

People with Disability: Their Perceived Stress, Education and Intervention

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ABSTRACT

People with disabilities have been facing difficulties not only from the imitations of their physical and mental capabilities but from the social, political and cultural factors. With their given abilities they try to adjust to the so called normal society. This remains far from expected as they have to face limitless challenges every single day. They most often have high level of perceived stress owing to the challenges which affect their normal adjustment to the society and the process of education. Internationally and nationally policies to aid them integrate to the mainstream have being acknowledged. Education not just skill training but education focused on psychological coping skill are aptly called for. Following which each individual can live a fulfilling life. The paper uses secondary data to depict the existing government policies and studies done by other researchers in this area. It contends that a flexible education module focused not only education but an amalgamation of their coping capacity is a must.

Keywords: *Disability, Perceived Stress, Education, Intervention*

The word 'disability' has been defined differently throughout the world, it lacks an agreed-upon definition. According to WHO, disability is part of being human. Almost everyone will temporarily or permanently experience disability at some point in their life. An estimated 1.3 billion people – about 16% of the global population – currently experience significant disability. This number is increasing due in part to population ageing and an increase in the prevalence of non-communicable diseases. International Classification of Functioning, Disability, and Health (ICF) defines disability as a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives.

The Survey of Persons with Disabilities in India (2021) with the objective to estimate the indicators of incidence and prevalence of disability, cause of disability, age at onset of disability, facilities available to the persons with disability, difficulties faced by persons with disability in accessing/using public building and public transport, arrangement of regular care giver, out-of pocket expenses relating to disability, etc. According to the survey, in India prevalence of disability (percentage of persons with disability in the surveyed population) was 2.2 per cent. It was 2.3 per cent in rural areas and 2.0 per cent in the urban areas.

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Prevalence of disability was higher among males than females. Incidence of disability in the population, that is the number of persons whose onset of disability (by birth or otherwise) had been during the specified period of 365 days preceding the date of survey per 1,00,000 persons was 86. 3.18.2 while according to the 2011 census of India, there are 26.8 million people with disabilities while other sources have offered higher estimates. The census additionally collected data on mental disability for the first time, and found that 5.6% of Indians with disabilities.

Under Ministry of Social Justice and Empowerment, the Department of Empowerment of Persons with Disabilities (Divyangjan) administers the following three Acts:

1. The Rights of Persons with Disabilities Act, 2016
2. The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999
3. Rehabilitation Council of India Act, 1992

The Rights of persons with Disabilities (RPwD) Act, 2016 covers the following specified disabilities:

1. Physical Disability
 - a. Locomotor Disability
 - i. Leprosy Cured Person
 - ii. Cerebral Palsy
 - iii. Dwarfism
 - iv. Muscular Dystrophy
 - v. Acid Attack Victims
 - b. Visual Impairment
 - i. Blindness
 - ii. Low Vision
 - c. Hearing Impairment
 - i. Deaf
 - ii. Hard of Hearing
 - d. Speech and Language Disability
2. Intellectual Disability
 - a. Specific Learning Disabilities
 - b. Autism Spectrum Disorder
3. Mental Behaviour (Mental Illness)
4. Disability caused due to-
 - a. Chronic Neurological Conditions such as-
 - i. Multiple Sclerosis
 - ii. Parkinson's Disease
 - b. Blood Disorder-
 - i. Haemophilia
 - ii. Thalassemia
 - iii. Sickle Cell Disease
5. Multiple Disabilities

The Ministry of Health and Family Welfare passed the Mental Health Care Act, 2017 to provide mental healthcare and services for persons with mental illness and to protect, promote and fulfil the rights of such persons during delivery of mental healthcare and services and for matters connected therewith or incidental thereto.

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The Rehabilitation Council of India Act (1992) was created to provide constitution of regulating the training of rehabilitation professionals and the maintenance of a Central Rehabilitation Register and for Matters connected therewith or incidental thereto. The Act also prescribes punitive action against unqualified persons delivering services to persons with disability. It was set up as a registered society in 1986. On September, 1992 the RCI Act was enacted by Parliament and it became a Statutory Body on 22 June 1993. The Act was amended by Parliament in 2000 to make it broader based. The Council lays down policy parameters regarding various aspects of training and education in the field of Rehabilitation and all institutions have to seek recognition from RCI as per provision of RCI Act, 1992

Recognizing that the Persons with Disabilities constitute a valuable human resource for the country and that a majority of such persons can lead a better quality of life if they have equal opportunities and effective access to rehabilitation measures, the Government, with a view to create an environment that provides such persons equal opportunities for protection of their rights and full participation in society, formulated and brought out the National Policy for Persons with Disabilities.

The Policy provides for the following:

1. Prevention of Disabilities
2. Rehabilitation Measures: Under rehabilitation,
 - a. Physical Rehabilitation Strategies:
 - Early Detection and Intervention
 - Counselling & Medical Rehabilitation
 - Assistive Devices
 - Development of Rehabilitation Professionals
 - b. Education for Persons with Disabilities
 - c. Economic Rehabilitation of Persons with Disabilities

Accordingly, the principal areas of intervention under the Policy are: Prevention, Early-detection and Intervention; Programmes of Rehabilitation; Human Resource Development; Education of Persons with Disabilities; Employment; Barrier free-environment; Social Protection; Research; Sports, Recreation and Cultural Activities.

Education plays a significant and remedial role in balancing the socio-economic fabric. Our country India with its billion strong population, are its most valuable resource which needs the nurture and care in the form of basic education to achieve a life of better quality. This warrants an all-round development of our citizens, which can be achieved by building strong foundations in education.

EDUCATION

According to the Oxford dictionary education is a process of teaching, training and learning, especially in schools, colleges or universities, to improve knowledge and develop skills. It is the act or process of imparting or acquiring general knowledge, developing the powers of reasoning and judgment, and generally of preparing oneself or others intellectually for a mature life. There are three main types of education, namely, Formal, Informal and Non-formal. Good quality education has the power to change the life of a person, a community and the future of the planet. It is a fundamental human right of every woman, man and child – no matter who and where they are.

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The right to education is available to all citizens including the disabled. Article 29(2) of the Constitution provides that no citizen shall be denied admission into any educational institution. Article 45 of the Constitution directs the State to provide free and compulsory education for all children (including the disabled) until they attain the age of 14 years. According to the Persons with Disabilities (Divyangjan) survey (2021), the education level among persons with disabilities:

- Among persons with disabilities of age 7 years and above, 52.2 per cent were literates.
- Among persons with disabilities of age 15 years and above, 19.3 per cent had highest educational level secondary and above.
- Among persons with disabilities of age 3 to 35 years, 10.1 per cent attended preschool intervention programme.
- Percentage of persons with disability of age 3 to 35 years who were ever enrolled in ordinary school was 62.9 per cent.
- Percentage of persons of age 3 to 35 years with disability who were ever enrolled in special school among those who were not enrolled in ordinary school or were enrolled in ordinary school but were not currently attending was 4.1 per cent.

Historically, children with disabilities have been excluded from the general education system and placed in 'special schools'. In some cases, they are separated from their families and placed in long-term residential institutions where they are educated in isolation from the community, if they are educated at all. Both practices persist in many regions, for example, Eastern Europe has the highest number of institutionalised children in the world and a child with a disability is almost 17 times more likely to be institutionalised than other children (UNICEF, 2012).

Children with disabilities have very low rates of initial enrolment. Even if they do attend school, children with disabilities are more likely to drop out and leave school early without transitioning to secondary school and beyond (Global Campaign for Education, 2013). Children with disabilities are also at increased risk of school violence and bullying, preventing the safe enjoyment of their right to education (UNESCO, 2016). Most people with disabilities in India and their families are focused on survival in the context of deep poverty. India's disability rights movement, however, mainly comprises elite, middle-class activists who generally mirror the goals of the disability rights movement in Western countries. Significant ongoing barriers to education faced by many people with disabilities, which include:

- lack of accessibility, both in terms of physically inaccessible school buildings and unsuitable learning materials
- discrimination and prejudice which prevents people with disabilities from accessing education on equal terms to others
- exclusion or segregation from mainstream school settings
- inferior quality of education, including in mainstream settings where children with disabilities have been 'integrated' into the existing non-inclusive system

Human rights law seeks to directly tackle these issues by placing obligations on states to respect, protect, and fulfil the right to education of people with disabilities, through the implementation of 'inclusive education'. Often there are multiple barriers that can make it extremely difficult or even impossible for people with disabilities to function. Often, more than one barrier occurs at a time namely,

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- Attitudinal
- Communication
- Physical
- Policy
- Programmatic
- Social
- Transportation

Even though legislature in India have enacted ample acts and interventions provided, every individual with disability invariably have high level of perceived stress, given the challenges they face daily. Attitudes towards disability vary considerably between regions and sub-cultures. While disabilities do not hold any universal social stigma, there are regions and sub-cultures which do not agree. In some places, people with disabilities are seen as wicked or deceitful, or as unable to progress to adulthood and dependent on charity and pity for assistance. In such scenarios, people with disabilities are often socially segregated, often as a results of ingrained cultural and religious attitudes. They are faced with negative social attitudes in the wider population. A person with disability on a daily basis have to face numerous psychological and sociological challenges and obstacles in their struggle to adjust in the society. These intrinsic and extrinsic factors, in the life of a person with disability in the educational path may well be stressful depending on how one perceives his or her situation.

PERCEIVED STRESS

Stress is an internal state which may be due to physical demands put on the body (illnesses, exercise, extremes in temperature, etc.) or the environmental and social conditions which are taken as potentially harmful, beyond control, or exceeding resources of coping in the individual. Stressed condition can lead to many psychological responses such as anxiety, hopelessness, irritability, depression, or a general feeling of being unable to cope with life. Virtually all changes in the environment, be it a pleasant one or unpleasant, demands person's ability to cope. Stress is productive in this way helping us to adapt to change. But beyond some point, "stress" becomes "distress." The act which may lead to distress varies significantly from person to person. Some events can also be definite stressors for most of us, majority being injuries, infections in the body, harmful, or annoying events in the environment, major transitions in life or changes which drives us to cope in a novel way and the anticipated/actual threats to self-esteem (Morgan CT, King RA, Weisz JR, Schopler J., 1993).

Perceived stress is different from stress. It's more about our feelings about the lack of control and unpredictability than the actual stressors. It is degree to which events in a person's life are assessed as stressful, unpredictable and uncontrollable (Cohen, Kamarck, & Mermelstein, 1983; Phillips, 2012). Perceived stress is a dynamic multidimensional concept, with a wide spectrum of causative and conducive factors. The perceptions comprise medical, physical, psychological, and psychosocial aspects and are both culturally and socially context dependent (K. A. Moore and C. L. Cooper, 1996). The degree of stress experienced and the ways in which a person reacts to it can be influenced by a various number of factors such as personal characteristics, lifestyle, social support, and appraisal of the stressor(s), life events, and socio-demographic and occupational variables (Awat Feizi, Roqayeh Aliyari, and Hamidreza Roohafza, 2012).

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Perceived stress is the subjective assessment of stress and the difficulties faced are different in all aspects, it is more difficult for person with disabilities. To name a few, they have difficulty with their self-image, feeling of inferiority, sadness of mood, irritability, low frustration tolerance, lack of motivation or self-motivation, difficulty of adjustment to name a few. These inversely add to their level of perceived stress. Societal attitude overt as well as covert towards them contributes to the daily hassles as they are already in their struggle to the so called normal society. Although the government and policy makers are making endless efforts by implementing laws and policies for their welfare, it remains largely on the part of the individual and their families to adjust daily and cope with the challenges. Expressed emotion of the family members towards them the individuals if negative, may also be a contributing factor which lead to high level of perceived stress.

Education although a means to aid them to help lead a self-reliant life with the obstacles mention above inversely become a challenge. Hence, with all the psychological and social debilitating factors present it is particularly difficult in the field of education for the person with disabilities. The students face attitudinal problems both from fellow students and teachers; lack of access to classrooms, libraries, administrative offices; unfriendly teaching methods; untrained teaching staff; hostile environment; lack of assistive devices and transport to, from and inside the campus (Khan, Itbar.2020). Not only the people with disability but people involved in their intervention faces challenges. The teachers of learners with special needs are confronted with higher demands, enormous challenges and low reward or motivation. Hence, stress among the teachers is inevitable with a resultant effect on behavioural and learning outcomes of learners with special needs. In a study conducted in Southwest Nigeria, significant positive relationship between the student-teacher relationship and perceived stress and an inverse relationship of work experience and work motivation with perceived stress among the participants was observed. An unfavourable working environment and lack of motivation were identified by the participants as major sources of stress. The study concluded that work environment-related factors triggered stress among teachers of learners with special needs (Adigun Olufemi, Tijani Faizat, Nzima Dumisani & Vivekanantharasa Raveenthiran, 2021).

Karim Savari, Maedeh Naseri & Yasaman Savari (2021) evaluated the role of perceived stress, social support, and resilience in predicting the quality of life among the parents of disabled children. The results showed that there was a negative and significant relationship between perceived stress and the quality of life of the parents of disabled children. While another study showed that parents of physically challenged and post graduate level of education have a better psychological well-being than the parents of intellectually challenged children and with only higher secondary level of educated (Thumar, K and Raval, S, 2018). These shows how social support, available resources and education level influence the psychological well-being of the parents while directly or indirectly impacting the perceived stress level of the children. Storyline of some notable movies are supported by psychological studies which propagates emotional and psychological support to the individuals with special need and stake holders resulting in the positive changes in the resilience for all. Notably, in the hindi movie “Black” (2005) the female protagonist who is blind, deaf, and mute but succeeds academically after considerable struggle. “Taare Zameen Par” (2007) explored the lives of people with dyslexia and gave intervention in the education of the boy with dyslexia. There were some earlier precedents to these more well-rounded portrayals, including “Koshish” (1972) and “Sparsh” (1980), which explored deafness and blindness respectively.

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In a study done in India, to study the impact of training on perceived stress of parents with intellectually disabled children. The overall perceived stress (scale) score was measured through family assessment scheduled (FAS) developed by NIMHANS revealed that the parent's perceived stress, have been reduced after providing 2 years of special training to their Children with Intellectual disability as compared to joining the school (training). The study showed that the level of perceived stress experienced by the individual could be reduced by identifying their coping mechanism and giving them training accordingly (Vankayala, N., & Anuradha, K., 2021). Such training on special intervention programs to overcome perceived stress needs to conduct largely across all sections of disability category, to identify which intervention type is appropriate according to their individual differences.

INTERVENTION

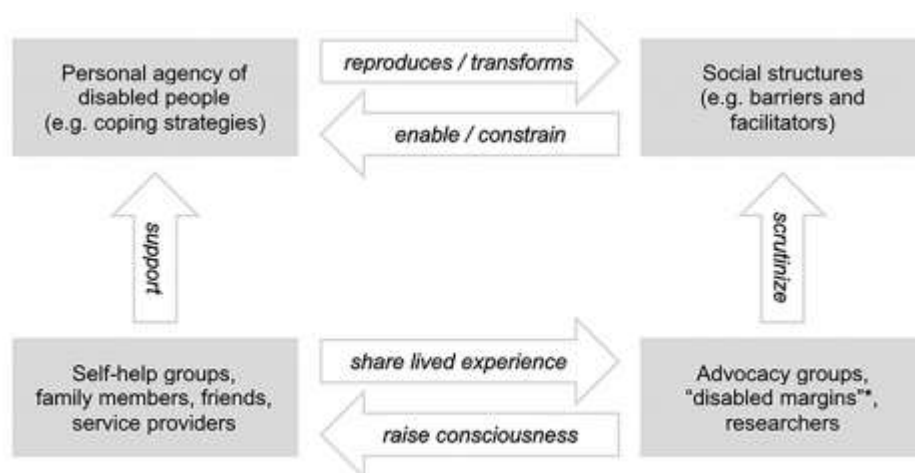
Empowering with special education

The person with disabilities need accessible buildings, accessible transport, capacity development of faculty in special and inclusive education, access to library and administration, curriculum revision, and implementation of policies regarding the inclusive education system (Khan, Itbar. 2020). Many educational institutions who encourage inclusive education, have given additional infrastructures to propagate the idea of acceptance of the fellow humans to their right to education and also nurture their student life so that they blossoms to the best capacity they can. In some educational institutions, there are counsellors and students cells where mental and emotional help are acknowledged and helps provided. However, availability of such educational institutions are quite limited. Even if such special arrangement could not be provided due to lack of funds, knowledge on the strengthening social relationships could be encouraged. For example, special classes on knowledge about the causes of disability, their nature and strengths and respect for individual differences could be provided to encourage educational oneness amongst the students. According to Cosden and McNamara (1997) students with disabilities do not have problems with their social skills or in their relationships. It is possible that students with disabilities who have stronger social relationships are more successful in education and are more likely to attend college. The results are possibly associated with the students' opportunities to develop social supports through campus programmes (Dr. Nageswara Rao Ambati, 2015). In their study students confirmed that many friendships were based on mutuality and reciprocity. Such special campus programmes would immensely help in countering perceived stress amongst the students with disability.

Mobilizing personal factors as well societal structures

In the struggle to counter the barriers, there has to be societal level changes as well as individual level strategies to overcome the challenges and hassles. This is supported by Carrie Sandahl (2017), enhancing the scope for participation of disabled people is by targeting both personal agency and social structures. By mobilizing personal agency of the individual namely the coping strategies available, the social structures, advocacy groups and self-help groups we can map out an innovative ways to normalize the lives of person with disabilities.

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Training on coping strategies

Coping strategies are strategies that people use in stressful and challenging situations to manage their own stress and anxiety (such as positive self-talk). As per the conceptual analysis of stress by Lazarus and Folkman (1984), principle of coping works on two cognitive appraisals:

- a. Perception of a threatening scenario and
- b. Person's available resources to deal with it.

Lazarus and Folkman (1984), refer to coping as “cognitive and behavioural efforts to master, reduce, or tolerate the internal and/or external demands that are created by the stressful transaction”. They propose two major forms of coping strategies: problem-focused and emotion-focused strategies. The first one aims at looking for and delivering resources to solve or constrain stressful problems while the latter deals with the ways of alleviating the emotional strain caused by the stress irrespective of the situation (Lazarus & Folkman, 1984). In an educational setting, coping strategies refer to the way in which learners predict, prepare, perceive, manage, react and alter their behaviour when stressed. This stress is often caused by failure, the threat of failure or the belief that failure is inevitable. The reactions to these threats are both conscious and sub-conscious; we cannot fully control our behaviour in every respect. Learning is more difficult when students lack the necessary strategies to manage stress and anxiety. As teachers want to make learning as easy as possible, it is logical that coping strategies should be explicitly taught. For a person with disability in an educational setup in order to face the daily stressors, one can apply both the problem- and emotion-focused strategies in stressful situations depending on the way they appraise the situation as given by Lazarus (1999).

In another study on the coping strategies of persons with disability **Bruno Trezzini, Sabrina Schüpbach, Victoria Schuller and Jerome Bickenbach** (2022), broadly assigned to three general types namely,

1) Adapting: Adapting to or living with the barrier or obstacle:

- i. accepting,
- ii. complying and
- iii. enduring.

These strategies usually do not involve direct attempts to remove the barriers, but rather result in the individual adapting to the circumstances.

2) Avoiding: This mode of coping involves strategies aimed at avoiding a barrier so that it no longer plays a role in the life of the person concerned. This can mean, for example, to leave a disabling work situation behind by quitting or to pursue one's original goal via alternative paths. In doing so, the affected person often requires personal determination and the ability to mobilize support.

3) Confronting: This coping mode refers to an individual's more or less active and directed attempt to confront and challenge an encountered barrier. An individual may aptly use a combination of these coping strategies at varying degrees to cope with their perceived stress according to his/her situation, individual capacities and the stressor.

Given the cumulative current scenarios, which influence the education of the person with disabilities. An education system which gives focus on training effective coping strategies is the call of the hour. Experts and researchers in the field could explore more on this dimension to enhance the quality of life of the individuals as well as their care givers so that they grow out to be self-reliant individuals.

CONCLUSION

Every individual is born special with one's own physical and mental endowments. A remarkable population of which are born with special needs. As they grow up in the community social and educational skills are imparted with varying capacities. Many of them are faced with the innumerable challenges, stressors and limitations. Because of these reasons, their perceived stress may be high owing to the lack of resources and support system. High level of perceived stress sabotage their capacities to function in the optimal capacity where they can lead a pleasant and fulfilling life. Hence, an all-round education system not just in academic or professional skills for livelihood but training on personalized copying style to face life challenges and reduction of their perceived stress would be an effective mechanism to instil their self-worth and self-esteem. This would inarguably make them able individuals who could make valuable contributions to our country and humanity as a whole.

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Conflict of Interest

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