

Majda Schmidt Krajnc

Ksenija Seršen

Quality of Life for Families of Children with Intellectual Disabilities

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ABSTRACT

The main part of the article presents the results of a recent empirical study about the quality of life for families in Slovenia that have a child with intellectual disabilities and other developmental disabilities. Using the FQOLS-2006, we analysed nine quality of life domains (Health, Financial Well-Being, Family Relationships, Support from Others, Support Services, Influence of Values, Careers, Leisure and Community Interaction) from the perspective of six measurement dimensions. The study also examines the differences among the measurement dimensions in the nine domains.

The sample consisted of 44 families. We used descriptive statistics and inferential statistics (Friedman test). The Family Relationships domain had the highest average rating of all measured domains regarding the quality of family life. The results in the domain of Support from Others are not encouraging, in particular the domain of Support from Services.

Families require powerful support programs from qualified professional teams as well as societal and political attention.

Key words: family quality of life, intellectual disabilities and other developmental disabilities, quality of life domains, quality of life dimensions

Družine z otroki z motnjami v duševnem razvoju in kakovost življenja

Izvirni znanstveni članek

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POVZETEK

V osrednjem delu prispevka predstavljamo najnovejše rezultate raziskave o kakovosti življenja slovenskih družin z otroki z motnjami v duševnem razvoju in drugimi razvojnimi motnjami. Podatke smo zbrali s pomočjo mednarodnega vprašalnika FQOLS – 2006. Z vidika šestih dimenzij smo analizirali devet področij kakovosti družinskega življenja (zdravje; finančno stanje; družinski odnosi; podpora drugih oseb; podpora služb; vpliv vrednot; poklic in priprava za poklic; prosti čas in rekreacija; interakcija s skupnostjo). Preučevali smo tudi razlike znotraj dimenzij na področjih kakovosti življenja. Vzorec je zajemal 44 družin. V raziskavi smo uporabili deskriptivno in inferenčno statistiko (Friedmanov test). Med področji kakovosti življenja so starši z najvišjimi povprečji z vidika šestih dimenzij ocenili področje družinski odnosi. Skrb vzbujajo rezultati na področju podpora drugih oseb, še zlasti pa na področju podpora služb. Družine potrebujejo pomoč usposobljenih strokovnih timov in vključenost v intenzivne podpirne programe ter tudi ustrezno družbeno in politično pozornost.

Ključne besede: kakovost življenja, motnje v duševnem razvoju in druge razvojne motnje, področja kakovosti življenja, dimenzije kakovosti življenja

Introduction

Raising a child with disabilities poses a considerable parental challenge at different periods of the parents' lives and entails responsibilities that surpass their abilities, as well as restricting their social lives (Lessenberry & Rehfeldt, 2004; Olsson & Hwang, 2002). Families often navigate within previously uncharted territory and must seek information about the diagnosis, interventions and education for their child (Iarocci, Virji-Babul, & Reebye, 2006).

Research (Gardiner & Iarocci, 2012; Hartley, Sikora, & McCoy, 2008; Shu 2009) has also shown the negative impact of the socially maladaptive behavior and behavioral deviation of children with autistic disorders on the well-being and mental health of parents and the quality of their lives. Low socio-economic and employment status likewise pose a risk that can reduce the quality of family life (World Health Organization, 2011). On the other hand, parenting a child with disabilities is not necessarily a negative experience for the family (Hoddap, 2007). Some studies have (Cuskelly, Hauser-Cram, & Van Riper, 2009; Hoddap, 2007) affirmed the resilience, strength, connection and coherence of families that have children with intellectual disabilities.

The ample literature also features claims that developmental and/or intellectual disability in an individual can influence the entire family (Reichman, Corman, & Noonan, 2008; Turnbull & Turnbull, 1997); that children with developmental disabilities are best taken care of in the context of family life (Parish et al., 2001); and that experts who actively collaborate with families can provide better support for the needs of children with disabilities (Brown & Wang, 2009). If families want to live a quality life and be competent in confronting the deficiencies and specific needs of a family member, they need a range of resources, particularly professional/emotional support, which can be formal (professionals, healthcare institutions, professional organisations etc.) or informal (relatives, friends, and non-professional sources of assistance) (Dunst & Trivette, 1986; Raina et al., 2005). We must not overlook the concern that society or the state should provide for the education, as well as the social, legal and health protection of individuals with disabilities and their families. Often, however, parents of children with disabilities feel dissatisfied with professionals who do not provide continuous intervention or who provide poor communication and limited service programs (e.g., the early education system) (Swick, 2004). In recent years, Family Quality of Life (FQOL) has become a construct that aims to consider a broader spectrum of family outcomes (Gardner & Iarocci, 2015). FQOL is defined as the conditions where the family's needs are met, and family members enjoy their life together as a family and have the chance to engage in activities that are important to them (Park et al., 2003).

The quality of life for families that have children with intellectual disabilities is an important holistic and multidimensional concept that influences policy-making, improves the functioning of professional services and enables a better life to individuals with intellectual disabilities and their families (Brown & Wang, 2009).

An international research team comprising researchers from Canada, Australia, Israel and the USA focused on conceptualizing family quality of life along six aspects or dimensions (Importance, Opportunities, Initiative, Attainment, Stability and

Satisfaction) of quality of life in nine main domains of family life (Health, Financial Well-being, Family Relationships, Support from Others, Support from Services, Influence of Values, Careers, Leisure and Community Interaction) (Brown & Wang, 2009). This team devised the "Family Quality of Life" (2006) questionnaire, which has been used in over 25 countries (e.g., the USA, Canada, Australia, Nigeria and many European countries, as well as some Asian countries such as Japan) (Rillotta et al., 2011).

The questionnaire was also used in the first survey in Slovenia about the quality of life for the families of children with intellectual disabilities (Čagran, Schmidt, & Brown, 2011; Schmidt & Kober, 2010). The main part of the present article reports the results of our most recent empirical study about the quality of life for families in Slovenia that have a child with both intellectual disabilities and other developmental disabilities (ID/DD).

The study also examines the differences among the measurement dimensions of family life (Importance, Opportunities, Initiative, Stability, Attainment and Satisfaction) within the nine domains.

Method

Participants

The sample was non-random and purposive. It comprised 44 Slovene families that have children with ID/DD. The families were from the eastern part of Slovenia. The major group in the sample were families living in the countryside or in small towns (61.4 %). 86.4 % of participants were members of two-parent families. The remaining 13.6 % were from one-parent families headed by mothers. All these children with ID/DD lived at home with their parents.

Instrument and Procedures

The data was collected using the *FQOLS - 2006* (Brown et al., 2006) survey for researching the quality of family life. The survey provided the basic data about the families and the data related to individual domains of life (Health, Financial Well-being, Family Relationships, Support from Others, Support from Services for people with ID, Influence of Values, Careers, Leisure, Community Interaction and in the Overall Quality of Life). Every domain with the exception of the Overall Quality of Life was rated from the point of view of six dimensions (Importance, Opportunities, Initiative, Attainment, Stability and Satisfaction) in intervals from 1 to 5; the Careers domain in an interval from 0 to 5.

The reliability of the survey used was good ($r_{tt} = 0.817$), which was confirmed by the Cronbach alpha coefficient ($\alpha = 0.783$).

Objectivity of the questionnaire was ensured through individual cooperation with the families because quantitative data from the nine domains of family life was supplemented by qualitatively obtained comments and opinions from and consultations with the parents.

Data analysis

Basic descriptive statistics was used to analyze individual domains of quality of life for families that have children with ID/DD (Mean, Standard Deviation, Minimum, Maximum value of an individual domain, Skewness and Kurtosis and Variability Coefficient (VC %) for the overall result of individual domain ratings).

The Friedman test was used to measure the differences between individual dimensions (Importance, Opportunities, Initiative, Stability, Attainment and Satisfaction) that were used to rate individual domains.

Results

Analysis of the measurement of individual domains of the quality of family life

Individual domains of the quality of life (Health, Financial Well-being, Family Relationships, Support from Others, Support from Services for people with ID, Influence of Values, Careers, Leisure and Community Interaction) were rated in terms of importance from the point of view of the six dimensions (Importance, Opportunities, Initiative, Stability, Attainment and Satisfaction), and the intervals used to rate the dimensions ranged from 1 to 5; for the Careers domain, it was from 0 to 5.

Table 1: Mean (standard deviation (SD), minimum (x_{min}) and maximum (x_{max}) value of the sum of dimensions for each individual domain, skewness (SKEW) and kurtosis (KURT) and coefficient of variation (CV %) of the overall result of the nine domain ratings

Domain	N	Mean	SD	Range		Coefficients		
				X_{min}	X_{max}	Skew	Kurt	CV %
Health	44	21.66	2.676	16.00	27.00	-0.311	-0.108	12.35
Financial Well-being	44	19.45	2.672	14.00	25.00	-0.062	-0.520	13.74
Family Relationships	44	25.52	2.445	19.00	30.00	-0.514	-0.295	9.58
Support from Others	44	18.84	3.953	12.00	27.00	-0.155	-0.739	20.98
Support from Services	44	18.40	2.920	11.00	26.00	-0.161	0.406	15.87
Influence of Values	44	20.36	4.856	10.00	29.00	-0.230	-0.568	23.85
Careers	44	19.77	6.415	2.00	28.00	-1.376	1.551	32.45
Leisure	44	20.82	3.943	12.00	27.00	-0.376	-0.367	18.94
Community Interactions	44	21.64	2.412	18.00	27.00	0.075	-0.833	11.15

Skewness in the domains of Health (SKEW = -0.311), Financial Well-being (SKEW = -0.062), Support from Others (SKEW = -0.155), Support from Services (SKEW = -0.161), Influence of Values (SKEW = -0.230), Leisure (SKEW = -0.376) and Community Interactions (SKEW = 0.075) show a relatively symmetric distribution; in the domain of Family Relationships, distribution measures show the distribution results to be slightly asymmetric to the left (SKEW = -0.514). Kurtosis shows a normal-like distribution in the domains of Health (KURT = -0.108), Leisure (KURT = -0.367) and Family Relationships (KURT = -0.295), or a flat distribution in the domains of Financial Well-being (KURT = -0.520), Support from Others (KURT = -0.739) and the Influence of Values (KURT = -0.568). In the Support from Services domain, the distribution is leptokurtic (KURT = 0.406).

The two coefficients that stand out are the asymmetry coefficient in the Careers domain (SKEW = -1.376), which shows that the distribution is asymmetric to the left, and the leptokurtic (KURT = 1.551), which has a cone-shaped distribution. This domain shows a trend towards a higher number of higher results. Skewness and kurtosis are highlighted in Careers, because distribution measures show results to be asymmetric to the left (SKEW = -1.376) and also leptokurtic (KURT = 1.551).

If we consider the distribution of means for rating the domains from the point of view of the six dimensions (Importance, Opportunities, Initiative, Stability, Attainment and Satisfaction), the highest average appears in the Family Relationships domain ($\bar{x} = 25.52$), followed by Health ($\bar{x} = 21.66$), Community interaction ($\bar{x} = 21.64$), Leisure ($\bar{x} = 20.82$) and the Influence of values ($\bar{x} = 20.36$) domains. Financial Well-being ($\bar{x} = 19.45$), Support from Others ($\bar{x} = 18.84$) and Support from Services ($\bar{x} = 18.40$) have the lowest ranking. It should be pointed out that the ranking does not include Careers because this is not comparable. In all domains included in the survey, the values on the rating scale ranged from 1 to 5; however, for Careers, the scale ranged from 0 to 5, which is why the mean value was lower.

The lowest variability was 9.58% in Family Relationships. Standard deviation for this domain was 2.445. Community Interaction was next with a variability of 11.15% and a standard deviation of 2.412, followed by Health with 12.35% variability and a standard deviation of 2.676, Financial Well-being with 13.74% variability and a standard deviation of 2.672, Support from Services with 15.87% variability and a standard deviation of 2.920, Leisure with 18.94% variability and a standard deviation of 3.943. The highest variability appears in Support from Others, with 20.98%; Influence of Values, with 23.85% and Careers, with 32.45%. In these domains, the highest standard deviations were measured. Standard deviation for the Support from Others domain was 3.953; for Influence of Values, 4.856 and for Careers, 6.415.

From the point of view of the six dimensions (Importance, Opportunities, Initiative, Stability, Attainment and Satisfaction), the Family Relationships domain had the highest average rating (25.52) of all measured domains regarding the quality of family life.

87% of the parents were satisfied or very satisfied with relationships in the family, as many believed that all family members had many or very many opportunities to establish good relationships with everyone in this domain. They also put the most effort into this domain, and regard themselves as successful in this regard; in addition, good relationships provide them with more stability.

As many as 65.90% of the parents report that each family member does their best to take responsibility regarding daily obligations in their family. A few parents (25%) believe that one or two people take the most responsibility, in most cases the mother.

It can be concluded on the basis of their comments that these families confront the challenges and demands in different ways and rely on their inner strength and the bonds among them. They see themselves as active and competent in the domain of mutual relations, a finding which has been confirmed by other studies (Neely-Barnes & Dia, 2008).

The highest results in the "Family Relationships" domain in our study are comparable to those from a previous study about the quality of family life (Čagran et al., 2011) in Slovenia; those, however, were based on a smaller sample.

In addition to Family Relationships, high average results regarding the six dimensions were measured in the Health ($\bar{x} = 21.66$) and Community Interaction ($\bar{x} = 21.64$) domains.

The parents rated the Health domain highly ($\bar{x} = 21.66$), even though most of them (70.45%) commented that the physical and/or mental health of the member(s) of the family with ID did cause them great concern (e.g., epileptic seizures in children, constant pain in the stomach, digestion disorders, special diets etc.).

77.27% of the parents expressed considerable concern because of the physical and/or mental health of other members of the family and a concern that they would not be able to provide the necessary care for the child.

They also reported that constant obligations and worries at home did have an effect on them (fatigue, exhaustion), and other health problems were also reported (e.g., back pain). Often the entire well-being of the family depended on the child's health problems. Some parents were worried about the future, the health condition of their child in the future and whether they would be able to provide the child with everything that he needed.

The families also rated the Community interaction domain highly (=21.64). As many as 63.6% of the families commented that they enjoyed living in their community; 31.8% enjoyed that very much and felt good within the community. Many families are members of the Sožitje and Sonček associations for people with disabilities. They also mentioned associations for hemophilia, celiac disease and autism, self-help groups etc. Other family members participate in various sports or excursion groups, fire-fighting and cultural associations.

Most parents (88.6%) stated that their family had experienced no form of discrimination in the community.

In contrast with Family relationships, Health and Community Interaction, the lowest average score from the point of view of the six dimensions was measured in the Financial Well-being (=19.45), Support from Others (= 18.84) and the Support from Services (= 18.40) domains.

In the Financial well-being domain (=19.45), the majority of parents (61.36%) who participated in our survey described their total family income in Slovenia as average. 22.73% said that their family income was above-average, while 15.90% considered their income as below average. The parents reported that therapies available from international experts and the necessary devices were very expensive (in excess of 1000 eur). As many as 40.90% of the families spent 10-25% of their total income on special care, medication, assistance or equipment for the family member with ID; 15.90% of the families spent 26-50% of their total income; and 11.36% spent more than half (51% and more) of their total income, including all payments for special care, medication, assistance or equipment for the family member with ID.

56.82% of the parents believed that the family income mostly sufficed for their personal needs (e.g., food, clothing, accommodation etc.); however, 58.1% of the parents reported that after their household had paid for all the monthly expenses, no money was left for optional items, which was a financial deprivation for their family. More than 90% of the families also commented that they received no financial support from the services in addition to their monthly income.

Other authors (Parish et al., 2004; Sen & Yurtsever, 2007) have reported that families that have children with disabilities experience financial difficulties, even though they do not report major economic problems; they sacrifice only some commodities and holidays. It is necessary to point out the finding of NGOs in Slovenia that social security income is relatively low and does not meet all the needs of children with ID and their families. The social security system in Slovenia does take sufficient account of the greater needs of parents who have children with ID. They have also found that, regarding social security, institutionalized care means better protection than home care (Kukova, Završek, & Urh, 2005).

The parents also rated rather low Support from Others (= 18.84).

More than half of these parents (56.81%) commented that they received very little practical support from relatives and friends. 27.27% of the parents said that friends and neighbors provided little practical support; 11.36% of the parents said that they had

some support; and 4.54% that they had a lot of it. The comments revealed that the parents wanted more practical support from other people: *"I think that relatives could offer more practical support. However, at the same time I understand their reservations. My husband and I know our children well and sometimes struggle to make it through the day. There are good days and there are bad days. Every day is unpredictable."*

Parents provided varied answers regarding emotional support from friends and neighbors in the sense of being good listeners or providing encouragement.

29.54% of the parents commented that the level of emotional support was very low; 27.27% said that emotional support was low; 25% thought that there was some emotional support; 11.36% thought that emotional support was high; and only 6.82% of the parents reported that emotional support was very high. In addition, the parents pointed out that discussion with others rarely touched upon emotional problems or the emotional side of life and that they did not want to be unduly burdensome to others, which is why they preferred to talk about daily life or work. The parents also said that they enjoyed considerable emotional support from other parents with similar problems, with whom they are connected through various associations. Regarding private social life outside the family, 47.73% of the parents described this side of their lives as somewhat less satisfactory than they would like. 31.82% of the parents thought that the situation was worse than they would like, and 20.45% thought it was as they wanted.

The parents reported that they often lacked time for networking. Their comments included the following: *"A feeling of guilt when enjoying one's own moments of happiness. It is hard when you know that someone is depending on you and you cannot leave them alone."*

Regarding support from others, the results show that most parents sacrifice their own well-being for the benefit of the child and put it before their own needs.

International studies about the quality of family life have also found similarly low levels of support from others for families who have children with ID (Ajuwon & Brown, 2012; Steel et al., 2011; Zuna, Turnbull, & Summers, 2009).

The Support from Services domain, which is of vital importance for these families, was ranked the lowest (= 18.40).

The parents from towns and villages (they comprised 61.4%) listed considerably fewer services as being available to them. They reported that no services were available in their hometown. Among the available services, they most frequently listed the following: social services, a legal office and special care/special education schools. The following services were next in frequency: assistance from the employment agency, institutions, hospital, family doctor, pediatrician etc. The parents listed a range of related services that they or their children had received, depending on the type and level of the child's disability. Among the available services, they most frequently listed the following: social services, special care/special education schools, and institutions. The families pointed out that there were not enough social services in their area; even if special services for people with ID existed, 37% of the parents said that these did not provide the necessary support.

The following were the types of support that they did not receive: physiotherapy, occupational therapy and special educators for autistic children. The following were the most frequently listed reasons why they did not receive needed support from services: the services are unavailable in our town; we do not know where to look for

support; the waiting periods are long, or the services do not provide enough support. The parents were most critical of services in terms of lack of information and the complexity of the support system: *"We as parents are uninformed, we do not know all of our rights, we are often let down by experts, of whom there are not enough or they do not have the right expertise". "The support system in Slovenia is too complicated. Support for such families should be automatic. The current system is based on resourcefulness, research and a search for rights."* Slovene experts have also highlighted the shortcomings of and problems with offering professional support to children with disabilities. They highlighted incomplete professional teams in the out-patient clinics, which lacked child psychologists, speech therapists and rehabilitation educators. In big cities (Ljubljana, Maribor), there are programs available through the centers for education of children with special needs; however, certain services are not available to those parents from more remote places (Opara et al., 2010).

The parents most frequently highlighted support from the special education schools that the children attended. They also mentioned the associations of which they were members.

Analysis of differences within the individual domains of family life

In this section, differences between the dimensions (Importance, Opportunities, Initiative, Stability, Attainment and Satisfaction) were rated within individual domains of family life (Health, Financial Well-being, Family Relationships, Support from Others, Support from Services, Influence of Values, Careers, Leisure and Community Interaction).

Table 2: Results of the Friedman test of differences between the dimensions (Importance, Opportunities, Initiative, Stability, Attainment and Satisfaction) within the domains

Domains	Dimensions	Friedman test		
		Average range	χ^2	P
Health	Importance	5.53	106.698	0.000
	Opportunities	2.19		
	Initiative	3.24		
	Stability	4.10		
	Attainment	2.53		
	Satisfaction	3.40		
Financial Well-being	Importance	4.80	86.808	0.000
	Opportunities	2.53		
	Initiative	4.84		
	Stability	2.89		
	Attainment	2.99		
	Satisfaction	2.95		
Family Relationships	Importance	4.68	110.106	0.000
	Opportunities	3.57		
	Initiative	3.82		
	Stability	3.91		
	Attainment	1.51		
	Satisfaction	3.51		

Domains	Dimensions	Friedman test		
		Average range	χ^2	P
Support from Others	Importance	4.83	54.326	0.000
	Opportunities	2.97		
	Initiative	3.88		
	Stability	2.49		
	Attainment	3.28		
	Satisfaction	3.56		
Support from Services	Importance	5.28	75.917	0.000
	Opportunities	2.70		
	Initiative	3.22		
	Stability	2.73		
	Attainment	3.40		
	Satisfaction	3.67		
Influence of Values	Importance	4.15	24.022	0.000
	Opportunities	3.23		
	Initiative	3.47		
	Stability	3.38		
	Attainment	2.84		
	Satisfaction	3.94		
Careers	Importance	4.78	45.706	0.000
	Opportunities	3.41		
	Initiative	3.51		
	Stability	3.24		
	Attainment	2.58		
	Satisfaction	3.48		
Leisure	Importance	5.09	73.009	0.000
	Opportunities	2.83		
	Initiative	4.01		
	Stability	3.05		
	Attainment	2.58		
	Satisfaction	3.44		
Community Interaction	Importance	4.56	72.397	0.000
	Opportunities	3.40		
	Initiative	3.82		
	Stability	3.53		
	Attainment	1.97		
	Satisfaction	3.73		

Table 2 reveals that statistically significant differences do exist between the dimensions (Importance, Opportunities, Initiative, Stability, Attainment and Satisfaction) in all domains (Health, Financial Well-being, Family Relationships, Support from Others, Support from Services, Influence of Values, Careers, Leisure and Community Interaction).

In all nine domains, the Importance dimension was rated the highest, which suggests that parents were aware of the importance of all domains for the quality of

life of their family. The Importance domain is the most prominent, in particular in the Health, Support from Services and Leisure domains.

The Opportunities and Attainment dimensions were evaluated lowest, and the Initiative and Satisfaction dimensions lower than Importance; however, still more than the Opportunities and Attainment dimensions. It can be concluded that parents have tried to change the family situation, on the one hand, but, on the other, the opportunities were limited and attainment was poor, which is why satisfaction with the results has not been what they wanted or expected.

The parents reported that they had the most opportunities in the Family Relationships, Careers and Community Interaction domains, and the fewest in the Health, Financial Well-being and Support from Services domains. Even though parents perceived few opportunities in the Financial Well-being domain and satisfaction was lowest in this domain, they had nevertheless tried to improve the situation because they made the most initiatives in this domain. It is more worrying that in the Health and Support from Services domains, where they saw few opportunities, the fewest initiatives were made to improve the situation. It can be concluded that these parents no longer believed or had hope that positive change and improvement were possible in these two domains in the future. Empirical data suggest that attainment was highest precisely in the Support from Services domain, which is perhaps unusual/surprising; however, it was conditioned by the fact that their children with ID continuously attended educational institutions that provided them with teaching, security and protection. Within a special school, the teachers-special educators and other experts cooperate with the parents and are available to provide a range of information during their office hours, joint meetings and informal meetings, which probably reduces and alleviates the concerns and fears and provides families with a feeling of accomplishment (Schmidt & Brown, 2015).

Discussion and conclusion

In this study, individual domains of quality of life (Health, Financial Well-being, Family Relationships, Support from Others, Support from Services, Influence of Values, Careers, Leisure and Community Interaction) of families with children with ID/DD were investigated. The study also examines the differences among the measurement dimensions (Importance, Opportunities, Initiative, Attainment, Stability and Satisfaction) within the nine domains.

In our study, Family Relationships emerged as the area that inspires more optimism in the life of families. Despite the pressure of and difficulties in daily life arising from parenting a child with ID, support, resilience and strength are present in their mutual relationships, which also confirms the results of recent international studies of the quality of life in the domain of Family Relationships (Čagran et al., 2011; Davis & Gavidia-Payne, 2009; Heiman, 2002).

The results in the domain of Support from Others are not encouraging, in particular the domain of Support from Services. Descriptive data indicate greater family isolation and distance from social life, and at the same time limitation and passivity in seeking sources of support outside the family, which decreases the quality of life. Full or partial absence of practical and emotional support from relatives, friends and neighbors is present for most families. On the one hand, the results of the study highlight the major problem of inaccessibility of existing support services, and on the other hand, the results confirm that services either do not exist or fail to provide the necessary assistance.

This fact is very disturbing. Parents' critical comments relate to poor information from the services, complexity in seeking help and rights enforcement. In any case, it is necessary to consider the situation. The needs of these families are constantly changing, so we can predict that families raising children with ID/DD will probably encounter more obstacles as their children grow up. Therefore, it is necessary to make changes and take certain measures, because Slovenia lacks specific professionals to work with children and people with ID and their families in health centers, hospitals and counseling centers (Čagran et al., 2011). Additionally, austerity measures at the level of public services are a contributory factor. It would be necessary to set financial strategies, including redistribution and reorganization of existing services, to overcome these obstacles (World Health Organization, 2011), and furthermore, to promote the development of private initiatives and non-governmental organizations.

It is also necessary to look for solutions in the inefficient functioning of existing services. Services should allocate more time for in-depth information and introduction of legislation for all parents, especially for those who come from distant urban settlements or towns, the unemployed, the socially isolated and those who have fewer opportunities for informal and self-directed learning (Finn & Sturme, 2009; Pretis, 2011). Important aspects of professional work include education and skill training for parents of children with disabilities and supporting them with practical coping strategies (Gardiner & Iarocci, 2015). Better quality and effective work by the professional services can involve the active connection of families with informal social/emotional support and help for parents in establishing self-help groups, which represent an invaluable source of assistance for many families (Raina et al. 2005; Tsai & Wang, 2009).

The issues of children and families need to be addressed through complex, interdisciplinary cooperation and coordination between the areas of health, education and social support (Opara et al., 2010).

The results of the analysis of differences between the dimensions within individual domains of family life has shown that in all nine domains the Importance dimension is the most highly rated, from which it is evident that parents do realize the importance of all domains of quality of life for their families. The Opportunities dimension and Attainment dimension were assessed the lowest. The Initiative dimension and Satisfaction dimension were assessed lower than the Importance dimension, but higher than the Opportunities dimension and Attainment dimension.

Generally, the findings from the point of view of families with children with ID/DD suggest that these families require powerful intervention support programs from qualified professional teams as well as societal and political attention.

In the future, it would be worthwhile to conduct longitudinal studies in which the quality of life of all family members would be tracked over an extended period of time, or through different cycles of life. The perception of quality of life is a dynamic process in which there are many influences and changes over time. Therefore, the obtained results are limited to a certain extent.

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