

Models of Disability and Rights of Differently Abled Persons

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Abstract

The various models of disability impose differing responsibilities and demand more rights from the States. In the vast majority of children with disabilities, no genetic cause can be identified. Yet, blaming the parents when children are born with these conditions seldom leads to productive parent – professional interactions. Sometimes, tracing the cause of disability to some factor related to the parents may prove helpful towards diagnosis and prevention of similar cases in future. Parent's reaction to the birth of a child with disabilities varies widely. While somewhat speculative, some emotional stages of parents are usually identified. They are (a) feelings of shock and disbelief, (b) denial, (c) anger and guilt or depression and (d) a shift from self-absorption to concentrating on now to deal with the child's needs. Whether all parents experience all these stages is still controversial, as is the exact sequence of stages. With the above in view parents of the differently abilities take on multiple roles, which are not separate and distinct from one another, nor do they fall into distinct chronological periods. Rather, they often overlap and share common elements. This requires more awareness of models of disability and the rights of differently able persons.

Models of Disability

The four major identifiable formulations of disability are: the charity model, the bio-centric model, the functional model, and the human rights model.

The Charity Model: The charity approach gave birth to a model of custodial care, causing extreme isolation and the marginalisation of people with disabilities. Unfortunately, in some contemporary practices the reflection of this model can still be traced. For instance, the findings of an investigative project undertaken by the National Human Rights Commission of India between 1997–99 confirmed that a large number of mental health institutions today are still being managed and administered on the custodial model of care—characterised by prison-like structures with high walls, watchtowers, fenced wards, and locked cells. These institutions functioned like detention centres, where persons with mental illness were kept chained, resulting in tragedies like the one at “Erwadi” in Tamil Nadu, in which more than 27 inmates of such a centre lost their lives.

The Bio-centric Model: The contemporary bio-centric model of disability regards disability as a medical or genetic condition. The implication remains that differently able persons and their families should strive for normalisation, through medical cures and miracles. Although, biology is no longer the only lens through which disability is viewed in law and policy, it continues to play a prominent role in determining programme eligibility, entitlement to benefits, and it also influences access to rights and full social participation (Mohit, 2003). Analysis of the charity and bio-centric models suggests that they have grown out of the “vested interests” of professionals to keep the differently able not educable or declare them mentally retarded (MR) children and keep them out of the mainstream school system.

The Functional Model: In the functional model, entitlement to rights is differentiated according to judgments of individual incapacity and the extent to which a person is perceived as being independent to exercise his/her rights. For example, a child’s right to education is dependent on whether or not the child can access the school and participate in the classroom, rather than the obligation being on the school system becoming accessible to children with disabilities.

The Human Rights Model: The human rights model positions disability as an important dimension of human culture, and it affirms that all human beings are born with certain inalienable rights. The relevant concepts in this model are:

Diversity: The Greek philosopher, Aristotle, once said that “things that are alike should be treated alike, whereas things that are unlike should be treated unlike in proportion to their unalikehood.” The principle of respect for difference and acceptance of disability as part of human diversity and humanity is important, as disability is a universal feature of the human condition.

Breaking down Barriers: Policies that are ideologically based on the human rights model start by identifying barriers that restrict differently able persons’ participation in society. This has shifted the focus in the way environments are arranged for the accessibility of schools in terms of both physical access (i.e., ramps, etc.) and pedagogical strategies.

Equality and Non-Discrimination: In international human rights law, equality is founded upon two complementary principles: non-discrimination and reasonable differentiation. Differences of treatment between individuals are not discriminatory if they are based on “reasonable and objective justification”. Moreover, equality not only implies preventing discrimination, but goes far beyond, in remedying discrimination.

Reasonable Accommodation: A reasonable accommodation is a means by which conditions for equal participation can be achieved. It has been defined as the ‘introduction of necessary and appropriate measures to enable a person with a disability fully to enjoy fundamental rights and

freedoms and to have access without prejudice to all structures, processes, public services, goods, information, and other systems.’

Accessibility: The United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) has defined “accessibility” as “the measure or condition of things and services that can readily be reached or used (at the physical, visual, auditory and/or cognitive levels) by people including those with disabilities.” (Rioux and Mohit, 2005)

Equal Participation and Inclusion: It requires that people with disabilities, and other individuals and institutions fundamental to society, are enabled to gain the capacity for the free interaction and participation vital to an inclusive society.

The human rights approach to disability on the one hand requires that the States play an active role in enhancing the level of access to public freedoms, and on the other requires that the enjoyment of rights by persons with disabilities is not hampered by third-party actors in the private sphere. Educational institutions and industry, both in the public and private sectors, should ensure equitable treatment to persons with disabilities.

Role of Parents and Professionals in Disability Management

In a family when a child is differently able, its responsibilities become more crucial. Every ordinary task becomes more difficult and more stressful. There is the expense, the time, the energy needed to care for the differently able member and his safety. Besides this there is the difficulty of helping the differently able member to develop a good self-image and social skills and the arrangements of an appropriate education.

Parents as Implementers of Professional Advice: If a child does not make satisfactory progress in the special education program, it is often assumed that the parents are not assuming their responsibility for implementing the program at home. The recent age therapists and educators have accepted the potential of parents. Parents are now active partners in not only implementing of professional advice but also plan out and carry out the same at home.

Parents as Service Providers: Parents' groups can serve as a mechanism through which parents give each other mutual support and share information. Parents' initiated and supported efforts often at great personal expense has won the legal right to free and public education in the least restrictive environment, better conditions in residential facilities and integrated vocational, residential and recreational services in the community, provisions for better financial security.

Parents as Teachers: Parents can play the role of a teachers and members of the multidisciplinary team. Parents can be provided training to make them more resourceful and for better involvement as an educator for differently abled.

Parents as Political Advocates: The development of parents' organisations evolved from small, local support groups of parents to national professional organisations. They perform the

functions of providing direct services to advocating for political, legal, economic and social change.

Parents as Family Members: Parents are becoming more aware of the necessity to consider the needs and roles played by all members of the family with a child with disabilities for developing and implementing programs for the differently able member. Family members have much to offer them from their day-to-day experiences living with the member with disability.

Role of the Family: The family constitutes the parents but also the siblings, grandparents, uncles and aunts and other extended family. Hence, the major responsibilities of families can be the economic responsibilities to generate income and provide financial support for living costs and related payments. Family must take care of the domestic and health care responsibility for meeting the daily needs of food, clothes, health and medical care and safety. The recreational responsibility for providing leisure environment and activities must be entertained. The responsibility for self-identity to increase each family member's sense of belonging must be fulfilled. The affectionate responsibility to show and share love, care, emotional feelings and companionship should be addressed. The responsibility for socialisation to develop social skills and enhance interpersonal relationships must be taken care of. The educational and vocational responsibility to assist and support schooling and career & selection and preparation must be fulfilled.

Duties of Professionals: The role of professionals in identification, referral, planning educational programmes, participation in rehabilitation and supporting the cause of disable and disability. There are a number of professionals like teachers, school doctor/nurse, school counsellor, special educator and disability specialist that are involved in disability management. For protecting the rights of needy ones the professionals must follow following principals of early intervention , compliance with legislation and regulations, effective coordination of all resources and stakeholders, providing meaningful and goal-oriented modified work, respect and dignity of the differently able and parents, adherence to ethical practices, a focus on wellness and prevention, effective communication systems, on-going evaluation and revision as necessary, transparent and accountable planning and actions, avoiding overlapping of roles with other professionals and parents

Role of Classroom Teacher: A classroom teacher should help in accommodating modifications needed for inclusion of a differently able child. He must lead in participating in rehabilitation as role assigned by the special educator and disability specialist. He should help in identification and screening process for a disability for providing referral service. He must keep in close contact with parents of other students and other professionals for sensitizing other students towards disability.

Conclusions

Along with above responsibilities the teacher in special school setting should design IEP for differently abled by working in close coordination with other related professionals. He must explore alternative media for learning and monitoring process of rehabilitation. Doctors/nurses should carry out regular check-ups and screening procedure for disability. They should actively participate in rehabilitation program chalked out by disability specialist and special educator. The school counsellor must organise psychological testing and actively participate in rehabilitation program chalked out by disability specialist and special educator. He must provide emotional support often needed by a differently able for adjustment, career options and crisis situations.

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