

OVERVIEW OF THE NEEDS OF FAMILIES WITH DISABLED CHILDREN IN BASRAH CITY

HAJER SALAM ESSA

College of Nursing, University of Basrah, IRAQ

ABSTRACT

Raising children with disability may yield a strong need for support among parents, to support these parents, information is required regarding the types of support they need and whether their needs are met; but evidence for some of these needs are unmet. The aim of this study was to investigate definite needs for parents (50mothers and 50 fathers) with disabled children according to *Family Needs Survey (FNS) questionnaire* at a governmental center for rehabilitation for disabled children in Basrah city. *Family Needs Survey (FNS) questionnaire* which included six subscales of needs such as need for information, social support, community services, explaining to others, financial support and family functioning. The most frequently cited need among parents is the need for information about the services that are presently available as their greatest need and the services that the child might receive in the future. Mothers reported the need for information about the services that are presently available (94%) while fathers expressed (80%) and the least was the need for paying for babysitting and deciding who do house hold (2%) by both parents. Out of six subscales of FNS, the need for information had the highest rating which was (94%) followed by need for social support (80%), need for community services (70%), need for financial support (48%), need for explaining to others (46%) and need for family functioning (34%) was expressed by mothers. The identified needs varied for both parents within the subscales.

KEYWORDS: Support These Parents Information, *Family Needs Survey (FNS)*

INTRODUCTION

All children have a right to care by a parent or trusted adult. As infants, this care extends to every aspect of the child's life: bodily functions, and physical, mental and emotional development. As the child grows, the care required changes and generally diminishes, so that the child needs less and less help from the adults around him. Children with different levels of disabilities require the same care and parenting as other children, with the addition of extra care due to impairments or chronic ill health. The extra care required may arise from different levels of disabilities of self-care skills and or a need for special care. According to the International Classification of Functioning, Disability and Health (ICF), capacities describe the individual's ability to execute a task or an action, and are defined as the highest probable level of functioning that a person may reach in a given domain at a given moment in a 'standardized or assumed' environment. Limitations in the capacities of the child will lead to the need for additional care. This additional care has been defined as 'dependency on medication or special diet, medical technology, assistive devices, personal assistance, need for medical care or related services or educational services over and above the usual for the child's age, or for special ongoing treatments, interventions or accommodations at home or in school (1). Therefore parents of children with disabilities often experience higher levels of parenting stress than parents both of typically developing children. Consequently, a substantial

number of parents of children with disabilities are in need of a variety of support, such as information, child care (e.g. respite care), family and social support (e.g. someone to talk to, leisure activities), community services (e.g. doctor), help with explaining the child's disability to others and financial support. As well as child-specific factors, the need for support and services is influenced by environmental factors. Thus, the relationship between level of dependency and support and service needs are complex. It is increasingly recognized that valid and reliable tools are needed to assess different kinds of disability and care needs and to guide service decisions. Determination of the level of service or funding that should follow on from assessment is a complex task, but it is a task that must be undertaken. Many countries providing financial assistance to parents of children with disabilities, in recognition of their additional care needs. Instead, most assessment processes use any information already available and evidence from health professionals. The identification of the parental needs is very important for the determination of mode, content and quality of the service provided for those families. Although every family has different necessities, those needs can be grouped.

In "The Preference Inventory for Family Information", Turnbull and Turnbull grouped the needs of the parents as five groups, study of children, collaboration with professionals, planning for the future, finding and using help and support for the purpose of the family relief. However, according to FNS (Family Needs Survey) developed by Bailey and Simeonsson (1988), the necessities of the family are classified as the need of knowledge, the need of support, guidance to explain the status of the children to others, public services, financial needs and social needs related to the functioning of the family. The determination of the needs of the families with disabled children is critical for minimizing the negative impacts of the situation of the family and maximizing the level of the support. Additionally, it provides appropriate services to be offered and healthy development of the children. The emotional strains, inability of the sufficient information on the situation of the disabled individuals, difficulties in explaining this situation to others, the health and behavior problems of the disabled children and the necessity of the consultation experts about the treatment and education constitute important sources of the stress for the families. In addition those stress factors, the efforts to find appropriate environment for education of the children, requirement of more time, energy and finance also lead families to increase the stress levels. It was detected that those difficulties lived by the parents lead to stress. (2,3,4,5,6,7,8)

METHODS

Basrah city is the second big city in Iraq located about 500 km south of Baghdad. The city has only one governmental center for rehabilitation of disabled children. A sample of 50 two- parents' families (primarily 50mothers, and 50 fathers) with disabled children aged below 10 years old attending to this center were invited to participate in the study. The study was carried out during the period September 2015 - April 2016. The tools were used for data collection:

Demographic data sheet: a structured questionnaire used in this study was designed by the researcher to collect information about parents' characteristics, such as age, education level, occupation, social status and residence. It also included questions about disabled child's age, sex, and rank in the family, type of disability, number of doctor's visit for children in the last year and number of hospitalization for children in the last year. The Family Needs Survey (FNS) scale: It was socio-culturally improved by Bailey and Simeonsson (1988) and used in this study to assess the needs of a family of children with disabilities (5). It is a 35 item scale and is composed of six subscales: information, social support, community services, explaining to others, financial support and family functions. there are three Likert-type marking choices: "I definitely need help with this(3)", "Not sure (2)" and "I definitely do not need help with this (1)" For each item, parents

were asked to select one of three response choices. (5) The maximum score of the FNS is 105 and the minimum score is 35. The high score got from the FNS suggests the degree of definite needs of the parents. The original version of FNS is in English language. Therefore, the FNS was translated into Arabic language. A Verbal consent was taken from every parents participating in the study. Each parent was individually interviewed.

STATISTICAL ANALYSIS

Results were analyzed using the SPSS (Statistical Package for the Social Sciences). Descriptive statistics was used to describe the frequency distribution of parent's socio-demographic characteristics, child's demographic characteristics and the degree definite of needs of the parents.

RESULTS

This study included 50 parents with disabled children; the distribution of child's demographic characteristics is shown in Table 1. More than half of the parents interviewed have male children (68%), children aged between 6-10 years old (56%) and have children with physical disability (42%). About (28%) of disabled children in the study was the first child for their parents. The parents had 5 or more of doctor's visits (40%) and 1 or 2 of hospitalization (54%) for their disabled children in the past 12 months. Moreover, In the research, (39%) of the parents were 40 years old, (38%) were primary school graduate, (42%) living in rural area, almost (78%) reported a family average monthly income of below 2000000 Iraqi dinar (92%), (28%) had three or four children and the majorities of mothers were housewives while the majorities of fathers were governmental employee (see Table 2).

Most and Least frequently Cited needs among parents:

The distribution of parents by type of need is presented in Table 3. Percentages of mothers or fathers indicating a definite need for help (as indicated by a response of 3). Eleven needs were identified by at least (70%) of the mothers, while only five were identified by at least (70%) of the fathers. All of the items related to the need for information were rated as needed help by more than 70% of the mothers. Other than the need for more information about child condition or disability, the services that are presently available, the services the child might get in the future, also reported that they needed more information about the child's development and growth (90%), the way to teach the child (88.2%), handle the child's behavior (86%) and play or talk to the child (76%), while only four of the items related to the need for information were rated as needed help by more than (70%) of the fathers. Eight items in the subscale of need for social support were endorsed by greater than two third of the mothers. The greatest need was for support from other parents (80%), followed by need for support from friends (70%), need for more time for themselves (70%), support from family members (66%), support from teacher or therapist (66%), and need for support from counselors (56%), religious person (30%). The most frequently chosen definite needs for community services were preschool services (70%), medical services (54%). For financial support, approximately 66% of mothers needed help in getting special equipments for child. In contrast, respondent's fathers reported less than (50%) for all items for both of the subscales of the need for social support and community services. Both parents (mothers and fathers) reported less than (45%) for all items of the subscales of the need to others and family functioning.

DISCUSSIONS

This study aims to determine the perceived definite needs among parents of children with disabilities. The needs

of the parents about their necessities of disabled children were described as information, social support, community services, and financial and explaining to others. The results are consistent with the previous studies of assessing definite needs among families of children with disabilities. For example, among the needs of those parents, priority belongs to the need of more information about the situation of their disabled children need for information remains largely definite (4, 5, and 9). Specifically, the present study indicates that the most frequently cited need among parents is the need for information about the services that are presently available and the services that the child might receive in the future. This finding is supported by other studies who stated that parents are more likely to get information about services presently available for their child and in the future and in fact, it was the highest definite need among the other needs (4, 5, 9, 10, and 11). This finding show that issues related to child's future becomes more important as the child gets older; suggesting that information regarding future services available to the children is often required by parents. A possible explanation is the parents are concerned and worried about the ongoing care for the child and in the future, especially If the parents pass away (12, 13).

Table 1: The Distribution of Some Characteristics of the Disabled Children in the Study (N =50)

Characteristics	Frequency	Percentage (n) (%)
Gender		
Male	34	68
Female	16	32
Age(years)		
<0	7	14
1-2	5	10
3-5	10	20
6-10	28	56
Birth Order		
First child	14	28
Second child	8	16
Third child	13	26
Fourth &over	15	30
Type of Disability		
Hearing	2	4
Visual	1	2
Physical	21	42
Mental	17	32
Speech	3	6
Learning	5	10
Multiple Disabilities	1	2
Number of Doctors Visits in the Past 12 Months		
None	1	2
1-2	14	28
3-4	15	30
5 &more	20	40
Number of Hospitalizations in the Past 12 Months		
None	5	10
1-2	27	54
3-4	7	14
5 or more	11	22

Table 2: The Distribution of Socio-Demographic Characteristics of the Parents in the Study (N=100)

Characteristics	Frequency(n)	Percentage (%)
Age (years)		
20-24	8	8
25-29	14	14
30-34	19	19
35-39	20	20
40&above	39	39
The Education Level		
Illiterate	5	5
Primary school	38	38
Intermediate school	36	36
High school	16	16
University	5	5
Occupation		
House wife	47	47
Government employee	52	52
Private sector	1	1
Family Average Monthly Income		
≤(Iraqi Dinars)1000000	7	14 (n=50)
1000000-2000000	39	78 (n=50)
n=50)>(2000000)	4	8
Place of Residence		
Rural	42	84 (n=50)
Urban	8	16 (n=50)
Number of the Children		
1-2	13	26 (n=50)
3-4	28	56 (n=50)
>4	9	18(n=50)

Table 3: Definite Needs Scores Reported by Parents

Type of Need	Respondent Mothers n=50 (%)	Respondents Fathers n=50 (%)
Information		
Information about my child's condition or disability	46(92)	39(78)
Information about how to handle my child's behavior	39(78)	12(24)
Information about how to teach my child	43(86)	32(64)
Information on how to play with or talk to my child	38(76)	23(46)
Information on the services that are presently available	47(94)	40(80)
Information about the services my child might receive in the future	40(90)	40(80)
Information about how children grow and develop	45(90)	37 (74)
Social Support		
Someone in my family that I can talk to more about problems	33(66)	12(24)
More friends that I can talk to	35(70)	17(34)
More opportunities to meet and talk with other parents	40(80)	12(24)
More time just to talk with my child's teacher or therapist	30(60)	10(20)
Meet more regularly with a counselor (psychologist, social worker, psychiatric	27(54)	12(24)
Talk more to religious person who could help me deal with problem	15(30)	23 (46)

Table 3: Condt.		
Reading material about other parents who have a child similar to mine	8 (16)	22(44)
More time for myself	35(70)	10(20)
Explaining to Others		
How to explain my child's condition to his or her siblings	23(46)	12(24)
Explaining my child's condition to either my spouse or my spouse's parents	11(22)	9(18)
My spouse needs help in understanding our child's condition	11(22)	8(16)
How to respond when others ask about my child's condition	13(26)	17 (34)
Explaining my child's condition to other children	5(10)	4 (8)
Community Services		
Locating a doctor who understands my child's need	27(54)	23(46)
Locating a dentist who will see my child	3(6)	17(34)
Locating babysitters who are willing and able to care for my child	3(6)	3(6)
Locating a preschool for my child	35(70)	19(38)
Getting appropriate care for my child during religious activity	3(6)	2(4)
Financial Support		
Paying for expenses such as food	24(48)	21(42)
Getting special equipment for my child's needs	33(66)	19(38)
Paying for therapy, daycare, or other services my child needs	24 (48)	36(72)
More counseling or help in getting a job	3(6)	2(4)
Paying for babysitting or respite care	2(4)	2(4)
Paying for toys that my child needs	3(6)	2(4)
Family Functioning		
Discussing problems and reaching solutions	17(34)	9(18)
Learning how to support each other during difficult times	5 (10)	3(6)
Deciding who will do household chores, child care, and other family tasks	2(4)	2(4)
Deciding on and doing recreational activities	3(6)	2(4)

As expected, there was considerable variability in level of definite needs among both parents rating for needs for information and others needs this discrepancy in rates of need for information and others needs can be partly explained due to that the burden of caring for a child with disability was borne primarily by the mother as in most published reports (14). Also the present study shows that the parents would like to get more information about; their child's growth and development, child's condition, how to handle the child's behavior, how to play, talk or teach their child as well as services presently available for their child particularly for mothers. Mothers expressed more needs than did fathers regarding the social support. These finding may reflect level of child care responsibilities for mothers and fathers which are consistent with other studies, where parents scored higher for support related to other parents of children with chronic conditions and disabilities (4, 5, 9, 15) With adequate professional and informal community services, parents may be able to access more resources and function more effectively, thereby promoting health in the child and reducing overall family needs. Therefore; the parents in the present study needed help to locate preschool and doctors, who understand their child's health needs and who are able to give treatment to their child.

These findings are consistent with the findings of other study who found that services related to medical care were often been reported by parents in caring for the child. Furthermore, the services offered for children with disabilities and their families are insufficient and priority is not given to them in terms of medical development. Thus, an immediate action towards overcoming these issues is needed. The financial needs contain not only basic needs, such as nutrition and clothing expenses, transportation, but also specific needs such as expenses for the health and education of the children. The results of the research showed that financial support is also a significant concern. Most parents in this study needed financial help to pay for expenses related to their child's condition. For example, they need to buy food; special equipment or devices and pay for the services obtained for their child similar finding can be found in other studies too. Need for explaining to others and family functioning, although reported much less frequently in the present study, in contrast to other study which found that almost half of parents in their study needed help in explaining about their child's disability to other atypical children (5). The possible explanation for this is because traditionally and culturally most parents receive assistance from their families when they realized that their child was disabled. Of those who received support, it came mainly from grandparents particularly maternal grandmothers. Maternal grandmothers gave support to the family of a disabled child primarily to support their daughter who carried the blame of giving birth to such a child. Also, maternal grandmothers sympathized with their inexperienced daughters because of the overall responsibilities associated in caring for children with disabilities. This is why they were quick to provide support in such situations.

CONCLUSIONS

In conclusion, This study shows the definite needs among parents of children with disabilities which was varied within the subscales; High parenting need for information which was the most frequently reported definite needs followed by need for more social support, community services and financial support; therefore Further research is needed to confirm the prevalence rate we found.

RECOMMENDATIONS

- The needs of the parents with disabled children should be identified and be provided necessary services.
- The families should be supported economically and socially, be assisted for getting support from the institutions and organizations socially, economically and psychologically, to face these unmet needs.

REFERENCES

1. World Health Organization: International Classification of Functioning, Disability and Health: ICF. Geneva, World Health Organization, 2001.
2. Buran CF, Sawin K, Grayson P, Criss S. Family needs assessment in cerebral palsy clinic. *Journal for Specialists in Pediatric Nursing* 2009; **14**(2): 86-93.
3. Harris H. Meeting the needs of disabled children and their families: some messages from the literature. *Child Care in Practice* 2008; **14**(4): 355-369.
4. Farmer JE, Marien WE, Clark MJ, Sherman A, Selva TJ. Primary care supports for children with chronic health conditions: identifying and predicting unmet family needs. *Journal of Pediatric Psychology* 2004; **29**(5): 355-367.

5. Bailey D.B., Simeonsson R J. Assessing needs of families with handicapped infants. *The Journal of Special Education* 1988; 22(1): 117-127.
6. Damiani, B. V. Responsibility and adjustment in siblings of children with disabilities: Update and review family's insociety. *The Journal of Contemporary Human Services* 1999; 1:34-40.
7. Byrne, E. A., & Cunningham, C. C. The effects of mentally handicapped children of families-a conceptual review. *Journal of Child Psychol Psychiatry* 1985; 26: 847-864.
8. Sucuoglu, B. Determination of parents' needs who have children with mental retardation. *Turkish Journal of Child and Adolescent Mental Health* (1995); 2(1): 10-18.
9. Graves C, Hayes VE. Do nurses and parents of children with chronic conditions agree on parental needs? *Journal of Pediatric Nursing* (1996); **11**(5): 288-299.
10. Bailey DB, Jr Skinner D, Correa V et al. Needs and supports reported by Latino families of young children with developmental disabilities. *American Journal on Mental Retardation* (1999); 104(5): 437-452.
11. Ellis JT, Luiselli JK, Amirault D et al. Families of children with developmental disabilities: Assessment and comparison of self-reported needs in relation to situational variables. *Journal of Developmental and Physical Disabilities*(2002); **14**(2): 191-202.
12. Lam LW, Mackenzie AE. Coping with a child with Down syndrome: the experiences of mothers in Hong Kong. *Qualitative Health Research* (2002); **12**(2): 223-237.
13. Murphy NA, Christian B, Caplin DA, Young PC. The health of caregivers for children with disabilities: caregiver perspectives. *Child Care Health Dev* (2007); 33(2): 180-187.
14. Heller T, Hsieh K, Rowitz L. Maternal and paternal care giving of persons with mental retardation across the life span. *Family Relations* (1997); 46 (4): 407-115.
15. Bailey D. B. Jr., Blasco P. M., Simeonsson R. J...Needs expressed by mothers and fathers of young children with disabilities. *American Journal of Mental Retardation* (1992); 97 :(1)1-10.