

Olgu Sunumu

Life Quality of Families With Disabled Children

Engelli Çocuğu Olan Ailelerin Yaşam Kalitesi

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Engellilik; engelli bireyi, ailesini, yakın çevresini ve ait olduğu toplumsal yapıyı ilgilendiren bir olgudur. Bu araştırma Muğla İli, Fethiye İlçesinde bulunan tüm Özel Eğitim ve Rehabilitasyon merkezlerinde eğitim alan engelli çocuğa sahip 160 ailenin yaşam kalitesini belirlemek üzere planlanmış, tanımlayıcı alan araştırmasıdır. Verilerin toplanmasında araştırmacı tarafından oluşturulan geliştirilen anket formu kullanılmıştır.

Araştırmaya katılanların %85.6'sı anne, engelli çocuğun %51.9'u 7-12 yaş grubunda, %53.2'sinin erkek olduğu, çocukların %3'ünün işitme engeli %3.4'ünün ruhsal ve duyuşsal engeli, %36.6'sının zihinsel engeli %25.7'sinin ortopedik engeli, %25.7'sinin konuşma bozukluğu %5.6'sının öğrenme güçlüğü vardır. Aile eğitimleri ile çocukların geleceklerinden kaygılanma, çocukların ayak bağı olduklarını düşünme, çevrelerinin bakış açısından rahatsızlık duymaları arasında istatistiksel açıdan önemli fark bulunmuştur ($p < 0.05$). Engelli çeşitleri ile çocuklarının geleceklerinden kaygılanma, çocuklarının ayak bağı olduklarını düşünme, kendilerine ve diğer aile bireylerine yeterli zaman ayırabilmeleri arasında istatistiksel açıdan önemli ilişki bulunmuştur ($p < 0.05$).

Anahtar kelimeler: Engellilik, Engelli çocuklar, Yaşam Kalitesi, Engelli Aileler.

Abstract

Disability; individuals with disabilities, their family, immediate environment and the social structure of is a phenomenon of interest. This study was conducted as a descriptive research in order to determine the quality of life in a total of 160 families with disabled children receiving education at all Rehabilitation Centers of Fethiye, Mugla region. Survey forms developed by the researcher were used as the data collection tool.

85.6% of research participants are mothers, 51.9% of disabled children are within the 7-12 age group, 53.2% are male, 3% of the children have hearing disorders, 3.4% have mental and emotional disorders, 36.6% have intellectual disorders, 25.7% have orthopedic disorders, 25.7% have speech disorders, 5.6% have learning disorders. Statistically significant relation was found between the family levels of education and experiencing concerns about the future of their children, considering disabled children to be hindrance and feeling embarrassed of disabled children ($p < 0.05$). Statistically significant relation was found between the type of disability and experiencing concerns about the future of their children, considering disabled children to be hindrance and the ability to spend sufficient time for themselves and other members of their families ($p < 0.05$). Pre-marital legal tests need to be implemented in order to carry out programs intended for decreasing the rate of kin marriages in our country.

Keywords: Disabled Children, Quality Of Life, Disability and their families.

Introduction

Disability is a phenomenon of interest involving individuals with disabilities, their family, immediate environment and their social structure. Individuals with disabilities have basic needs that are not different from those of other individuals. Disability is defined as a person's inability to meet normal vital needs as a result of constant loss of functionality/dysfunction at a certain rate in the person's physical, cognitive, spiritual and social characteristics (1).

Indicators that define the life conditions of disabled families are the age of parents, region and place of residence, social environment, social and cultural relations, family structure and population, housing situation, health and nutrition conditions, social security conditions, type of insurance/benefits from social welfare, urban life facilities and organizations, activities directed to assisting the disabled. Families with children with disabilities are able to experience serious financial difficulties. The most important field that defines the quality of life of individuals with disabilities and their families are the economic conditions (2). Families with disabled child are living their own specific anxiety. This anxiety is to parenting a disabled child. Families experience mixed feelings with the birth of a disabled child, they go through a certain period before accepting the situation (3).

Mothers and fathers experience stress being confronted with such a case, which is difficult to come in terms with, they

have difficulties meeting their daily needs, and interpersonal relations such as marriage, emotional relations become tense. Inappropriate reactions and such guilt feelings experienced by a family lead to a depression occurring in parents; moreover, parents experience stress due to the additional time, money, energy needed to provide the child with care (4).

Quality of life is a concept used to describe the health problems of individuals and shows their feelings, their daily life activities and the extent, to which they are performed by the individuals (5). The quality of life is determined by sociological, psychological, economic and cultural factors in order to generally define the wellbeing of an individual. Turkey is a country with very high rates of disability due to the large amount of kin marriages in certain regions. Kin marriages still continue to occur at high rates. Therefore, the results of our study is important in terms of promoting the social policies to be determined in our country for individuals with disabilities and their families.

Material And Method

This study was conducted as a descriptive research in order to determine the quality of life in families with disabled children. Two of Special Education and Rehabilitation center is available a total of 200 families, all families formed the universe. Study and work carried out between 28.11.2006-10.12.2006 were 160 families. 40 families were not included in the study due to attendance of unaccompanied children and refusal of families to respond

to the survey questions. Written permits from respective organizations and written consent forms from the participating families were obtained in order to conduct the study.

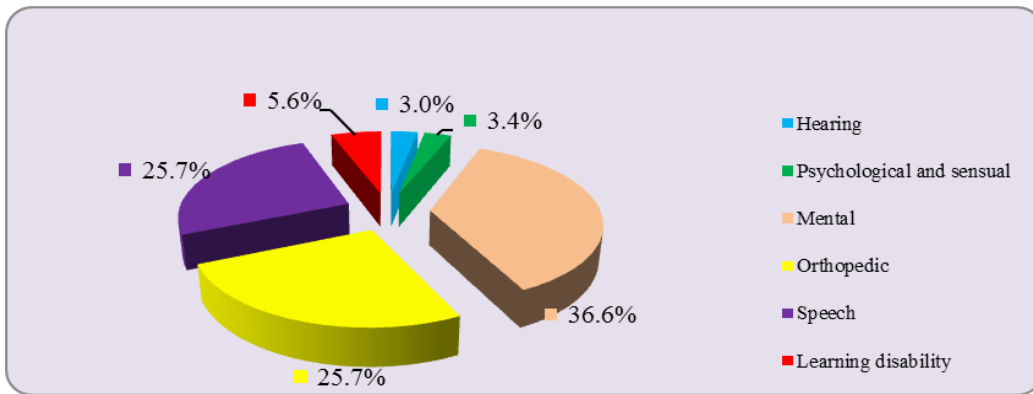
A survey form developed by the researcher was used as the data collection tool during the study. The survey form contains a total of 33 questions aimed to determine the social-demographic characteristics (13 questions) and the quality of life in families (20 questions). Pre-application was conducted with 20 families and incoherent expressions of the survey form were corrected, families included in the pre-application were excluded from the evaluation. Special Education and Rehabilitation centers, a total of two weeks (14 days) were visited family in consultation with individual data were collected.

Findings

It was determined that among the participants of the study 85.6% were mothers, 14.4% were fathers; 26.2% of parents were within the 20-30 age group, 48.9% were within 31-40 age group, 20.5% within 41-50 age group, 4.4% within 51≤ age group. It was determined that 6.2% were illiterate, 77.5% were elementary school graduates, 7.5% high school graduates, 8.8% university graduates; 81.9% were nuclear families, 18.1% were extended families. 63.1% resided in the city, 36.9% resided in a village; 4.3% had income higher than expenses, 48.8% had income equal to expenses,

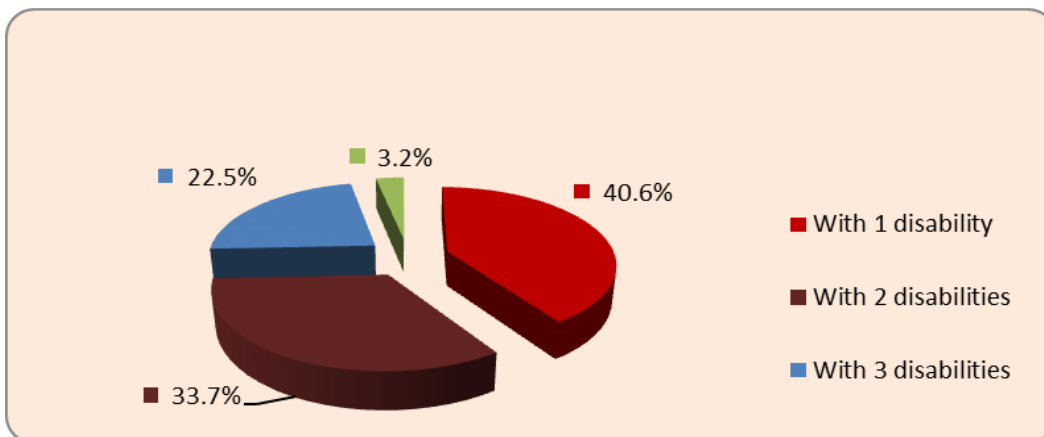
46.9% had income lower than expenses; 90.7% had a health insurance; 65% resided in a rented apartment. It was found that 26.3% had 1 child, 49.2% had 2 children, 19.8% had 3 children, 4.7% had 4≤ children; among these children 97.5% were 1, 1.9% were 2, 0.6% were 3 disabled children; 45.0% of the families had 1, 36.9% had 2, 12.5% had 3, 5.6% had 4≤ disabled children.

It was determined that 46.8% of the disabled children were female, 53.2% were male; 31.2% were within the 0-6 age group, 51.9% were within 7-12 age group, 11.9% were within 13-18 age group, and 5% were within 19-26 age group. It was found that 15% of the families with a disabled child had problems between the spouses, 10.6% had partial problems between spouses; 75.6% indicated that disabled children created psychological problems in parents, 14.4% indicated having only partial psychological problems; 45.6% indicated having expenses affected by disabled children, while 28.1% indicated having expenses partially affected by disabled children. It was determined that 16.2% indicated receiving social assistance due to their disabled children and 83.8% were not receiving any social assistance. It was found that 10.6% indicated having a person to help them around, 89.4% indicated not having a person to help them; 10.7% experienced problems in reaching the rehabilitation centers; 12.5% indicated having another person in their household in need of care, 87.5% indicated not having another person in need of care.



Graph 1. Distribution of families with disabled children by the types of disabilities.

36.6% of the disabled children were found to have cognitive, 25.7% - speech, 25.7% - orthopedic, 5.6% learning difficulties, 3.4% mental and emotional disabilities.



Graph 2. Distribution of families with disabled children by the number of disabilities child.

40.6% of the families have 1, 33.7% have 2, 22.5% have 3, and 3.2% have 4≤ disabled children.

Table 1. Distribution of Anxiety Among Families With Disabled Children

	n	%
Disability Cause		
Prenatal	32	21.0
Postnatal	53	33.1
During birth	52	31.8
Genetics	19	11.6
Other (accidents)	4	2.5
Performance of Daily Life Activities by the Disabled Individual		
No assistance	48	30.0
Partial assistance	53	33.1
Completely dependent	59	36.9
Families' Acquisition of Knowledge Regarding the Disability of Their Child		
Yes	48	30.0
No	72	45.0
Partial	40	25.0
Being Embarrassed of the Disabled Child		
Yes	13	8.1
No	113	70.6
Partial	34	21.3
Experiencing Future Concerns Regarding Their Disabled Child		
Yes	134	83.8
No	11	6.9
Partial	15	9.3
Considering Their Disabled Child to be Hindrance		
Yes	29	18.1
No	88	55.0
Partial	43	26.9
Having Their Social Life Limited by the Disabled Child*		
No limitation	62	20.0
Unable to go to a cinema	9	2.9
Unable to read books	15	5.0
Unable to spend time with friends	81	26.0
Unable to do sports	8	2.6
Unable to travel	73	23.6
Unable to work	62	19.9
Reaction of a Non-Disabled Siblings to Disabled Sibling		
Jealousness	26	16.3
Anger, rage	4	2.5
Embarrassment	13	8.1
Tolerant and understanding	76	47.5
No siblings	41	25.6
Experiencing Discomfort Due to Social Looks on the Disabled Child		
Yes	89	55.6
No	36	22.5
Partial	35	21.9
Unable to Spend Sufficient Time on Themselves or Other Family members		
Yes	45	28.1
No	56	35.0
Partial	59	36.9
Total	160	100.0

*n was multiplied due to more than one option being selected

It was found that disabilities of 21% of children were caused before birth, 33.1% after birth, 31.8% during birth, disabilities of 11.6% were genetic, 2.5% were caused by accidents; 30.0% of children with disabilities were able to perform daily life activities without help, 33.1% with help and 36.9% were completely dependent on others' assistance.

30.0% of families acquired knowledge about disabled children, while 45% did not acquire such knowledge and 25.0% acquired partial knowledge; 83.8% had concerns about the future of their disabled children, 9.3% had partial concerns; 18.1% considered their disabled children to be a

hindrance, 26.9% considered them to be a partial hindrance; in relation to their social life 26.0% of families indicated inability to spend time with their friends, 23.6% indicated inability to travel, 2.9% indicated inability to go to a cinema; 55.6% experienced discomfort in terms of environment, while 21.9% experienced partial discomfort; 28.1% indicated spending sufficient time on themselves and other family members, 35% indicated not being able to spend sufficient time on themselves and other family members, while 36.9% indicated being partially able to spend time on themselves and other family members.

The study shows that 16.3% of non-disabled siblings having angry feelings towards their disabled brothers/sisters, 2.5% feel jealous and rage, 8.1% feel embarrassed and 47.5% are tolerant and understanding.

It was found that 15.0% of the families had problems between the spouses, 10.6% had partial problems between

spouses; 75.6% indicated that disabled children created psychological problems in parents; 45.6% indicated having expenses affected by disabled children; 83.8% were not receiving any social assistance; 89.4% indicated not having a person to help them around the household; 35.6% indicated having health problems.

Table 2: Distribution of The Disabilities of Children in Terms of Parents, Place of Residence, Type of Disability, Performance of Daily Life Activities

	Families Considering Disabled Child to be Hindrance			Families Experiencing Discomfort Due to Social Looks on the Disabled Child		
	Yes n (%)	No n (%)	Partial n (%)	Yes n (%)	No n (%)	Partial n (%)
Parents						
Mother	25 (18.2)	73 (53.3)	39 (28.5)	78 (56.9)	28 (20.4)	31 (22.7)
Father	4 (17.4)	15 (65.2)	4 (17.4)	11 (47.8)	8 (34.8)	4 (17.4)
	$\chi^2 = 1.501$ p = 0.492			$\chi^2 = 2.342$ p = 0.310		
Place of residence						
City	12 (11.9)	64 (63.4)	25 (24.8)	77 (76.2)	14 (13.9)	10 (9.9)
Village	17 (28.8)	24 (40.7)	18 (30.5)	44 (74.6)	5 (6.0)	10 (19.4)
	$\chi^2 = 9.836$ p = 0.007			$\chi^2 = 7.911$ p = 0.019		
Physical Disability	3 (12.5)	17 (70.8)	4 (16.7)	14 (58.3)	4 (16.7)	6 (25.0)
Intellectual Disability	4 (9.8)	27 (65.9)	10 (24.3)	13 (31.7)	15 (36.6)	13 (31.7)
2 ≤ Disabilities	22 (23.2)	44 (46.3)	29 (30.5)	62 (65.3)	17 (17.9)	16 (16.8)
	$\chi^2 = 8.102$ p = 0.088			$\chi^2 = 13.727$ p = 0.008		
Independent Performance of Daily Life Activities by the Disabled Individual						
No assistance	5 (10.4)	37 (77.1)	6 (12.5)	21 (43.8)	14 (29.2)	13 (27.0)
Partial assistance	10 (18.9)	22 (41.5)	21 (39.6)	27 (50.9)	13 (23.5)	13 (23.5)
Completely dependent	14 (23.7)	29 (49.2)	16 (27.1)	41 (69.6)	9 (15.2)	9 (15.2)
	$\chi^2 = 15.885$ p = 0.003			$\chi^2 = 7.835$ p = 0.098		

According to the parents participating in the study, when comparison is made among the parents considering their disabled children to be a hindrance; 18.2% mothers and 17.4% fathers consider disabled children to be a hindrance. Families considering their disabled children to be hindrance was not considered a significant indicator in parent statistics ($p > 0.05$). When comparing parents experiencing discomfort due to social views on their disabled children, it was found that 56.9% mothers and 47.8% fathers experienced discomfort. Families experiencing discomfort due to social views on their disabled children were not considered to be a significant indicator in parent statistics ($p > 0.05$) (Table 2).

When comparing families considering disabled children to be a hindrance in terms of place of residence, 11.9% of city residents and 28.8% of village residents considered their disabled children to be a hindrance. Families considering their disabled children to be hindrance were found to have a significant relation to the place of residence ($p < 0.05$). When comparing families experiencing discomfort due to social views on their disabled children in terms of place of residence, 76.2% of city residents and 74.6% of village residents experience discomfort. Families experiencing discomfort due to social views on their disabled children were found to have statistically significant relation to the place of residence ($p < 0.05$).

When comparing families considering disabled children to be hindrance in terms of the type of disability, 12.5% of children with physical disabilities, 9.8% of children with cognitive disabilities and children with 2≤ disabilities are considered by their families to be hindrance. Families considering their disabled children to be hindrance were found to have statistically significant relation to the type of disability ($p < 0.05$). When comparing families experiencing discomfort due to social views on their disabled children in terms of the type of disability, families 58.3% of children with physical disabilities and 65.3% of children with 2≤ disabilities were found to have experienced discomfort due to social views, while 36.7% of families with children having cognitive disabilities did not experience discomfort. Families experiencing discomfort due to social views on their disabled children were not found to have statistically significant relation to the type of disability ($p > 0.05$).

When comparing families considering disabled children to be hindrance in terms of the ability to independently perform daily life activities, 77.1% of children unable to perform activities without assistance, 41.5% of children receiving small amounts of help and 49.2% of completely dependent children were considered to be a hindrance. Families considering their disabled children to be hindrance were found to have statistically significant relation to the

ability to independently perform daily life activities ($p < 0.05$). When comparing families experiencing discomfort due to social views on their disabled children in terms of the ability to independently perform daily life activities, 43.8% of families with disabled children not receiving assistance, 50.9% receiving partial assistance and 69.6% families with completely dependent children experienced discomfort. Families experiencing discomfort due to social views on their disabled children were not found to have statistically significant relation to the ability to independently perform daily life activities ($p > 0.05$).

Discussion

The study shows that majority of children with disabilities have intellectual, speech disabilities followed by physical and hearing disabilities. Nowadays, when a significant portion of the world population includes individuals with disabilities, the World Health Organization estimates that 10% of the population in developed countries and 13% in developing countries consist of individuals with disabilities caused by intellectual, physical or emotional disorders. According to the research published in December 2003, 12.29% of our country's total population is comprised of individuals with disabilities (6, 7). Literature indicates that parents of a disabled child, when compared to parents with no disabled children, are subject to higher levels of stress and anxiety (8 - 11). Beser et al. in Aydın, disability prevalence, etiology, to assess the disability dependency in activities of daily life and society of the disabled into perspective in their study on 2700 people; 17.5% had intellectual, and 9.2% had hearing disorders (12). By Yılmaz in 2004 in Ankara, In order their problems of disabled people in working life and to determine the factors affecting these problems, according to his work 341 disabled employees; 48.7% of disabled individuals had orthopedic, 14.1% had hearing, speech and language, 3.5% had intellectual, 2.3% had mental and emotional disabilities (13). Due to the fact that the rate of intellectual disabilities is lower and the rate of hearing and orthopedic disabilities is higher than the values determined during this study, due to the variety of risk indicators despite the closeness of regions, a study should be carried out.

More than half of the families were found to have more than one disabled child. Additionally, it was found that approximately half of the families had no knowledge regarding the disability of their child and one fourth of the families had partial knowledge about the disability. Lafçı et al. in Adana, mentally handicapped children in order to identify the difficulties of the family, according to his work with 55 families; 10.6% of families have no knowledge about the disability of their child (14). Bahar et al. found in their study performed in 2009 that 13.3 of the families had more than one disabled child (15).

Uskun et al. in Isparta, disability prevalence, etiology, to determine the causes of disabilities, according to a survey conducted with 3500 people; 9% of individuals had 1 disability, 2.9% had 2, 0.6% had 3, 0.2% had 4 and more disabilities (16). The high rates of results of this study can be related to the fact that the study incorporates individuals visiting the rehabilitation center. According to the study conducted by Ozsenol et al. in 2003 in Ankara, 18.8% of children had more than 1 disability (5). Beser et al. in Aydın, disability prevalence, etiology, to assess the disability dependency in activities of daily life and society of the disabled into perspective in their study on 2700

people; 10.7% of disabled individuals had more than 1 disability (12). According to the distribution of disabled population of Turkey in terms of the disability groups executed according to the Results of the Research on Disabled Individuals in 2002, 11.4% individuals had more than one disability (17).

The fact that the rates of all studies are lower than those of our particular study is saddening for our region. Measures employed in this regard in our region (opening of a third rehabilitation center and special education school) are elating. Moreover, this study yielded the results that majority of parents are elementary school graduates and have low level of education, rates of village residence are high, and at the same time families have low levels of income, and such various factors prevent them from having sufficient knowledge regarding the disability of their children.

The study shows that among the causes for disability, one third is caused by postnatal, one third during the birth and one fifth by prenatal factors. Therewith, disabilities caused by accidents and genetic factors also have a significant percentage (13.1%). According to the study conducted by Yılmaz in 2004 in Ankara, 68.4% of disabilities are caused by postnatal, 29.2% by prenatal factors, and 2.3% are caused during the birth (13). According to the study conducted by Beser et al. in 2003 in Aydın, 19.8% of disabilities are caused by prenatal, 68.5% by postnatal factors, and 12% are caused during the birth. 52.2% of the prenatal factors is due to the fact of kin marriages (12). Özsoy, Özkahraman and Callı in Izmir, in order to determine the challenges faced by families with children with disabilities, in his study with 110 families, the blood relations of spouses are designated to be 12.7% close relatives, 21.8% distant relatives, 65.5% not related (18). During the periods of first definition of a disability, the problem was based completely on genetic factors. Moreover, the fact that the rates of disabilities caused by the birth process are high in our country and the birth process is very important in terms of the mother's and the child's health, measures shall be taken urgently to deal with this issue.

The study shows that nearly all the families have concerns about their future. Özsoy, Özkahraman and Callı in Izmir, in order to determine the challenges faced by families with children with disabilities, in his study with 110 families, nearly all the families have concerns about their future lives. According to the study conducted by Ozsenol et al. in 2003, a major portion of families have experienced future related anxiety (5). According to the study conducted by Chaud et al., families were found to experience serious psychological issues. (19). According to the IAN research report, families experience fear and sadness when thinking about the future of their children (20). This study is consistent with the literature. It is thought that families experience future anxiety due to the worries such as "who will look after my child when I am not around or when I pass away". This is caused by the fact that our country has no complete planning for the future of disabled individuals.

The study shows that approximately half of the siblings feel angry, jealous and in rage, embarrassed. According to the study conducted by Lafci et al. in 2014, nearly all siblings experience adaptation problems (14). Özsoy, Özkahraman and Callı in Izmir, in order to determine the challenges

faced by families with children with disabilities, in his study with 110 families, majority of siblings experience adaptation problems (18). According to the study conducted by Mulroy et al. in 2008, disabilities were found to create negative effects on the siblings (21). Macks et al. found in their study that disabled children have negative effects on their non-disabled siblings (22). The reaction of each child having a disabled sibling varies according to their age and level of development. They may experience guilty feelings because they are not disabled. Variables such as the family structure, family's financial and psychological resources, parents' level of education, cultural differences, religion, mother-father-child relations, child characteristics may affect the compliance of the children with their disabled siblings, their emotional and behavioral reactions.

The study shows that two third of the families experience discomfort due to the looks of the society. According to the study conducted by Lafci et al. in 2014, majority of families experience discomfort due to social views (14). Özsoy, Özkahraman and Callı in Izmir, in order to determine the challenges faced by families with children with disabilities, in his study with 110 families, 78.2% of families were concerned about the views of the society and 21.8% were not concerned (18). It can be related to the fact that cities have large populations and the social pressure is higher there.

The study shows that majority of families indicated the inability to spend more time on themselves and other members of the family. According to the study conducted by Lafci et al. in 2014, families indicated the inability to spend more time on themselves and other family members (14). Özsoy, Özkahraman and Callı in Izmir, in order to determine the challenges faced by families with children with disabilities, in his study with 110 families, families indicated that they do not pay sufficient attention to family members other than the child (18). Studies conducted in the field indicate that mothers pay insufficient attention to their children, spouses and themselves, their social communication decreases, they have concerns about the future of their children, become anxious, parents have low self respect, marriage relations are corrupted and personal adaptation is reduced (9, 23).

Conclusion

The study shows that majority of families have intellectually disabled children, children with more than one disability, families have no knowledge regarding the disabilities of their children, disabilities of children are mostly caused by postnatal factors and during the birth, families experience serious future anxiety, other siblings experience adaptation problems, families experience discomfort due to the social views, parents are unable to spend sufficient time on themselves and other family members. Moreover, it is determined that spouses have problems with each other, disabled children cause psychological problems in parents, disabled children affect their expenses, large rates of families are not receiving social assistance, families have nobody to help them around the household.

Families should be assisted in accepting the disability of their child, diagnosis of the child's disability should be explained to the families and families should be provided with sufficient information on the subject, families should be provided with social assistance, caretakers of the disabled should spend time on themselves and other family

members, their physical and psychological health should be protected, disability prevention programs should be developed, programs should be conducted to reduce the rates of kin marriages in our country, genetic consulting should be performed, prenatal and postnatal tests should be encouraged, pre-marital legal tests should be implemented.

Resources

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Sorumlu Yazar:

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