PARENTAL NEEDS AND PROVISION OF SUPPORT SERVICES TO PARENTS RAISING CHILDREN IN DIFFICULT CIRCUMSTANCES

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LITERATURE REVIEW

The child's well-being is determined by both social context and family environment, which makes parenting support extremely important, particularly when it comes to parents who are raising their children in difficult circumstances. In addition to providing direct parenting support, it is equally important to influence the parenting context and develop comprehensive measures that will facilitate the raising of children (Moran et al., 2004). Thus, we differentiate between parenting support programs aimed at parenting skills and competences and family support programs aimed at wider social conditions in which children are raised, including measures in the areas of combating poverty and social exclusion, housing, health, education, employment, etc. (Daly et al., 2015).

The upbringing and nurturing of children always presents parents with a number of demands and challenges, but those demands and challenges are multiple times higher in the case of parents who raise their children in difficult circumstances, such as adolescent parents, parents from one-parent families, parents with disabilities, parents of children with developmental disabilities and lower socioeconomic status parents. Research has shown that such parents are more often faced with higher levels of stress, anxious and depressive symptoms, somatic disorders, emotional exhaustion and exhibit more burn-out symptoms and lower life satisfaction (e.g. Brooks-Gunn & Duncan, 1997; McLoyd, 1998; Cairney et al., 1999, 2003; Lipman et al., 2001; Weiss, 2002; Liao, 2003; Manuel et al., 2003; Hassal et al., 2005; Cheshire et al., 2010; Resch et al., 2010; Parker et al., 2011). Although these circumstances may present risks to the child's development, it is important to note that the mere existence of risks, such as the parents' age or disability, does not necessarily lead to worse outcomes for their children and that the worse outcomes may actually appear due to the lack of adequate support and insufficient access to services of those parents (e.g. Kirshbaum & Olkin, 2002; Aunos et al., 2008). This is why the existence and use of parenting and family support programs is of such importance to parents who raise children in difficult circumstances. For these parent groups, it is important to have available the "standard" parenting support programs focused on improving their functioning as parents, their parenting skills and relationship with the child, as well as promoting the child's well-being and development. Additionally, the low socioeconomic status and social exclusion of these parent groups have proven to be a major problem, indicating the importance of family policies, as well as policies in the labor market and within the social welfare system related to combating poverty and social exclusion. This applies to all parent groups at risk, but each group is also confronted with additional specific difficulties and therefore has needs for specific parenting and family support programs. These specific difficulties and needs are described herein.

Teen-age parents are often faced with several specific problems. First, there is the problem of identity diffusion, meaning that they are going through the so called dual developmental crisis, since the developmental phase of adolescence conflicts with the role requirements of early parenting (Sadler & Catrone, 1993). Second, during the first three years, adolescent mothers frequently exhibit a significantly lower level of mental health, that is, a higher level of depression than older mothers (Liao, 2003) and can have more difficulties with trust and lack of independence as well as lower self-esteem when compared with adult parents (Osofsky et al., 1993 in Letourneau et al., 2004). Third, it is more likely that adolescent mothers will be exposed to socioeconomic deprivation and lack of social and human capital, meaning that they often have limited social support options (Moffitt et al., 2002). In view of all of the above, including that teen-age mothers may demonstrate less understanding of the child's development and lower parenting skills, this may hinder their parental role. Research studies have shown that adolescent mothers are characterized by lower breastfeeding rates (Hamlyn et al., 2002) and that they give less attention to their child, engage the child in less verbal interaction and are less responsive to their child's needs, display more punitive attitudes toward their child, perceive their child's temperament as being more difficult and are at higher risk of abusing their child (for review, see Letourneau et al., 2004). All of the above may have negative impacts on children's outcomes. For instance, research has shown that children of adolescent parents have a higher incidence of emotional and behavioral problems and higher rates of illnesses, accidents and injuries (Moffitt et al., 2002). They exhibit more learning problems (East & Felice, 1990) and achieve lower educational outcomes (Moffitt et al., 2002). In addition to support programs, this parent group can benefit from prevention programs because social environment factors, such as the education system (e.g. provision of school-based health education), community (e.g. social norms related to sexual activity, peer and media influences) and social conditions (e.g. experience of childhood poverty, employment prospects, housing and social conditions), may contribute to a higher or lower rate of teenage pregnancies (Harden et al, 2006). Prevention programs most often involve interventions in the form of informing and educating youth about sexuality and responsible sexual behavior, improving their self-esteem and other skills (e.g. trust in relationships, decision-making and communication of decisions), programs based on advocating and promoting abstinence, as well as birth control information and availability programs (Swann et al, 2003). Youth programs focused on building their self-esteem, including volunteering work, educational and vocational support, health care, sports and arts activities, etc. have shown to be most effective in the prevention of teenage pregnancies. (DiCenso et al., 2002; Swann et al., 2003; Kirby, 2007). When it comes to support programs for this parent group, in addition to standard support programs, it is also important to develop more intensive interventions, such as programs related to antenatal care, career development, educational support and services, housing, accessible preschool education programs, etc. (HDA, 2004; Barlow et al., 2012), as well as programs aimed at strengthening the participation and role of fathers in childcare (Bunting & McAuley, 2004).

Numerous foreign research studies have shown that one-parent families also encounter a series of significant socioeconomic and health problems. Mothers in one-parent families exhibit higher rates of chronic diseases and serious health problems (Baker, 2002) and higher levels of depression and anxiousness (Cairney et al., 1999, 2003; Lipman et al., 2001). As they carry the primary responsibility for children alone, one-parent families also encounter increased demands arising from the role requirement of simultaneous parenthood and labor market participation (see e.g. OECD, 2011; Cook, 2012a; Minnotte, 2012), have more difficulties in finding employment (Mattingly et al., 2011) and are more likely to be unemployed (OECD, 2011.), live in poverty and material deprivation (Amato, 2005; OECD, 2011). They more frequently encounter a lack of social support (Cairney et al., 2003), particularly difficulties in organizing childcare (Cook 2012a; 2012b). Research projects carried out in Croatia (UNDP, 2006; Raboteg-Šarić et al., 2003) additionally confirm the findings about unfavorable living conditions of one-parent families, as well as the lack of support (Raboteg-Šarić & Pećnik, 2005) and existence of discrimination against one-parent families (Raboteg-Šarić & Pećnik, 2010). The listed difficulties may reflect on the quality of parental behavior and result in negative outcomes for children. Research has shown that children from one-parent families are more likely to experience cognitive, emotional and social problems (for review, see e.g. Amato, 2005) and are more likely to have lower educational outcomes and leave school earlier than children from two-parent families (for review, see Pong et al., 2003). A father's involvement in the life of his child has shown to be a protective factor for both the child's and mother's well-being (Amato & Gilbreth, 1999; Jackson et al., 2013; Choi et al., 2014). Therefore, the support system for one-parent families should first and foremost include measures to facilitate the combining of family obligations and paid work (see e.g. Esping-Andersen, 2006a; 2006b), which is primarily related to the availability of preschool and school programs (Burstrom et al., 2010; OECD, 2011; Cook, 2012a; 2012b). There is also evidence that this population can benefit from parenting programs aimed at assisting parents in improving children’s post-divorce adjustment through reduced interparental conflict and their more active involvement in childcare (Fackrell et al., 2011; Schramm & McCaulley, 2012). Finally, programs intended only for non-custodial divorced fathers have also shown to be successful (Cookston at el., 2006).

Parents with disabilities, particularly parents with intellectual disabilities, are one of the most-at-risk parent groups because they lack the necessary support and are faced with many prejudices, such as being perceived as incapable of properly caring for their children, and are the group of parents at most risk of losing custody (Murphy & Feldman, 2002; Booth & Booth, 2005; Morris & Wates, 2006). The present literature points to a consensus that there is no reliable relationship between parental disability and the success of their parenting, as well as that the mere existence of parental disability is not a determining factor for children's difficulties. Factors related to problematic parenting behaviors of persons with disabilities are generally identical to those found in the general population (Kirshbaum & Olkin 2002; Aunos et al., 2008). Research shows that parents with disabilities generally experience problems related to socioeconomic conditions due to their unemployment and the inadequate benefits shemes (Ehlers-Flint, 2002; Morris & Wates, 2006) and health-related conditions (Aunos et al, 2008; O’Keeffe & O’Hara, 2008; McGaw et al., 2007), as well as the absence of social support reflected in negative attitudes of the wider community and service providers (Murphy & Feldman, 2002; Aunos & Feldman, 2002) and are characterized by restricted social networks (Kroese et al., 2002) and social isolation (Ehlers-Flint, 2002; Feldman et al., 2002; O’Keeffe & O’Hara, 2008). Further, they encounter problems related to finding available and affordable adaptive parenting equipment, lack of transportation and disability access issues (Kirshbaum & Olkin, 2002), as well as a series of obstacles related to court proceedings for custody of their children (Booth & Booth, 2005). Studies also show that, with appropriate support, parents with disabilities can adequately meet the child's needs (Kirshbaum & Olkin, 2002; Starke et al., 2013). In general, the support available to parents with disabilities focuses on developing parenting skills and providing services that facilitate their parental role, with a special focus on "compensating" for those parenting segments where the disability limits the provision of childcare, thus enabling them to fulfill their parenting responsibilities. Services most frequently include children's day-care services, respite care, co-parents or mentor parents, home-based parenting training programs, assistance in money management, domestic work, etc. Technological support is also important, whether it is provided in the form of infant equipment adapted to the needs of disabled parents (e.g. adaptive cradle and cooking and feeding appliances) or a "step-by-step" guide to parenting (Lightfoot & LaLiberte, 2011). Evaluations point to the efficacy of programs providing coverage for adaptive parenting equipment (for review, see e.g. Kirshbaum & Olkin, 2002), which have positive impacts on parent-child interactions, reduce difficulties and pain related to everyday childcare, while at the same time protect the parent from new injuries and secondary complications. With regard to other services focused on the development of parenting skills, those services that are held at the beneficiary's home and those employing a behavioral approach have shown to be successful (for systematic analysis, see Wade et al., 2008; Coren et al., 2010; Wilson et al., 2014). It is also important to adapt educational materials to the needs of parents, such as visual manuals and audio instructions (Llewellyn et al., 2002; Wade et al., 2008). Additionally, this parent group should have access to programs aimed at strengthening their informal social support network (McGaw et al., 2002) and advocating the rights of parents with intellectual disabilities (Tarleton, 2007).

Parents of children with developmental disabilities are also faced with higher demands and challenges in childcare. They can feel more time-pressured in meeting their child's needs because of frequent visits to doctors (Green, 2003), performing therapy exercises with the child, supporting the child's mobility, etc. (Whittingham et al., 2010). They are unable to plan family and non-family activities as it all depends on how the child feels at that moment (Resch et al., 2010). They can also feel stigmatized because of the child (Pim, 1996) and experience negative reactions caused by the child's behavior in public (Resch et al., 2010), as well as accusations that they are responsible for the child's problems (Green, 2003). Further, there is the constant struggle to keep children included in the community, kindergartens and schools (Green, 2003; Resch et al., 2010), as well as concerns about the child's future when parents are no longer here (Green, 2003; Resch et al., 2010; Whittingham et al., 2010). Families of children with developmental disabilities may also be more vulnerable financially as they can devote less time to work (Hassal et al., 2005; Resch et al., 2010) and, in comparison with other families, have higher costs for their child's services and related transportation (Whittingham et al., 2010; Pećnik, 2013). This parent group is characterized by their greater need for professional assistance (Whittingham et al., 2010; Pećnik, 2013) and more positive attitudes towards such assistance (Pećnik, 2013); however, studies show they are often dissatisfied by the lack of understanding exhibited by professionals and by poor functioning of the service organization and management (Leutar et al., 2008; Resch et al., 2010; Pećnik, 2013). There are very few evaluations of interventions within this family group because interventions were mostly focused on the child and its psychological and physical development, instead of the parents or family as a whole (Pećnik, 2013). Family-centered interventions have shown to be particularly successful (Dunst et al., 2007; Dempsey & Keen, 2008) and elements of such practices are increasingly being incorporated in today's interventions (Dunst, 2002; Espe-Sherwindt, 2008). Moreover, a specific requirement of these parent groups is also the need for the respite care services. Their success is based on reducing parenting stress and distraction (Mullins et al., 2002; review in Strunk, 2010) as well as on providing opportunities for children and youth with developmental disabilities to interact with their peers and to achieve a certain level of independence (Merriman & Canavan, 2007).

The effects of growing up in poverty have been studied for a number of years and numerous studies have shown a strong link between the family's socioeconomic status and the child's development and achievement. Studies have consistently shown that the socioeconomic status of the family in which the child is growing up is associated with its cognitive functioning (Duncan et al., 1994; Brooks-Gunn & Duncan, 1997; McLoyd, 1998; Entwisle & Alexander, 1999; Bradley & Corwyn, 2002) and school achievements (Haveman & Wolf, 1995; Brooks-Gunn & Duncan, 1997; Bradley & Corwyn, 2002; European Commission, 2008; for Croatia: Gregurović & Kuti, 2009). Factors contributing to negative effects of childhood poverty include a lower health status (Guo & Mullan Harris, 2000; Šućur et al., 2015), poor nutrition (Bradley & Corwyn, 2002; European Commission, 2008; for Croatia: Šućur et al., 2015), poor housing conditions (McLoyd, 1998; Bradley & Corwyn, 2002; European Commission, 2008; Šućur et al., 2015), less developmentally-stimulating materials in the family home (Duncan et al., 1994; Guo and Mullan Harris, 2000; Šućur et al., 2013), inadequate parental expectations (Duncan et al., 1994; Guo & Mullan Harris, 2000) impaired family and neighborhood relations (Pećnik, 2013) as well as the lack of support and services (Pećnik, 2013.; Šućur et al., 2015). The most evaluated support programs are the U.S. based early development compensatory programs that involve intensive work with children in preschool programs, work with parents during home-visits and health services, and which have shown long-term benefits (review in Karoly et al., 1998; review in Vandell, 2004; Reynolds et al., 2004; review in Barnett & Belfield, 2006). Some factors that contribute to the successfulness of parenting support programs include: assistance to parents with challenges in daily life (Breitkreuz et al., 2011; Furlong and McGilloway, 2014); establishing a relationship with parents before the start of the program (Furlong and McGilloway, 2014) and continuing the support after intervention (McGilloway, 2012). This group of parents is most directly in need of adequate cash allowances as well as education and employment services.

SUMMARY OF FOCUS GROUPS WITH PARENTS AND SERVICE PROVIDERS

In order to complement the findings from international literature with insights as to the needs and support services for parents who are raising children in difficult circumstances in Croatia, we have carried out a field research using focus groups. Participants were parents of children with developmental disabilities, parents with disabilities, low socioeconomic status parents, parents from one-parent families, adolescent parents, and professionals.

The aim of this research was to identify the needs for parenting support services and collect experiences with community-based services for parents and children - from the perspective of parents, providers of social welfare services and civil society organizations (hereinafter: CSOs). Research questions were focused on problems and needs for fulfilling the parental role, availability of informal and formal parenting support and experiences in using services and programs intended for parents and children. The research was carried out in June 2015 using seven focus groups with the total of 38 parents (of which seven fathers) in three smaller settlements in Slavonia and in Osijek, Zagreb and Pula. Participants were parents who are members and/or beneficiaries of programs organized by approximately ten CSOs and beneficiaries of the SWC[1] or family centers. Focus groups were established according to their target theme, namely teen-age mothers, parents from one-parent families, parents of children with developmental disabilities, parents with disabilities, low socioeconomic status parents and parents with three or more children. It often happened that a member of one focus group had characteristics that could place him/her into one or more of the other vulnerable parent groups in question, which reflects the heterogeneity of parental characteristics, experiences and life circumstances, as well as the artificiality of categorization into vulnerable parent groups according to just one of their characteristics. For instance, members of the focus group on mothers with disabilities included several single mothers, mothers who also had children with developmental disabilities and/or a lower socioeconomic status. In addition to biological mothers and fathers, one adoptive mother and two foster guardians participated in focus groups.

The views regarding activities aimed at meeting parental needs related to parenting support were collected from professionals from around 20 social welfare centers (social workers, psychologists, social pedagogues and lawyers who in their professional capacity have contacts with parents from the listed groups) through four focus groups. The focus groups included professionals from family centers (branch offices of SWCs) in the following counties: Virovitica-Podravina, Osijek-Baranja, Vukovar-Srijem and Istria. The focus groups were held in November 2014 in Virovitica, Osijek and Vinkovci, and in March 2015 in Pula. Concurrently, four focus groups were held in the same towns for civil sector providers of services (representatives of 21 CSOs). The research questions were related to social services which are (or can be) received by parents and children from a particular group, followed by unavailable yet required services for groups of vulnerable families with under-age children and views regarding what social services are needed by parents and children from vulnerable families and how to best meet them.

The findings of analysis of qualitative data collected in these focus groups are summarized below. The results are organized according to groups of parents raising children in difficult circumstances: (1) teen-age parents, (2) parents from one-parent

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[1] SWC – Social Welfare Center, SWC/FC – Family Center, a branch office of the Social Welfare Center

families, (3) parents of children with developmental disabilities, (4) parents with disabilities, and (5) lower socioeconomic status parents.

Teen-age parents

This focus group comprised 5 teen-age mothers placed in institutions, i.e. outside their family. As problems encountered in child rearing, these mothers cited the demanding nature of childcare, particularly when the child is ill or non-cooperative. They also complained that parenthood is preventing them from going out at night and restricts the fulfillment of their own interests in general. Furthermore, as one of the problems in childcare, they mentioned failure to recognize the child's needs and, in this regard, some mothers do not react to the crying of their child in order not to "spoil" it too much. External factors include the issue of stigmatization due to being placed in an institution and fear of not having support after leaving it.

Mothers from the focus group are heterogeneous with regard to the level of support they have, but the majority of them mentioned a lack of support from own family and poor informal support in general. Some mothers stated that they have support from the child's father and his family, by the institution in which they live, as well as by female professionals working in the institution (social worker, psychologist, nurse), while experiences with their respective Social Welfare Center (SWC) are varied: on the one hand, they list examples of positive experiences and, on the other, issues regarding the lack of appropriate support.

The focus group with SWC employees showed that the professionals in question rarely have contact with this population of mothers. They are most often contacted by pregnant teen-age girls regarding their expert opinion on the conclusion of marriage for minors. The SWC employees consider that pregnant teen-agers and teen-age mothers generally require a low level of support; however, this depends on the level of informal support available to them, whereas those with no support and/or placed in institutions require long-term and comprehensive support. Additionally, the Family Center (FC) employees pointed out the issue of unclear roles which can occur in a family if the grandmother takes over the role of the child's mother, as well as the need for support with regard to planning abortion or adoption.

When it comes to available community-based services, SWC and FC professionals point out that they are based on the Family Act and Social Welfare Act and include counseling services, accommodation services and supervision over the execution of parental care. They consider it is important to adapt education services, i.e. school attendance, to the needs of teen-age pregnant girls and mothers, as well as to develop high-school-based prevention activities related to sexuality, contraception, etc. The program New Baby (Nova Beba) and the Caritas Counseling Center for Pregnant Women were mentioned as examples of providing good parental support. The program New Baby was limited in both scope and time. In general, professionals identified problems related to the distance that parents from smaller towns and villages must travel to access services, non-cooperation of local communities with mobile teams and their failure to recognize which programs are needed. In view of this, they suggest the introduction of phone and online counseling services.

Professionals consider that there is a lack of parenting support services for teen-age mothers. This primarily relates to the need for prevention of unwanted pregnancies by introducing the civic education curriculum in schools. Furthermore, it relates to the need to provide support during pregnancy, which would include counseling centers for pregnant teen-age s and teen-age mothers within the health care system, courses for pregnant women and future mothers that would be more adapted to the needs of teen-age mothers. Professionals suggest that, without such counseling centers, care providers would not even know about those pregnant teen-agers before they give birth. They also highlighted the need to work with the whole family, and proposed to include volunteers who would provide practical assistance in everyday life. According to the proposal, the measure of supervision over the execution of parental care (supervision order) should be supplemented with support groups for teen-age mothers as well as their parents. Finally, professionals recognize the need for providing accommodation even after the child's first year of life, as well as the option of placing the mother and child in a foster family. Their opinion is that the SWC should be informed about all existing services.

Members of CSOs underlined the heterogeneity of the population of teen-age mothers in view of their problems that may be quite complex, such as addiction, distrust in institutions, etc. They recognize the lack of services available to teen-age mothers, as well as the lack of CSOs involved in prevention of teenage pregnancies and providing assistance to pregnant teen-age s and teen-age mothers, which usually rely on the SWC and are mainly of religious character. They find that reasons for the lack of services lie in the fact that teen-age mothers are not a sizeable population and that pregnant teen-agers are unwilling to seek help because of the fear of judgment and the impression that they do not need the parenting education course. Professionals underlined the need to educate parents, their families and communities. In their opinion, it is important to raise awareness in schools and local communities because how teen-age mothers will be accepted depends on the public's attitude toward them. Moreover, both the members of CSOs and professionals stressed the need to provide information and support to those pregnant teen-agers who wish to terminate their pregnancy as well as the need to provide long-term accommodation and counseling services to pregnant teenagers with no support from their family. In their view, this could be in the form of a foster/homes or residential communities.

One-parent families

This focus group comprised 8 mothers and 2 fathers. When it comes to encountered problems, respondents first mentioned problems related to poor living conditions, unemployment and their subtenant status. Second, they encounter a lack of understanding at work with regard to their absence when the child has health problems. One father even got fired for taking too much sick leave. Third, they have no one to share their parenting decisions with or to check whether their decision was correct or not. Finally, they observe situations in which, for example, the oldest son takes over the father's role, which reflects negatively on his school performance. With regard to the existing services, respondents point out the SWC's lack of support, while also being concerned that the Center's interventions will result in them losing custody. The proposed services listed by parents include: the need for professional parenting assistance in order to more adequately respond to the child's needs, particularly in families experiencing domestic violence; the need for a program that would enable parents to establish cooperative co-parenting arrangements and reduce negative effects of divorce on children. It is further proposed to introduce remedial school classes for these children, establish a parenting training course aimed at providing learning assistance for children and having more activities for children in the community.

The informal support available to single parents varies. Some mention the support of extended family members, friends with similar experiences, ex-partners and their parents. However, a significant number of parents have no support, particularly those without their family's support. This makes employment, and taking care of one's own health, more difficult. The forms of formal support include: professional school staff, such as SEN educationalists (defectologists) or speech therapists who talk with the child and parents, professionals from the family center who provide individual counseling in the case of problems with children, and CSOs that provide learning assistance for children (although such programs are usually too short, while FCs and SWCs fail to properly inform users about the existing services). A number of parents show resentment toward the SWC's work, while a general distrust in professionals and CSOs is evident. The parents' proposals for improving services intended for them are: organizing meetings, workshops and recreational activities with other parents of similar age, with parallel activities for children without a babysitter; organized learning assistance for children; support for children at school in order to prevent stigmatization by teachers; organizing free and continuous sports, creative and socialization workshops for children; creating a special school fund for expenses related to children whose parents are in a vulnerable situation; and that the class teacher should deliver written information because of insufficient time to ask all the questions during parent-teacher meetings. Parents consider that SWC employees should change their attitude towards them because they feel stigmatized.

The SWC and FC professionals consider that the needs of single parents are: support groups, supervision over the execution of parental care (measure from the Family Act) and longer working hours of kindergartens. With regard to available services, they list counseling services at the FC, while the SWC has no special services for single parents, but includes them in the existing services, when required. Some examples of the mentioned individual programs include: program for strengthening parental competences of parents from one-parent families; kindergartens with extended working time and volunteers to babysit children while parents work.

Representatives of CSOs were not informed about programs for these parents and also consider that they are included in general family services. Additionally, they mentioned that parents from one-parent families, when necessary, use the services of CSOs that provide financial support and those that provide assistance to victims of violence.

Parents with disabilities[2]

Depending on the type of disability, parents with disabilities experience various problems in fulfilling their parenting role. Mothers with motoric disabilities encounter the problem of not being able to lift or carry their child or accompany the child to activities. Mothers with hearing or visual impairments have difficulties in helping their children with their homework, while mothers with hearing impairments also fear they will not hear the child when it cries. In any case, parents talked about fears that their disability is

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[2] 8 participants at the Ombudswoman's office + 1 in Pula = 9 participants with physical disabilities, but also 2 in the group of poor/with intellectual disabilities?

negatively affecting the development of the child's personality, such as children having to assume responsibilities earlier than their peers. In terms of the external factors encountered by parents, respondents mentioned prejudice and comments that they should not be parents and that children will have developmental problems, while parents with disabilities living in rural areas are particularly isolated. As regards the social welfare system, parents underlined problems related to the lack of information about their rights and non-transparent criteria for evaluating the impact of the parent's health condition on his/her parenting skills. With regard to their needs, they listed: practical assistance in everyday life, physical disability-related adaptations in their environment, improved availability of sign language interpreters, providing information about their rights and available support programs, and raising awareness of the public and professionals about the proper treatment of persons with disabilities.

When it comes to support, most parents are supported by their partner, but in some cases that support is lacking due to the partner's death, relationship break-up or alcohol addiction. The next most often mentioned source of informal support are grandmothers. However, it is important to avoid situations where the child's grandmother takes over all childcare responsibilities and in that way weakens the mother's feelings of parental competence and autonomy, or the mother accepts the situation and eventually has less and less contact with the child. Therefore, it is important to provide assistance in the way that strengthens parental competence and participation. In this regard, parents pointed out the need for systematic assistance because the 10-minute daily visit from the community nurse is insufficient. The other mentioned providers of informal support are friends and neighbors. These parents receive great assistance from CSOs of persons with disabilities, where they can obtain information about their rights, a sighted companion, interpreter, personal assistant, while some parents are also employed in such CSOs. Additionally, there is an example of cooperation where the FC psychologist provides counseling services for members at the association's premises. Experiences with the health care and education systems are varied, but mostly negative. Their personal experiences include, among others, when a gynaecologist said to the mother that it is wrong for a person with disability to want a child because it is too risky, medical staff thinking that the baby was born with the Down syndrome because of the mother's disability, a pediatrician not even trying to communicate with the mother in a way that would be understandable to her, emergency medical staff refusing to transport the mother in a wheelchair with her son, school staff ignoring peer bullying of the blind mother's child, and the existence of physical barriers preventing access to the school. Parents also listed positive experiences from the course for pregnant women, in the maternity ward, as well as with kindergarten and school teachers.

In any case, parents proposed the following: removing physical barriers in the environment, training of sign language interpreters, additional services for parents, children and families aimed at providing support to children and adults, prevention of the child's separation from family, and providing systematic assistance to mothers because the 10-minute daily visit from the community nurse is insufficient.

The SWC and FC professionals state that parents with disabilities mainly contact the SWC with regard to cash allowances, when the parenting issues are not discussed. They also receive substantial support from CSOs, but also in a lesser extent when it comes to motherhood. Professionals mention individual examples where mothers with disabilities participated in a common parenting support program, but agree that there is a need for targeted services as well. They recognize that the fact that mothers are in fear of their child being taken away from them and feel lost and helpless might also be a problem. Although specific services for these parents are very rare, there is a growing awareness within SWCs of the need to provide parenting support programs for parents with disabilities in cooperation with CSOs and FCs. With regard to available services, professionals listed counseling and supervision of executing the parental care by the SWC, and separation of children from family for parents with intellectual disabilities and psychiatric diagnoses. Likewise, they consider there is a lack of professional supervisors of parental care with regard to the current needs. Professionals suggest: services of everyday practical assistance as well as learning assistance for children provided by CSOs; parenting support programs for persons with disabilities in partnership between SWCs, FCs and CSOs; training of professionals with regard to treatment of persons with disabilities.

Representatives of CSOs state that parents with disabilities are not recognized as a special group of users who require specific assistance, and give examples of several difficulties in the work of CSOs. Although there are a number of disability CSOs, they are not easily accessible in smaller towns and villages, while the remaining issues are the public's lack of information on the existing services and lack of interest of some users.

Parents of children with developmental disabilities

The eight participants in this focus group described a number of increased demands in the care of children with special needs. First, parents are burdened and stressed by the child's actions and behaviors, such as screaming, not talking, not sleeping, etc. This is followed by constant therapy activities with the child in order to ensure better effects of early childhood intervention, which often includes travelling to distant towns for rehabilitation sessions several times a week. They feel that their private life has come to a complete stop and that they have fully adjusted to the child's needs. In addition, they experience a lack of understanding at their workplace by managers and colleagues because of frequently being absent. They feel a general lack of understanding from the wider community, while they perceive prejudice and comments made by outsiders and employees in health care, education and social welfare systems as an extreme source of stress. They point out problems and obstacles in exercising the right to early intervention and inclusive education process. Parents also described their constant struggle to keep children in kindergartens and schools, while feeling that the system is not on the side of the child and parents, and does not promote equality and equal opportunities. They describe instances when educational institutions, instead of removing them, established barriers to the child's full social inclusion. The problem is that principals, teachers and professional school staff members are consistently trying to transfer the child to a special school or separate it in a special class, which has no common lectures with children from regular programs. Schools do not provide information on possibilities of including children with developmental disabilities in the educational process, for instance, explaining the meaning of a special class, adjusted or special program, because when parents are uninformed, they can be manipulated. Some parents mentioned an additional problem related to their children not being accepted by their peers and even cases of peer violence towards the child, while the school does nothing to solve the problem, fails to see the real reasons or, if the school applies measures like lecturing on violence, they are ineffective. There is a general lack of information about their rights and assistance programs offered by institutions, while the main source of information for parents is the internet and informal conversations with other parents. In such circumstances, they are often confronted with contradictory information from different sources, which is an additional source of stress. They also perceived the lack of information in the health care system where no one instructs parents as to which medical exams the child should take, as well as in the social welfare system, and the lack of communication within and between the two systems. Moreover, parents are concerned that taking care of a child with developmental disabilities affects their relationship with other children, feeling they are depriving them of something.

They list their husband as the main and sometimes the only source of informal support, although mothers at times feel like they are carrying all the burden of childcare and household work. Other than husbands, support is provided by the child's grandparents, friends, and in some cases even by parents of their child's classmates. Self-organization of parents into different CSOs is frequent, wherein they can receive and provide assistance, obtain information, receive emotional support, advocate for improving the status of children with developmental disabilities, organize various lectures and meetings, provide practical assistance such as transport by van, get assistance from volunteers, speech therapists, psychologists, etc. who carry out activities with children, organize humanitarian actions and collect donations for their association's activities and submit different projects for funding.

With regard to formal support, there are some positive experiences with kindergarten teachers who implemented a successful inclusion and with the work of speech therapists and SEN educationalists that helped in the child's speech development. However, experiences are predominantly negative. Parents underline their dissatisfaction with the way how they were informed about child's disability in the maternity ward, low availability of speech therapists and SEN educationalists, services provided by specialized professionals and restriction of their right to reimbursement of travel expenses for different therapy sessions. In the field of education, they mentioned cases when kindergartens refused to enroll their children, and parents managed to enroll their children only after the Education and Teacher Training Agency threatened to sue the kindergarten. Likewise, they experienced problems in enrolling children into school, because schools routinely instruct parents to enroll their children into a specialized school, which is not located in their place of residence. Schools are lacking teaching assistants. Teachers themselves feel they lack knowledge to work with children with developmental disabilities, but do not want to attend training courses. When it comes to education and employment of children with developmental disabilities, the expectations of both professionals and parents are generally too low. The education system does not encourage the idea that one day they could be independent, reflecting the attitude that those children do not need to attend school. All of the above, together with the mentioned non-acceptance of children by teachers who do not want them in their class and by other children, especially when it comes to children placed in special classes, causes parental resentment, distrust and feelings of disappointment and of being alone in their fight, not supported by anyone.

The proposals provided by parents include: raising awareness of the wider community in order to establish the acceptance of differences as a cornerstone for a healthy, inclusive community; training maternity ward personnel on how to inform parents that their child has developmental disabilities; reducing the frequency of expert evaluations in cases when the child's condition is highly unlikely to change; training teachers and other professional school staff regarding the options for children and their needs, as well as on methods for their inclusion in the education process; psychological support for parents; respite care services.

The SWC professionals consider that these parents require additional support, while underlining that parents living in rural areas are in a substantially worse position because of the reduced number of available services, lack of understanding and stigmatization by the local community and are more frequently faced with the child's separation from family, so that it may be placed in educational institutions in larger cities. Professionals consider that the practice of separating the child from family can be explained by the lack of teaching assistants, lack of information by kindergarten and school teachers and expert personnel about how the adjusted program works, and not being interested in educating themselves. Professionals warn about the need to support parents in their fight for the child's inclusion in regular school, because parents often get frightened and give up because of so many obstacles. They also recognize the need to support parents in their relationship and also to support other children in the family, as well as the need for respite care. They listed the following services for parents of children with developmental disabilities: accommodation in a social welfare institution when the child leaves his or her home for schooling; support groups for families with children with developmental disabilities, including joint activities of parents and children, support programs for parents of preschool-age children with developmental disabilities implemented by FCs, CSOs and specially trained kindergarten staff, to which parents are referred also by SWCs, as well as the speech therapy counseling center at the FC. They also listed a positive example of deinstitutionalization where specialized institutions for accommodation of children with developmental disabilities are transformed into community service centers. They recognize the lack of services aimed at empowering parents and the lack of practical parenting assistance and suggest the following: continuation of the Growing Up Together for strengthening parents used by professionals from kindergartens; rehabilitation centers, family centers, CSOs and other, expanding the availability of the program by including new service providers, assistance to other children in the family; more involvement of CSOs in assisting children and parents, linking with other service providers and state institutions that provide support; improved use of volunteers in providing learning assistance; mobile expert teams for families in rural areas and mobile volunteer teams for informing about services and promoting their use, together with reimbursement of travel expenses for participating in services; and professional assistance from speech therapists.

Members of CSOs often point out they receive no support because it is unavailable, but also because parents are uninformed about such support services, high transportation costs to access a service, as well as because of inertness of parents. They mentioned that parents can turn to CSOs providing professional assistance for children with developmental disabilities, CSOs of persons with disabilities according to the type of disability, and to CSOs providing general assistance to families in need. However, the problem is that there is no list of CSOs and it is hard to find information on who provides what kind of assistance and therefore CSOs should be more active in promoting own services and increasing their availability. Similarly as other participants in focus groups, association members underline the issue that CSOs are mainly concentrated in larger cities and unavailable to those from rural areas. When it comes to the inertness of parents, they explain it is hard to motivate parents to seek assistance because they are preoccupied with other concerns and roles, economic situation and different institutions, of which each has its own work plan and program for the child.

Lower socioeconomic status parents

Parents with a lower socioeconomic status are exposed to higher levels of stress caused by problems in providing for their family's basic needs, the child's problems at school and lack of support in the family and community. This focus group highlighted their financial problems, unfavorable living and housing conditions and conflicts between children because of confined space. Furthermore, children have problems in coping with the school curriculum, and parents do not know how to help their children to do homework and study for school. They cannot provide internet access and have difficulties in buying school books for their children. They consider that the elementary school program is too demanding and unsuitable. At school, children are exposed to physical and psychological peer violence, while there are no activities or even interest of teachers to efficiently resolve violence between children. Children from lower socioeconomic status families are discriminated against by teachers and other children. For example, their children are not invited into homes of richer kids; other children's parents refuse that their child should sit next to poor children. This leads to the child becoming withdrawn, uncommunicative and refuses to go to school trips. Parents mentioned that their children often suffer from hyperactivity and behavioral problems, and that they feel helpless in their parental role and incompetent in directing the child's behavior. Further, they encounter problems in managing several children, particularly if one child is ill or has developmental problems and the other exhibits demanding behavior. They also observed judgment and lack of understanding from the community that criticizes the child's behavior, thus causing stress for parents.

The majority of them responded that no one helps them in child care. Only one mother is supported by her husband, while two mothers are supported by their parents. Some parents also mentioned the support of a brother, neighbor and the oldest daughter. Parents find that school is the most available source of support, but sometimes also a source of stress. In their opinion, teachers should apply a more individualized approach to children, particularly when that is recommended by the school professional staff. They observed that teachers give more attention to the needs and interests of the most successful students and neglect the needs of those less successful and that they are biased and favor certain children over others, whereas lower socioeconomic status children are predisposed for lower grades. The only available school service for learning assistance is remedial classes, but parents point out that they are insufficient. On the other hand, some parents shared positive experiences and examples of successful cooperation between parents and the teacher that were empowering for parents and improved the child's behavior and learning. In particular, parents underlined the support of teachers in not allowing violence between children. When it comes to other forms of formal support, parents valued the support of professionals from the social welfare system related to the child's behavioral problems, but were also confused and frustrated because every professional who they came in contact with had his/her own opinion about the problem and possible solution, which ultimately left them feeling like they were the only ones helping their child. One father expressed his dissatisfaction with the speech therapist's work. Parents are satisfied with workshops on learning assistance organized by CSOs and FCs with the help of volunteers, but the problem is that the use of such programs may be stigmatizing because of the belief that those are only for "social cases", so some parents avoid attending them.

Parents listed the following proposals: improving the level of school services with regard to the needs, social integration and school achievements of students from lower socioeconomic status families and students with problems in coping with the school curriculum; continuing to hold learning assistance workshops; and providing psychological assistance for their child.

The SWC professionals highlighted that lower socioeconomic status families are a heterogeneous group in respect of their needs, depending on whether it comes to one-parent families, intellectually impaired parents, families with many children, families with children with behavioral problems or neighborhood families with several social problems. They recognize the need for the half-day stay service within which children are provided learning assistance and quality leisure time, but underline the low level of awareness among parents about available parenting support and professional assistance services, so parents contact them only in crisis situations. As an obstacle for a more frequent use of services, they listed stigmatization that may occur by using such services. In their opinion, CSOs should organize continuous quality programs, and SWC professionals would then refer parents to such programs. As regards available services, they primarily listed cash benefits. Parents may also contact CSOs that provide parenting support programs for all parents. Each SWC has one and the same set of services and measures prescribed by law, regardless of specific needs of users or the perceived requirements related to parenting. Lower socioeconomic status parents represent the majority of users of the half-day stay service where children are provided learning assistance and parents can receive counseling services by the SWC professional team. The providers of this service are public institutions and CSOs, while SWC employees are involved in the half-day stay through the counseling of parents. Also, professionals provided an example of an association's program consisting of educationally stimulating workshops for parental skills improvement which are held once a month and to which the SWC refers parents from families with many children. With regard to available services, they mentioned activities for parents under short-term projects and CSOs offering humanitarian aid.

Similarly, members of CSOs point out that these parents have multiple needs. With regard to available services, they listed cash benefits, providing information on the rights and entitlements, providing learning assistance and leisure time services for children, which is particularly important in cases when there are other risk-bearing circumstances and lack of support. They also highlighted the issue of limited duration of programs, their low availability in rural areas, as well as parents' hesitation to seek help, particularly in the case of parents who are without income for the first time. Similarly as SWC professionals, they confirmed that CSOs for these parents are very rare, but that parents may seek assistance from other CSOs focused on the family that can inform and refer them to the SWC. When it comes to other available services, they also listed the social store and the Red Cross.

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