



ISSN: 0976-3031

Available Online at <http://www.recentscientific.com>

CODEN: IJRSFP (USA)

International Journal of Recent Scientific Research
Vol. 8, Issue, 9, pp. 19955-19958, September, 2017

**International Journal of
Recent Scientific
Research**

DOI: 10.24327/IJRSR

Research Article

THE NEED FOR FAMILY-CENTERED CARE (FCC) EARLY INTERVENTION FOR INFANTS AND TODDLERS AT RISK OF DISABILITIES

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DOI: <http://dx.doi.org/10.24327/ijrsr.2017.0809.0794>

ARTICLE INFO

Article History:

Received 15th June, 2017
Received in revised form 25th July, 2017
Accepted 23rd August, 2017
Published online 28th September, 2017

Key Words:

Family centered care, children with disability, early intervention.

ABSTRACT

Family centered care (FCC) is part of an early intervention program provided to families of infants and toddlers with disabilities which is an essential component of high-quality early intervention services. It is estimated that around 300,000 children in the United States of America from birth to 3 years of age are affected by developmental disabilities. Unfortunately, the incidence is on the rise due to advancement in the care of sick newborns and neonates which eventually lead to increased survival rates of such infants. The increment in financial and socio-medical burden on governments and communities lead hospitals to change their strategies towards early hospital discharge of fragile neonates and children. FCC was found to be an ultimate solution to appropriately follow these children by involving their families to work with health professionals as partners collaborating in well designed early intervention program to meet all medical, social, financial, and psychological needs of both children and their families. There is significant lack of such unique service in developing and underdeveloped countries worldwide accompanied by insufficient data and research. In conclusion, a lot of efforts must be made in order to adopt such program to support children with disabilities and their families.

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INTRODUCTION

Due to continuing advancement in the care of sick newborns and preterm babies in particular, the survival rate of such infants is in the rise and many are discharged home and join the community. Unfortunately, the incidence of having children with developmental disability concomitantly increased. It is estimated that around 300,000 children in the United States of America from birth to 3 years of age are affected by developmental disabilities [1]. It is well known that the best approach to decrease the incidence of developmental disabilities among children is by conducting early intervention program which aims at early detection of signs of possible future deviation from normal development, and hence, starting immediate early intervention to prevent or minimize future handicap for infants who were labeled as high-risk group at birth. These interventions may include physiotherapy, occupational therapy, speech therapy, social support, psychological intervention, rehabilitation multidisciplinary intervention, and other medical interventions such as ophthalmology, ENT, pulmonology, orthopedics, and any other specialty needed based on each individual infant's need [2].

Emotional and psychological strain is placed on families of sick and premature neonates who are at increased risk of neurological and developmental problems well into adulthood, and there is increasing financial burden on society to provide specialized care for such neonates. Health care providers were forced to reduce hospital stay based on financial burden of providing needed intensive care for such infants leading to early release of these fragile infants into ill-equipped communities which will make them outside the reach of the health care system, denying them from the highly demanded health, special education, occupational, physical, and speech interventions [3].

Early intervention programs that support parents post discharge actually minimize the health risks (specifically the risk of future disability) associated with prematurity and being critically ill at birth [4].

The aim of this review article is to review the literature to describe and discuss the following: family-centered care (FCC) within early intervention program, barriers to implementation of FCC, the role of social workers in running such program,

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and quick review of the local situation in Saudi Arabia regarding FCC.

LITERATURE REVIEW

Based on the U.S census Bureau (2005), almost around 300,000 children from the age of birth to 3 years are disabled by any type of disability. Despite all intervention strategies and the existence of Part C of the Individuals with Disability Education Act (IDEA, 2004) which is also known as the early intervention program which made it mandatory for health care providers to provide all therapeutic and educational services to infants and toddlers with disabilities, the number of these children with disabilities increases between the age of 3-5 years to 475,000 children in USA [5].

Disabilities may cause psychosocial impact on the child's family. Children with severe and multiple disabilities are often totally dependent on parental assistance for daily activities such as self hygiene, eating, and dressing. There might be an increased risk of depression and reduced quality of life for Parents and other family members of children with disability. Accordingly, families of such children have unique needs for support along with their children in order to cope with such disturbing situation as well. Families often require social, financial, psychological, and other related community services. A family-centered approach is considered by many researchers as one of the best approaches to meet all the needs of children with disabilities and their families [6-9].

Family centered care (FCC)

It is part of Early intervention program designed to evaluate and treat infants and toddlers with disabilities based on practice principles made to enhance self-determination of parents, collaboration between parents and health care providers to make proper decisions, and parents self-efficacy [10,11].

For family centered care to succeed, the staff member should: care about the entire family, not just the child with special needs, make it clear that the family (not the professional) is responsible for deciding what is done for the child and family, and understand that parents know their child better than anyone else does. Providers of FCC assume the role of facilitators and collaborators, they should spend enough time with the child, listen carefully to the family, give them appropriate information, and let family feel like partners in the child health care.

With proper conduction of FCC, engaged families are more likely to be satisfied with the care they receive from their health care professional and, in turn, are more likely to follow instructions and suggestions from their physicians, including referrals to needed specialties for continued therapy including physical, occupational, speech therapy, and health services [12].

Family-centered assessment entails working with families to develop goals that are suitable for their social, environmental, and cultural needs. Professionals assist the child and family needs and focus on the family's strengths and ability to encourage the child's development, includes specific information about the child's current situation and discussing the family goals which may include participating in play groups to enhance parent-child relationships and social skills,

improving income to overcome inadequate household facilities, or participation in special programs for parent training to develop skills in parenting and discipline techniques [13].

Barriers to Implementing Family-Centered Care:

Diversity

Families of children with disabilities from deferent ethnic origins may have different concerns, opinions, and needs based on their cultural backgrounds.

In a study, Asian parents disagreed with professionals who considered independence and self-esteem to be primary goal, and instead, they considered obedience and respect to elders, parents, teachers, and therapists more important goal in achieving success. In addition, professionals may alter family habits by suggesting changes in their daily routines or schedules or ask parents to implement daily programs that are not consistent with their system or culture [14].

Barriers Related to Sharing Information and Documentation:- Professionals may experience pressure to provide services to infants and toddlers with disabilities and their families by private insurance companies or governmental funds, instead of services the family needed. It was also found in some studies that providers did not offer information on the existence of family programs, because funding was linked to individual children not to the family as a whole. Some family participants also felt that professionals hide information from them because they did not want to encourage families to request all possible services. Some professionals looked at families who held divergent views on practice decisions as resistant or unmotivated instead of empowered partners representing their children. These issues may lead to lack of trust between families and providers and may eventually interfere with successful implementation of proper FCC [15].

Barriers related to Health Care Settings

Primary health care setting is the source of Early Intervention Program referral.

Lack of primary care provider knowledge of the developmental delays the child was experiencing, and lack of referral information from the primary care provider for families, are the two major barriers to influencing the proper provision of FCC. However, those children who receive proper FCC are more likely to receive proper developmental evaluation in pediatrician office, have better referral system, and receive needed preventive measures such as immunizations [16].

The Role of Social Workers

Social workers may help to address barriers to providing FCC for children with disabilities and their families. They are properly trained to discuss environment situation, psychosocial assessment, treatment issues, and concerns of parents. Social workers working in FCC have skills to help empower families; they may provide empathy support, teach and train parents to improve their knowledge regarding disability and introduce them to FCC and other early intervention programs. They can also coordinate with agencies in the community, work as mediators between family members or between the family and professionals, and they can also help the family to manage their daily activities and communicate their needs and desires as

well as helping them to solve all problems related to health care provision and available resources. In order to enhance family-centered care, it is recommended that social workers should have additional social work education regarding systems and processes, early childhood development, family relations, and available policies related to disability [17].

Disability and Family Centered Care in Saudi Arabia

Children disability in Saudi Arabia is an alarming problem which is still underestimated due to lack of adequate professional research and critical lack of available data. There were scattered small sized, limited population studies published in Saudi Arabia regarding prevalence and magnitude of this problem and the influence and impact on families and community. One study revealed prevalence rate of childhood disability in children under 15 years of age to be 18 per 1000 total population [18].

Impact of having disabled child on the family is not deferent from other communities. It was found that mothers of disabled children suffer higher anxiety and psychosocial depression in comparison to control group [19].

Disabled children in Saudi Arabia are mainly managed by rehabilitation centers which run programs depending mainly on charitable organizations supported by Ministry of labor and social affairs and by public donation from citizens. Private sector is very active in this regard, and over the past decade, more private rehabilitation centers were launched under governmental supervision. It was noticed that there is improvement in the practice of special education services for students with various disabilities. On the other hand, there is tremendous lack of family centered care programs or any home centered approach strategy, this is mainly due to social restriction as we have very conservative community, and also the lack in numbers of social workers or trained persons to run such programs [20].

CONCLUSION

Family centered care (FCC) approach could be one of the best solutions to deal with children with disability and their families especially when there is lack of resources in the community that are needed to support disabled children and their families and decrease the negative impact of this situation on the community. A lot of work must be done to overcome the shortage in data related to disability in developing and underdeveloped countries through extensive research to recognize the actual magnitude of this problem and hence design appropriate programs to support disabled children and their families. Social workers are the corner stone of family centered care program to be successful, so, more effort should be done to train and educate social workers to be involved in community services programs aiming at Providing FCC to families of infants and toddlers with disabilities which is an essential component of high-quality early intervention services.

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How to cite this article:

Badr Hasan Sobaih.2017, The Need For Family-Centered Care (Fcc) Early Intervention For Infants And Toddlers At Risk Of Disabilities. *Int J Recent Sci Res.* 8(9), pp. 19955-19958. DOI: <http://dx.doi.org/10.24327/ijrsr.2017.0809.0794>
