PREVENTION OF CHILDHOOD DISABILITY: A NECESSITY FOR DEVELOPMENT

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Abstract

The analysis of theoretical and empirical studies showed that childhood disability exists among people of all races. It cuts across ethnic, gender and professional boundaries. The known causes are traced to the human interactions, diseases, drugs, chemical and the genetic composition of parents. From this analysis, childhood disability is increasing in developing countries. In Nigeria, enough plans have not been made to adequately address the needs of the disabled. The older disabled persons are calling for more intervention efforts from the government agencies and NGOs. Policy and practical efforts are required to meet the educational, physical, social and emotional needs of the disabled children. Rather than pay for the reconstruction, intervention and rehabilitation when disability strikes, it is more advantageous to prevent disability from occurring. The efforts put into prevention beyond here include: medical, social or educational strategies or a combination of strategies. These prevention activities are categorized into primary, secondary and tertiary levels. In this analysis, it is suggested that prevention measures be designed and monitored for effective implementation at both local and state levels in Nigeria.

Recently the three terms closely related to this analytical study, were briefly explained by Kavanagh & Willacy, (2012). First, impairment is an abnormality in the structure and functional capacity of the body; such as long eyeball. The second and the more relevant one to this topic is disability which has been described as a restriction or loss of ability due to impairment in performing an activity in a manner considered normal for a human being of that developmental stage; such as myopia or shortsightedness which prevents an individual from seeing objects as much as normal. The abnormality is described as a handicap if the disadvantage for an individual, arising from a disability, places some limitation on the achievement of desired goals. An example of such presentation is poor visual acuity which is due to a problem associated with the eye and vision. A handicap is a relative thing, arising from barriers impacted on people with impairments. Smith (2011) used the term exceptional to mean those who require special services in order to perform tasks like the normal. This category of

persons includes the disabled, handicapped and the gifted. Emphasis in this treatise is on the disabled children though mention may be made about impairment, handicap and the normal.

According to the International Classification of Functioning, Disability, and Health (ICF), disability is conceptualized as the product of the interaction between the person with a health condition and the environment, manifested in the dimensions of body functions, performance of activities, and participation. The functions of the body provide coverage of "the physiological functions of body systems (WHO, 2001). Thus a disabled child is the one that has defects in the body and or is unable to perform personal, social, mental, emotional or personal functions as the average person of his/her age. A disability may be physical, mental, emotional, sensory, and developmental or a combination of these.

Causes of Disabilities

Childhood disability may be acquired from prenatal damage, perinatal factors as well as neonatal factors (*El-Hazmi*, 1997). The causes may include genetic factors, trauma, toxic exposure, infections, or nutritional factors which result in either perinatal or postnatal damage. The development of disability among children occurs at different stages as follows: (i)At the prenatal stage childhood disability is due to genetic factors, maternal age, maternal diseases, drugs, chemicals, radiation, consanguinity, ethnic group, etc. (ii) At the perinatal, the problems associated with childhood disability are: low birth weight, prematurity, asphyxia, trauma during labour, intracranial haemorrhage, etc. (iii) The postnatal factors causing disability includes: infections (such as tuberculosis, poliomyelitis, meningitis, encephalitis), accidents, malnutrition, tumours, environmental factors, poisoning, psychosocial problems, etc

The Issue Related to the Prevalence of Childhood Disabilities

It has been reported that the last 30years have witnessed a significant drop in mortality rates among children from zero to 5 years of age in developing countries (Gogia & Sachdev, 2010). Also it has been said that medical practices has reduced still birth and infant mortality which have led to an increase in child survival at the early stages(http: //www .c4eo.org.uk/themes / disabled chi ldren /increasingquality/).This has resulted in the production of more children with complex needs surviving early childhood. Improvements in health care delivery also meant that childhood disabilities are being diagnosed at a younger age. These innovations arising from medical practices have placed a heavy demand on education, especially for early interventions. In Nigeria, the issue is strikingly a serious matter. A report has it that

> "Up to 200 million children, that is, ten percent of the world's young people are born with a disability or become disabled before the age of 19. In

developing countries, including Nigeria, only about two percent of children with disabilities receive education while more than 80 percent have no access to services" (Ezeam, 2011p1).

The chairman of the House of Representative Committee on Education stated that government at all levels in Nigeria has not lived up to its responsibility for the welfare of disabled children in the society. A call was then made on that occasion to schools and the public to come to the aid of the disable citizens coupled with a stress to use immunization as one of the ways to reduce childhood disability (Okafor, 2011). To confirm this claim here is a part of an account from Elizabeth Oke, a disabled Nigerian living oversea.

> "I plead with everyone of you, when you go out today and you see a person who is not able bodied, or someone who is not standing up as tall as you are, because of a birth defect, an accident, abuse, neglect, or a disease, Please lend a helping hand to them…If you are anarchitect, a construction worker, remember to make the buildings you're making accessible to those with physical disability. If you're a citizen, trying to get on a bus, watch carefully, look at that guy who can't run to the bus as fast as you can, and give him the chance to get inside the bus. If you're a teacher, remember that, the boy on a wheelchair who can't participate in sports could be the best on the debate team. Everybody has a part to play here" (Oke, 2010 p2).

According to Oke (2010), without education and access to basic necessities of life a disabled individual is more susceptible to being poor and to remain a beggar for money and basic of every day necessities. Still on this issue, in her 3rd national workshop an NGO, Building Hope for Special Children Learners (BHSL) said that there was an increase rate of disabled persons in the country without proper facilities. It called on Nigerians to join hands to provide health and educational facilities and opportunities for the disabled persons in the society (Okafor 2011).

It is now clear that disabled children are increasing even in developing countries. In Nigeria, there is a slow rate of activities designed to help the disabled. To be effective in meeting the needs of these persons requires the activities of the family (including parents, siblings and wards), voluntary agencies, the government, schools, medical practitioners, counsellors, the immediate community, cultural and religious beliefs (Kavanagh & Willacy, 2012)

Implications of Having a Disabled Child

The issue of having a disabled person in the family has some notable implications. For example, the parents will need to embrace a lot of current information in addition to having to cope with the emotional difficulties of adapting to the news. They have to face making important decisions about the condition of

their child at different stages. From one stage to another, further emotional and practical adaptations may be involved with more decisions to be made. The family may be involved in social isolation, financial adjustment and sibling adjustment.

In terms of social isolation, the families of the normal children may have negative attitudes towards those of the disabled children which can lead to social exclusion of the whole family, including siblings. In addition, the community to which the disabled child belongs may have some negative responses to disability. Thus parents have to cope with additional negative and stigmatizing beliefs about causes of disability as well as managing the situation within the family (Croot, Grant and Cooper, 2008).

In terms of poverty implications, the parents may have difficulty to maintain full-time employment and there may be some housing adjustment to meet the child's needs. Again, this may pose a burden to the family. In addition, the expenditure on a disabled child's basic needs is likely to increase; for example, increased spending on transport and car park fees when attending multiple healthcare professional clinics (Kavanagh & Willacy, 2012). The presence of seriously disabled children may manifest itself in a variety of ways on the siblings. Some children may experience jealousy, embarrassment, the sense of neglect and the sense of exploitation (e.g. working more than the other child, having to stop school for a while in order to keep company with the affected child etc). A disabled person's experience of life will be greatly influenced by his/her own personal attributes, the family, community and the nature of care given him/her. It is important to note that there may be increased levels of need at some key points in the disabled person's life such as starting school and going through puberty (Zacharin, 2008). Special attention is required for the educational needs of a disabled child which will be a particular area of concern to parents. Special educational services or special school may be considered for the child.

Prevention

Society grows because the human components are healthy. The health of the people depends on the birth and rearing of healthy children. To sustain a healthy society, there is the need to prevent disorders and developmental disabilities. In addition, there is the need to uncover possible disorders early, in order to apply timely medical intervention. Intervention efforts are necessary in order to reduce the magnitude and severity of disability. The ability of disabled child to cope with and adapt to everyday life may be minimal compared to the normal child. The disabled child may continuously suffer as he/she attempts to perform the functions as the normal does. This can have a serious influence on the personality of the child which in turn can affect the normal course of development. It is pathetic but true to hear that some disabled children never reach adulthood and some are at risk of

developing other associated complications which may further disrupt their social and emotional development. Disabled children and their families are continuously faced with mental and physical stress. Comprehensive services are required in order to help the children live a near normal life (Hobbs & Perrin, 1985 and Drotar, Crawford & Ganofsky, 1984). Furthermore, many disabled persons require a continuous home help, health care system, and other supportive services.

This makes it costly to cater for these individuals in the society. To manage disabled persons requires substantial medical, social, educational and rehabilitative care (Gortmaker & Sappenfield,1984; and Hobbs & Perrin 1985). According to El-Hazmi (1997) the cost of preventive efforts is substantially lower the management efforts and thus cost-effectiveness favours early prevention approach.

Levels of Prevention of Childhood Disability

The importance of early prevention is based on the understanding that childhood disability can be prevented at primary, secondary, and tertiary levels. Viewed from this perspective, the condition of developmental delay or disability in children can be tackled at each of the three levels to effect a reduction of its expression, magnitude, its duration or extended impact. The three levels of prevention can be implemented in the context of community based rehabilitation to address the following goals: (i) to enhance development and minimize the potential for delay; (ii) to minimize the need for special education and related services; and (ii) to minimize the likelihood of institutional or other restrictive care outcomes (Simeonsson,1991). Continuing further Simeonsson (1991) stated that the three levels of prevention constitute a useful framework for the problem of childhood disabilities in developing countries and that the model is based on the following assumptions:

> "1) developmental delays and disabilities are preventable both prenatally and postnatally; 2) causal chains can be delineated for differentiating postnatal prevention at the three levels; 3) prevention efforts can be potentiated by capitalizing on lead time in early development; 4) at each level of prevention, there are indicated services for the child and linked services for families; and 5) the levels of prevention provided in a given system will be governed by that system's philosophy, priorities, and resources"(Simeonsson,1991 p1).

Primary Level of Prevention

The goal of the primary level is to reduce the occurrence of developmental disability by reducing the risk factors such as low birth weight and malnutrition as well as giving families information about their influence on child development. El-Hazmi (1997) noted that primary prevention involves the prevention of the manifestation of disability. It may be a universal programme or be restricted to a

selected population at risk. Efforts at this level are directed toward reducing the actual occurrence of disabilities and employing measures that prevent the conception of a disabled individual or delaying the disabling process. Notable primary prevention efforts are: genetic counseling, improved prenatal and postnatal care, immunization programmes and regulations and legislation

Genetic counselling is the process of providing information on genetic risk; the nature and consequence of genetic disorders and the means available for the prevention of transmission of defective genes (Harper, 1988). The three major aspects essential to effective counselling which are: (i) diagnostic aspects, where an accurate diagnosis is required for a secure foundation for advice (ii) estimation of risk and (iii) preventive or ameliorative measures to ensure that those who are advised will benefit (El-Hazmi, 1995). One major effort in genetic counselling programme is to ascertain which individuals are at risk of having disabled children so that they can be offered advice. Genetic screening and counseling of individuals prior to conception is essential for the control of genetically determined disabilities .El-Hazmi (1997) noted that several studies have shown that the number of children born with serious genetic disorders leading to disability decreases significantly due to genetic counselling. An example is the thalassaemia control programme in Cyprus in 1974, 1988 and 1990.The percentage of successful prevention of genetic disorder was 1.8% in 1974, 100% in 1988 and 97% in 1990 (Cerreto & Travis, 1984)

Immunization programmes done during infancy have led to a remarkable decrease or in some cases complete absence of several infectious diseases that used to be a major cause of childhood disability. Some of these infectious diseases are: poliomyelitis, tuberculosis, meningitis and encephalitis (Meisels & Shoukoff, 1990). This aspect of prevention concentrates efforts on the management of maternal risk, delivery issues and the support given to the premature children and neonates. Health regulations and legislation can play an important role in primary prevention of childhood disability. For example, a state can make it mandatory for parents to immunize their infants. Parness (1983) has the view that laws promoting the prevention of childhood handicaps should be made more direct, thereby recognizing the unborn as persons entitled to protection from prenatal acts likely to cause them handicaps

Secondary Level Prevention

The goal of the secondary prevention level is to reduce the extent of manifested childhood disability and shorten its duration. Secondary level of prevention aims at reducing the duration or severity of disability. The intention at this level is provide early identification of the disabling condition followed by strategic treatment and intervention to minimize the development of disability. Secondary prevention strategies can be applied at the

prenatal or neonatal stage (El-Hazmi (1997). Infant stimulation and remediation programs are operated at this level. These are complemented by efforts of the family to foster the promotion of child development (Simeonsson, 1991).

Some of the conditions can be diagnosed during the prenatal and neonatal stages (El-Hazmi (1997). Neonatal screening is an important preventive approach and it includes both clinical and biochemical screening. This screening is the organized examination of all neonates in order to diagnose specific disorders for the purpose of treatment. Information needed for such screening are readily available in some countries but not in others. The best known example of secondary prevention is neonatal screening for phenylketonuria (PKU) and other haemoglobinopathies. Once the baby is diagnosed as having an abnormality, some of the measures taken are the provision special diets and hormone replacement therapy, which encourages normal development and prevents complications such as mental retardation (Irons, 1993 and Al-Hosni, Salah, Saade, Osman & Al-Zahid, 2003). New forms of secondary prevention, including genetic or surgical manipulation of an affected fetus in order to eradicate the biochemical or anatomical abnormality are being tried. Some of the trials have yielded a high degree of success. Example of such cases includes congenital heart disease, cleft lip and cleft palate and congenital dislocation of the hip (El-Hazmi (1997).

Tertiary Prevention

The goal of tertiary prevention is to prevent or reduce complications of disability that result in to institutionalization (Simeonsson, 1991). Tertiary prevention is intended to limit or reduce the effects of a disorder or a disability that is already present in an individual. El-Hazmi(1997). It is long-term care and management of persons having chronic disabling condition such as the rehabilitation of an individual or correction of the disability by surgical measures or by adopting strategies by which the disabled individual can lead a normal life or near normal life. Simeonsson, (1991) recommends that there may be a need for family counseling and that the intervention program should be conducted within the context of the primary health care system with every effort made to strengthen the family's role as the central determinant of child health and development. The measures in tertiary prevention also include special education programmes. Special schools with special services and specially trained teachers have provided excellent education programmes which have helped disabled persons achieve life and educational goals, similar in many ways, to normal individuals (Meisels & Shoukoff,!990; Guralnick & Bennett,1987).

Conclusion

The improvement in medical practices and awareness in primary health care has led to the reduction in child mortality. In turn, this has given room for the survival of disabled children. The

implications of having more disabled children are many. The first implication is largely hinged on the parents of the child: it is costlier to bring up a disabled child than the normal. It affects the attitude and social life of the parents as well as the siblings. Where there is no practicable state policy on the care for the disabled children and the parents are not aware of the caring and coping measures the disabled child suffers neglect rejection. This is the case of the Nigerian disabled child. The older and more enlightened disabled persons have called for active participation of government agencies, NGOs and individuals to support the neglected disabled children in order to develop their social, vocational, emotional and physical potentials. Literature used in this treatise collected from experts in US, Scotland, UK, United Arab Emirate, etc shows that our country has a lot to learn with respect to intervention and prevention of childhood disabilities.

Recommendations

The first recommendation is early intervention. Some people can say we are involved in intervention already because parents go to hospitals for baby check-ups and they present their babies to the paediatrician when a disability is suspected. Also teachers and counselors occasionally refer children to experts in the hospital. These cannot be regarded as early prevention. Early prevention is structured. It follows a programme of activities involving primary, secondary and tertiary prevention strategies. These three stages of prevention should be introduced in order to achieve observable success. Strategies for the prevention of childhood disability should be included in premarital counselling for Nigerian youths and for intending couples. Similar strategies should be included in family life education for all college and university students. A multi-disciplinary committee should be set up to draw up operational guidelines for the state and local authorities as well as monitor the intervention and management services for the disabled children. The federal ministry of health and education can liaise with science teachers to organize periodically seminars on how to reduce childhood disabilities in communities where they teach. The federal ministry of health can as well design an alternative community-based programme aimed at educating citizens about the intervention and prevention of childhood disability.

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