The Socio-Family and Care Staff Opinion of Services and Role of Children with Special Needs in Qatar

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Abstract

In general, families face challenges when it comes to providing care for their children with special needs (D' Aboville, 1993). This issue is even more complex for families in Qatar as such care is culturally based--as a result, children with disabilities have been isolated and treated differently at both the social and institutional levels. This paper is based on empirical research. Its main objective is to elaborate on the existing laws and policies and the corresponding views of families and care agencies as an avenue to identify the obstacles and means of improvement of services to children with special needs in Qatar.

Paper Key Words: Children with special needs, Family, Care agencies, legislation and policies

Introduction

This paper aims to bridge the knowledge gap when it comes to the relationships between the family and the care service providers to children with special needs in Qatar. Its main objective is to elaborate on the existing laws and policies and the corresponding views of families and care agencies identify better ways of promoting the social role of the children with special needs. Several studies refer to the importance of focusing on social solidarity in treatment of individuals' behaviours and interactions since family ties reproduce themselves in different forms in the public realm (Ben Salim, Family Structure, 1994). This is typical in the case of treatment of children with special needs in Qatar. Their reality is multiple and complex, due to the predominant influence of culture on their families which, as investigated by this paper, results in their marginalization from mainstream social activities and institutions.

Children with Special Needs: International Perspective

The International Convention on the Rights of the Child Convention, Article 3, states that:

States' parties undertake to ensure the child such protection and care necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures. The International Convention on Rights of the Child encourages government to put at the center of the rights of children in their legislative and policy frameworks to ensure that they will have a status and role to contribute to the social equilibrium and prosperity. The UN Convention on the Rights of Persons with Disabilities of 2008 also calls for enjoyment of all human rights and fundamental freedoms by children with disabilities, and points to the importance of early intervention and their inclusion in the education system from an early age to ensure their visibility and roles in society. In addition, it is noted that social programs responsive to individual needs and respectful of diversity benefit all children and contribute to building the foundations of an inclusion society. (MCGregor, et al., 2007, p. 369) UNESCO Policy Brief (June, 2009) reported that early child care and education is a powerful means of nurturing diverse abilities and overcoming disadvantages and inequalities if to effectively respond to the needs of children with disabilities. Comprehensive care and education should encompass the stimulation of parental support and access to relevant services to enhance the effects of intervention for children with special needs. To attain 'effective, accessible and equitable services,' the policy should invoke early assessment and intervention and integration of family at an early stage. The specialized social work literature illustrates broader categories for disability. For instance, Townsend (1979) suggested five broad categories of disability which include: abnormality or loss, clinical, functional limitations, deviance, and disadvantage. This includes physical disabilities, chronic illness, communication needs, mental illness, loss of sensory power such as deafness, and learning difficulties. People with disabilities can be more fully integrated as the social system and resource provision are altered (Oliver, 1990). This represents a move from an individual to a social model of disability. The individual or medical model locates the 'problem' of disability within the individual. The medical model itself is disabling by displaying negative images of people with impairments and attempting to treat the disability, not the person. The functional limitations or psychological losses are assumed to arise from disability (Oliver, 1999). The social model puts the problem outside the disabled person and into the collective responsibilities of society as a whole. It also as D'Abovile (199:69) holds: Within the social model, disability is seen as arising, not as the direct result of an impaired, but out of interaction between an impaired individual and an essentially hostile environment. ...the social model focuses on the steps not the wheelchair. Accordingly, disability is recognized as the restrictions placed by society, which isolate and oppress them. The barriers to education and employment are created by institutions and organizations such as schools, colleges and universities, which are without proper lifts, transport facilities, and hearing and visual aids. UPIAS (1976) defined the social model: In our view it is society which disables physically impaired people.

Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (p. 14)In addition, it is well reported by UNESCO 2009 that children with disabilities cannot be independent if there is discrimination against them within the educational system, which does not educate them to move toward employment. As stated by Middleton, (1999), "disabled children are construed by the majority of society as noncontributing. This model implies they will also be perceived as non--participating..." (p. 121). In the context of assessment, many of the problems faced by disabled children are not caused by their conditions or impairment, but by societal values, service structures, or adult behavior. Middleton (1999) argues that: Children who are disabled are excluded not because of soundly evidenced rational arguments, but because of continuing prejudices and beliefs about disabled children and the adults they may become. Not only are disabled children likely to experience discrimination, they are also victimized.In this way, the problem is not only with the prevalent discriminatory social practices, but with the education policy that unconsciously reinforce them by supporting the establishment of separate schools for children with special needs. Discrimination against children with special needs damage their developing sense of self-worth and self-esteem. One of the state's duties is to safeguard the development of children and to eliminate any discrimination against them by integrating them in the regular schools.

Children with Special Needs: Qatari Issues

Qatar is a rich, small country with a strong Arabic culture stemming from Islamic principles and long practised social norms and traditions. Despite social and economic transformation experienced by Qatari society in the last decades, as any other country in the Arab World, individuals still preserve their traditional views when it come to the role of the family and their responsibilities towards it especially during stressful times. The Qatari family is large compared with families in most Western countries. Over three quarters of the parents have three or more children in the family; 78% (75) and 21.9% (21) have six children or more in the family. Consequently, the financial, social, and educational demands on parents are high. This is an increasingly difficult task due to growing social, political, and economic demands and changes.

Qatari Family Values

Qatari society is part of Arabian society. This society was a closed one with very limited interaction with the world outside the State until 1996, the year that saw political changes more towards an open society, a democracy and a free market. Qatari society has, until recent years been ruled by a strong tribal culture, tradition and religion. The family is a very important element of the identity of both in individual and the State. The majority of the State citizens are still called by their traditional family names and individuals are still proud about their family and tribal roots.

Tribal Traditions and Values

Tribes played an important part in Arab societies in developing norms and values within the society. Tribes were (and still are in some Arab societies) the rulers and the source of these social norms and values which still persist. Individuals are still to some extent extremely loyal to their tribal origin in social, economic and political sense. Individuals may vote for candidates in a general election based on their tribe loyalty. In problems and crises members come together to support and help each other.

Families, Family Structure and Values

In Qatari society, the family still has a strong influence on culture and tradition. The relationships between individuals are strong and controlled according to a set of values and norms that have been inherited over many years. The father still represents the head of the family and has the major share of power. He is the main decision-maker regarding most issues related to the family. Children of the family, including the adults, obey the head of the family without discussion or argument. There are also still certain rules within families that need to be followed by all family members. Children still must kiss the nose of their father or any adult of their family as a sign of respect toward the adult members of the family. Children must not interfere with or contribute to any adults discussions. The child shouldn't eat before his/her father. Children should also behave according to certain rules within society. They cannot travel alone, mix with adults, smoke, drink alcohol or chat with members of the opposite sex. The child must interact within the limits of behaviour accepted by society.

Extended families are still the norm among many Qatari families. They provide help and support in looking after the children. Over half the parents live with their extended family, that is, with the husband or wife's family. This is not surprising as Qatari society is conservative with a strong emphasis on religion and on Arabic culture and tradition. The traditional views influence the family relations in many respects as Ahmed (Women and Gender in Islam, 1992) said see the superiority of men in the household as absolute. Great respect for the father and mother, which is part of Islamic religious education, represents one of the most important characteristics of Qatari families. This extends to parents giving orders and having financial control over their married sons. Many married couples live with their families. In any society, due to a mix of many factors, including religion, culture and the mass media, a set of social values will emerge to which individuals will respond accordingly. This may be observed by their actions and words, as Petrie (1994, p. 59) states: "Values may be seen as operating at different levels." Despite that the government provides social services and all types of education, according to the Arab Women Development Report: Reality and Prospects (2003: 183) the family plays a key role in the lives of the Arab young; the family is the first source of education before the religion, the school, the traditions or the social class.

According to the UN Special Rapporteur on Disabilities (2007), "the general condition of children with disabilities in Arab societies is invisibility." In particular these children are considered sources of shame and a burden on their families. Families with children with disabilities experience multiple stress factors, including psychological and economic pressure. Due to the traditional division of social roles within the family that assigns the mother the reproductive role and considers her the custodian of the family values, the burden of care of the disabled children shifts to her. In most of the cases, the mother has inadequate knowledge and abilities to raise their disabled children effectively or to respond to their special demands proactively.

Disability Issues

In the Arab world, inclusive of Qatar, the laws are formulated to protect children in a similar way to those adopted in the west and are based on the principles of the United Nations Convention on the Rights of the Child. However, the policy implementation and practices in Qatar fail to address the actual needs of families to support their children with special needs in becoming contributing citizens. Recently, social work in Qatar has developed tremendously, particularly with regard to children with special needs. Yet there is no comprehensive research that asks how families and care agencies view the treatment and role of these children as a way to identify what has worked, and what has not worked, in order to induce scientifically based strategies to connect the efforts of different players in promoting fulfilling lives for children with special needs. The social care profession in general and childcare in particular in the State of Qatar is new. The literature review of the applicable laws and policies revealed that Oatar has included children with special needs in its education laws and policies. However, the literature noted several gaps that need to be addressed to deliver quality services to children with special needs, which are delineated in the following paragraphs. First, one of the identified major gaps by the review is that the definitions of disability vis-à-vis the special need are not comprehensive. This distinction is critical for tailoring appropriate and quality services to effectively address the special needs of disabled children. The Disability Discrimination Act (1995) defines the disability as, "A physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities." The Education Act, 1996, Section 312(1) also defines the disability as "A child has 'special educational needs' for the purpose of this Act if he has a learning difficulty which calls for special education provision to be made for him." Another problem with the policy approach of education of children with special needs in Qatar is that education is oriented towards responding to the immediate basic needs rather than their long term strategic interests such as the self development which are key to strengthen their abilities to contribute as equal members of society. To address this gap there is a need to adopt a proactive approach to provide a range of skills development based services to provide the children with special needs with multiple learning opportunities and to become confident in using the acquired skills in his or her day-to-day activities and interacting with other members of society.

The problem is also compounded by the fact that in Qatar, children with special needs are also separated from the mainstream education system. They are left in schools of their own. There is no mainstream school or college which contains classes for children with special needs. In a way this education policy approach mirrors the prevalent social attitudes which treat children with special needs as incapable, difficult to integrate, and/or better separated from the mainstream. As mentioned above, children with special needs and their families face social barriers in accessing work. Current care services are focused on the child as a problem child, without consideration of the parents and their circumstances. There are no facilities to encourage children with special needs aware of the world of work and interested in acquire work skills. Further, places of employment lack awareness of the needs of workers with disabilities. Central to the problem of the education framework is that there are no clear strategies for systematically providing families with information about the rights of their children, the goals of the educational programs, and the change process in order to effectively engage and advocate for their children. Such type strategies will allow the parents to play a key role in their child's education.

Legislation and policies should promote programs to strengthen partnerships between parents and the school, based on shared responsibility, understanding, mutual respect, and dialogue provide a base for meeting the needs of the children. Family Health Associations programs should be streamlined with the education framework and diversify players in this sector for the families and care services to collaborate. This approach is consistent with Qatari traditional values which emphasise the importance of family ties and the key role of the family in taking responsibility for meeting the child's needs. For parents of children with special needs, the issues are more challenging. Parents need access to information about their rights, their children's educational program, and the behavioural change process in order to effectively support and play a fundamental role in their child's learning development and subsequent contribution to society. On the other hand, parents can be an important source of information about their child better and can interpret most actions which may help or ease the agency's tasks. (Strong, 1979, p. 132) said:

Even though parents might normally be considered to have the most extensive knowledge of their child and to be the best interpreter of their words, actions and feelings, such knowledge was treated as partial and as able to be overridden when staff saw fit. Parents sending their children to an agency are expecting a mixture of services to meet the needs and satisfaction of the child as well as themselves. The main parental expectation is an education programme that can support the child in learning to play a normal role in society. This is expected to include techniques to develop his/her social communication. A typical day in the care agency includes an educational programme as the core of the service provision, accompanied by an entertainment period. Unfortunately, in Qatar the reality for the family of children with special needs is more complex for a number of reasons.Children with special needs and their families face social barriers in accessing work in Qatar. Current care services are focused on the child as a "problem" child, without considering the conditions of the parents and their circumstances. There are no facilities to encourage children with special needs to be aware of the world of work and to encourage them to acquire work skills. Further, places of employment lack awareness of the needs of workers with disabilities.

Research Methods

Survey methods were the primary source of information in this study. However, first, the author conducted a literature review to identify whether or not the existing legislative and policy frameworks in Qatar are adequate when it comes expanding information to integrate families in the care provided to their children with special needs. Then, the author prepared a semi-structured questionnaire to investigate and analyze the opinions and attitudes of parents with the children with special needs. Families were interviewed about the services provided by the care agencies, as well as issues related to the children with special needs themselves. Finally, the author interviewed staff at child care agencies. In selecting the research sample for this research two points were considered. First, Qatar is a small country and there are few care agencies for children with special needs. The existing care agencies for children with special needs in Qatar are the Al-Shafalah Centre, The School for the Mentally Disabled, The Al-Noor Institute (for people who are blind or have vision impairments), and The Special Needs and Audi School (for people who are deaf or have hearing impairments). Therefore, to increase the reliability of the data, all professionals engaged in working with children with special needs and all families were invited as participants in this study. All of the staff in care agencies for children with special needs, social workers, care staff, and other authorities were included in research interviews. The questionnaire designed for the parents of children with special needs included four major sections: a) general information, b) problems and obstacles in the care agency, c) current situation of the policy towards childcare in the State, and d) opinions and attitudes towards the services in the care agency. Information gathering was carried out in two stages. The first strategy was to collect data about the care agencies, including the number of families served, attendance times, and parent engagement at the care agency as they visited their children and participated in regular meetings. This was achieved through a preliminary planning visit to the agency management. The second stage involved distributing the questionnaire and collecting it from all of the parents during their first and final agency activity sessions.

Research Findings

As mentioned in the methodology, the research aim was to collect family views to identify gaps and explore strategies in promoting better services to children with special needs.

Parents

Fifty-nine percent of the parent participants (n=57) were females and 41% (n=39) were males. Because divorce is uncommon in Qatar, 79.2% (n=76) of respondents were married and 16.75% (n=16) were widowed; only 4.2% (4) were divorced. Almost 73% (n=70) of the parents had a job and only 27.1% (n=26) were unemployed (the vast majority of this number are females [n=24]). The majority of respondents were between the ages of 31-40 years old. The vast majority of the respondent parents have only one child receiving care (94.8%; 91). Therefore, how parents cope with more than one child in care will not be substantially addressed in this study. The majority of children receiving care were aged 5-10 years; (69.8%, n=67 were at primary school age). Due to a lack of awareness and medical examinations, children enter care at a relatively late age. Parents start to experience concern once the child reaches school age. Finally, the vast majority of the families surveyed have children attending the care agency every day (92.7%, n=89). Only 3 children in the sample attend as infrequently as once a week.

Parents' Satisfaction with Care Agency Services

The vast majority (80.2%; 77) of the parents agreed/strongly agreed that the care agency meets the needs of their child. It also shows that only 6.2% (6) disagreed/strongly disagreed that the care agency meets the needs of the child receiving care. The majority (65.6%, n=63) felt that the care agencies meet and satisfy the needs the parents, while 7.3% (n=7) felt that the care agency does not meet the needs of the parents. Parents sending their children to an agency are expecting a mixture of services to meet the needs and satisfaction of the child as well as themselves. The main parental expectation is an education programme that can support the child in learning to play his/her normal role in society.

This is expected to include techniques to develop his/her social communication. A typical day in the care agency includes an educational programme as the core of the provision, accompanied by an entertainment period. Unfortunately, social skills are only provided for a short period. The families of the children receiving care agree that the care agencies react swiftly and sharply towards any child abuse in their agency. Almost 90% (87.5%, n=84) either strongly agreed or agreed and only 4.1% (n=4) disagreed/strongly disagreed.

Respondents agreed that both the family and child should be involved in any child abuse investigation. The vast majority (79.2%, n=76) agreed/strongly agreed that the child and the family should be involved in such investigations and only 5.2% (n=5) disagreed/strongly disagreed. Although children are most often the victims of abuse, it was found that there is no policy statement regarding how the families and the child are involved in any such investigation. Just over half (55.2%, n=53) of the families of children receiving care believed that the care agency had a clear policy towards child abuse. Almost half of the parents were neutral (25%, n=24), 18.8% (n=18) disagreed; and only 1% (n=1) strongly disagreed. This indicate that the parents lack awareness of the care agency policies. It may, in part, be a reflection of the lack of involvement of parents in the agency's activities and in their child's plan and progress review.

Support for the Family

Of the parents interviewed, 72.9% (n=70) are receiving help and support for the care of their children. The figure shows families to be the most common source of help (69.8%, n=67). The wife's family represents 43.8% (n=42) and the husband's family 26% (n=25). Child-minding by non-relatives as a source of help is utilised by 22.9% (n=22) while others represent only 7.3% (n=7), including help from cousins and friends. Those who do not rely on family support are wealthy enough to have in home help who can look after the children. In home help is increasingly common in the Arabian Gulf families. School teachers also play a major role in identifying children with special needs, especially for families without a strong educational background. The vast majority (81.3%, n=78) of the parents agreed/strongly agreed that the agencies put their values into practice and only 2% (n=2) of the parents disagreed/strongly disagreed. It seems that the main support that families are receiving 'moral support'. Emotional support is especially needed by families with children with special needs to help relieve the stress its takes on the family. It is not surprising that only 5.2% (n=5) of the families surveyed receive financial support from the government. The government does provide support for the agency and few working families experience financial constraints.

Only a small group of families in the sample appear to have financial problems. Further, only 3 out of 96 respondents received help with transport from their families, due to the fact that Qatar is a small country and most families have a car. The main problem facing the families is convincing their children to attend the care agency (52.1%, n=5). Almost a tenth (8.3%, n=8) of respondents felt that transport was a problem. Another 30.2% (29) of the parents believed that one of the main problems is the social loneliness of children with special needs. A surprising response, 20 out of 96, was the desire to keep the child busy while the parents were at work. Because of the Arabian cultural norm, it is the duty of all members of the family to look after their relative with special needs. This may not be in the best interest of the child who is not getting their social and educational needs met. The child may have very restricted social communication as he/she is isolated in the family environment. Therefore, attending the social environment of the care agency provides the context for developing social communication and the social skills that he/she lacks. Care staff believes that building social confidence in the child on arrival is an important element in convincing the child to adapt to the new environment.

The family's main concern when their child is in care is the safety of the child and his/her education. More than a third (35.4%, n=34) were concerned about their child's safety and another 15.6% (n=15) were concerned about the child's treatment by the care staff. The quality of the services provided by the agency seems to be the main reason for the families bringing their child to a particular agency. It shows that 60.4% (n=58) of the families bring their child for this reason and only 2.1% (n=2) bring their child because of the rules and guidelines offered by the agency. Agency values came second in the main reasons with 21.9% (n=21). The main reason parents take their child to the care agencies appears to be an educational one (26 out of 96).

This is quite understandable as it is part of Arabic culture that sons/daughters MUST be successful at school, regardless of their ability, needs and interest. Introducing a child to social life is the second reason (22 out of 96). Almost a third (32.3%, n=31) had concerns about their child's education. Education was a concern because it was one of the main reason for bringing the child to the care agencies is to get an education to improve his/her social role and life changes.

Input from Childcare Staff

Most of the agencies in the Qatar state that their values and aims are clearly presented to the children's families. Their primary goal is to educate children with special needs and to prepare them to integrate into society. It is believed that this can be achieved by training them in basic vocational skills to allow them to join local industries. Some of the agencies stated that they strongly valued the potential of children with special needs. Some families are relieved because they believe that the agencies are doing them a favour by looking after their children.

The staff work to treat the children with great respect and to develop their social skills. When the family arrives at the agency they are usually provided with a leaflet, which outlines the main aims and values of the agency. "Their main aims are to provide the children with their educational and social needs to be easily integrated into society". The question remains as to how the parents can be sure that the agency complies with their stated aims and values. There is no auditing of the agency; also most of the families are not well educated or aware of the process of auditing and inspection and their rights to challenge the agency. The parents of children with special needs are not aware of their rights and roles in their children's planning and progress. This may be due to two factors. The first is lack of education and the second is that care agencies' services are relatively new in the State of Qatar, resulting in a lack of experience. The care agencies are currently neglecting the parents' rights. There are no rules and legislation identifying these rights within the care system and there is a general lack of awareness of parents' rights among the care staff. The establishment of partnerships between care agencies and parents would strengthen the system and the responsiveness to the children.

Discussion

Disability is recognized as the restriction placed by society, which isolate and oppress children with special needs. It creates barriers for children to education and employment which are created by institutions and organizations such as schools, colleges and universities. It is important that the education laws provide for broad definition of disability and clear categories for special needs to tailor appropriate services and programs for children with special needs. The fieldwork analysis revealed that there are still negative attitudes towards children with special needs. It identified that these attitudes represent a barrier towards to the inclusion of children with special needs into society. Accordingly there is a need of organizing public awareness and education programs to transform these attitudes and to emphasis on the potential contributions by children with special needs to society. This can be achieved by increasing the awareness through schools' curricular, the media and proactive interventions at an early stage in the state's education system. Discrimination against children with special needs may damage their developing sense of self-worth and self-esteem. One of the state's duties is to safeguard the development of children and to eliminate any discrimination towards children with special needs by integrating them in the regular schools.

Qatari education policy should promote the integration of children with special needs in the regular schools. The infrastructure of Qatari schools and colleges should be expanded to ensure that they have appropriate services for the children with special needs. While there is problem in the overall lack of belief in establishing the rights of children with disabilities, this research identified how much the care agencies value and belief in the rights of the children with special needs. There should be programs to educate children and in particular those with special needs of their rights on the one hand, and to organize training sessions for care agencies on child-rights based approach. The institutionalization of practices based on respect of child rights will allow children with special needs to be confident and to be able to interact with their peers on equal footing.

An analysis of the documentation used by these agencies showed that they lack a clear policy on this, however, and there was little evidence of these procedures being used. One of these policies needs relates to how the agency reacts towards a suspected child abuse case.

Therefore, this issue is taken seriously in all sectors involved in childcare, education, and work. Moreover, within this education framework, there are no clear strategies for systematically providing families with information about the rights of their children, the goals of the educational programs, and the change process in order to effectively engage and advocate for their children. Such type strategies will allow the parents to play a key role in their child's education. The parents of children with special needs should be aware of their rights and roles in their children's planning and progress. To realize this goal, parents should be provided adequate information on how to respect their children rights and to reinforce equitable practices in raising their children with special needs. The care agencies should be provided training to design programs to communicate and inform families on how to focus on the development of the learning skills of their children and to be sensitive to their rights.

The government should also provides rules and legislation identifying the parents rights within the care system. In addition, partnerships should be established between care agencies and parents to strengthen the care system to become responsiveness to the demands of children with special needs. According to the UN Special Rapporteur on Disabilities is that, "the general condition of children with disabilities in Arab societies is invisibility". In particular these children are considered sources of shame and a burden on their families. There are several specialized programs on mass media that should be created to educate society on the importance of integration of children with disability in order to prevent discrimination against them. The Arab Council for Childhood for example organizes public service announcements (brochures, banners and posters) and events to educate society to accept vulnerable children-such as the street children. The Council also mainstreams its public communication programs through collaboration with government institutions and non-governmental organizations and the children themselves as a medium to reach the society at large.

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