

National Advisory Council

Recommendations on the proposed Disability Rights Legislation

“ People with physical or mental disability are not only among the most deprived human beings in the world, they are also, frequently enough, the most neglected.”
- Amartya Sen

Estimates of persons with disabilities (PWDs) in India vary greatly depending on the source. The 2001 census found 21.91 million disabled persons (2.13 % of the population), but there are serious constraints of methodology, definition, invisibility and social stigma in census estimates. Using more inclusive definitions and methodologies, the World Bank (2007)¹ estimates that disabled persons are anywhere between 4 to 8% of India's population, or about 40-90 million persons. But direct spending by the government on the disability sector has been merely 0.05 to 0.07% of its budget.

Legal Rights of Persons with Disabilities

In India, currently the legal rights of persons with disabilities (PWDs) are protected by the Persons with Disabilities (Equal Opportunities) Act 1995 (PWD Act 1995). The Government of India appointed a Committee chaired by Dr Sudha Kaul to draft a new law, and this Committee has submitted a draft Rights of Persons with Disabilities Bill 2011 (RPDB), which is under consideration by the Government.

The National Advisory Council finds the draft Bill much more progressive than the current law, and in much greater consonance with the UNCRPD². It has attempted to engage with various views on the draft Bill, and to outline certain principles and suggestions to assist the process for a strong and consensual law for the rights of disabled persons to emerge. This note summarises some of the key issues which have been debated around the new draft Bill, and the recommendations of NAC with regard to each.

1. Single or multiple laws

There are multiple laws in India that provide and protect the rights of people with disability in India. These are the

- National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 (NTA 1999),
- National Mental Health Act, 1987 (NMHA 1987),
- Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 (PWD 1995)
- The Rehabilitation Council of India, Act 1992 (RCI 1992)

¹ People with Disabilities in India: From Commitment to Outcomes. May 2007.

² The United Nations Convention on the Rights of Persons with Disabilities was adopted in Dec 2006, and India was the first major country to endorse it in 2007

- Right of Children to Free and Compulsory Education Act, 2009 (RTE).

Some experts believe that all of these statutes should be merged to become part of one law. They suggest that the first four laws listed above should be converged to achieve one holistic law for the rights of persons with disability.

All these disability related laws in India are currently in the process of amendment. The processes of amendment for each of these however, are mostly working in relative isolation of the others. Separate Ministries too are involved in amending these bills and acts, for instance the Ministry of Social Justice, the Ministry of Health and the Ministry of Human Resource Development are involved in ensuring the rights of persons with disabilities. Hence there are legitimate concerns of duplication, possible overlap or inconsistencies while drafting of the various amendments of these laws.

The NAC recommends that all relevant laws concerning rights of persons with disabilities may be reviewed from the view point of avoiding inconsistencies and duplication; and amendments if necessary may be carried out in close coordination by various Ministries to ensure furtherance of rights of persons with disabilities.

All the concerned Ministries concur with this approach proposed by NAC.

2. Definitional issues: Medical and Social Models

The first issue that needs resolution in any law concerning the rights of Persons with Disabilities (PWDs) is how PWDs are defined. Contemporary debates centre round the question of whether disability should be defined in medical or social terms, or a combination of both.

Traditionally disability, both in law and government programs, has been defined mainly in terms of the medical impairment a person lives with. A 'medical model' looks at disability mainly in terms of the medical impairment a person lives with. However, a 'social model' recognises that it is not the medical impairment which disables a person; it is social, economic and cultural barriers which persons with disabilities face, which disable them.

All current laws define PWDs entirely on a medical model and the RPDB is the first draft which tries to break out of the medical model. The RPDB defines 'Persons with disabilities' as '*persons with any developmental, intellectual, mental, physical or sensory impairments including those mentioned in Schedule 1 of the Act, which are not of a temporary nature, and which in interaction with various barriers may hinder full and effective participation in society on an equal basis with others.*' The definition contains many welcome elements of a social model, but critics still believe that the definition is nonetheless in 'the medical model', because the Schedule 1 mentioned in the definition itself is entirely based on a medical understanding of disability, with no social elements.

The Ministry of Social Justice and Empowerment is of the view that whereas the definition of disability should follow the social model as enunciated in the UNCRPD, the Schedule based on the medical model should be retained in the definition, because benefits like reservations should be based on clearly verifiable medical impairment. The NAC does not agree, because

this would be contradictory. If the definition of disability is socio-medical, it is inconsistent for the Schedule to be exclusively medical. The Government of India will need to develop a socio-medical model for measuring both medical and social disabilities faced by a person, and not just the medical impairment. There is considerable international experience about how such scales can be developed.

Therefore the NAC recommends that the definition of disability should shift even more clearly to a social model as mandated by the UNCRPD, by suitably modifying Schedule 1 in the Bill to develop appropriate socio-medical scales and systems for evaluation for defining and measuring disability.

The definition of PWDs needs to also take into account concerns voiced by the Ministry of Health and Family Welfare, and mental health activists. Many persons with mental illness have fluctuating disability. Mental illnesses are of different forms and types, some of them are subject to relapses, where the person may recover and then have another episode of illness. The RPDB draft rules out disability which is temporary, but does not recognise that psychiatric disability can be episodic. The definition also does not make a distinction between illness and disability. Some persons may have mental illness but may not be disabled; or may not regard themselves to be disabled.

The NAC therefore further recommends that the Bill needs to take into account that psychiatric disability can be episodic. It should also clearly distinguish between psychiatric disability and psychiatric illness.

3. Legal Capacity of the disabled

One of the most contested debates around a law concerning the rights of PWDs pertains to the question of legal capacity of PWDs. The issue of legal capacity centres round the question of whether persons with disabilities, especially intellectual, psycho-social and persons with multiple disabilities, are able to responsibly think for themselves and whether they should be legally empowered to take decisions for themselves, or whether they should be 'protected' by guardians who decide on their behalf.

Legal capacity has two components, namely: a) that one is recognized as a person before the law, and b) that one is presumed to have the ability and the maturity to comprehend the nature and possible consequences of a given action.

Many laws and even some clauses in the Constitution do not recognise the full legal capacity of PWDs. The NAC recommends that the Law Ministry should review all statutes in order to include an acknowledgment of full legal capacity as provided for in RPDB.

In India, for some categories of persons with disabilities, equal rights to own and inherit property exist, but not the right to decide what to do with this property. Many parent groups believe that some kind of appropriately safeguarded form of substituted decision-making like guardianship is necessary to protect these categories of persons with disabilities from exploitation, abuse and neglect. On the other hand, many persons with disabilities groups oppose any form of substituted decision-making, because they fear that it can oppose or distort a person's will, foster lack of responsibility and growth, and even be exploitative.

RPDB attempts a middle path in this debate. It recognises the legal capacity of all persons with disabilities on an equal basis with others. It ends systems of 'plenary guardianship', whereby subsequent to a finding of 'incapacity' in a PWD, the guardian substitutes for the person with disability as the person before the law and takes all legally binding decisions for him or her. (Under plenary guardianship, the decisions of the person with disability have no binding force in law during the subsistence of the guardianship. The guardian is under no legal obligation to consult with the person with disability or determine his or her will or preference whilst taking decisions for him or her.)

But RPDB does not rule out all forms of guardianship or substituted decision-making. It stipulates that those persons with disabilities who may require support to exercise their legal capacity will be provided such support, through provisions for 'limited guardianship'. ('Limited guardianship' is 'a system of joint decision making which operates on mutual understanding and trust between the guardian and the person with disabilities'. It provides that all limited guardians shall act in close consultation with the person with disabilities to arrive at legally binding decisions).

Critics, however, fear that retaining even 'limited' guardianship without adequate checks and balances can result in practice in legal capacity being denied. Guardianship fosters a lack of responsibility and growth. RPDB also does not address the issue of lack of agreement between the guardian and the person with disability in a joint decision making process, ignoring also the vast difference in power between them. In a joint decision making process, both parties have equal rights to either agree or disagree, but the procedure when the two cannot agree has not been specified in the Bill. The NAC believes that these issues need to be resolved, and greater protections need to be built into the law to protect the PWD whose guardian is making decisions on her behalf.

The NAC endorses the principle which recognizes the need of supported decision making in certain cases. However it is convinced that there is a need to introduce further appropriate safeguards in RPDB, as specified by the UNCRPD for exercise of supported decision making, to protect the interests of persons with disabilities. The NAC suggests that where local networks of disabled persons exist, they should be given a much greater role in ensuring that the supported decision reflects the true aspirations and best interests of the PWD. There is also a need to have a stronger mandatory review system of these supported decisions, to ensure in such cases there is no conflict of interest, exploitation, , and that the will and best interests of the PWD were indeed secured to the extent feasible.

The Ministry of Social Justice and Empowerment and Ministry of Health and Family Welfare both concur with NAC's recommendations around legal capacity.

4. Special versus Integrated Education:

Opinions vary whether disabled children should be educated in 'special' schools or in ordinary schools. There are some who believe that children with sensory disabilities would benefit from education in separate settings which are specifically geared to meet specific needs, in a supportive environment. Others believe that education is the key to the promotion of positive attitudes to persons with disabilities. Segregating children with disability perpetuates stereotyping and lack of understanding of difference leading to discrimination in all areas of life.

RPDB does not take a position on the debate exclusively on the side of special or integrated schools. It mandates neighbourhood schools to provide education to children with disabilities, but also includes schools that are exclusively or predominantly catering to children with disabilities.

The NAC concurs with the approach laid in the RPDB insofar that it is appropriate to allow choice to children and guardians about which kind of school they would like to access – inclusive or special. The NAC further recommends that the RTE should sufficiently safeguard the interests and rights of children with disabilities, and be in conformity with RPDB.

Parliament recently approved an amendment to the RTE, in which children with disabilities are included within the meaning of 'child belonging to disadvantaged group'. This corrects the first great anomaly of RTE relating to children with disabilities, establishing effectively that they have the same right to education as all other children.

In operational terms, however, a great deal still needs to be clarified in RTE. The RTE provides all children right to education, including disabled children, in a neighbourhood school. This is reiterated also in the response of the Ministry of Human Resource Development (MHRD). In operational terms, this would imply that every neighbourhood schools would be required to be inclusive. If this is the case, then the RTE norms for schools contained in the Schedule of the Act needs to be revised to indicate the mandatory requirements that schools should adhere to, in order to ensure that they are accessible and educationally appropriate for all forms of disabled children. This would include but needs to go well beyond having ramps: the full meaning of school inclusion for *all* forms of disability would have to be specified in the same Schedule. If all schools are inclusive, this would also imply that all schools would require teachers trained with basic skills of special teachers.

The MHRD in its response implies that all schools indeed may not be inclusive, by stating that if a neighbourhood school cannot admit a disabled child, then safe transport will be provided. But this needs to be clearly built into the language of the law, its Rules and Schedule, if the disabled child is to have a legally enforceable right to education. If it is not feasible to make every neighbourhood school inclusive, then the Act needs to clearly define what would be the maximum distance norms for a disabled child to access an inclusive school.

At the same time, since the choice of special schools is also guaranteed in RPDB, RTE needs to indicate norms for special schools, and at which level special schools will be available. For

instance, there can be a distance norm, or that every district will have special schools, as well as numbers per population in cities and towns. The RTE will need to indicate the qualifications of teachers in special schools, and the system of certification.

The NAC recommends that the Ministry of HRD should amend RTE suitably to ensure that the right to education to all children with disabilities is safeguarded and the choice to such children to study in an inclusive school or special school is real. It would need to clarify in the law whether the right to education of every child with disabilities would be in every neighbourhood school, or in neighbourhood schools within a specified distance norm. It will also need to indicate the minimum norms of teachers' training, infrastructure and equipment in inclusive as well as special schools.

5. Poverty and Exclusion:

The NAC concurs with the need for RPDB to further recognize poverty and social exclusion as crucial factors affecting the rights of children and persons with disabilities and the nuances of how disability as a social vector of exclusion intersects with other traditionally socially excluded groups such as the dalits, adivasis, and the Muslims to create complex matrix of vulnerability in the Indian context.

Further the NAC also feels given that there is high level of malnutrition in the country, the draft Bill should link the rights of the disabled explicitly to existing programmes and entitlements for ensuring food and livelihood security in India.

The RPDB prescribes that: 'The appropriate government shall formulate schemes to provide for social security benefits, aids and appliances, medicine and diagnostic, corrective surgery without cost to persons with disabilities belonging to economically weaker sections of society'; and this is welcome.

At the same time it must also recognise and have protections and support for families with disabled members. Also for many disabled persons, the inability to work is not a direct result of their disability, but rather due to societal discrimination and other barriers which restrict their access to employment.

The NAC recommends that families with disabled members should be given higher weightage during identification of poor households and surveys for BPL and food insecure households. RPDB should guarantee preferential access to households with PWDs to all poverty alleviation and social security programmes, including social security allowance.

From an equity lens, destitute disabled women and men, single women who are disabled, poor persons who are disabled, homeless disabled, and the aged disabled women need specific social protection over and above any blanket social security given to all the disabled.

RPDB should contain stringent anti-discrimination provisions to lower barriers to their productive employment, thus enabling greater participation of PWD in the workforce. RPDB should also mandate support to families with persons with disabilities themselves in engaging in or accessing gainful employment, including financial and tax benefits to private employers of

PWDs, subsidies and finance incentives for starting small scale income generation activities by PWD households.

The Ministry of Social Justice and Empowerment concurs with the recommendations of the NAC.

6. Institutions for Enforcement

RPDB, as well as other amendment laws concerning rights of PWDs would create a wide range of overlapping institutions at national, state and district levels. A brief listing of the institutions under various statutes is given below:

- i. The existing PWD Act 1995 created a Chief Commissioner of Disabilities at the national levels, and state level Commissioners.
- ii. RPDB provide for a 'National Disability Rights Authority' (NDRA) and 'State Disability Rights Authorities' (SDRA), with policy advice, review, recommendatory and grievance redressal functions.
- iii. RPDB also provides for a National Disability Rights Tribunal (NDRT), State Disability Rights Tribunals (SDRT) and District Disability Rights Tribunals (DDRT) for grievance redressal, with powers to issue binding directions to realize the rights guaranteed under the law.
- iv. The National Trust Act amendments provide for a Board of Trustees of the National Trust, which would also appoint a Technical Advisory Committee for advocating and planning inclusion and support for persons with disabilities, and a National Support Mission vested with the responsibility of formulating plans. It also sets up State Level Committees responsible for monitoring of the implementation of programmes and schemes for persons with disabilities; and Local Level Committees.
- v. The RCI Bill 2000 provides for a Rehabilitation Council with powers of certification, and supported by a number of inspectors.
- vi. The Mental Health Care Bill 2011 prescribes the establishment of a Mental Health Review Commission, which in turn is empowered to appoint and function through State Panels. These will ensure protection of the rights of persons living with mental illness, including issues of involuntary admission, grievance redressal, advising government, and punishing mental health establishment violating the law with an exemplary fine or cancellation of registration of the mental health establishment.

The Ministry of Social Justice and Empowerment believes that there is a role for separate institutions concerned with disability rights: with separate institutional frameworks for advisory, ombudsperson and adjudicatory functions. However, the NAC believes that these functions can be effectively converged in a single institution, with these diverse functions clearly defined. This will save costs, and also have the merit of providing a single window of redress to persons with disabilities.

The NAC therefore proposes that this wide diversity of institutions concerned with rights of PWDs are converged and rationalised to the extent possible. This would save costs, prevent the

creation of a large bureaucracy, and above all provide a single window of contact at the central, state or district level for PWDs to access their rights and secure redressal of their grievances.

According to the NAC there should be a single National Disability Commission, and State Disability Commissions, on the lines of National Commissions for other socially disadvantaged groups, such as Women, Children, Minorities, SC and ST. Much thought would need to go into the composition of these bodies, ensuring due representation to PWDs across a wide range of social categories, PWD collectives, associations of parents and guardians of PWDs, human rights organisations and NGOs working with PWDs.

The law also needs to distinguish clearly between advisory, oversight and adjudicatory powers of these Commissions, including powers to impose penalties such as cancellation of registrations, imposing fines, and even proposing criminal action. The proposed National, State and District Disability Rights Authorities would need to be established under a separate dedicated statute, because it will have powers which cut across many statutes. The suggested institutional architecture will have to be devised in a manner that there is no overlap or duplication and the institutions proposed can effectively secure the rights of PWDs.

7. Penalties

RPDB provides for grave penalties in the event of violation of rights: ‘Whoever fails to comply or contravenes any of the provisions of this Act, or the rules made or orders or directions issued hereunder, shall, in respect of each such failure or contravention, be punishable with imprisonment for a term which may extend to six months or with a fine which may extend to fifty thousand rupees, or with both’. It also introduces the notion of command responsibility, by providing that if any establishment is deemed guilty, it is the head of that establishment who will be held guilty.

On the other hand, the specific crimes listed in the RPDB often overlap with provisions of IPC and other laws in ways that are unclear. For example, Clause 155 (‘Penalty for denial of food and fluids’) overlaps with the provisions of Section 299 of the IPC, which deal with culpable homicide. Hence these need to be reviewed to ensure that the draft Bill is not inconsistent with relevant laws.

The NAC finds the general penalty clause of RPDB too generic, and these make no distinction between civil consequences and criminal consequences arising out of the various possible violations of the provisions of the proposed bills. The penalties need to be more specific and cannot be for blanket violation of all entitlements under the bills. In cases of criminal consequences, the overlap with existing laws needs to be clarified.

The Ministry of Social Justice and Empowerment concurs with these recommendations of the NAC.