.

## Challenges and Limitations of the Family Outreach Service for Families with Children with Disability

Data provided by the family outreach workers on **interventions** point to the fact that in the initial stage of work, the family associates work primarily towards joining the family and building the relationship, while to a lesser degree they respond to family needs for specific and material support. The needs for specific and material support are later addressed through various interventions (assistance in food, clothing, equipment and renovation of the household, transport etc.). Advocacy, referral and providing information, usually regarding mental health services are left for later stages of work. Advocacy and exercise of rights in material assistance are 'left' to be done in both initial and later stages of work, which is obviously a large and significant area of assistance to the observed families.

Family outreach workers intervened in the majority of families — 3/4 of them — in the area of parental skills, parent-child communication, development achievements of children and relationships and communication among adults), followed by school attendance, household management skills, hygiene, and/or state of the household.

Where family outreach worker intervened less, less progress could be observed. As the most resistant and, at the same time, most neglected areas are sources of informal social support — family and friends, while with semi-formal networks (community groups, citizen associations, recreational groups etc.) interventions were only occasional. One of the main limitations of the service is that **family outreach worker interventions did not sufficiently target informal and semi-formal networks of family support in the community.**

To summarize, statements of the family members and assessments made by family outreach workers point to the fact that the service was designed to actually respond to the needs of approximately 2/3 of interviewed families which, in addition to having child with developmental disabilities, have other multiple difficulties (material vulnerability, social isolation, family violence, absence of an informal support network etc.).

At 1/3 of interviewed families, it is likely that **prolonged low-intensity support is needed over a longer period.** What the service **has not sufficiently ensured,** although that aspect is also present, is inclusion of family members in semi-formal support networks and activation of informal family support networks.

Most of the interviewed families need **inclusion and stabilization of their participation in semi-formal support networks** (community groups and organizations).

## Recommendations

Since the findings of the research point to the fact that the Family Outreach Service produces significant favorable outcomes in ensuring a safe and encouraging environment for the child's development, improvement of parental capacities and preserving caring aspects of family life, it is important **to use the existing legal possibilities in order to standardize and introduce the service in the social protection system**, as a service available to families with multiple and complex needs, which are at a high and moderate risk of having their child separated from them.

However, in order to prevent the consequences of social exclusion, the 'burn out' of families with children with difficulties, the secondary consequences of children's disabilities, the disintegration of family and the removal of these children from the framework their innate family, it is necessary to:

- **develop a set of services of different intensity levels** for supporting families with children with disabilities (but also for other vulnerable groups of children), in order for the support to be flexible and available;

- **ensure stable financing** of the service, in order to allocate funds in the national budget and to develop legal solutions that prevent removal of vulnerable children from the family, and/or which support residence of such children in their innate families;

- **embed the principles of the Family Outreach Service which provide evident benefits, as much as possible,** in other social and child protection services: voluntary basis, participation, coordination among services and social sub-systems and normalizing the family needs for support, dedication and expertise of workers, working with the family as a whole and ensuring individualized support. Future activities in the improvement of service standards should be heading in that direction, so that standards become reliant largely upon the value aspects of the service quality;

- work on **restoration, building and maintenance of informal and semi-formal support networks in the community.** It is a big challenge and task for social welfare: encouraging informal and building and maintaining semi-formal support networks is a **serious field for the policy development and social inclusion practice**, for families with children with disabilities, and for other socially isolated and marginalized groups in the society.

# Outcomes of Temporary Fostering as a Shared Parenting Service for Families with Children with Disability

## Purpose and Goals of the Research

The general goal of the research was to acquire more a detailed knowledge on the outcomes that the temporary fostering service produces for children with disabilities and their families, in order to improve the social protection practice, in compliance with the social inclusion policy. The research has dealt with outcomes that the service produced from the perspective of the service users, in this case the children's parents, primarily in order to improve the aspects of the service contributing to social inclusion.

Thus, we studied the views of both parents and case managers regarding referring a child to the service, expectations and needs, experiences, relationship with the case manager and the temporary foster parent, adequacy and intensity of the service usage, effects, participation and satisfaction with the process and outcomes.

## Methodology

Evaluative and exploratory design has been developed on the basis of the logical framework, created through the consultation process with the organizers and service providers before piloting the service. The research was carried out in two stages, by implementating a combination of qualitative and quantitative methodology. In the first stage, during the first month of service usage, and in the second stage, 10–12 months since the provision of service started, parents of children with disabilities who are users of the temporary fostering service were interviewed and they filled in questioners, which included data on the social isolation of families, their neighborhood and the parents' stress. At the same time, both in the first and the second stage, case managers filled in the entry and the exit questionnaire, which were used for acquiring data on family characteristics, assessment on the needs and strengths of the family, data on the service use, on children with disabilities, and, in the exit version, data on the outcomes of the service and the family' further needs.

Interviews included 17 families that used the temporary fostering service. There were a total of 34 children in families up to 18 years of age, of whom 20 children with disabilities. 15 families in total participated in the repeated, second round of interviews. Out of the 17 interviewed families, more than half (9) were families with both parents living

in the household, while in the case of single-parent families, seven families were with single mothers and one family with a single father. Out of 20 children with disabilities, 5 were girls and 15 were boys. Regarding difficulties, and/or type of a child's disability, autism spectrum disorders (11) are prevalent, followed by intellectual disabilities (9) and physical disabilities (4), while 6 children have multiple problems and conditions.

## Characteristics of the Temporary Fostering Service for Families with Children with Disability

**The Temporary Fostering Service was piloted in families with good and moderately developed support networks and with a considerable need for respite.** Judging by the data provided by case managers in the entry and exit questionnaire, families selected to pilot this service were of good mental and moderate physical health, who socially and occupationally functioning, not affected by poverty, although slightly less than half the families have moderate problems in this field. Furthermore, the families which were included had well-developed parental, communication and living skills, and a solid, but possibly 'burnt out' social support network. Those are families with developed or, in a small number of cases, moderate capabilities for searching and using community resources, without special problems regarding children's behavior, except those regarding disabilities.

**Parents see the service as an opportunity to get some rest and relief , while it is important for them that the child is safe and that it spends high-quality time with a person it trusts.** Most of the selected foster parents have supported the parents earlier and participated in providing child care (only 5 of them had not provided informal support to the parent earlier). The service introduced new dimensions with these families, primarily through financing which helps parents not to hesitate to ask for assistance when they need it, and also the community's recognition and making this relationship official. In essence, parents see temporary fostering as a service used to strengthen informal social networks by means of organizational and financial support of the community.

Well established relationship with case managers from the Center for Social Work and the need for support have contributed to easier inclusion in the service, despite skepticism, distrust and fear of 'foster care' as a form of support. With **complete information provided** and **voluntary basis** as prerequisites, decisive factors for accepting the service were as follows:

➤ current well-being of the child,

➤ future needs of the child,

- respite and saving parental resources,
- financial support,
- need to assist in the development of new services for children with disabilities.

When selecting a person who provides temporary foster care and support to the parent and the family, the aim was to strengthen the direct informal support network, that parents get control over the process, in order to appreciate and strengthen their competences. Out of 17 families included in the research, the case manager suggested a person for provision of support in only one case, while parents themselves appointed all the others. They were mostly close relatives (11), namely the child's grandmother, aunt, uncle..), followed by friends (3) and acquaintances, while in two cases children, parents and foster parents met through the service. The parents did not want to expose the child to new and vague relationships, so a previously built relationship and parent's trust in the person to whom they entrusted the child were crucial.

Despite the previously established relationship of trust in the foster parent, during the pilot stage of the service **this relationship acquired new qualities.** Parents stressed that after experiencing the service, they felt 'closer' and mutually more knowledgeable than before, and that the relationship acquired new dimensions. This is reflected in making the engagement of a temporary foster parent official and validating it, and also in the new contents that the child received in the redefined care arrangement.

## Main Findings

- **THE SERVICE PRODUCES BENEFITS AT SEVERAL LEVELS: WITH PARENTS, CHILDREN, FOSTER PARENTS, SOCIAL SERVICE PROFESSIONALS AND AT THE COMMUNITY LEVEL**

After 10–12 months since start of the service, parents and case managers highlighted several key items as the service outcomes.

- **Parents feel more relaxed and relieved.** They ask for assistance when they need it with less reluctance, they state that the continuity of child care has been established and they have more time for themselves. Such feelings emerge due to **organizational and financial support** of the community, which ensures that the parents ask for support more freely feel guilty much less when they rely on each other.
- **Better inclusion of both the child and parents in the community.** In the second round of interviews, almost all parents stressed that the child was then significantly more included in the community, that it had broadened its experiences and contacts, which contributed to its socialization. One of the parents stressed that

participation in the service opened up possibilities to activate and inform other parents on the needs and rights of children with disabilities and their families.

- ► **Effects of the service on the child** are assessed by both parents and case managers as very favorable, in several areas:
  - ⮡ The child has acquired new experiences outside family, it spends quality time,
  - ⮡ The child has developed a network of contacts in the community, expanded the family,
  - ⮡ The child is engaged through creative activities and learns new skills,
  - ⮡ The child is happy, enjoys new experiences, exposed to other contents, the social network is expanding,
  - ⮡ The child is independent, less reliant on the mother.

- ► **Temporary foster parents,** in addition to a modest and insufficient financial support (according to the parents) have acquired new knowledge enabling them to improve their skills, while some find the validation of their position in the community significant.

- ► According to the parents and case managers, the service has contributed to breaking barriers and to achieving an increased visibility of children with disabilities and their families in the **community**. New partnerships, established during the piloting of the service (with inter-sectoral teams, schools, community associations) are valuable resources for further work on social inclusion.

- ► Social workers from the Center for Social Work, Center for Foster Care and other social protection institutions participating in piloting of the temporary fostering service, had a great opportunity to **reconsider and improve their own practices,** thanks to a collaborative relationship, cooperation and mutual exchange with parents.

These outcomes show that the temporary fostering as shared parenting service contributes to the creation of safe and supportive environment for the child, that it preserves and cherishes parental resources, broadens options and capacities for child care in the community, thus contributing to a **decrease in the risk of placing these children in institutions.**

- ► **FLEXIBILITY OF THE SERVICE IS CRUCIAL IN ENSURING POSITIVE OUTCOMES**

For the majority of families, the engagement of a temporary foster parent meant the following: **brief daily socializing in the parents' house**, followed by **using the service in order for the child to participate in recreational and artistic activities in the community** (walks, recreation, relaxation, community events), and for some families (5) it meant **bried daily socializing in the foster parents' house**.

During the first month of using the service, only one family used the possibility for the **child to spend more than one day in the temporary foster parent's house**, while in the last interview that possibility was used by 6 families. It seems that the largest number of interviewed parents do not need child care in the temporary foster parents' house for more than one day except when that is done for the purpose of child's socialization (planned thematic weekends) or in exceptional circumstances (trips, healthcare treatments etc.). Agreement and mutual adaption of the parents and the temporary foster parent regarding the needs of the child actually dictated the modalities of service usage.

The outlined **time and modalities** of service provision are **convenient** for the majority of parents, as long as they can negotiate with the temporary foster parents on that matter. This means that **planning and mutual adaption** of all involved parties is important, because parents and children find that **reliability and predictability** of accessible support is important.

### ► ORGANIZED SUPPORT FOR ACCESSIBLE INFORMAL SUPPORT PRESERVES THE NETWORK FROM FATIGUE AND 'BURNOUT'

It includes collaborative needs assessment and planning of family-focused and child-centered activities, training of foster parents and parents, establishing relationships of trust and cooperation with the case manager, connecting to other community services and networks and financial support. Such support validates, directs and facilitates mutual relationipss, supports the balance between mutual giving and receiving support. Where certain elements of support were neglected (particularly relationships between the family and the case manager) and not managed professionally enough, the service turned out to be unsustainable.

### ► THE SERVICE SUPPORTED THE INFORMAL FAMILY SUPPORT NETWORK, WHILE IT PRODUCED LESS INPUTS AND EFFECTS IN THE AREA OF CONNECTING WITH FORMAL AND SEMI-FORMAL SUPPORT NETWORKS

Including families with children with disabilities in the temporary fostering service was also an opportunity to intervene in various aspects of family life, so that the parents could be referred to other services and departments and included in the community networks and groups.

According to the parents' statements, case managers mostly **informed them, provided assistance in exercisinig their rights** and a number of them **contacted other services and professionals,** tried to find information for them, directed, referred and counseled them in the exercise of their rights.

In the majority of cases — 2/3 of the families — case managers intervened in the area of 'stability of family life', while in 1/2 of families they did so in the area of encouraging the child's development, parental skills, encouraging emotional and financial support of a broader family. It can clearly be seen that with one in four included families, the interventions were in the area of using community resources and connecting to the support system and community groups.

### ► DESIGNING AND PILOTING OF THE SERVICE HAS PROVIDED AN OPPORTUNITY FOR IMPROVEMENT OF THE RELATIONSHIP BETWEEN THE FAMILY AND THE SOCIAL WORKERS FROM CSW

Prior to inclusion in the temporary fostering as shared parenting service, families had contacts with Center For Social Work mostly because the child was the user of the increased allowance for assistance and care, and such a relationship is described as fair but insufficiently dedicated. Those who have contacted the center due to a complex family situation, describe the relationship as traumatic. The most favourable descriptions were provided by parents who, within inter-sectoral teams for children with disabilities, had more intensive relationsships with case managers from centers for social work. It appears that the **inter-sectoral commission is the framework that may facilitate communication and setting up of a colaborative relationship.** In the repeated interviews, in 10 to 15 interviewed families, the relationship with the case manager has evolved and became stabilised in terms of productive collaboration; two parents describe it as fair, three parents express open dissatisfaction with certain actions of the workers during the project.

The characteristics of the case manager, which the parents consider to be the most releant in building a successful relationship are: **humanity, dedication, accessibility, reliability, fairness and expertise.** It facilitated the development of a relationship that is characterized by **trust, honesty, kindness and reciprocity.**

Parents who expressed **dissatisfaction** in the second round of interviews actually had a completely opposite experience: they were motivated and included in the service, but were later left on their own, without information and contacts. They listed **unclear communication, lack of information, unreliability and insufficient dedication**, even **lack of knowledge in case managers.** These parents believe that during piloting of the service **they invested more than they received.**

## Challenges and Limitations of the Temporary Fostering Service for Families with Children with Disability

Despite great efforts, a relatively **small number of families has been engaged** for the temporary fostering service. The **stigma** regarding 'foster care' as a form of service, **ambuguities** regarding financing, the procedure, duration, future and sustainability of the service were all certainly the constributing factors.

During the piloting of the service, implications were been sufficiently considered regarding **engaging and including persons out of the existing family support network**, which is of great importance for parents to whom such support is not available. These parents and their children probably need support of shared care even more than the ones that currently have such support at their disposal.

**Limited finances and certain procedures regarding the service** (issuing a order each month, complicated opportunities to use the time spent with a temporary foster parent flexibly from month to month etc.) prevents them from receiving a tailored and timely support and assistance, despite the achieved high degree of adjustment with the foster parent.

The biggest difficulty is that the **procedures** for using the service developed by the social protection system during the piloting of the service are **rigid** ('stiff'), complex, demanding for parents, temporary foster parents and for social workers as well. It appears that temporary fostering, as an exclusive form, represents 'tight shoes' for all the parties in the process.

## Recommendations

In order to carry out essential aspects of the support required by parents and children, which are: the **importance of the relationship of trust, reciprocity and organized support** (which includes financing and recognition by the community), the temporary fostering form is not sufficiently flexible, nor even necessary. Such a form has requirements that are unnecessary for numerous service users, such as complicated procedures, complex administrative process etc., which makes the service more expensive without contributing to its quality. Thus, it is important to **consider the possibility of simplifying the procedures** in order to increase the number of families whom this service is regularly accessible to. Findings from this and previous researches in Serbia point to the fact that support to the informal support network is necessary to numerous parents with children with disabilities, so it is important to **create other, more flexible service**.

On the other hand, parents and children to whom support is not available or who have insufficient support within their informal family and friends' network, probably need a projected form of temporary fostering which recognizes the lessons learned during this pilot cycle: **development of relationships, voluntary basis, partnership between the invovled parties, trust, flexibility, child-centeredness and liaising with the community networks.** The program for the implementation of this service should be designed precisely according to these aspects, for they are the ones that contribute the most to achieving the established outcomes.

The social welfare system may not, on its own, resolve an insufficiently developed social inclusion and child care system, both regarding children with disabilities and their families. Such a system may not even resolve the insufficient financing of the necessary health services for these children. It is possible to think and work in the following frameworks:

➤ It is necessary to ensure **stable financing** for the support services to families with children facing high risk of social exclusion and removal of the child from the family. In this regard, it is necessary to:

  ➤ **Define an integral family support and social inclusion policy within the framework of the child's rights.** To do that, it is necessary to have inter-sectoral cooperation and a more visible participation of 'more powerful' social systems (education and health), while social welfare, except for specialized services, should be engaged more actively in advocating and networking with other systems.

  ➤ Use the available legal possibilities to finance the service via **special-purpose transfers,** so that high-priority services which ensure family preservation and reduce the risks of removing children from parental families would be financed in less developed municipalities.

  ➤ Develop **new legislative solutions** for financing these services from the national and local communities' budgets.

➤ **Develop a set of flexible support forms** to informal family support networks, strengthening and building social networks. That can also be done within the services defined by the current Social Protection Law (2011), by means off new legislative solutions within this law, and beyond, by strengthening semi-formal, voluntary community support networks. It seems that the time has come to **develop additional mechanisms to formalize and shape the support to the development of the civil society**, because the previous methods (practices) have been exhausted or compromised due to the their insufficient or inadequate use. The shared parenting and shared care concept needs to be 'unpacked' and embedded in a set of

services and modalities of support, because they have turned out to be effective. It certainly includes temporary fostering as a specific service, but it cannot stop at that, because the capacities of this service to meet the needs of children with disabilities and their families are limited. In the way it was conceived, this service can probably be used only by a very limited number of families. The space that exists **within the daily community services is possible and necessary to be used for further development of the concept of shared care** for vulnerable groups of children.

➤ Systemic recognition of the needs of parents of children with disabilities for **respite and support** is a significant contribution to social inclusion of these families. **This is an important field for further development of services and modalities of support.**

➤ **Parents and children are associates.** The power of parents' and children's participation, of the built partnership and engagement of all actors are visible even on a small population that participated in piloting temporary fostering as service. Activities on their further inclusion can certainly develop new solutions for the children and families.