



Formal and informal support for Croatian and Serbian people with disabilities and their families: A scoping review

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Introduction. Formal and informal support are important for quality of life of people with disabilities and their families. *Objective.* The aim of this paper was to (a) identify types of and satisfaction with support for Croatian and Serbian people with disabilities (PWD) and their caregivers and (b) summarise the effects of support reported by PWD and/or their caregivers in Croatia and Serbia. *Methods.* A systematic search was conducted, followed by eligibility screening of the peer-reviewed articles published from 2000 to June 2020. EBSCOhost, Hrčak, and the Serbian Citation Index [Srpski Citatni Indeks] databases were searched. We also searched the grey literature using Google Scholar and employed backward reference searching. The authors scanned articles and extracted the data related to the country, study's aim, study's design, sample, methodology, and findings. Twenty-seven studies were included in this review. *Results.* Croatian and Serbian PWD and their caregivers received informational, emotional, practical, and financial support at different degrees. They were most satisfied with informal support, while the degree of satisfaction with formal support varied. They highly valued support programs. *Conclusion.* Croatia and Serbia, in general, lack a formal support system, and informal support is the most prevalent for PWD and their caregivers. There is a need for more support programs for families of PWD.

Keywords: children with developmental disabilities, people with disabilities, caregivers of individuals with disabilities, formal support, informal support

Introduction

Social support for people with disabilities (PWD) and their families positively affects their well-being (Bishop-Fitzpatrick et al., 2018; Ekas et al., 2010), increases opportunities for fulfilling social roles, independent living, and inclusion (Leutar et al., 2020), and serves as a buffer for stress and depression (Ekas et al., 2010; Faw, 2018). Further, support for individuals with disabilities and their family members increases opportunities for fulfilling social roles, independent living, and community inclusion (Leutar & Buljevac, 2020).

In the literature, two types of social support are commonly identified: formal and informal support (Garcia et al., 2008). Formal support refers to support provided by professionals, institutions, and non-governmental organizations (NGOs) (Duvdevany & Abboud, 2003) and refers to provision of information, exercise of rights, and engagement in services and programs (Leutar et al., 2020). Informal support is provided by family members, friends, relatives, or neighbours (Leutar et al., 2007). Within these two types of support, the most common supports are informational, practical (i.e., instrumental), emotional, and financial (Keller & Honig, 2004). Informational support means that a person receives necessary information, such as information about a diagnosis, characteristics of disability, available services, rights, available resources in communities, etc. (Tétreault et al., 2014; Vanegas & Abdelrahim, 2016). Practical support refers to pragmatic advice or guidance that helps a person to do or achieve something, as well as practical aid or assistance (King et al., 2006, pp. 911). Emotional support aims to reduce social tensions, sustain family harmony, and promote a better adaptation to the child's condition (Tétreault et al., 2014). Financial support is manifested through monetary contributions, mostly from a government (Gibson & Mykitiuk, 2012).

Findings related to satisfaction with formal support (e.g., support in educational settings, support from the service providers) are not unequivocal, although many PWD and their families expressed dissatisfaction (Anderson et al., 2020; James et al., 2013; Finn & Boland, 2021; Renty & Roeyers, 2005). Many research studies showed that satisfaction with formal support varies, depending on who was providing support, what type of support was given, etc. (James et al., 2013; Renty & Roeyers, 2005). When it comes to satisfaction with informal support, previous research showed that PWD and their families were the most satisfied with the support from family members, and PWD were also satisfied with support from their friends, who are very often people with the same type of disability (Burns, 2009; Davis & Gavidia-Payne, 2009; Lippold & Guinea, 2001; Lysaght et al., 2012).

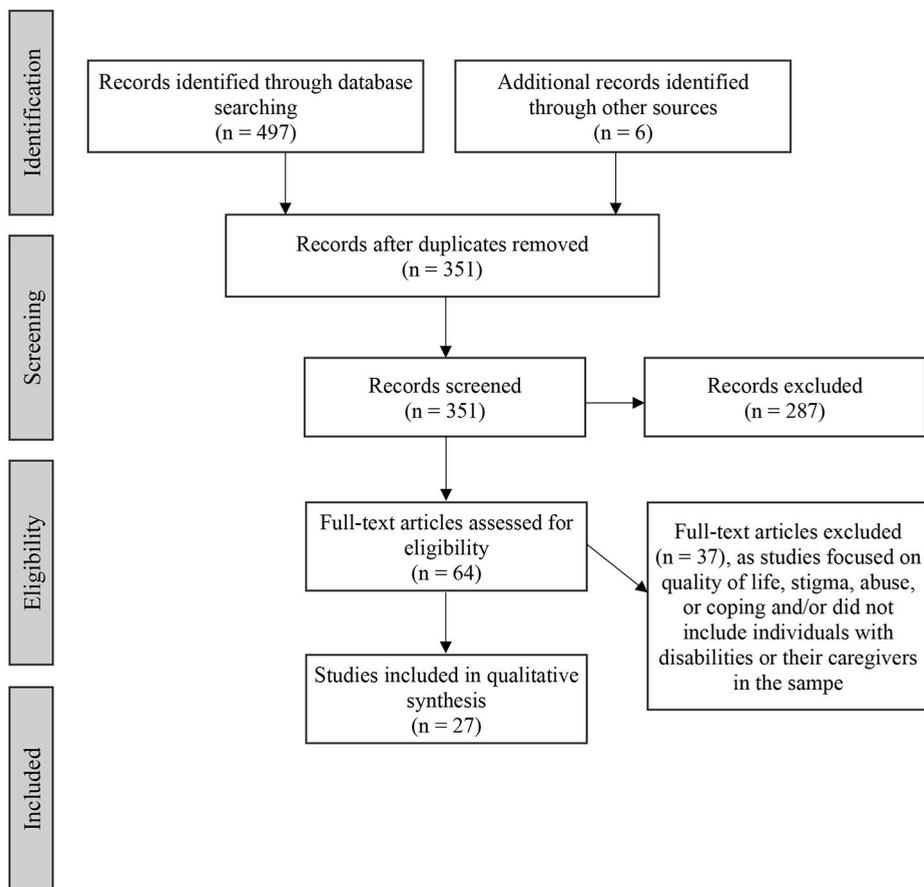
The State of Support in Croatia and Serbia

Croatia and Serbia are countries in Southeast Europe with populations of approximately four and seven million people, respectively. Croatia and Serbia were part of the civil war during the early 1990s, which significantly affected the quality of life of their citizens. For the past two decades, both countries have made efforts to adopt laws that should improve the quality of life of families of PWD, such as the 2006 United Nations Convention on the Rights of Persons with Disabilities, the Law on Social Protection, etc. As Croatia is a European Union member, some laws and strategies from the European Union have also become part of the Croatian national legal system. Although the laws were adopted, they have been rarely enforced in practice (Čolić & Kaljača, 2014; Marković, 2014; Mikuš, 2018). Various support programs are often provided by NGOs whose funds come from different governmental and non-governmental grants, and they mainly terminate when the grant ends. As systematic formal support is lacking in the majority of areas, people often need to make tremendous effort to receive it. Without adequate support, it is not surprising that some Croatian and Serbian families of PWD experienced stigma, discrimination, and social exclusion (Buljevac et al., 2020; Čolić & Milačić Vidojević, 2021).

Given the current state of support in these countries, we were interested in exploring what types of support are available to families of PWD and their satisfaction with support. Rather than evaluating laws and strategies, we analysed their lived experiences. The purpose of this review was to (a) summarise the types of and satisfaction with support reported by PWD and/or their caregivers in Croatia and Serbia and (b) summarise the effects of support reported by PWD and/or their caregivers in Croatia and Serbia. Our research questions were (a) What types of support are available to Croatian and Serbian PWD and their families? (b) To what degree are Croatian and Serbian PWD and their families satisfied with support? and (c) What are the perceived effects of support on the life of PWD and their families?

Methods

We performed a scoping review by applying the guidelines of Arksey and O'Malley (2005), such as explicit search criteria, inclusion/exclusion criteria, and a review of the studies conducted by two independent reviewers. Furthermore, we used PRISMA guidelines (see Figure 1) for reporting search strategy and identification of the studies (Moher et al., 2009).

Figure 1.*Flowchart of articles identification*

Search Strategy

First, we completed electronic searches of the EBSCOhost, Hrčak, and Serbian Citation Index [Srpski Citatni Indeks] databases to identify peer-reviewed articles. Hrčak is Croatian and the Serbian Citation Index [Srpski Citatni Indeks] is a Serbian bibliographic database. We also searched the grey literature using Google Scholar and employed backward reference searching. The search was limited to the peer-reviewed articles published from 2000 to January 2020. We used the term support as a key search term in combination with the following terms: Croatia, Serbia, autism, disability, intellectual disability, deaf or hard of hearing, blind or visual impairment, and physical disability. We performed a broad search, as we wanted to be inclusive and to hear the voices of all PWD and their caregivers in Croatia and Serbia. Second, once we located

studies, we reviewed titles and abstracts manually to assess their inclusion eligibility. Finally, we read the articles identified for inclusion after abstract review in full and included the ones that met inclusion criteria as described in the next section in a final list.

Inclusion and Exclusion Criteria

An article was included if the following criteria were met: the article (a) was published in Croatian, Serbian, or English, (b) explored support reported by PWD and/or caregivers of PWD, (c) included PWD of any age and/or caregivers of PWD, and (d) was empirical, peer-reviewed research. We excluded the studies about support from other sources (e.g., governmental reports, opinions of different professionals) and studies whose focus was other than support, such as quality of life, stigma, etc.

Data Extraction

A Microsoft Excel© database was created to extract theoretically and/or methodologically relevant data. Both authors scanned the articles and extracted the data related to the country, study's aim, study's design, sample, methodology employed, and main findings. Both authors agreed with the studies' characteristics that were extracted. We then summarised the findings and reported them via thematic analysis (Thomas & Harden, 2008).

Results

Identified Studies

We included 27 studies in the final review out of 351 identified (see Figure 1). Following the screening of the 351 articles by the title and abstract, we read 64 full-text articles and checked them for eligibility. We excluded 37 papers as they did not fit the inclusion criteria. In Table 1, we presented data from the 27 studies regarding the sample, the instruments, and the focus of the studies relevant to the support reported by families of PWD. These studies are not homogenous regarding study topic and/or methodology. For example, some studies interviewed both professionals and PWD and/or caregivers (e.g., Leutar & Marković, 2011). Some presented data not only related to support but different subjects as well, such as stigma (e.g., Buljevac et al., 2012), experience with certain programs (McConkey et al., 2013), performance and skills (e.g., Štambuk et al., 2012), and satisfaction with life (e.g., Blažeka Kokorić et al., 2012). Due to the small number of studies that explored only support, we decided to include each study that examined support at any degree, even if that was not the main aim. Therefore, in the paper, we focused solely on methodology and findings related to support reported by PWD and/or their caregivers.

Table 1
Summary of study characteristics, instruments, and aims related to support

Authors, (country)	Sample	Parent or PWD ages –Years (range and /or mean)	Child ages – Years (range and /or mean)	Instrument related to a support	Focus of the study related to support
Avramović & Žegarac (2016) (Serbia)	20 children with disabilities	7-17	N/A	Semi-structured interview “Me at the Centre”	To gain insight into the experiences of children with disabilities and their perception of the community services
Blažeka Kokorić et al. (2012) (Croatia)	391 PWD	18+	N/A	Types of formal and informal sources of social support in everyday life	Types of formal and informal support among PWD
Buljevac et al. (2012) (Croatia)	5 PWD	22 – 48	N/A	Focus groups	To gain insight into the experiences of PWD with support
Buljevac & Leutar (2017) (Croatia)	22 caregivers of individuals with intellectual disabilities	24-86 (M = 56.63)	M = 34.09	Semi-structured interview	To gain insight into experiences of family members of people with intellectual disabilities
Čagalj et al. (2018) (Croatia)	5 mothers of children with PWS	20–63 (M = 44)	6-35	Semi-structured interview	To gain insight into experiences of mothers of children with PWS with the formal support system
Daniels et al. (2017) (Croatia ^a)	146 caregivers of children with ASD	Not stated	M = 6.1	The Caregiver Needs Survey	Caregiver needs and what their perception is about ASD services in community
Ignjatovic Dzamonja et al. (2017) (Serbia)	153 caregivers of children with disabilities	20 - 66 (mothers M = 38.3, fathers M = 41.4)	3 – 42 (M = 14.56)	The Family Quality of Life Scale	What the effect of community-based services is on family quality of life

Golubović et al. (2015) (Serbia)	100 parents of children with disabilities	Not stated	3 - 7	The questionnaire regarding the first symptoms, treatment, professionals, and usefulness of information provided by professionals	Caregivers' perception of informational support from different professionals
Jelić & Mihajlović Babić (2018) (Serbia)	26 PWD	19-81 (M = 45.5)	N/A	Questionnaire regarding welfare services provided by civil society organizations on the territory of the City of Kraljevo; Questionnaire regarding users' satisfaction with welfare provided by non - governmental organizations/ associations in the city of Kraljevo	To explore how PWD evaluate quality of social services/welfare and their satisfaction with services
Karačić (2012) (Croatia)	150 adolescents with physical impairments	N/A	15-21	Questionnaire about support	To gain insight into frequencies, types and sources of support
Krsmanović et al. (2017) (Serbia)	281 caregivers of children with ASD	Not stated	M = 10	SEAN questionnaire	To explore the availability of educational support and social protection services for families of children with ASD
Leutar et al. (2007) (Croatia)	480 persons with disability	18-83	N/A	Formal and informal support questionnaire	Types of social support through formal and informal sources
Leutar & Marković (2011) (Croatia)	10 PWD, 10 parents of PWD	DD: 23 - 67; Parents: 37 - 60	N/A	Semi-structured interview	To provide insight into social work with PWD and support from the social workers
Levačić & Leutar (2011) (Croatia)	8 persons with physical disabilities	34-56 (M = 46)	N/A	Semi-structured interview	Types and sources of support for persons with physical disabilities in their parenting role and their needs

Leutar & Oršulić (2015) (Croatia)	161 parents of children with disabilities	27-59 (M = 41.74)	1 -18, (M=10.8)	Family Impact Questionnaire; Social support questionnaire	To gain insight into social support from parents of children with disabilities
Lisak et al. (2017) (Croatia)	6 parents of children with intellectual disabilities or ASD	38 – 55	3-19 years	Structured interview using narrative approach	Caregivers' experiences with support in educational system
McConkey et al. (2013) (Serbia ⁹)	5 individuals with intellectual disabilities, 5 parents of PWD	Not stated	Not stated	Individual and group interviews	Young athletes' and their caregivers' perception of social inclusion through the sport programs
Mihic et al. (2016) (Serbia)	8 mothers of children with disabilities	Not stated	Preschool age (not specified)	Qualitative interview during focus groups	To examine effect of support program on (a) family well-being, (b) caregivers' relationship with their child, (c) acceptance of diagnosis
Milic Babic & Dowling (2015) (Croatia)	9 students with disabilities	20-30	N/A	Semi-structured interview	Types of support available to the students with disabilities and what barriers they face
Milic Babic et al. (2017) (Croatia)	3 mothers of children with Williams syndrome	35-42 (M=38)	5-8	Semi-structured interview	To examine experiences with formal and informal support parents receive
Milic Babic et al. (2018) (Croatia)	28 women with disabilities	20-63 (M = 39)	N/A	Semi-structured interview	To obtain insight into the personal experiences of women with disabilities and their perceptions of abuse
Pejovic Milovancevic et al. (2018) (Serbia)	231 parents of children with ASD	Not stated	M = 10.5	The Caregiver Needs Survey	Caregiver' perception of and satisfaction with different ASD support systems in community

Petrović et al. (2016) (Serbia)	23 people with intellectual disabilities	Up to 30 years - 39%, older than 30 years - 61%	N/A	Competency scale for people with ID; Eco-map; Self-esteem scale SPROSIT S; Questionnaire for self-determination; Choice-making and decision-making questionnaire; Level of problem-solving skills questionnaire	To examine effects of community-based supported housing on life of people with intellectual disability who were previously institutionalized
Štambuk et al. (2012) (Croatia)	114 PWD	65-91 (M = 74.34)	N/A	Satisfaction with sources of support in everyday life; Support in crisis situations	Types of support in everyday life and in crisis situations among PWD
Stančić et al. (2015) (Croatia)	870 students with disabilities, 90 parents	Not stated	Students were in high school	Questionnaire on students' satisfaction with the support system in secondary education; Questionnaire on satisfaction of parents of the students with disabilities	Level of support and satisfaction with the support system in high school among students and their caregivers
Stanimirović et al. (2012) (Serbia)	32 persons with visual impairments, 64 parents	Not stated	14-26	Semi-structured interview; Perceived support scale	Level of support and satisfaction with the school support system students and their caregivers
Žganec et al. (2012) (Croatia)	391 PWD	Not stated	N/A	Questionnaire for PWD in the area of social rights	Perception of PWD regarding accessibility of social rights and the level of their needs

^a These studies were conducted in several countries, but we presented data only related to Croatia and Serbia.

Overview of the Studies

In total, 17 studies were conducted in Croatia and 10 studies in Serbia. Out of these studies, 12 studies included PWD in their design, 11 involved caregivers of PWD, while four encompassed both PWD and their caregivers (Table 1). Over half of the studies recruited participants from the urban areas (i.e., larger cities), seven recruited sample from both urban and rural areas (Blažeka Kokorić et al., 2021; Buljevac et al., 2012; Čagalj et al., 2018; Leutar & Marković, 2011; Lisak et al., 2017; Milic & Babić Dowling, 2015; Žganec et al., 2012), one was conducted in urban, rural, and suburban area (Ignjatovic-Dzamonja et al., 2017), and one was conducted in rural area (Mihčić et al., 2016). Two studies (Daniels et al., 2017; McConkey et al., 2013) were carried out across multiple countries, but we presented results related to Croatia and Serbia only.

Sample Characteristics

The total sample size of PWD varied from five to 870, while the number of caregivers ranged from five to 281. The age range of PWD was from seven to 91 years, while the age range of caregivers was from 20 to 86 years (Table 1). The majority of the studies did not report specific types of disabilities, or their sample consisted of people with multiple disabilities or caregivers of individuals with multiple disabilities. Three studies focused on intellectual disabilities (Buljevac & Leutar, 2017; McConkey et al., 2013; Petrović et al., 2016), one included mothers of children with Prader–Willi syndrome (PWS) (Čagalj et al., 2018), one mothers of children with Williams syndrome (Milić Babić et al., 2017), three focused on autism spectrum disorder (ASD) (Daniels et al., 2017; Krsmanović et al., 2017; Pejovic Milovancevic et al., 2018), one included persons with visual impairments (Stanimirović et al., 2012), and two studies focused on physical disabilities (Karačić, 2012; Levačić & Leutar, 2011).

Types of Support Reported by Caregivers

Our review showed that Croatian and Serbian caregivers of PWD received informational, emotional, practical, and financial support at different degrees. Informational support was depicted through information about rights, characteristics of disability, children's health needs, and available formal support (Čagalj et al., 2018; Daniels et al., 2017; Golubović et al., 2015; Krsmanović et al., 2017; Milić Babić et al., 2017; Stanimirović et al., 2012). The main sources of information were other caregivers of PWD, internet, and NGOs, followed by psychologists and teachers, while primary care physicians and social workers were mentioned less (Čagalj et al., 2018; Daniels et al., 2017; Golubović et al., 2015; Krsmanović et al., 2017; Lisak et al., 2017; Milić Babić et al., 2017; Pejovic Milovancevic et al., 2018).

Emotional and practical support were gained from other caregivers of PWD, some professionals, family members, and NGOs (Čagalj et al., 2018; Daniels et al., 2017; Leutar & Oršulić, 2015; Lisak et al., 2017; McConkey et al., 2013; Mihić et al., 2016; Stanimirović et al., 2012). Some examples of practical support were grandparents helping caregivers in everyday life activities, teachers providing individualised support to children, and professionals showing caregivers how to manage their child's needs (Čagalj et al., 2018; Lisak et al., 2017; Stanimirović et al., 2012).

Financial support was obtained by exercising the rights defined by legislation (Čagalj et al., 2018). In two studies, around 70% of caregivers received special government assistance for their child with ASD (Daniels et al., 2017; Pejovic Milovancevic et al., 2018), while some parents of children with different developmental disabilities (DD) received financial support from family (Leutar & Oršulić, 2015; Lisak et al., 2017).

A large majority of caregivers reported scarceness of systematic support, such as professionals' lack of knowledge about the characteristics and needs of PWD, lack of empathy, lack of coordination between professionals, and lack of assessments and services (Buljevac & Leutar, 2017; Čagalj et al., 2018; Lisak et al., 2017). They did not obtain services for their child because services were not available in their area, they were on a waiting list, or costs were high (Daniels et al., 2017; Pejovic Milovancevic et al., 2018). Obtaining a diagnosis was a common challenge for families as there were not enough qualified physicians in their hometowns, so they had to travel to larger cities or even abroad (Čagalj et al., 2018; Daniels et al., 2017; Krsmanović et al., 2017; Lisak et al., 2017; Pejovic Milovancevic et al., 2018). The majority of the families reported various challenges with the school system as well (Čagalj et al., 2018; Daniels et al., 2017; Lisak et al., 2017; Pejovic Milovancevic et al., 2018).

Types of Support Reported by PWD

Informational support included mostly information about rights (Leutar & Marković, 2011; Milić Babić et al., 2018; Žganec et al., 2012) and it was provided by NGOs and media, and less from physicians and social workers (Leutar et al., 2007). Youth with disabilities received informational support mainly from their parents and friends (47%), followed by siblings and relatives, while teachers were mentioned rarely (Karačić, 2012).

The results regarding financial support show that adults obtained some financial assistance from the government, such as care allowance or personal disability allowance (Leutar et al., 2007; Leutar & Marković, 2011; Milić Babić & Dowling, 2015; Žganec et al., 2012), while youth with disabilities received it from their parents (Karačić, 2012).

Service providers provided practical support during therapies (Daniels et al., 2017; Krsmanović et al., 2017; Pejovic Milovancevic et al., 2018), education

(Lisak et al., 2017; Pejovic Milovancevic et al., 2018; Stančić et al., 2015), and different social services (Avramović & Žegarac, 2016; Jelić & Mihajlović-Babić, 2018; Karačić, 2012; Leutar & Marković, 2011; Milic Babic & Dowling, 2015; Žganec et al., 2012). The most common therapies provided to children with ASD were standard developmental non-pharmacological treatments (Daniels et al., 2017; Krsmanović et al., 2017; Pejovic Milovancevic et al., 2018). Children with DD attended special schools most frequently, followed by inclusive classrooms and special classrooms in mainstream schools (Krsmanović et al., 2017; Pejovic Milovancevic et al., 2018). Through community-based services, children with DD acquired skills needed for leisure activities and activities of daily living, as well as for socialisation and community inclusion (Avramović & Žegarac, 2016). PWD reported day habilitation services and personal assistance (Jelić & Mihajlović-Babić, 2018; Žganec et al., 2012), while home assistance was less frequent (Leutar et al., 2007; Žganec et al., 2012).

Emotional support was provided to a small sample of adults through socio educational activities and counselling (Jelić & Mihajlović-Babić, 2018; Milić Babic & Dowling, 2015; Žganec et al., 2012). For youth with disabilities, the main sources of emotional support were their parents and friends (Karačić, 2012), while in another study, teachers were mentioned as a source of emotional support (Stanimirović et al., 2012).

The lack of available support for PWD was commonly stated in the reviewed studies. According to Leutar et al. (2007), 42.6% of participants did not get any kind of support because they did not have information about available support. Furthermore, some social workers did not provide assistance, did not have time for PWD, or they lacked empathy (Leutar & Marković, 2011). PWD often had to follow professionals' decisions without being able to ask for more information or participate in the decision-making process (Buljevac et al., 2012). Scarcity of support was also evident in educational settings, especially for children with ASD (Lisak et al., 2017; Krsmanović et al., 2017; Pejovic Milovancevic et al., 2018), while college students with disabilities did not get adequate professional and financial support (Milic Babic & Dowling, 2015).

Effects of Support

Several studies about the effect of support showed positive changes in the lives of PWD and their families. Through support, caregivers were able to gain insights into their parental role, learn coping strategies, define what kind of support their children need, build their confidence, and learn more about children's needs and strengths and how to provide care (Čagalj et al., 2018; Golubović et al., 2015; Mihić et al., 2016; Pejovic Milovancevic et al., 2018; Stanimirović et al., 2012). Their well-being was improved as their children received community-based support (Ignjatovic-Dzamonja et al., 2017). Children with DD became more skilled, educated, and independent by learning different

self-help skills, basic literacy, and social skills (Avramović & Žegarac, 2016; McConkey et al., 2013). PWD became more independent, developed new skills, improved self-esteem and community inclusion (Jelić & Mihajlović-Babić, 2018; Petrović et al., 2016).

Satisfaction with Support

Caregivers were the most satisfied with informal support (Leutar & Oršulić, 2015; Milić Babić et al., 2017) and support given through different projects (Jelić & Mihajlović-Babić, 2018; McConkey et al., 2013; Mihić et al., 2016). Different levels of satisfaction with formal support ranged from dissatisfaction and negative experiences to positive experiences (Buljevac & Leutar, 2017; Čagalj et al., 2018; Daniels et al., 2017; Leutar & Marković, 2011; Leutar & Oršulić, 2015; Lisak et al., 2017; Milić Babić et al., 2017; Pejovic Milovancevic et al., 2018; Stančić et al., 2015). Some factors that contributed to satisfaction with support were good cooperation among professionals and caregivers (Lisak et al., 2017), respect, empathy, and commitment (Čagalj et al., 2018; Leutar & Marković, 2011; Milić Babić et al., 2017).

PWD were satisfied with the support from their partners, children, and/or caregivers, and less satisfied with support from friends, neighbours, and relatives (Blažeka Kokorić et al., 2021; Milic Babic & Dowling, 2015; Stančić et al., 2015). Although satisfaction with formal support varied, PWD were dissatisfied with governmental support (Blažeka Kokorić et al., 2021; Buljevac et al., 2012; Milic Babic et al., 2018; Štambuk et al., 2012). PWD were most satisfied with personal assistance support (Jelić & Mihajlović-Babić, 2018), followed by support from health professionals, teachers, and social workers (Blažeka Kokorić et al., 2021).

Children with DD were highly satisfied with extracurricular activities, such as participation in team sports with peers without disabilities and community-based centres where they could meet other peers and develop different skills (Avramović & Žegarac, 2016; McConkey et al., 2013). Students with disabilities in secondary education reported moderate satisfaction with support systems (Stanić et al., 2015; Stanimirović et al., 2012). College students were mainly satisfied with the teaching staff as they did not treat them differently. However, they were dissatisfied with financial support from the state and the coordination between the formal system providers (Milic Babic & Dowling, 2015).

Discussion

Overall, the findings show that PWD and their caregivers were most satisfied with informal support and least satisfied with support from the government, while the degree of satisfaction with support from professionals varied.

Types of Support Reported by Caregivers

Caregivers received informational, emotional, practical, and financial support in Croatia and Serbia at different degrees. Studies from other countries (Magaña et al., 2017) also highlighted that other caregivers of PWD and the internet were the most common sources of informational support. Support from other caregivers is an important type of psychoeducational and emotional support (Magaña et al., 2017). Since around 77% of the Croatian and Serbian population have access to the internet (World Bank 2020 a, b), it is not surprising that parents found the internet to be the main source of information. Although, in the last decades, the internet has become one of the most important sources of informational support (Gibson et al., 2017), the question arises of how well parents can identify the most relevant information on the internet about their child's disability, available support, and whether there is reliable information available in Croatian and/or Serbian language. For example, some parents in the U.S. were ambivalent regarding the internet as a source of information because it can have too much information and it is hard to select the right one (Gibson et al., 2017).

The findings that caregivers reported professionals as a source of informational support less often than the internet are in line with results from studies conducted in Western countries (Mackintosh et al., 2005) and highlight the lack of systematic support. One of the main problems with formal support in Croatia and Serbia is that the majority of professionals work in larger cities, so not all families receive the support they need. The lack of systematic informational support leaves caregivers to search for information using their own resources, which can be overwhelming. Moreover, deferring information when a diagnosis is given can lead to delayed treatment.

Caregivers received emotional support from family members, other caregivers of PWD, NGOs, and some professionals. In earlier studies, family members were the most important sources of emotional support for caregivers (Bruns & Foerster, 2011). The result of family members as a source of emotional support is expected because Croatian and Serbian societies are mainly collectivist. In addition, Croatian and Serbian caregivers very often limit their interactions because of the existing family stigma in society (Buljevac & Leutar, 2017; Čolić & Milačić Vidojević, 2021), which could also be one of the explanations for why family members stay connected.

Practical support for caregivers was provided by other caregivers of PWD, family members (especially grandparents), NGOs, and some professionals. Family members are an important source of practical support in Croatian and Serbian society because three-generation family households are very common. Studies in other countries also showed that grandparents and older siblings are the main sources of this support (Baumann et al., 2005; Mackintosh et al., 2005). Caregivers did not report having access to respite care in any of the

reviewed studies, which is to some extent in agreement with a study from the United Kingdom that showed a small number of parents obtained respite care (White & Hastings, 2004). There is a lack of programs for children with DD that could provide respite time for Croatian and Serbian caregivers because the majority of programs are during the parents' work hours.

Furthermore, caregivers received practical support from different NGOs who provided various support programs through funding from governmental or international agencies. The findings related to practical support from professionals are mixed, but the majority of caregivers felt that systematic support was lacking, compared to the other countries where practical support was provided to a much greater degree by different professionals (Vanegas & Abdelrahim, 2016; White & Hastings, 2004). In Croatia and Serbia, it is common that support is provided for families with higher socioeconomic status as most treatments are paid out of pocket, and usually, more educated caregivers have better access to resources. This review points to the dearth of support in smaller cities and rural areas because most formal support sources are in capitals or in larger cities.

Although the literature identified different types of governmental support, such as welfare programs or professionally provided services (Turnbull et al., 2007), the most significant governmental support that Croatian and Serbian caregivers reported was a financial one. In Croatia, for example, many children with severe disabilities receive personal disability allowance and child allowance, while many parents of children with severe disabilities receive monthly payments for taking care of their child. Financial support is important because raising a child with disability results in greater life expenses (Burton & Phipps, 2009) and many parents must reduce their working hours or even decline job offers (Parish & Cloud, 2006).

Support for PWD

Our review showed that PWD obtained informational, emotional, practical, and financial support at different degrees. PWD were given little informational support from professionals. The majority of individuals, especially the older ones, did not know how to access different services, obtain various aids, or exert their rights. They learned most about their rights from the media and NGOs. Without adequate informational support, PWD would have limited access to the needed assistance that could affect their quality of life (Potvin et al., 2016; van Asselt-Goverts et al., 2015a).

When we analysed the results regarding emotional support, youth with disabilities received support from their parents and friends, while professionals provided emotional support to a small number of adults that was valued positively. Inadequate or lack of emotional support to PWD is also a common finding in other countries (Havercamp & Scott, 2015; Rimmer et al., 2004).

Practical support was provided by some service providers during therapies, in educational settings, through support programs, and different social services. Earlier studies also highlighted that PWD need specialised support from professionals (Potvin et al., 2016; Vanegas & Abdelrahim, 2016). Although some studies showed that friends were the most significant source of practical support for PWD (e.g., Lippold & Burns, 2009) our analysis did not yield the same findings.

The results about financial support are similar to the findings from studies in other countries that indicate governmental financial support for PWD is very often insufficient (Angela, 2015). There are barriers for Serbian PWD to apply for governmental support. For example, they need to submit a huge amount of documentation, the small monetary amount they would receive discourages application, and the application process is lengthy (Dinkić et al., 2008). In Croatia, the personal disability allowance is 200 Euros per month. All of this implies that sometimes the Croatian and Serbian families of PWD struggle financially.

Effects of and Satisfaction with Support

In general, Croatian and Serbian PWD and their families reported positive changes because of support. In line with the results from other countries (Magaña et al., 2017; Tétreault et al., 2014), parents shared that information provided by professionals was extremely valuable. Parental well-being was improved as their children received community-based support and mothers were able to understand their child and family relationship better.

Our analysis regarding the effects of support programs provided to PWD showed that they become more skilled and independent. Various support programs contributed to their personal growth, better quality of life, and better community inclusion, which is also found in some earlier studies (Chou et al., 2011; Howarth et al., 2016).

The results regarding satisfaction with support from the professionals are mixed; some caregivers were satisfied with support in general, while some of them were dissatisfied. Some factors that contributed to better satisfaction highlighted by caregivers were good cooperation, understanding, and commitment. Caregivers were satisfied with support from family members, which was also found in studies in other countries (Davis & Gavidia-Payne, 2009). Friends were not mentioned as a source of parental support in any of the reviewed studies. One possible explanation is that parents very often limit their social networks or become socially isolated due to existing stigma.

When it comes to satisfaction with support, PWD were highly satisfied with the support from family members and less satisfied with support from friends, neighbours, and relatives. Similarly, earlier studies showed that PWD were the most satisfied with family support and support from friends who are

very often people with the same type of disability (Lippold & Burns, 2009; van Asselt-Goverts et al., 2015b). PWD were highly satisfied with the support gained through various projects, such as sports programs, community-based participation, etc. The majority of them believed that professionals did not support them enough, and they were mostly dissatisfied with support from the government and local authority.

Limitations

Although this review has made a contribution to the literature pertaining support for PWD and their families, it has limitations. First, we included only peer-reviewed articles and thus, relevant grey literature may have been missed. Second, we reviewed only the articles indexed in three databases. For instance, in both Croatia and Serbia, it is common for researchers to present papers at the conference, but full data are later published in local peer-reviewed journals which are often not indexed in databases. Lastly, certain experiences with support could be related only to a specific disability and do not necessarily imply that the state of support is the same for individuals with other disabilities and their families.

Conclusion

Our review showed that PWD and their caregivers received informational, emotional, practical, and financial support at different degrees. Croatian and Serbian families of PWD were most satisfied with informal support from close family members and least satisfied with formal support. In Croatia and Serbia, informal support sources are extremely important because sometimes they are the only available ones. On the other hand, this review showed that formal systematic support is lacking and that, very often, positive experiences with professionals depended heavily on personal and ethical values of a given professional. However, when PWD and their caregivers were part of different support programs, they were highly satisfied with them. Therefore, it is important to develop support programs that more individuals would be part of, not only in larger cities but in rural areas as well. As this review pointed out, it is important to recognize the areas in which support is missing and work toward building support for PWD and their families in Croatia and Serbia.

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Formalna i neformalna podrška osobama sa invaliditetom i njihovim porodicama u Hrvatskoj i Srbiji: Pregled literature

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Uvod: Formalna i neformalna podrška važne su za kvalitet života osoba sa invaliditetom i njihovih porodica. *Cilj:* Ciljevi ovog rada bili su da se (a) identifikuju vrste podrške koju dobijaju osobe sa invaliditetom i njihove porodice, kao i zadovoljstvo podrškom i (b) analiziraju percipirani efekti podrške koju su dobile osobe sa invaliditetom i njihove porodice u Hrvatskoj i Srbiji. *Metod:* Sprovedena je sistematska pretraga literature objavljene od 2000. do juna 2020. godine, koja je potom praćena proverom podobnosti članaka. Pregledane su EBSCOhost, Hrčak i Srpski Citatni Indeks data baze. Takođe, pretražena je Google Scholar data baza i skenirane su reference iz članaka uključenih u sistematsku pretragu. Autori su skenirali članke i zabeležili podatke koji se odnose na zemlju, cilj studije, dizajn studije, uzorak, metodologiju i rezultate. U ovaj pregled uključeno je dvadeset sedam studija. *Rezultati:* Osobe sa invaliditetom iz Hrvatske i Srbije i njihovi staratelji dobili su informativnu, emocionalnu, praktičnu i finansijsku podršku u različitom stepenu. Najzadovoljniji su bili neformalnom podrškom i programima podrške, dok je stepen zadovoljstva formalnom podrškom bio različit. *Zaključak:* Formalni sistem podrške za osobe sa invaliditetom i njihove porodice generalno nedostaje u Hrvatskoj i Srbiji, dok je neformalna podrška najzastupljenija. Postoji potreba za više programa podrške osoba sa invaliditetom i njihovih porodica.

Ključne reči: deca sa razvojnim poteškoćama, osobe sa ometenošću, staratelji osoba sa ometenošću, formalna podrška, neformalna podrška

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