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Research Article

Differently Abled People and Their Life

Abstract

Background: Being differently abled is a complex phenomenon and also concept of disability has shifted from individual impairment to social phenomenon.

Objective: Present simple review is to get information for planning services and to share.

Context

Incidence: Numbers vary across countries, lowest reported incidence is from Lithuania (0.58%), highest from Poland (4.0%). European Academy of Childhood Disabilities reported a disabled child rate of 2.5%, additional 8% child population has learning and/or behavioural disorders. In India with lack of awareness, lack of resources, lack of community based services, many babies born with abnormalities continue to live without proper diagnosis, therapy. Sometimes it goes beyond childhood to adulthood, years beyond.

Types of disabilities: There are many disabilities which make person differently abled. Hearing loss is one of the most common birth disorders. There are 285 million people with visual impairment worldwide. Limb deformities vary. Psychiatric disorders, by virtue of their very nature, display different patterns of disabilities when compared to physical ailments.

Present status: Disability studies are growing as multi-disciplinary field in view of various issues involved.

Effects: Having differently abled child in a household affects family's quality of life, parents' gender roles, financial resources, and employment status use of time, health, even occurrence of demographic life events, divorce or birth of another child.

Possibilities: Disability must be seen in wider context of human development and social justice. Those working in community disability programmes have responsibility to look into local cultural factors affecting disabled people, communicate findings to policy makers, program managers.

There is need for thinking about disabilities as social issue so that needs of disabled persons are met by inclusive rather than exclusive social attitudes, coupled with individually focused rehabilitation process where necessary. Problems are many in resource poor countries. There is need to do community based research.

Background

WHO [1], has said that 'differently abled is a person who has impairment that produces functional limitations, restrictions in activities or has social handicap'. Being differently abled is a complex phenomenon which reflects an interaction between the features of a person's body and the features of the society in which he or she lives. Such persons are seen as being restricted in performing daily activities because of a complex set of interrelating factors, some pertaining to the person and some to the environment and social/political arrangements. Giulio and philipov [2], report that the social concept of disability introduces the notion that society has erected barriers, physical or attitudinal, which affect a differently abled person's life. Also comparative dimensions or the cultural and social welfare differences influence the well-being of families with disabled in different contexts. In the past three decades, the concept of disability has shifted from individual impairment to a more social phenomenon. Singh [3], reports that the essential basis of disability studies is that, disability is a culturally fabricated narrative of the body, a system that produces subjects by differentiating and marking bodies.

Disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being [4].

Handicap is a disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual and impairment is any loss or abnormality of psychological, physiological or anatomical structure or function [5].

Objective

Present simple review is to get information for planning service oriented research and to share with health professionals.

Incidence

Giulio and Philipov² have reported 1.9% incidence of a differently abled child, amongst families. There are reports that 10% to 20% of individuals have some kind of developmental disability [6]. The percentages vary across countries, the lowest is reported from Lithuania (0.58%) and the highest from Poland (4.0%). The European

Academy of Childhood Disabilities considers a disabled child rate (out of all children) of at least 2.5 per cent. They also consider that an additional 8 per cent of the child population has learning and/or behavioural disorders [5]. This makes the overall share of children with disabilities and special needs in any given population about 10 per cent. Recent WHO [7], estimates reveal the rate of differently abled among 0 to 14 aged children for high income countries as 2.8%. In India with lack of awareness, lack of resources, lack of community based services, babies born with abnormalities continue to live without attempts at proper diagnosis and possible therapies. This is much more with female babies especially in rural areas. Sometimes it goes beyond childhood to adulthood and years beyond.

Population-based studies have limitation at the national level for authentic data on the prevalence and incidence of disability in India. The National Sample Survey Organisation [8], estimated that approximately 100 million Indians are affected with one or more disability, project nearly 10% of Indians with some disabling condition, however, according to the Census 2001, approximately 5% of people in India are affected with impairment or disability [8]. There are more than 3,000 special schools in India today. Of them, 900 are schools for the hearing impaired, 400 for children with visual impairment, 700 for those with locomotor disabilities, and 1,000 for the intellectually disabled [6].

An estimated 500 million people worldwide have visual, hearing, mobility or cognitive impairments. Typically, disabled people are among the poorest of the poor. Statistics show they are most likely to have incomes below the poverty line, be less educated and participate less in society. And their employment opportunities are extremely limited [9].

Types of disabilities

There are many disabilities which make a person differently abled. Hearing loss is one of the most common birth disorders in the United States [10]. The largest single form of hearing loss is sensorineural disorders, with more than half caused by genetic factors that affect 17 million in the U.S [11]. In fact, the prevalence of hearing loss is greater than that of several other conditions screened for in every state, including phenylketonuria, hypothyroidism, and sickle cell anemia [12]. Early screening, early intervention, close and continued monitoring of all aspects of a child's development are essential [13]. Visual disability is a global issue. There are 285 million people with visual impairment worldwide. Of them 39 million are blind, 246 have low vision and 90% live in developing countries [1]. Weeraratne et al. [14], reported the problems which visually disabled and partially sighted people face for survival like use of medicines for diseases they may be suffering if they live without the assistance of sighted relatives. Psychiatric disorders, by virtue of their very nature, display different patterns of disabilities compared to physical ailments. It is important to note that social and work related functioning is more important in those with mental illnesses. Also mental disability in the form of apathy, motivation, poor self-care, communication difficulties and poor inter personal skills are not visible unlike disabilities, like blindness or locomotor disability. Further, disability is not only a medical issue and the medical model cannot be used to the complete exclusion of the social model. Also one cannot say that all problems faced by differently abled people stem from negative social attitudes; impairment is definitely a factor. That is why disability

is not exactly parallel to race or gender, as a social issue. There are instances when disability benefits like bus passes are denied because they look physically strong. Also it is compounded by stigma and discrimination. People may be living with varying types and degrees of disabilities, mental and physical with the different barriers and situations [15].

Present status

Disability studies are a growing multi-disciplinary field. Whyte [16], reported that in poor communities, where disabled people are not seen as a priority for development, nor included in most of the mainstream development programmes, an awareness of cultural issues surrounding disability is a key part of the process of integrating disability into general development activities. In most poor communities, where everybody is struggling for survival, disability is usually not seen as a priority in development, except by disabled people and their families. In particular it is rare for mainstream development planners to consider the impact of their plans on disabled people, or to include disabled people specifically in their programmes. But disability must be seen in the wider context of human development and social justice, and for this purpose all development workers need to have an understanding of the disability issues.

Prenatal risk factors include chronic maternal illness, certain maternal infections, toxin exposures and nutritional deficiencies. Risk factors in the perinatal period include pregnancy-related complications, prematurity and low birth weight, and infection exposure during pregnancy or at time of birth. The lack of maternal and child health care is a significant problem in developing countries⁶. So the risk is more in developing countries.

The Global Disease Control Priorities Project estimates that 10% to 20% of individuals worldwide have a developmental disability of some kind [17]. In the U.S. alone, it is estimated that 9% of children younger than 36 months of age have a possible developmental problem [18], while 13.87% of children 3 to 17 years of age have a developmental disability [19].

Prenatal risk factors include preconceptional factors, Infections, Exposure to toxins, maternal chronic illness, and maternal nutritional deficiencies.

Perinatal causes may include pregnancy-related complications, Infections, Rh isoimmunisation, Prematurity and low birth weight [6].

Preconceptional causes of developmental disability relate predominantly to genetic disorders or malformation syndromes. Genetic disorders are the most commonly identified causal factor for intellectual and other disabilities, and include single gene disorders, multifactorial and polygenic disorders, and chromosomal abnormalities. Genetic disorders associated with developmental delay include aneuploidies and inborn errors of metabolism. Consanguinity increases the prevalence of rare genetic disorders and significantly increases the risk for intellectual disability and serious birth anomalies, especially in first cousins [20].

In the developed world, CMV is the most common congenital viral infection, with an overall prevalence of 0.6% [21]. Ten per cent of affected infants show signs of infection at birth, with a substantial risk of neurological sequelae such as sensorineural hearing loss (SNHL) [6].

Congenital toxoplasmosis occurs at a rate of 1.5 cases per 1000 live births and causes neurocognitive deficits such as intellectual disability, seizures and visual impairment caused by chorioretinitis [22].

There are an estimated 110,000 cases of congenital rubella annually worldwide. Maternal infection during pregnancy transmits the rubella virus to the fetus, causing deafness, congenital cataracts, microcephaly, seizures and intellectual disability [6].

Congenital syphilis can cause deafness, microcephaly, intellectual disability and visual impairment through interstitial keratitis [23].

Prenatal exposure to the pesticide commonly known as DDT is associated with neurodevelopmental delays in early childhood [6].

Folic acid deficiency is associated with neural tube defects. Iodine deficiency is considered by the WHO to be the leading and most preventable cause of brain damage worldwide [24].

Birth weight below 1500 grams is associated with a threefold increase of developmental disability [17].

Congenital transmission of herpes viruses 1 and 2 is associated with a high risk of long-term neurological problems. Without treatment, 30% to 50% of infants born to mothers with untreated gonorrhoea, and up to 30% with untreated chlamydia, will develop ophthalmia neonatorum, which can lead to blindness if not treated early. Worldwide, an estimated 1000 to 4000 babies born annually become blind secondary to ophthalmia neonatorum [23].

Invasive GBS disease is associated with long-term disabilities, including seizures, developmental disabilities and vision and hearing impairment. Important risk factors for GBS to screen for include a history of fever in labour, a preterm delivery <35 weeks, prolonged rupture of membranes >18 hours and maternal chorioamnionitis [17].

Effects

In the early 1970s, it was recognized that “a family with a child who has a disability is a family with disability” [25], because having a differently abled child in the household affects the family members’ quality of life, the parents’ gender roles, financial resources, the employment status, the use of time, health and even the occurrence of demographic life events, such as divorce or the birth of another child. Down syndrome, Cerebral palsy and Autism affect children’s lives and the lives of their caregivers [2].

Coleridge [26], also reported that in the former communist countries, as an extreme but at least frank example, anybody working with disabled persons was called a ‘defectologist’. Disabled people are regarded as defective in the medical model. The individual medical model of disability says that the disabled persons must try to overcome their disability by some means or others in order to join in with the mainstream. This implies that the disabled person is intrinsically of less value because of the disability. This has devastating implications for the disabled person’s ability to grow and develop. It is very insidious, and is present in just about every encounter between a disabled person and other people, especially professionals. There is a problem of marriage, dependence on parents, not being able to get a job.

Some authors report less marital satisfaction among parents of disabled children [27] and higher prevalence of single parenthood [28,29], usually due to elevated parental stress [30]. According to a study done in the US, divorce is relatively common among the parents of disabled children (with congenital problems or chronic illnesses). Disabled children are more likely than healthy ones to be subjected to poverty, loss of parental time and the emotional stress that follows divorce [31]. On the other hand, some parents might try to avoid divorce, even if their relationship has soured, because of the excessive emotional and financial costs that the remaining parent would have to bear or because of the attachment to the child. According to a Danish study, children with a disability are at greater risk of growing up in a single-parent household [32,33]. It has been shown that the parents of child with Down syndrome are less likely to get divorced than the parents of children without disabilities or with other birth defects. This may be because the parents of children with Down syndrome are often older, better educated and married, all factors that are protective against divorce [34]. MacInnes [35] reported that the “mothers of the children with disability have a lower hazard of having a second child; that is, raising a child with a disability slows or hinders further childbearing”. The parents of children with disabilities generally exhibit higher stress levels and poorer mental health than other parents. When comparing children with developmental disabilities and the general population, Byrne et al. [36], Guyard et al. [37] and Rentnick et al. [38] and others, found this to be true in the case of cerebral palsy. Physical health tends to be poorer in the families with disabilities, after controlling for the confounders [39]. Coleridge [26] reported that disabled people tend to be most disempowered because they are caught in a vicious circle where negative social attitudes create low self-esteem which produce a type of behaviour that in turn fosters negative social attitudes.

In India, children with physical disabilities born into families without the time, education and resources to give them adequate support typically find themselves at increased risk of infanticide or abandonment [40].

Possibilities

Those working in community disability programmes have a responsibility to research the local cultural factors affecting disabled people and to communicate their findings to the general development debate around them.

The only way out is for disabled people to start the process of change in themselves, though the social model poses the opposite view. It says ‘even though the person has an impairment that cannot be changed, she or he is still of equal intrinsic worth. It is society that must come to terms with their disability and accept them as they are’ and should look into protection of the infant’s and family’s rights through informed choice, decision making, and consent [41]. There is a need for a rehabilitation process which does indeed try to lessen the handicap. There is a need to think of disability as a development and social issue in which the rights and needs of the disabled persons can be met by inclusive rather than exclusive social attitudes, coupled with an individually focused rehabilitation process where necessary [26]. The problems are many in resource poor countries. In view of this, there is a need to do community based research.

Developmental disabilities may last a lifetime but early recognition of their existence, timely diagnosis and an appropriate treatment plan can make a difference for the children and families involved. In many parts of the world, suboptimal conditions and care during pregnancy and childbirth can have a range of impacts on developmental health [6].

The National Iodine Deficiency Disorder Control Programme of 1986 aimed to prevent occurrence of goitre, mental retardation and hearing impairment. Government of India offers special concessions to the disabled in the following areas:

CORP children with disabilities program [40].

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