

Counselling Intervention and Support Programmes for Families of Children with Special Educational Needs

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Abstract

All couples look forward to having normal healthy babies. The issues of disabilities in their children shake the families and serve as sources of severe psychological disruption to family adjustment. The parents of such children live with many difficult issues and frequently experience trauma, grief and stress. Intervention programmes are necessary part of the process involved in supporting families with children with special educational needs. Such intervention requires active involvement of a wide range of professionals such as social workers, teachers, psychologists, therapists, medical officers and many others. Skill training, parent education, advocacy roles on part of parents and professionals alike are required. Counsellors should also be aware of the wider inadequate systematic supports for parents and to advocate for more generous social and financial resources for these parents.

Keywords: parents of children with special educational needs; trauma; counselling intervention; family security; family support models.

Introduction

Ozozu (2005) sees the family as a system in which the action of each individual member has an effect on the family as a whole. Okeke (2001) describe the family as “an interacting communicative network in which every member influences the nature of the family system and is in turn influenced by the system.” The family system therefore is such that any problem affecting a member will definitely affect the other members. Family is the most important institution to any child. It is the primary arena that a child learns his/her initial experience, he/she learns to interact and learns from this interaction with his/her parents and siblings. The parents have the most important influence on their children, whether they are normal or abnormal (Mamman 2007).

The birth of a child with disability in a family is said to be a shock to the parents and to the family, and poses many challenges for them. The special educational needs child as well as his/her family experiences trauma, grief, guilt, aggression, rejection, stress, and strain, and even inclination towards murder and suicide (Obi, 1998; Cantwell-Barti, 2009; Kaur, 2010). Initially the parents of children with special educational needs are faced to accept their powerlessness to prevent the catastrophe that had happened. The future seems bleak with the never ending expenditure of energy and resources to provide care to the child (Jaswal and Jaswal, 2000). Children with severe special needs drain enormous amounts of time, energy, and money. Marital problems are reported to be present to a greater degree because of the lack of time for nurturing the marriage and the frequent problem of parents disagreeing on what needs to be done for the child (Heller, 2012). Contemporary research on parents of children with disabilities has found that parents frequently experience traumatic stress and that traumatic symbols can endure (O’Neill, 2005). Parents may experience trauma at various times such as the time of diagnosis, or in response to treatment, or when a child is hospitalized, particularly if the child has to spend long periods in hospitals.

Grieving is an ongoing features of raising a child with disability. For example, parents could grieve over the child’s lack of achievement of developmental academic and social matters, and ongoing stigmatization. Parents are likely to also grieve for themselves and the lost opportunities for personal growth and achievement as every aspect of their life may be threatened and changed. They are more likely to be socially isolated as friendships change, and extended family can withdraw in response to the child’s disability (Cantwell-Barti, 2009). Many children with disabilities have challenging behavioural disturbances or complex physical needs which can place an enormous stress on families. Parents are likely to be confronted with limited support resources in the community and long waiting lists, or they may encounter unsympathetic health professionals that they have to struggle with to access resources. As well, many families of children with disabilities are economically strained as mothers may not be able to return to work and there may be extra expenses in supporting the child (Cantwell-Barti, 2009). Akkoh (2000) and Okeke (2001) emphasize those families with children with special educational needs need a lot of support from the community, philanthropists, and governments in order to care adequately for them.

Concept of Children with special educational needs

Children with special educational needs are those that deviate from the societal norms, to an extent that adapted

programme or special methods are required to meet their needs (Owen, Froman and Moscom 1981; Kirk, 1992). Ozozi and Mugu (1999) saw children with special educational needs as people with significant sensory deficits, or unusual high intellectual ability, that is not properly addressed in the regular school programme. Heward (2003) defined children with special educational needs as those who need modification in curriculum and instruction in order to help them maximize their potential. According to him, modification of curriculum and instruction are necessary as a result of their disabilities. Alli (2003) defines children with special educational needs as people with unique educational and/social needs or desiring extra attention in virtually all aspects of life. Venden and Peter (2004) view children with special educational needs as those exceptional children differently challenged, who may be physically, socially or intellectually different, either below or above average that require individually planned and systematically monitored arrangements of physical setting. According to them, modification of curriculum and instruction are necessary as a result of their disabilities.

Categories of Children with Disabilities

A. The National Policy on Education (2008) categorized special needs children into three main categories. These are:

1. The Disabled: Under this category are people with impairment (physical, sensory) and because of impairment/disability cannot cope with regular school/class organization and methods without formal special education training. They include those who are visually impaired, hearing impaired, physically impaired, mentally retarded, emotionally disturbed, learning disabled and those with one form of handicapped or the other.
2. The Disadvantaged: Those who fall under this group are the children of nomadic pastorals, migrant fishermen, farmers and hunters. They are those who due to their lifestyles and means of livelihood are unable to have access to the conventional educational provision and therefore require special education to cater for their particular/peculiar needs and circumstances.
3. The Gifted and Talented: These are children who possess very high intelligent quotient and are naturally endowed with special traits and therefore find themselves insufficiently challenged by the regular school programmes.

B. Heward and Orlansky, (1992) also classified children with special educational needs under the following categories:

1. Mental Retardation: This is said to be a term used to identify “performance deficit” that is failure to demonstrate age appropriate intellectual and social behavior. It is a developmental disability characterized by significantly sub average general intellectual functioning, with concurrent deficit in adaptive behavior. Mental retardation is used when a person has certain limitation in mental functioning and skills such as communicating and social skills. These limitations will cause a child to learn and develop more slowly than a typical child. Children with mental retardation may take longer to learn to speak, walk and take care of his personal needs such as dressing or eating (Heward and Orlansky, 1992; Ozozi, 2005; Mamman,2007; Ali (2012).
2. Learning Disability: This means a disorder in one or more “basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen , think, speak, read, write, spell or do mathematical calculations”(Heward and Orlansky (1992). It refers to variety of disorders that affect the acquisition, retention, understanding, organization or use of verbal and non-verbal information. Children who exhibit one or more deficits in the essential learning process of perception, conceptualization, language, memory, attention, and impulse control are said to having learning disability (Okeke, 2001; Ali, 2003; Mamman 2007; Ali, 2012).
3. Behaviour Disorders: Children with emotional disturbance are referred to as children with behavior disorders. Behaviour disorders have been defined as “deviation from age appropriate behavior which significantly interferes with the child own growth and development” (Okeke, 2001). A child behavior to be classified disorder must differ markedly and chronically from current social or cultural norms.
4. Communication (speech and language) Disorders: Interaction is the major means by which human beings learn and successful interaction requires communication. Communication is said to be “transmitting and receiving of information through a common system or symbol” (Okeke, 2001). Children who are not able to make themselves understood or who cannot comprehend ideas that are spoken to them are said to suffer from communication disorders. Thus, communication disorder is impairment in the ability to understand or use words in context.
5. Hearing Impairments: Hearing is vital to every aspect of our daily existence. Hearing impairment refers to the ability of a person to hear sound. It is impairment in hearing whether permanent or fluctuating that adversely affects the child educational performance. It can be total, “deaf” or partial “hard of hearing”.
6. Visual Impairment: Vision is fundamental to human development. It is a visual factor in the development

process and the wellbeing of the child. Visual impairment is the functional loss of vision. It is an impairment or difficulty with vision. The visually impaired include children that are partially sighted, children with low vision, and children that are totally blind. A child with little or no vision is unable to rely on visual signals such as eye gaze and smiling by parents, siblings and peers in social exchange, therefore; social interaction is limited and sometimes misinterpreted.

7. **Physical and Other Health Impairment:** This refers to a broad range of disabilities. It indicates a medically diagnosed chronic physical or health impairment, either congenital or acquired. Their intellectual functioning may be normal or below normal. Many physical or health impaired children adjust to their conditions. Some use special devices or equipment such as wheelchair, because of their disabilities or illness they may require modification in physical environment.

Physical and Health Impairments include:

- Orthopedic Impairments
- Neurological Impairment
- Cerebral Palsy
- Traumatic Head Injury
- Spinal Bifida
- Limp Deficiency
- Epilepsy
- Cystic Fibrosis
- Diabetes
- Asthma.

8. **Severe Handicaps:** These are the children that “exhibit extreme deficits in intellectual functioning and may also need special services because of motor impediments, communication, visual and auditory impairments and medical conditions such as seizure” (Heward and Orlansky, 1992). Children with severe handicaps often have combination of disabilities because of their intense physical and behavioural limitations they tend to learn much slowly than any other group of children (including other children considered children with special educational needs or handicapped).

9. **Gifted and Talented:** These are said to be children who “who give evidence of high performance capability in areas such as intellectual, creative artistic or leadership capacity”. A gifted or talented child is one who demonstrates above average intelligence; possess creativity, leadership qualities, and abilities in visual art. According to Kolo (1991), “giftedness implies surplus of cognitive powers indicated by a high level of observable precocity”. The gifted who is also a child with special educational needs demonstrates exceptional abilities both in and out of the class.

Problems of Families of Children with Special Needs

The arrival of a new child in the family is a thing of joy. However, the joy turns to shock and dismay when the child turns out to be handicapped. The presence of such a child is both restrictive and disruptive in nature, and this affects the family socially, economically, emotionally, psychologically and physically (Ali, 2012).

Social Problems: The societal attitude towards children with special educational needs is a major problem to most their families. Most societies look down at the presence of a child with special educational needs as a curse to the family. Exceptionality is often explained in superstitious term in most societies. It is believed that the child is with special educational needs because the parents offended the gods. Such beliefs affect the parents as well as the whole family that it may lead to the exclusion and /or withdrawal of the child and family from social life so as to avoid embarrassing comments and constant reminder of the child handicapping condition. The societal stress may also arise when relatives and neighbours become frightened by the handicap and this may lead them to become cruel and distanced themselves from the family. In some cases, neighbours and relatives may come oozing pity to the family of a child with special needs. This may complicate the family’s problem that they may begin to consider themselves abnormal and begin to ask God what they have done to get such a child (Akintode, 1988; Okeke, 2001; Ozofi, 2005; Ali, 2012).

Economic Problems: A handicapped child is often a financial burden to the family. Lack of financial resource for parents of special needs children may result to change in eating habits and reduction in the amount of money spent on clothing and recreation, this in most cases places the father under strain to find a better paying job. To look for help and care for the child, the family sustains a lot of expenses these are increased medical bills, expenses for special equipment, purchase of prosthetic devices, and cost in enrolment in therapeutic settings, consultation fees and transport. These add financial burden to the family and in the end leads to neglect as most families of children with special educational needs cannot cope with this economical demand. Etten (1980) states that the father is always concerned about the handicapped child’s inability to learn a trade and become an independent adult. They become dependent on the family that sometimes led them to begging for alms.

Ignorance: Many families including the educated are unfamiliar with or ignorant about the cause, impact and prognosis of impairment on children (Ozozu, (2005). Families of children with special educational needs suffer from stress and emotional trauma mostly as a result of lack of information of their child's problem and how such a child could be helped to succeed in life. They are ignorant about the type of services their child should have, where to go for help and educational opportunities for the child. Ozozu (1985) is of the view that ignorance leads the parents of children with special educational needs to seek the services of quacks like unqualified native doctors or self-styled spiritual mediators

Psychological Problems: Once a child with special educational needs is born in the family, the family suffers psychologically for having an abnormal child. Most people believe that an abnormal child is a curse to the family; as a result the family is psychologically disturbed for having an abnormal child. It takes great effort for the family to accept the child. In most cases some members of the family experience psychological breakdown.

The Need for Counselling the Family of Children with special educational needs

Counselling is a profession by which a troubled person is helped to feel and behave in a more satisfying manner through interaction with a counsellor who provides services which stimulates the client to develop behaviours which enable him to deal more effectively with himself and his environment. Counselling therefore, is a profession that is central to proper adjustment of an individual. It is therefore imperative that parents and families of children with special educational needs need counselling for effective management of the handicapped child Ali (2012). Most families of children with special educational needs find it difficult to accept them due to ignorance, superstitious beliefs, pride, fear misconception and misinformation. Hence, counselling is very needed by parents of children with special educational needs for enlightening.

Families of children with special educational needs need counselling so as to bring about behavioural change, positive mental health, problem resolution, personal effectiveness and decision making (Obi, 1998). Counselling therefore helps these families to effectively cope with the demand of children with special educational needs. Counselling helps the parents of children with special educational needs to examine their roles as parents and become aware of the parent-child relationship. It helps to remove the sense of guilt that some families feel when they have children with special educational needs. It also helps the family to overcome the negative attitude they have towards the special needs children (Ali, 2012).

The family of children with special educational needs need counselling to assist them to acquire social, physical, emotional and cognitive skills necessary to successfully cope with the disability experienced. Counselling assist the family of children with special educational needs to learn how to manage stress associated with boredom of routine in parenting a special needs child. It equips the family with skills to develop assertiveness, problem solving, decision making and goal setting skills in their wards. Counselling also helps parents develop independence in them and in their children (Okeke, 2001; Mamman, 2007). The Counsellors are of great help to the family of children with special educational needs by providing professional information on how to detect and manage their children, in order to give the m hope for living.

Counselling Intervention Programmes

Andazi and Amwe (1995) stressed the need for intervention programmes for families of children with special educational needs through counselling, social services, family education, skill training and advocacy activities. They pointed out that an enlightened society should give parents new and expanded roles in their handicapped child's education and care. Parents are also expected to function effectively as decision makers and teachers. Orlansky (1962) is a great contributor in this area and believes that parents need professional support that will enable them become more active in the care of their children. A major area of concern in intervention programmes has to do with the involvement of parents in planning and evaluating the child's public education programmes. Andazi and Amwe (1995) considered intervention programmes and the role of the family particularly in the areas of skill training, family education, counselling and parental rights.

(i) **Skill Training:** Skill training focusing on instructing parents and siblings in physical and behavioural management of a special educational needs child's family members is an important area of involvement by both professional and parents. Professional should be able to assess the needs of parents and other family members, this will enable them design individualized education programmes of support for them. This of course requires knowledge of theories and concepts of family functioning and development and a basic understanding of the family as a complicated and unique system.

(ii) **Parent Education:** Many parents in most parts of Nigeria are illiterate and consequently need to be given factual information about causes of disability, skill development, how to use existing resources, ways by which they could help and similar concerns. Parents training can take many different forms depending on the needs of

particular families. Parents may require to be taught how to assist their child master basic academic skills. Most parents are responsible for the teaching and programming for their handicapped child and the support professional normally helps them to do this successfully. The training of parents in the organization of parents groups is a necessary part of programmes for families with children with special educational needs. This can be encouraged at Parents Teacher Association (PTA) meetings or at social functions.

(iii) **Counselling Practices:** Intervention through counselling arises out of the fact that most families with children with special educational needs have many concerns about both the present and the future and as indicated in many instances, they may worry about their own competence as parents. They may fear that something did cause the handicapped condition. They may be angry or may be grieving that services are not being provided for their child. They may even feel rejected or stigmatized by other parents or people within the community. Group counselling can be organized around specific topics suggested by the parents or by professional. Such meetings give parents the opportunity to meet parents of children with special educational needs and thereby making it possible for personal support network outside the group context. Teachers and others can play active roles by developing or helping locate respite care services, day care programmes for children with special educational needs. Information support provides the family with necessary information so that services could be easily located.

(iv) **Parental Rights and Advocacy:** There is need to understand that parents are the owners of their children and apart from having their own rights over their children; they also need to be protected legally against wrong notions. When their children attend school, these rights should be recognized by the school authorities concerned. Parents should fight for the existence of strong regulations and laws protecting them and their children in the Nigerian community.

Parents Support Services

The Importance of Parent Support Services

Research indicates that parents of children with special educational needs children are particularly vulnerable to stress, for example, high levels of distress have been found in up to 70% of mothers and 30% of fathers of severely children with special educational needs (Sloper and Turner, 1993). In addition, both the general psychological literature and specific studies of children with special educational needs show that parental distress and family functioning impact on children in numerous ways, affecting their cognitive, behavioural and social development (Wallander and Varni, 1998). Thus, lack of parent support and high levels of parental distress will affect the child's well-being (Middleton, 1995).

A. Sloper (1999) categorized four support service models for parents.

i. **Key worker models:** A 'key worker' or link person is a named person whom the parent approaches for advice about any problem related to the children with special educational needs. The key worker maintains regular contact as needed with the family, and has responsibility for collaborating with professional from a range of services, and coordinating support for the family. Particularly important aspects of the service are the key worker's knowledge of and ability to access information and services from a range of agencies.

ii. **Parent Counselling Models:** Dunst, Trivette and Deals (1994) carried out a number of studies of family support services in the USA. Their findings suggest that many elements of effective support services centre on interpersonal aspects of the relationship between families and service providers. It matters as much how professional assist families in mobilizing resources as it does which supports are mobilized. Features of effective help-giving are identified as: relationship building; communication, honesty and clarity; understanding of families own concerns, and responsiveness to family values and goals.

iii. **Parents Partnership Models:** Relationship between parents and professionals is a crucial aspect of service effectiveness. Evaluation of such an approach employed by the KIDS Family Centre points to positive effects. The centre employed a range of services from which parents could choose. Professional practice was based on a negotiating model of partnership (Dale, 1996) whereby time, listening, openness and discussion are used to help parents and professionals to reach consensus on needs and actions.

iv. **Coping Skills Models:** In general, these interventions have used the ideas from stress and coping theories to inform parent training in problem solving and decision making, communication skills, skills in accessing and utilizing social networks, and coping strategies such as positive self-statements, self-praise and relaxation. These models focus on services that take a holistic approach to parent support. One of their strengths lies in their ability to work with parents to determine their needs and to provide opportunities for parents to access a range of other

services as appropriate.

B. Kaur (2010) also categorized parents and family support models into eight.

1. Network of NGOs with families: NGOS play an important role in the development of society. They focus on the empowerment of depressed sections of the society. There are NGOs working especially for deaf, dumb, mentally retarded, and physically impaired and for visually impaired. They also organize camps for the children with special educational needs like wheel chairs, hearing aids, braille etc. Therefore, counsellors should connect NGOs with families of children with special educational needs children who would provide them adequate knowledge about care of the children with special educational needs member.
2. More Interactions with Families among Themselves: Families should interact with each other to provide appropriate and rehabilitative care to the children with special educational needs at home. They should help themselves through transfer of knowledge and skills and on finding ways to change and adopt according to the needs of the children with special educational needs member.
3. Counselling Services for Families with Special focus on Sibs: The inability of any person who is significant to the family interferes in the family's home and social environment. Every member of the family experiences burden of responsibilities and lack of resources to provide adequate care to the disabled. Sibling disability has a negative impact on the normal sibling's personality. They experience isolation, anger, depression, fear and frustration because of their children with special educational needs sibling. Counselling services should be provided to families with special focus on sibs to release their anger, frustration, fear and depression.
4. Education about Balanced Nutrition and Personal Hygiene: Families should be educated by counsellors on balanced nutrition, malnutrition, infectious diseases and personal hygiene. Rural families lack resources particularly in health and education sectors. They must be provided with the appropriate knowledge, which would help them to provide a healthy environment to their children with special educational needs member.
5. Education about Disability: Majority of the families lack knowledge about disability, its causes and treatments, which is an important reason for anxiety in parents. They should be provided with the adequate knowledge about the disability and ways to understand and to cope up with the disability of the family member.
6. Frequent Medical Checkups: A major health care challenge for rural areas of the developing countries is lack of access to medical facilities; due to which children with special educational needs are not being properly medically check up. Special care and attention regarding treatments of the children with special educational needs should be provided to the families.
7. Stress Busting Exercises for the Families: Stress is very common among families of disabled, they should be provided with knowledge about stress busting exercises. Exercise is the best way to diminish the effects of stress. Conflicts arise from negative thoughts, actions and, conflicts can be resolved by focusing on positive thoughts, actions and feelings should be inclusive. A student should not be excluded from school, because he or she has disability. Well-developed inclusive practices which give attention to special educational needs children are less expensive than segregated one.
8. Provision and Access of Literature and Audio-Video Information: There should be provision and access of literature and audio-video information by counsellors on various topics related to disability i.e. management of disabled, causes of disability, sanitation, hygiene etc should be introduced to the families to make them aware about "what disability is?" "How it is taken care of?"

Conclusion

Constant psychological stress, misunderstanding within the family, economic burdens, grief and strain were significant factors associated with the families of children with disabilities. Presence of a special educational needs child in a family hinders opportunities for social intervention. Though, it cannot be disputed that parents of children with special educational needs face a great deal of stress. Intervention programmes such as skill training, parent education, advocacy roles on part of parents and professionals are a necessary part of the process involved in supporting families with children with special educational needs. Such intervention requires active involvement of a wide range of professional such as social workers, teachers, psychologists, therapists, medical officers and many others.

Recommendations

- Parents need to feel supported and to have opportunities to tell their stories without censure, so a counsellor who is emphatic can be deeply therapeutic.
- Parents may also be supported in noting their resources, capacities and adaptability in caring for their child. Many parents need to be acknowledged for the courage and loving that is manifest in the care of

their child.

- Counsellors should be mindful that parents need advocacy from health professionals who understand their situation because the barriers and the difficulties in negotiating support structures can be exhausting.
- Counsellors should also be aware of the wider inadequate systematic supports for parents and to advocate for more generous social and financial resources for these parents.
- School systems should encourage parents to participate fully in school programmes affecting their children.
- Advocates should endeavour to relate their efforts to helping families with children with special educational needs secure needed services that may offset the efforts of disability in children, and conducting family education groups is a necessary venture.

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