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AWARENESS OF PARENTS OF CHILDREN WITH DISABILITIES ABOUT EARLY SUPPORT SERVICES

INFORMIRANOST RODITELJA DJECE S TEŠKOĆAMA U RAZVOJU O USLUGAMA RANE PODRŠKE

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ABSTRACT

Parents of children with disabilities receive many different forms of support, and among those is also the support provided by professionals from different systems. It is very important for parents to be informed about early support services so that their children can be included in the services in a timely manner. The aim of this research was to determine parents' awareness of the system of early support services for children with disabilities and their families in Brod-Posavina and Istria counties. In total, 152 parents participated in the study, out of which 63,8% were female and 36,2% were male. The average age of parents is 38 years. Data was collected using a questionnaire specifically designed for the purpose of this study, which is a component of a large-scale research on early support provided to children with disabilities and their parents. The first part of the questionnaire concerns sociodemographic characteristics, while the second part deals with the parents' awareness of the system of early support services with regard to sociodemographic characteristics of parents. Considering the findings of the regression analysis, parents with a higher education were also better informed about early support services ($ß = .25$, $p < .01$). The collected data are a useful source about information of early support services by parents.

Key words: system of early support services, parents' awareness, children with disabilities.

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SAŽETAK

Roditelji djece sa teškoćama u razvoju dobijaju mnogo različitih oblika podrške, a među njima je i podrška koju pružaju stručnjaci iz različitih sistema.

Vrlo je važno da roditelji budu informisani o uslugama rane podrške kako bi njihova djeca bila na vrijeme uključena u usluge. Cilj ovog istraživanja bio je utvrditi informisanost roditelja o sustavu usluga rane podrške djeci s teškoćama u razvoju i njihovim obiteljima u Brodsko-posavskoj i Istarskoj županiji. U istraživanju su učestvovala 152 roditelja, od čega 63,8% žena i 36,2% muškaraca. Prosječna dob roditelja je 38 godina. Podaci su prikupljeni pomoću upitnika osmišljenog za potrebe ovog istraživanja, koji je dio šireg istraživanja usluga rane podrške djeci sa teškoćama u razvoju i njihovim porodicama. U prvom dijelu upitnika prikupljeni su podaci o sociodemografskim karakteristikama, a u drugom dijelu podaci o informiranosti roditelja o uslugama rane podrške s obzirom na sociodemografske karakteristike roditelja.Uzimajući u obzir nalaze regresione analize, roditelji sa visokim stupnjem obrazovanjem bili su bolje informisani o uslugama rane podrške ($ß = .25$, $p < .01$). Prikupljeni podaci su koristan izvor o informisanosti o uslugama rane podrške od strane roditelja.

Ključne riječi: usluge rane podrške, informisanost roditelja, djeca s teškoćama u razvoju

INTRODUCTION

Early support for parents should be provided by different systems in society: educational, health and social systems and cooperation with other participants within the community such as associations and religious communities and other participants in the development of a certain local community (Leutar and Oršulić 2015).

The need for information is most pronounced need for support from parents of children with disabilities. Košićek et al. (2009) state the existence of insufficient cooperation between parents and professionals, resulting in insufficient information on the part of the professionals themselves about the work of professionals in other professions, which leads to insufficient and inadequate information for parents who have a child with disabilities.

Sloper (1999) believes that the relationship between parents and professionals is a crucial factor in the effectiveness of services. Parents should be active participants in the system of early support services because they are the ones who raise and care for the child, along with the professionals who provide services and with the support of those who make policies and financial decisions. Transdisciplinarity also plays an important role as a model of teamwork, and its goal is to simplify and speed up the process of obtaining appropriate support for the child and family. Parents are participants who present themselves as partners to professionals in the process of providing early support (Milić Babić et al., 2013).

Analyzing the context of interdisciplinarity and transdisciplinarity within the early intervention system, it is necessary to identify all persons who are involved in early child development and encourage them to actively participate (Ivšac Pavliša, 2010; Ljubešić, 2012).

An understanding of family values, beliefs, and priorities is necessary for professionals and parents to seek creative solutions to problems and individualized approaches to providing services and support to families (Ali et al., 2009; according to Underwood and Frankel, 2012).

The coordination of the work of parents and professionals and appropriate mutual communication are important prerequisites for the harmonious development of the child, and adults are responsible for acting in the best interest of the child. Parents can and should seek and receive information and/or professional advice related to the child's growth and development, therapeutic procedures and the way of working with the child.

High-quality and reciprocal communication between parents and professionals enables a common understanding of children and the development of appropriate ways of working with the child, aligned with his individual and developmental peculiarities.

If parents do not receive adequate support from professionals, they independently inform themselves about the health status of the child, the rights of the child and the family, refer parents to appropriate support services, or seek the support of other parents with similar or the same problems. Iversen et al. (2003) point out that parents of children with disabilities express the need for better information about support service systems offered in the community.

Brajša-Žganec et al. (2011) state that parents' lack of information is the result of the lack of an adequate early intervention network in Croatia. Košiček et al. (2009) state that parents want clear and useful information from professionals. Iversen et al. (2003) and Bailey et al. (2004) state that the work of professionals with parents should be aimed at strengthening self-confidence in parental abilities to cope with the challenges of parenthood.

However, there are also studies that show parents' dissatisfaction with the support services provided, resulting in insufficient information about the support services.

Košiček et al. (2009) and Ivšac Pavliša (2010) state that some studies show parental expression of dissatisfaction with the poor availability of information, so they encounter difficulties in finding relevant and useful information.

They also found a high level of parental dissatisfaction with the information provided about rehabilitation options and dissatisfaction with cooperation and communication between professionals, because 54% of the respondents (f=82) did not receive information about rehabilitation options after the diagnosis, but had to find out on their own through books and the Internet.

The problem of this research was focused on informing parents of children with disabilities about early support services, and the following aim arose from this: to examine the awareness of parents of children with disabilities about early support services with regard to sociodemographic characteristics.

MATERIAL AND METHODS

Sample of participants

For the purpose of this study, a convenience sample of 152 participants (63,8% mothers and 36,2% fathers) was used. Participants are parents of children with disabilities whose age range spans from the new-borns to school goers, coming from two counties in Croatia, Brod-Posavina County (68,4%) and Istra County (31,6%). Both parents from certain families partook in the study. Average age of the participants is 38 years (*M= 37,6, SD= 6,3*), the majority of participants who took part in the study are between the ages of 31 and 40. As for the level of education, the majority of the participants have achieved the high school level of education (55,9%) while the least number of participants (2,0%) have neither level of education achieved, i.e., they are classified as unskilled workers. What is more, 26,3% of the participants have a MA degree, 10,5% of the participants have a BA degree, and 2,6% have a post-graduate/doctoral degree, the same percentage goes for participants with primary level of education. Half of the participants are parents to a child from six to eight years of age (50,4%), and 40.8% of the children were diagnosed with disabilities at the earliest age (up to one year of age). The majority of the participants have their own housing bought with a loan (38.2%), while some have their own housing bought without a loan (36.2%), and the least are those who are tenants (8.6%). More than half of the participants (60,5%) consider their housing arrangements to be adequate, whereas 4,6% consider their housing arrangements to be absolutely inadequate for living. The same percentage of the participants (46,1%) state that they sometimes or never have financial issues, while 7,9% state that they have serious financial issues. As it was mentioned before, both of the parents from certain families partook in this study, hence the number of parents is not equal to the number of children.

In the total subsample of children with disabilities (N=103), parents report the following disabilities: speech-language and vocal disorder (65%), motor impairments (28,2%), behavioural disorders (20,4%), health difficulties (17,5%), intellectual disability (13,6%), autism spectrum disorders (13,6%), visual impairments (13,6%), hearing impairments (1,6%), personality disorders (1%), and one deafblind child. For 10,7% of the children, parents state that their development is irregular, but children have not been diagnosed as of yet. The children had multiple difficulties.

Method of conducting research

The Ethics Committee of the Faculty of Education and Rehabilitation Sciences approved the conduct of this study, and therefore, the study was conducted in accordance with the Code of Ethics of the University of Zagreb (2009)[2]. After having received the positive feedback, the conduct of the study began. Data about the number of parents of children with disabilities was collected from multiple sources, such as the Croatian Institute of Public Health, kindergartens, NGOs and the Administrative Department for Health and Social Welfare.

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[2] Etički kodeks (bez dat.). http://www.unizg.hr/o-sveucilistu/dokumenti-i-javnost-informacija/propisi/

Survey questionnaires were sent out to the participants via e-mail or post, and their written consent to participate in the research, with a description of the research attached, was requested. Participants were given a fortnight to fill in the questionnaire which were then sent back to one of the study’s authors via e-mail or post.

Measuring instruments

For the purpose of this study, which is a component of a large-scale research on early support provided to children with disabilities and their parents, a questionnaire intended for the parents of children with disabilities was specifically designed – Questionnaire on awareness, satisfaction and expectations of the early support for the children with disabilities and their families (Autors, 2015). First part of the questionnaire was used to accumulate data about sociodemographic characteristics of the participants (sex, age, place of residence, employment status, level of education, marital status, number of children in the family, number of members of the household, housing arrangements, financial status, children’s age, children’s age when they were diagnosed, and the type of disability). In the second part of the questionnaire, data was collected on parents' awareness of early support services for children with disabilities and their families. For 30 different support services, parents indicated with +/- the following 3 categories: knowledge of the service, where ″+″ indicated that the parents knew the service, while ″-″ indicated the opposite.

The score on the scale of awareness of parents of children with disabilities about early support services was formed as the sum of the services that the parents indicated they knew. The possible range of scores is from 0 to 30 *(M=14.15; SD=5.87).*

Cronbach's alpha is 0.852 and indicates that *The scale of* awareness *of parents* has very good reliability.

Data processing methods

In order to verify the hypothesis set forth in this research, a regression analysis was conducted in which awareness is the criterion, and the sociodemographic characteristics are the predictors.

RESULTS AND DISCUSSION

In this research, parents were expected to indicate witch early support services they know. Parents were supposed to mark all the early support services offered in their area that they know. It was expected that the majority of responses were in support of knowing the service of including children with disabilities in kindergarten (90.8%), pediatricians in the health center (90.1%) and the services of professionals from kindergartens: advisory support of educators (82.9%), individual work of an educational rehabilitator/speech therapist (78.9%), advisory support of an educational rehabilitator (71.7%), advisory support of speech therapists (69.7%) and advisory support of psychologists (67.1%).

It can be assumed that parents are more familiar with and involved in the services of pediatricians because they make the first contact with pediatricians in primary health care to monitor their children's development.

Also, it is evident that children are included in kindergartens, which is positive information. Since early support services are intended for children of early and preschool age and their families, kindergartens are part of the system of these services because the period of early development is sensitive and important for the child's long-term outcomes (Ljubešić, 2012; Pećnik, 2013). Professionals employed in kindergartens have different educational profiles and cooperate with other professionals from the system of upbringing and education, healthcare and social welfare, which ensures continuity in upbringing and education, but also the provision of early support services.

Partnerships between parents and professionals play a major role in the provision of early support services, because if there is a mutual willingness to cooperate and the child's needs, they can be adequately met.

The variable Awareness of parents of children with disabilities about early support services was formed through 30 particles that indicate knowledge of a particular service.

Before conducting a regression analysis between potential predictors and criteria of awareness of parents of children with disabilities on early support services (Table 1), the relationship between parents' awareness and sociodemographic characteristics was determined, and the results indicate that there is a statistically significant but low correlation of awareness of parents of children with disabilities in development and level of education (r = .27, p < .01).

Table 1. Awareness of parents of children with disabilities about early support services with regard to sociodemographic characteristics: Results of regression analysis

Predictors	**B**	**SE B**	**ß**	**R²**
Age	.08	.08	.08	
Gender	.93	1.01	.08	
Self-assessment of material condition	.28	.85	.02	
Level of education	1.40	.47	.25**	.10*
Child's age	.02	.02	.10	
Type of child's disability	-.05	.15	-.03	
Place of residence	-1.10	1.11	-.09	

Remark: N=151, *p<.05 **p<.01

Legend: B – unstandardized coefficient, SE B – error of unstandardized coefficient, ß - standardized beta coefficient, R² - coefficient of multiple determination

Table 1 shows the results of predicting parents' awareness based on parents' age and gender, self-assessment of material condition, level of education, child's age, type of child's disability and place of residence.

The results showed that only the level of education is a significant positive predictor of awareness (ß = .25, p < .01). This means that parents who have a higher level of education are more informed about early support services. In total, 10% of the variance of the awareness of parents can be explained by sociodemographic characteristics.

Parents who are more educated probably find more sources of information and they are more focused on obtaining information regarding their child's disabilities and ways of working with the child. Poćnik (2013) states that more informed parents of children with disabilities used the services more. It is assumed that parents who are more informed about early support services will use this information to seek professional advice and support.

When it comes to sociodemographic characteristics and support, most research focuses on parents who do not have children with disabilities.

It is interesting to show these results because of the mentioned socio-demographic characteristics in this research. Poćnik (2013) states that parents with primary level of education, parents with middle socioeconomic status and parents from Slavonia and Northern Croatia rarely choose professionals as the most desirable providers of support for parenting. There are relatively more fathers, parents with primary levels of education and parents younger than 25 years of age that have no need for the professional guidance by the professionals. Addis and Mahalik (2003) report that there are clear gender differences which show that women are more likely to look for support than men. As far as the level of education is concerned, research shows that parents with higher levels of education (BA or MA degree) have thought about the professionals' advice more than the parents with primary levels of education.

CONCLUSION

One of the bigger problems is the insufficient awareness of parents about support services, which creates additional concerns for parents. Some parents do not find out about support services on time, which calls into question success of the service.

Data on the awareness of parents of children with disabilities about early support services show that parents are most familiar with the services of pediatricians from health centers and the services of specialists from kindergartens. It is expected that parents are most familiar with the services of pediatricians from health centers, because pediatricians are the ones who monitor the child's development.

Also, parents are familiar with professionals from kindergartens (educator, educational rehabilitator, speech therapist, psychologist), which is very positive information because it indicates that parents are familiar with the work of the aforementioned professionals.

The results in this study showed that the only statistically significant, positive predictor of parental awareness was the level of education, i. e. parents who had higher education were also better informed *(ß = .25, p = <.01).* It is assumed that more educated parents are more resourceful in finding information and thus are more able to seek better quality early support services.

This study can be an incentive for further research across the entirety of Croatia or even further, so as to accumulate more precise data on the parents' awareness about system of early support.

The study has certain methodological limitations, because the generalization of the results is limited by the convenience sampling – the size and type of the sample. Due to the fact that the study covered only two counties in Croatia, the representation of the other counties cannot be commented on. Moreover, mothers are far more prevalent in the study than fathers, and the same goes for parents with higher financial status. In future research other Croatian counties, fathers, parents with lower financial status, parents from urban and rural regions and those who come from dislocated parts of the country should also be included.

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