Stigma of Developmental Disabilities as Reported by Families of Disabled Children and Adolescents in Port Said

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There is still stigma attached to mental illness and negative discriminations that are usually associated with stigmatization and are significant obstacles to the development of appropriate mental health programs for developmentall disabled children and adolescents. 70 families of a sample of developmentally disaybled children and adolescents enrolled in rehabilitation institutions in Prot Said City in Suez Canal Area were assessed through a direct interview questionnaire about their life experience regarding the way they feel about their child being disabled. The samples of identified children and adolescents were mostly males (61%), of age ranging from 13 years and older (61%), and with predominant principal diagnosis of Mental Retardation (94%) and Epilepsy (41%). More than half of them (52%) were of moderate degree, and mostly were from middle socioeconomic status (67%), attending institutions regularly (57%). Whereas 63% of families studied reported positive attitudes towards their disabled youngster and 40% of parents reported positive perception and care from local society. While, sense of shameness was reported by 41% of parents and family members, only 28.5% mentioned that the presence of developmentally disabled child provokes internal feeling of stigma, 68.5% reported the child causing psychological strains and 57% admitted feeling of an economic burden. While more than 50% reported the use of traditional and popular medicine (alternative medicine), (20% religious,, 20% exorcise, 11% amulet, and 4% magic), 54% families pointed out psychiatric services as the major source of knowledge in their management. Although 71% admitted that specialized medical services for those developmentally disabled subjects are not available, 40% asked for health education programs mainly in the form of day care institutions (38%). The results will be presented to illustrate the current status of attitude towards developmental disabilities. Our findings suggest the need for mental and community health educational programs to change the attitude toward developmental disabilities.(Egypt.J.Psychiat., 2001, 24 :137 -147).

INTRODUCTION

Developmental disability is a long-term condition that significantly delays or limits mental or physical development and substantially interferes with such life activities as self-care, communication, learning and decision-making, capacity for independent living and mobility. It is usually diagnosed before a person reaches age 21. It includes mental retardation, head injuries, infantile autism, epilepsy and certain learning disabilities (Center for Disease Control, 2000).

Stigma is attached to mental illness and developmental disabilities in all societies. Stigma and intolerance of differences have grown in recent decades. It most often results in a negative discrimi-

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nation against the individual who has the disability . Stigma and discrimination because of developmental disabilities extend to the families, the caregivers and the institutions. (Murray and Lopez, 1996). Parental perception of psychiatric disorders in children and adolescents is crucial to management planning (Abou Zekry and Farid, 1990).

According to Kamel et al (1990) the reaction and attitude of Egyptian parents of children with Down's Syndrome suggest that stigma was inherited in the perception of the family and the social relations and studies in Egypt has shown that parents of children with developmental disabilities were more concerned with stigma associated with having such a child, particularly with high social standards (El-Dod et al, 1998).

Objective of the Study

Primary

To study the stigma of developmental disabilities in a group of disabled children and adolescents in special educational and rehabilitation institutions in Port Said City as representative community in the Suez Canal region.

Secondary

To study some factors that lead to this stigma.

Subjects and Methods

Study Design

Type of the study

Descriptive cross sectional

Study Site :

Rehabilitation and educational institutions in Port Said City.

Study and Target Population

Disabled children and adolescents attending those institutions.

Sampling

Purposeful sample , 70 family members of disabled children and adolescents .

Data Collection

* **Minisurvey** of knowledge and attitudes was obtained from families of disabled children by using a modified interview questionnaire (Parental Attitude Scale), Hamza (1992), and it includes the following dimensions:

a- Awareness and understanding of the problem

b- Optimism / Pessimism

c- Acceptance / Rejection

d- Stability / Hesitancy

e- Equality / Discrimination

Scoring of these 5 dimensions is classified as low, medium, and high.

*** Focus Group Discussion**

This is a qualitative method for assessing and understanding the deeply rooted phenomenon. It includes group discussion composed of 6-8 subjects of family members of developmentally disabeled children and adolescents.

Stigma and discrimination associated with developmental disabilities lead to :

1- Social isolation, delay of search for treatment.

2- Discrimination in health care and education, "no use" "no need" attitude.

3- Extend to family members and to those who provide health care services

4-Common cultural beliefs misconceptions and myths about developmental disabilities, for example, it is infectious , it is the parent's fault, it is untreatable, they are dangerous and even violent unpredictable behaviors, and it is caused by evil spirits, curse or "evil eye".

RESULTS

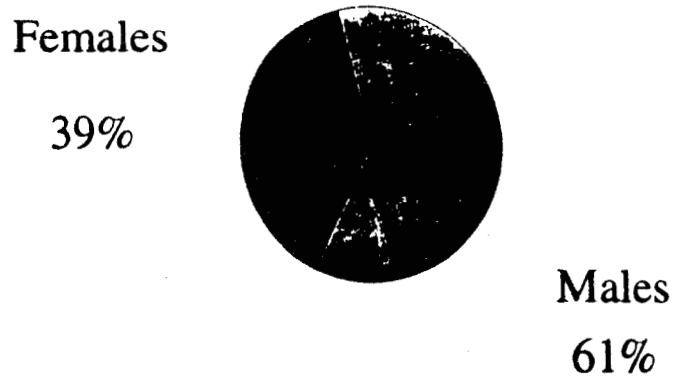

Figure I : Sex Distribution of Disabled Children & Adolescents

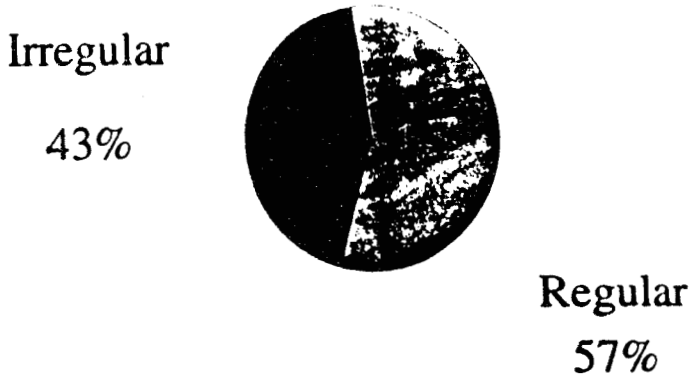

Figure II : Attendance of Disabled Children & Adolescents to Educational and Rehabilitation Centers

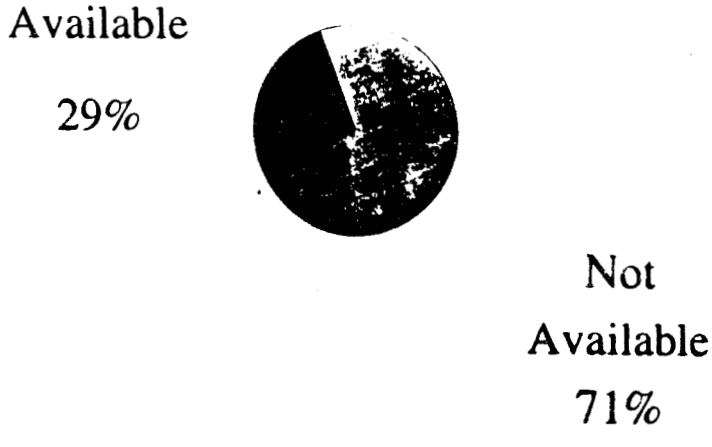

Figure III : Availability of Medical Services

Figures I, II, III show the sex distribution, regularity of attending rehabilitation centers, and availability of services for disabled children and adolescent.

Table (15) shows a statistically significant association between higher scale of parents, attitude and higher socioeconomic status ($p<0.05$) and this agrees with Abdel Gawad et al (1994) which revealed that low socioeconomic status places greater value on physical disabilities rather than mental ones, while higher socioeconomic groups tend to place greater emphasis on educational disabilities and limitations in the child's cognitive skills.

Table (16) shows a statistically significant association between parental attitude score and degree mental retardation ($p<0.05$). This agrees with Grocker (1989) and Kamel et al (1990) to be among a variety of factors that directly affect parental reaction, and that the Down's syndrome child higher I.Q. score was more accepted by his parents who encouraged him to be independent.

Table (17) shows relationship between attitude score of parents and the sex of the index child ($p<0.05$) in favour of female sex, this is in contrast to Kamel et al (1990), and in agreement with Farrag (1995), who suggested that parents to be generally more accepting of the presence of mental handicapped daughters and less likely to accept mental handicap in their sons.

Table 1
Age Distribution of Groups among Developmentally Disabled Children & Adolescents

Age Group	Number	%
0-4 Yrs	1	2%
5-9 Yrs	9	13%
10-12 Yrs	17	24%
>13 Yrs	43	61%
Total	70	100%

Table 2
Shows Distribution of Socioeconomic Status of Parents among Developmentally Disabled Children & Adolescents

Socioeconomic Status	Number	%
Low	18	26%
Moderate	47	67%
High	5	7%
Total	70	100%

Table 3
Diagnostic Categories of Developmental Disability in Children & Adolescents in Port Said

Type of Developmental Difficulties	Number*	%
1- Mental Retardation	66	94%
2- Epilepsy	29	41%
3- Learning Disability	45	64%
4- Developmental Disability (including Autism)	26	37%
5- Cerebral Palsy	11	15%

Number are not mutually exclusive

Table 4
Degree of Mental Dysfunction (I.Q) in Developmentally Disabled Children & Adolescents

Type	Number	%
Mild mental retardation	7	10%
Moderat emental retardation	36	52%
Severe mental retardation	27	38%
Total	70	100%

Table 5
Reported Risk Factors among Developmentally Disabled Children & Adolescents

Risk Factors	*Number	%
Positive consanguinity	14	20%
Antenatal Factors	9	13%
Natal Factors	7	10%
Postnatal Factors	7	10%
Downs' Syndrome	7	10%
Inborn Errors of Metabolism	4	5%
No Reported Risk	22	22%

* Numbers are not mutually exclusive

Table 6
Items of Attitude Scale of Parents towards Developmentally Disabled Children and Adolescents

Item	*Number	%
1- Knowledge of Nature of Disease	61	87%
2- Knowledge of Risk Factors of Disease	44	63%
3- Acceptance	70	100%
4- Inequality	45	64%
5- Negligence	7	10%
6- Stability	37	53%
7- Treat Child Badly	26	37%
8- Sense of Shamness Towards Child	10	14%
9- Sense of Shamness of Other Members of Family toward Child	19	27%
10- Sense of the Child is a Gift from God	70	100%
11- Independence	59	84%

* Numbers are not mutually exclusive

Table 7
Reported of Attitude Score of Parents towards Developmentally Disabled Children & Adolescents

Attitude Score of Parents	Number	%
Low	19	27%
Medium	44	63%
High	7	10%
Total	70	100%

Table 8
Reported Source of Knowledge of Parents About Management of Developmentally Disabled Children & Adolescents

Source of Knowledge*	Number	%
Psychiatry	38	45%
No Source	24	34%
Natural Medicine	15	21%
Religion	14	20%
Exorcise	14	20%
Make Amulet	8	11%
Magic	3	4%

* Responses are not mutually exclusive

Table 9
Reported Source of Knowledge
About Nature of Disability

Source of Knowledge	Number	%
TV	4	5%
Doctors	62	90%
Others	4	5%

Table 10
Reported Opinion of Port Said Society towards
Those Children from the Parent's Point of View

Opinion	Number	%
Good Opinion and Care (Positive)	28	40%

Table 11
Reported Stigma and Burden of Developmental
Disabilities on Families

Stigma	Number	%
Stigma	20	28.5%
Psychological burden	48	68.5%
Economic burden	40	57%

Table 12
Reported Opinion of Parents Towards Management

Opinion of Parents	Number*	%
Health Education Programs	28	40%
Building Special Institutions	26	37%
Develop Community for Rehabilitation	20	28.5%
Knowledge of Drugs	19	27%
More studies	18	26%
School Health Education	17	24%
Knowledge of Risk Factors	14	20%
Select groups of patients for rehabilitation programs	5	7%
All of above	2	3%

* Numbers are not mutually exclusive

Table 13
Preferred Center for Management Reported by Parents

Care Preferred	Number	%
Day care institutions	27	38%
Special institutions	22	31%
Special boarding schools	13	18%
School	9	12%

Table 14
Relationship Between Age Groups & Attitude Score of Parents

Attitude Score	Age Group		Total
	10-12 Yrs Old	> 13 Yrs Old	
	N	N	
Low	5	12	17
Medium	10	27	37
High	2	4	6
Total	17	43	60

P >0.05

Table 15
Shows the Relationship Between Socioeconomic Status and Attitude Score of Parents

Attitude Score	Low	Moderate	High	Total
	N	N	N	
Low	6	12	1	19
Medium	9	32	3	44
High	3	3	1	7
Total	18	47	5	70

P <0.05

Table 16
Relationship Between Attitude Score and Degree of Developmentally Disabled (Mental Retardation)Children Adolescents

Attitude Score	Mild	Moderate	Total
Low	2	4	6
Medium	9	21	30
High	7	15	22
Total	18	40	58

$P < 0.05$

Table 17
Relationship Between Attitude Score of Parents and Sex of Affectes Child

Sex	Attitude Score			
	Low	Moderate	High	Total
Male	11	27	6	44
Female	8	17	1	26
Total	19	44	7	70

$P < 0.05$

DISCUSSION

The end of the last millennium witnessed an uprecedented degree of public awareness regarding mental disorders and disabilities as well as motivation for policy change. Hinshaw and Cicchtti (2000) pointed out that the continued stigmatization of mental illness may well be the central issue facing the field of psychosocial services and rehabilitation . A developmental disability is a life - long condition where people grow and develop more slowly than others. Historically, people with developmental disabilities have been segregated from mainstream society, the result is that many of us have never met a person with developmental disability, but we have been deeply influenced by a variety of myths and stereotypes regarding their capabilities.

Our findings suggest that children and adolescents with developmeatal disabilities represent psychosocial and economic burden on families. However, also, our results preclude generalization. We have not survey the total number of developmeatally disabled children and adolescents in Port Said Community which, of course, methodologically and practically very difficult.

It is possible that children and adolescents with the most severe forms of developmental disability together with adverse psychosocial / economic family background are enrolled in educa-

tional and rehabilitation centers. Nevertheless, it has been our impression from the focus group discussion with the families of disabled children and adolescents as well as the caregivers at these inistitutions that evidences of stigma and discrimination against those children are abundant, for example, the fear of the stigmatization of the society against their developmental disalsilities lead the family to go through a process of denial and lack of acceptance which results in delayed registration, evaluation, enrollment, and receiving the appropriate remediation and rehabilitation measures.

On the other hand, the efforts of the local non-profit, non governmental social agenies that provide help for those children and adolescents and their families are not enough. There should be unified efforts from all sources of child and family support groups together with governmental and health care authorities to fight the stigma and discrimination because of developmental disabilities.

Our findings that only 28.5% of families of developmentally disabled children and adolescents reported the experience of stigma from the society suggest that disabilities in small communities have a better chance of social support than larger societies, however, 41% admitted the feeling of shameness which complicates the picture. In addition, it is possible that the perception of stigma is related to the social class, i.e. as El-Dod et al (1998) have found that parents with high social standards were more concerned with stigma. It can be argued that the stigma perceived by our families is embedded in the high reports of psychological strains.

Although a developmental disability is not a illness, 71% of the families reported that they need specialized medical services which were not available. The care of developmentally disabled individuals needs an integrated psychosocial and medical services. Perhaps this might be the reason behind the psychological (68.5%) and economic (57%) burden.

Our findings that over 70% of our families reported the use of folklore, religious and cultural healing methods suggest the need for community rehabilitation and educational programs targeting families of developmentally disabled children and adolescents.

What Should We Do About Stigma and Discrimination Because of Developmental Disabilities ?

We should

1- Educate the community and increase knowledge about developmental disabilities and outreach initiatives.

2- Change and improve attitudes towards developmental disabilities.

3- Take actions to reduce stigma and discrimination and improves the quality of life of disabled children and adolescents and their families .

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وصمة الإعاقات النمائية كما يذكرها آباء وأمهات الأطفال والمراهقين فى بورسعيد

أجريت هذه الدراسة المسحية للتعرف على الوصمة المرتبطة بالإعاقات النمائية لدى الأطفال والمراهقين فى بورسعيد، فتم تقييم ٧٠ من آباء وأمهات الأطفال والمراهقين الذين لديهم إعاقات نمائية مثل التأخر العقلى والصرع والذاتوية وذلك بإستخدام استمارات استبيانية لدراسة استجابات الأهالى وردود فعل المجتمع المحيط، وقد طبق استبيان موقف ووجهه نظر الوالدين تجاه الابن (الابنة)، وقد أظهرت الدراسة أن حوالى ٤١٪ من الوالدين وأفراد الأسرة يشعرون بالخزى والخجل وأن ٢٨٪ من الوالدين يشعرون بالوصمة والعار لوجود طفل معاق لديهم، وأن ٦٨,٥٪ قد قرروا أنه يمثل عبء نفسى و٥٧٪ عبء مادى على الأسرة، كما أظهرت الدراسة أن حوالى ١٠٪ من الآباء يتجاهلون أطفالهم المعاقين بينما ١٤٪ يشعرون بالخزى تجاههم وأن ٢٤٪ من أخوتهم يخجلون منهم كذلك، وقد أقر أكثر من ٧٠٪ من الأهالى أنهم لجأوا إلى العلاج بالطب الشعبى (٢١٪) والرقى (٢١٪) والأحجبة (١١٪) وإلى المعالجين بالكتب السماوية (٢٠٪)، كما وجدت الدراسة أن برغم هذه الاتجاهات فإن ١٠٠٪ من الآباء والأمهات قد قرروا أنهم يشعرون بأن الطفل ذو الاحتياجات الخاصة له مكانة خاصة لديهم.

وتناقش الدراسة وجهه نظر الأسر فى برامج التثقيف الصحى، والتأهيل وتقديم الخدمات الخاصة لهؤلاء الأطفال والمراهقين فى بورسعيد.