



RESEARCH ARTICLE

EMPOWERMENT OF GIRLS AND WOMEN WITH ASD

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ABSTRACT

In the 1980's Autism Spectrum Disorders (ASD) was virtually unheard of in India. A diagnosis of ASD in India was rare, and there was little information available. The majority of children with ASD routinely received a diagnosis of mental retardation. Others were diagnosed as having 'Minimal Brain Dysfunction', were called slow learners or deemed to have behaviour problems. The prevalence rate of ASD is approximately 1 in 500 or 0.20% or more than 2,160,000 people in India. The incidence rate of ASD is approximately 1 in 90,666 or 11,914 people in India. If attending school at all, children with ASD mostly were found in facilities for the mentally retarded, where the same intervention techniques were provided to all children. Generally women are subjected to social, cultural and economic disadvantages, making it more difficult for them to take part in community life. They also experience inequality in hiring, promotion rates and pay for equal work, access to training and retraining, credit and other productive resources, and rarely participate in economic decision making. Girls and Women with ASD face significantly more difficulties in both public and private spheres in attaining access to adequate housing, health, education, vocational training and employment, and are more likely to be institutionalized. Women and girls with disabilities experience double discrimination, which places them at higher risk of gender-based violence, sexual abuse, neglect, maltreatment and exploitation. The World Bank reports that every minute more than 30 women are seriously injured or disabled during labour and that those 15-50 million women generally go unnoticed. Nowadays, both educational and workplace environments become increasingly competitive, autistic children specifically, prevalence rates for sexual abuse are estimated to be 16.6% and 18.5% of children with ASD have been physically abused. Promoting gender equality and empowerment of girls and women are essential to the achievement of the internationally agreed development goals. In India, appropriate legislation and services for people with disabilities are few. This paper explains what are the provisions, legislation and schemes available for empowerment of the girls and women with ASD.

INTRODUCTION

The word 'Autism' was first used by Bleuler, a Swiss psychiatrist in 1911 to refer to schizophrenia. Over the next few years, Kanner (1943) would see ten other children who were similarly self-absorbed and who had severe social, communication, and behavioural problems. In 1943, Kanner published a paper applying the term 'early infantile autism' to this group of children. Children with the symptoms originally described by Kanner are now the minority of those diagnosed with autism, while Kanner published his paper in 1943, Hans Asperger in Austria independently published a study on autism in 1944. In the late 1970s, there were a few centres in India that were diagnosing children with ASD (Daley, 2004). From the late 1980s through today, autism in India has experienced an intense period of activity relative to the previous decades. Psychologists, physicians, educators and parents remain largely uneducated and uninformed regarding high functioning autism and Asperger's Syndrome,

particularly in girls and women, and the person is often misdiagnosed (Fattig, 2007). Traditional frameworks may indicate that the female with Asperger's Syndrome is just shy, quiet, perfect at school so her parents must be exaggerating, tomboyish, moody, overly competitive, aloof, Gothic, depressed, anxious, or a perfectionist. Autistic women learn to appear "normal" by copying others and by minimizing their behaviours or they hide and socially isolate whenever they can, many autistic children are perfectly normal in appearance, but spend their time engaged in puzzling and disturbing behaviours that are markedly different from those of typically developing children they may show little or no interest in people including their parents, and pursue repetitive activities with no apparent purpose. They have often been described as living "in a world of their own". Some, but not all people with ASD are non-verbal. Some autistic individuals may be remarkably gifted in certain areas, such as, music or mathematics, etc. (Sue, *et al.*, 2000). Women with ASD find ways to cope just as all women do. Many women with autism are poets, musicians and actresses. They are free thinkers and highly creative in their own way. More girls are now being diagnosed, but there are many of us that were missed purely and simply because ASD

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was not understood when we were children. That doesn't mean that we struggle any less. If a woman is lucky enough to get a diagnosis, there is very little post diagnosis support and this has to be changed. People with ASD typically struggle with executive functioning skills, such as organization and timeliness, in addition to social skills (Wing, 1996). Support programmes help to close that gap. The girls and women with disabilities are often at greater risk both within and outside the home, of violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation.

Problem faced by girls and women with ASD

Yet, as both educational and workplace environments become increasingly competitive, autistic children specifically, prevalence rates for sexual abuse are estimated to be 16.6%; 18.5% of children with autism have been physically abused; Children with ASD who are removed from their caregivers' homes are often not placed with families after they are removed; people with ASD were not thought to be 'conscious' enough to appreciate the effect of being abused; Children with learning disabilities who are being maltreated are also highly likely to run away from home (Bauman, 2010). Mothers who have ASD are also highly likely to lose custody of their children (Gray, 2002). Infuriatingly, children with ASD are over-represented in the juvenile justice system, as well, which causes them considerable distress and compounds their difficulty with adjustment and reintegration.

The other issues are given hereunder

- Abused by parents and other caregivers, ranging from psychological abuse to dangerous quack "cure" regimens
- Bullied by students and adult peers, Harassed by school officials and other bureaucrats
- Denied a fair and appropriate public education and disability accommodations in schools
- Denied appropriate employment opportunities and discriminated against on the job
- Denied treatment for non-autism-related medical conditions, Forced to live in nursing homes and other institutions because of lack of supports for living in the community
- Exploited in sheltered workshops at subminimum wages; Brutalized by law enforcement officers who misunderstand autistic behaviour
- Murdered by parents and caregivers
- Denied jobs and educational opportunities and Abused at institutions, as they are helpless.

Girls and Women with ASD need empowerment, not pity a policy for women have traditionally made disability is invisible, and disability policies have overlooked gender. But if they are woman or girl with disabilities, they face discrimination and barriers because they are female or disabled, or female and disabled. States need to empower women by raising their self-confidence, guaranteeing their participation, and increasing their power and authority to take decisions in all areas affecting their lives. Girls and women with disabilities need to be recognised as individuals who enjoy the same rights as others to make decisions about their lives (Attwood, 1998). The UN Convention on the Rights of Persons with Disabilities (CRPD), article 6 - Women with

disabilities requires that states parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms (Carter, 2014).

Its key recommendations are

- Ensure that women with disabilities can effectively and fully participate in political and public life and like this participate in decision making.
- Education policies and programmes with the aim to include disabled women and girls must be included in a post-2015 global development framework.
- Women with disabilities need to be included in the labour market. They need to have the same chances as their non disabled peers in order to avoid living in poverty.
- As disabled women have the right to relationships and motherhood, effective and appropriate measures have to be adopted to combat stereotypes, prejudices and harmful practices and to promote awareness of their capabilities and contributions to society.
- Health services and health related rehabilitation must be accessible for disabled women. Health services have to have the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.
- All women, girls and boys with disabilities have to be protected from violence, sexual violence and abuse. They need effective women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse are identified, investigated and, where appropriate, prosecuted

Its Key facts

It is important to protect the gender equality principle by combating prejudices, overcoming cultural, traditional, religious and other customs that aggravate gender inequalities, establishing norms with regard to the gender equality principle within or outside constitutional law, prohibiting discrimination on the grounds of a person's gender in both the public and private sector (Kyle, 2014).

Education

UNESCO and other international organizations estimate that globally speaking, disabled women's literacy rate is at 1%, while the overall literacy rate among disabled people is at 3%. Statistics show that fewer women with disabilities complete vocational trainings than men with disabilities.

Work and Employment

On a world-wide scale, women with disabilities are excluded from the paid labour market by 75%, and by up to 100% in developing countries, even though the majority of them perform household work such as cooking, washing and taking care of children and relatives.

Health

Disabled women from all age groups face difficulties when it comes to accessing health services. Women with disabilities

are exposed to a higher risk of being infected with HIV or other sexually transmitted diseases. This is partly due to the lack of sex education. The percentage of women and girls affected by depression is twice as high as the percentage among boys and men.

Violence and abuse

According to the United Nations, women and girls with disabilities suffer from sexual violence twice as often as girls and women without disabilities. According to the EU, women with disabilities' risk of experiencing sexual violence is as much as three times higher than the risk faced by women without disabilities. The danger is particularly high among girls and women who are living in institutions.

Government Schemes and Programmes

There are several government schemes and programmes that can be availed by a person with disability in India. The schemes and programmes that are also relevant to people with autism and their families are mentioned below. The government of India has enacted three legislation for person with disabilities viz. (Mahdi, *et al.*, 2014).

- Person with disability (ASD) (Equal opportunities, protection of rights and full participation) Act, 1915, which provides for Education, employment, creation of barrier free environment, social security, etc.
- National trust for the welfare of persons with ASD, cerebral palsy, mental retardation and multiple disability Act, 1999 has provision for legal guardianship of the four categories and creation of enabling environment for as much independent living possible.
- Rehabilitation Council of India Act, 1992 deals with the development of manpower for providing rehabilitation services (Escher, 2005).

National policy statement

The National policy recognizes that persons with ASD are a valuable human resource for the country and seeks to create an environment that provides them equal opportunities, protection of their rights and full participation in society. The focus of the policy shall be on the following

Prevention of Disabilities

Since disability, in a large number of cases, is preventable, there will be strong emphasis on prevention of ASD disabilities. Programme for the prevention of diseases, which result in disability and the creation of awareness regarding measures to be taken for prevention of disabilities during the period of pregnancy and thereafter will be intensified and their coverage expanded.

Rehabilitation Measures

Rehabilitation measures can be done by in the three ways they are i) Physical rehabilitation, which includes early detection and intervention, counselling and medical interventions and provision of aids & appliances. It will also include the development of rehabilitation professionals. ii) Educational rehabilitation including vocational education ,children with

disabilities in the age group of 15-18 years are provided free education under Integrated education for Disabled children scheme (ASD), Sarva Shiksha Abhiyan launched by the Government has the goal of eight years of elementary schooling for all children including children with disabilities in the age group of 6-14 years by 2010 and iii) Economic rehabilitation including employment in Government establishment, wages employment in private sector, self employment, priority in financial support will be given to self help group formed by the persons with disability.

The District Rehabilitation Center (DRC)

The district rehabilitation centre scheme was launched in early 1985 to provide comprehensive rehabilitation services to the rural disabled. This was done in collaboration with the national institute of disability and rehabilitation research (NIDRR), Washington, U.S.A.

The Regional Rehabilitation Training Center (RRTC)

Four regional rehabilitation centers have been functioning under the DRCs scheme in Mumbai, Chennai, Cuttack and Lucknow since 1985 for the training of village level functionaries, training of DRCs professionals, orientation and training of State Government officials, research on service delivery and low cost aids, etc.

Assistance through Overseas Development Administration, UK

Urban based community rehabilitation programs have been taken up in the cities of Calcutta, Bangalore and Visakhapatnam under the Overseas Development Administration of the United Kingdom (ODA). Training the UK under the Colombo plan: Every year, officers/NGO is sponsored to for undergo training in the UK under the Colombo plan. The officers are nominated from Central, State Governments, National Institutes and from non-governmental organizations that is actively engaged providing welfare services to the disability.

UNICEF assistance in collaboration with the government of India

The master plan operation (MPO). 1991-95 was launched in 1991, with the help or UNICEF, to prevent childhood disabilities in India.

The master plan of operation shortlisted the following components of programmes as major areas of activities

- Strengthening and integrating disability prevention and rehabilitation in existing government services at the community level.
- Support for communications, including audio-visual and print-media for advocacy, information and training.
- Support to research and planning, especially to studies which promote interventions that can be taken up by the community in rural areas and/ or in urban slums.

Implications

Every state should arrange Protection and Advocacy Agency to protect individuals with developmental disabilities from abuse

and neglect. State Protection and Advocacy Agencies should offer training, case management, and legal counsel to the girls and women with ASD. They should arrange some activities that include workshops, forums and publications on issues such as developments in human rights legislation, workplace, harassment, employment equity and education equity. For the empowerment of girls and women with ASD, more focussed programmes should be initiated by the government aimed at eliminating violence, including sexual abuse and exploitation, perpetrated against girls and women with ASD. Girls and Women with ASD can only be liberated, if they are economically independent, which require them to work outside the home. With regard to women with developmental disabilities' right to self employment it is noted that work has an added value to women natural role as a maker and considered it her most sacred and respectful duty. To that end girl and women with ASD should have the same opportunities as men and access to education should be availed at work places.

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