Psychosocial Issues and Challenges of Adolescents with Neurological Disabilities: The Way Forward

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Abstract--- Neurological disabilities are recognized disorders of the brain and nervous system. They play a major role because of its magnitude, manifestation and long-term impact of the person and his/her family as a whole. The above said impact becomes manifold especially with reference to adolescents. The authors based on clinical insight and literature review highlight the various psychosocial issues and challenges faced by the adolescents with disabilities at home, family, peers, cultural setting, workplace, and propose remedial measures to address their special need.

Keywords--- Disability, Adolescent, Psychosocial Issues.

Introduction
Neurological disorders are recognized as disorders of the brain and nervous system. These disorders have different origins; e.g. toxic, genetic, metabolic, vascular, infectious, immunologic or traumatic (Leonard & Ustun, 1997). Most of the neurological disorders results in long-term disability as many have an early onset. The disability may be reversible or irreversible. Socioeconomic demands of care and treatment put strain on entire family. Social isolation and stigma often adds to the medical and financial burden borne by the patient and the families. The education, employment, marriage, productivity and child rearing are severely affected. This is more so in women. Poliomyelitis, spinal cord injury, transverse myelitis, Gullian – Barre syndrome, T.B arachnoiditis are some of the neurological disorders causing locomotor disability.

Locomotor impairments can be classified as congenital and acquired. Congenital and developmental examples are cerebral palsy, CTEV, meningocele, meningomyelocele, phocomelia and congenital dislocation of hips. The acquired locomotor impairments can be grouped into infective and traumatic. The infective may be due to tuberculosis of spine or other joints, chronic osteomyelitis, septic arthritis, acute poliomyelitis, G.B. syndrome, leprosy, encephalitis, AIDS, etc. The traumatic impairments are accidents (traffic, domestic, industrial, agricultural, fall from heights, bullet injuries, explosion, violence, sports injuries) and natural catastrophes like earthquakes, floods, etc.

Definition of Concepts
Adolescent and adulthood is a phase of life marked with experiencing risk and increasing responsibilities. Major physical and emotional changes occur during adolescents. These changes are difficult to handle when they are coupled with neurological disabilities indicating locomotor impairments. Disability is any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being (WHO, 1980). Rehabilitation Council of India (RCI) Act, 1992 states that “locomotor disability means...
a person’s inability to execute distinctive activities associated with moving, both herself and objects, from place to place, and such inability resulting from affliction of either bones, joints, muscles or nerves”.

According to PWD Act, 1995, “locomotor disability” means disability of the bones, joints or muscles leading to substantial restriction of the movement of limbs or any form of cerebral palsy.

Some of the problems of adolescents with locomotor disability are obvious. Depending on the type of disability they can have:

- Restricted mobility
- Difficulty in managing ADL
- Problems of self-care like passing urine, cleaning oneself, etc.
- Sexual problems
- Barriers in participating in educational, vocational, social and recreational activities.

Methodology

The present study adopts a descriptive research design which aims at portraying the problems of adolescents with disabilities through clinical experience and extensive review of literature.

Transition

For a person with disability, normal transition periods are the worst times -when peers are getting their first jobs, having relationships, marrying, having children, etc., (Wagner, 1989). Roles of student, worker, wife or husband may seem to be impossible to obtain. These students face both physical and attitudinal barriers within the university environment. Majority of the students indicated that they had embraced barriers to their education due to lack of understanding and cooperation from administrators, faculty, staff and other students; lack of adaptive aids and other accommodations and inaccessibility of buildings and grounds. The basic right of a person with disability is the right to a barrier-free environment. In India, most of the public places are not disabled friendly. They face numerous challenges while travelling by public transport, attending classes to which staircase are the only access, working on outdoor projects and assignments and attending fieldwork.

It is widely acknowledged that adolescence is a stressful period for many youth, and that these interpersonal and intrapersonal struggles can potentially lead to serious psychological conditions such as substance abuse, affective disorders, violence, eating disorders and a variety of other psychiatric conditions (Havery and Spignier, 1995; Hoffman, Cerbone, and Su, 2000).

Lack of Support

Many of the tasks for an individual with disability may be caused more through lack of resources rather than lack of individual skills or will. A strong network of social support is consistently found to result in better adjustment and more successful outcomes (Clarke, 1999). Social networks have a strong influence on an individual’s personal values and attributional tendencies.
Body Image

The adolescent years are often times of great self doubt. The adolescent’s body changes quickly; they are very self-conscious. Every change or event brings in a new trauma-acne, unruly hair. Appearance is very important, as is the approval of peers. To be different is a problem, belonging to a group is important. Physical disability can affect the body growth. Disability such as cerebral palsy causes evident and major differences; short stature due to tone deformities makes one obviously different.

Body image affects adjustment, social acceptance, athletic competence and romantic appeal than the nondisabled peers. They are less likely to have friends, enter into relationships, date and attend college than able-bodied adolescents.

Sexuality

For adolescents, body image is tied into a growing sexual awareness. The real or perceived lack of attractiveness (in normal ways) to the opposite sex begins to affect their social life. A disabled adolescent may be able to maintain normal social relationships to same sex peers, but at the onset of puberty may be socially isolated from opposite sex relationships. Often, the adolescent with physical disability may exhibit inappropriate sexual behaviour for many reasons-loneliness, attention seeking and self-gratification. The individual may not have been taught other social skills, and so may use sexual activity as a way to draw attention to their need. Fear of negative evaluation may prevent disabled persons from developing sexual intimacy with the opposite sex.

Peer Attitude

Students with disabilities may be isolated or rejected by their peers, and in general, the more visible the disability, the more rejection and isolation because children are generally concerned with physical skills and activities, perhaps being unable to take part means that the child is incapable of any activity. The differences of having a disability, using a wheelchair, having problems of muscle control often stigmatize the individual giving rise to feelings of shame.

Adolescents and Disability-Vocational Issues

Young people with disabilities are more likely to be unemployed, underemployed (working fewer hours, working at seasonal jobs) or employed at a lower wage than their non-disabled peers. Young people with disability are also more likely to be hired for jobs that require little training and have few opportunities for advancement. Very few work outside home doing menial tasks; usually they work long hours within the family home or on the family farm. They cook, clean, babysit, care for ailing and aged relatives, or tend gardens, fields and flocks (UNICEF, 1999). The employability of the disabled is a matter of grave concern.

Adolescents and Disability-Gender Issues

Studies on the situation of girls with disabilities document a range of obstacles that these girls faced. These included high rates of physical and sexual abuse and neglect (Cross, Kaye & Ratnofsky, 1993) and high rates of teen pregnancy and poor academic achievement (Wagner, 1992). Female adolescents with disabilities have the same low level self-esteem as non-disabled female adolescents. The situation of women in
general, and consequently that of a disabled woman in particular, is closely related to the social, economic and cultural backgrounds of the country where she lives. In most societies disability devalues the worth of the disabled individual. It is easier for a disabled man to solicit help on the roads in the market places and in business centres, help is easily available to him in times of crisis, but the same do not happen in case of women with disability due to negative cultural values.

Constitutional provisions have proved of limited help. The rights created by constitutional and legal provisions have been treated as an end in themselves instead of means. There is a lot of gap between policies and practice. Most women with disabilities feel that the cost of equipments and expensive medical treatment prevents them from accessing any rehabilitation services. Access to transport denied their chances of taking up employment outside their locality. Even families resist women from going to jobs outside for the fear of exploitation. Women with disabilities are emotionally abused many a time in their life. They feel that they are verbally attacked /abused by their own family members because of their disability.

Most of the women feel uncomfortable to spell out their needs, which could be because of the culture they were brought up. The Disabled Women's Network of Canada (Ridington, 1989) surveyed 245 women with disabilities and found that 40% had been abused and 12% had been raped. Perpetrators of the abuse were primarily spouses and ex-spouses (37%), strangers (28%), followed by parents (15%), service providers (10%) and dates (7%). Available data suggests that disabled girls experience violence within the family, institutions and community at higher rates than their nondisabled peers, and the violence they face may be more chronic and severe such as withholding essential care. Part of the explanation may be that disability limits them, making it more difficult for some girls to assess violent situations, to defend themselves and/or flee, or to report incidents of violence. However, negative attitudes may be greater and are seen as easy targets. They are also regularly deprived of skills and opportunities they need to recognize and address violence, including adequate sex education. Finally, the police and community members may fail to respond appropriately to incidents of violence against disables girls, doubting the credibility of the reporter (Rousso, 2001).

UNESCO suggests that only 2% of disabled children are in school, with disabled girls even more underserved. These findings in education are part of a larger picture of double discrimination based on gender and disability that pervades the lives of women and girls with disabilities in all areas including employment, income level, healthcare, marriage and parenting. Disabled women and girls are commonly stereotyped as sick, helpless, childlike, dependent, incompetent and asexual, greatly limiting their options and opportunities. The biggest barrier to educational equity for girls with disability may be their invisibility. They are not on the radar screen of either the policy makers or the educational authorities. The schools are either too distant or does not have a disabled-friendly infrastructure like elevators or ramps. The scholarships or educational grants awarded through various schemes do not have any meaning unless it is affordable, accessible and timely.
Families often assume that a disabled daughter will not marry, which may add to her devaluation, since in some cultures, the prospect of a good marriage is the primary value given to girls. In contrast, it is assumed that boys, even those with disabilities, will become breadwinners as well as marry. In addition, in many cultures disability is a source of stigma and that having a disabled daughter is seen as a double liability that can lead to devaluation of the whole family.

**Discussion**

Family as partners in care does speak about the family’s role in taking care of the person affected with neurological disability. Therefore, it is important to look into the family’s facilitating role in functioning of person affected with neurological disability. Stigma is known to be one of the critical factors in a person affected with neurological disability, for not being gainfully employed. The factors contributing for stigma can be realized for further community-based interventions. In-depth study can be done with the employer who provides support in employing people with neurologically disabled, assessing their interaction patterns, motivational factors and job retention. Body image is insignificant when one’s social group highly values intelligence and abilities over appearance; it is much easier to adjust to physical differences.

The role of a psychiatric social worker in the area of neurological rehabilitation is very important and manifolds where the person with neurological disability is placed. It is crucial to explore the impact of psychiatric social work intervention on work skills, work adjustment and effective vocational outcomes. Problem of women with disabilities with regards to fulfillment of traditional gender roles, access to rehabilitation services, participation in community life and exploitation of merit needs greater attention. Disability is **Human Rights Issue** more so when it is women.

**Implication**

The study implies that person with disability have less success than able-bodied individuals in external and interpersonal spheres. Hence, services like counseling and remedial education have to be provided in institutional and non-institutional settings in areas like marriage, health, education, employment, transportation not just by legislative measures but through proactive policies and programmes initiated by public, private agencies. Mass media have to highlight the ordeals faced by women with disabilities in their daily lives. Sheltered workshops and supported employment should address the problem of employability of the disabled. Mobility camps should provide aids and appliances for the disabled like wheelchairs, crutches, walkers, collar belts, etc.

**Conclusion**

The government and civic agencies should work for providing barrier-free access. There are barriers placed by the society, environmental barriers, institutional barriers, attitudinal barriers and informational barriers.

Disabled persons are entitled to have their special needs taken into consideration at all stages in economic, social and healthcare planning.
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