

The Challenges of Implementing Article 12 of the UNCRPD in India

Paper presented by **Ms Poonam Natarajan**
Chairperson, National Trust
For Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple
Disabilities
Ministry of Social Justice & Empowerment
Government of India



Poonam Natarajan*

First they ignore you,
Then they laugh at you
Then they fight you
And then you win.....

These words of Mahatama Gandhi resonate the experiences of people with disabilities whilst implementing Article 12, of UNCRPD in India. Even as the paradigm of legal capacity with support would require changes in several laws in India I am limiting my narration to the manner in which questions surrounding legal capacity are being addressed in the National Trust for persons with (Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities) Act of 1999.

I have two reasons for this limitation. One, as the Chairperson of the National Trust I best know this legislation and two, at this point in India all major proposals recognizing the legal capacity of persons with disabilities have been put forth in the draft amendments to the National Trust Act.

The National Trust Act (for persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities) (hereinafter NTA) was created in India as answer to the universal question 'what happens to my child when I am no more?' The anxiety and apprehensions in this question are based on the old and traditional belief of incapacity of people with all disabilities and to a larger extent of people with the above named disabilities. This belief was the dominant influence when the legislation was drafted which is shown by the fact that the Trust was established to strengthen facilities to provide support to person with disability to live within the family; to deal with problems of persons with disability who do not have family support and to promote measures for the care and protection of persons with disability in the event of death of their parent or guardian, In furtherance of these objects the statute approved programs for the launch of respite, foster family care and day care services; and to set up residential hostels and homes for persons with disabilities. In acceptance of the lack of capacity in persons with disabilities, the NTA also laid down the procedure for the appointment, monitoring, and removal of Legal Guardians through Local Level Committees which were quasi judicial bodies operating at the District Level.

To legally acknowledge the lack of capacity of persons with disabilities and to make alternative arrangements to deal with this exigency was the dominant but not the sole objective of the NTA. The objects of the Trust, as stated in the Act, were also to enable and empower persons with disabilities to live as independently and as fully as possible within and as close to the community. To further this object the Trust could pursue any program which promoted

* Chairperson National Trust for Persons with Disabilities, New Delhi India



resulted in development of self help groups of persons with disabilities to pursue the realization of their rights. Plenary guardianship was not put forth as the automatic and inevitable choice for all persons with disabilities, insofar as section 14 (3) of the NTA allowed a guardian to be appointed only if required, and to only perform those functions for which assistance was required by a person with disability.

The NTA empowered persons with disabilities insofar as it provided for the management of disability affairs by the electing and nominating members of the community both on the Board of the Trust and the Local Level Committees. This feature of the Act accorded a proactive role to civil society in the implementation of the Act. The statutory provision did not ensure that the voice of the person with disability would be heard; such a consequence primarily depended upon the awareness and skill of the Local Level Committee.

The above description shows that the NTA 1999 was an amalgam of paternalistic and self empowering motivations. These objectives have been accorded varied importance in the last 10 years of implementing the statute. The self empowering features of the statute started to acquire greater significance as the negotiations of the Disability Rights Convention started to gain momentum. These deliberations brought home the importance of creating opportunities, to build capability and to perceive guardianship as a flexible institution of support rather than as an all or nothing regime. This thinking became the driving force for the activities of the Trust. This thinking acquired sharper focus and these activities greater momentum as India ratified the UNCRPD, In what follows I put down the challenges faced by India to implement Article 12 and how the National Trust is responding to each of these challenges.

In taking forward Legal Capacity in India the main challenges are:-

1. Supporting Parents and families to examine their roles as advocates and decision makers for their children.
2. Raising Awareness and changing attitudes towards a rights-based understanding of disability.
3. Harmonizing the present National Trust Act and other laws to the UNCRPD.
4. Systematic changes in practice to ensure these Rights.

1. Parents, Families, Carers and Guardians:

In the earlier paradigm, persons with developmental disabilities especially intellectual disabilities and multiple disabilities were people who were only seen as needing care and protection. The understanding was that people with intellectual disabilities cannot learn or evolve and will therefore be



example, in law they can own property but in practice, decisions regarding property, were taken by other people in authority.

This understanding, led to Parents living with the identity of being parents of children with intellectual disabilities. They became the advocates and decision makers for them. People with disabilities are also regarded as a 'burden' and therefore, appointing a Legal Guardian beyond the biological parent, was a cause of concern.

In this scenario, the concept of 'Supported decision making' and support networks met with understandable resistance. In the Indian culture, important life decisions for even non-disabled children are made by parents, therefore, 'autonomy' and 'choices' for their children with disabilities is a difficult concept. Parents are concerned about unwise decisions and the incapacity of the person. There has been much debate and discussion and some anger and anguish.

The Federation of Parents Association in India, 'Parivaar' has however, taken on the challenge and they are now piloting Support Networks in different parts of the country. These are small projects but are making families and parents think of different dimensions. One of the main outcomes of this has been the emergence of 'self advocates' of people with Intellectual Disabilities; whereas earlier, all the advocacy in disabilities, was done by people with either physical or sensory disabilities. These freshly emerged 'self-advocates', though small in number have made a significant impact on the socio-legal discourse on legal capacity. The emergence of these self advocates is in itself a statement on capacity and the right of all persons with disabilities to Legal Capacity.

2. Raising Awareness and Changing Attitudes

The two main challenges here are that firstly, people with other disabilities, especially sensory and physical disabilities, do not understand or accept the capacity of people with developmental disabilities. Secondly, the mindset and level of awareness in the community, professionals and government functionaries at all levels is steeped in ignorance and stereotypes. This needs to be challenged and changed, even as it is acknowledged that the process of change would be slow and gradual.

I would like to enumerate some positive experiences of the last year, which point to the emergence of a rights based movement in India.

- In a Landmark Judgement of July 22nd, 2009 The Hindu a daily newspaper reports, "The Supreme Court on Tuesday allowed a mentally retarded rape victim to bear her child by refusing medical termination of her 19 week old pregnancy. The girl is staying in a home for the mentally challenged in Chandigarh. A Bench consisting of Chief Justice K.C. Balakrishnan, Justice P. Sathasivam and B.S. Chauhan, stayed an interim order of the Punjab and Haryana High



she had limited mental capacity to bear the child”.

The young woman has grown up as an orphan and though had been through a traumatic experience, said she would like to keep the child. A young and enthusiastic advocate took up her case in the Supreme Court and appealed against the High Court order. The National Trust also supported the appeal and right of the young woman to make a 'choice'. In this landmark judgement the highest court in the country, ensured that India lived up to the spirit and mandate of the UNCRPD.

The young woman has had a baby girl, and is a happy mother. The state is ensuring all the required support. This incident was widely covered by the press, there was a public outcry that such an order was harmful for a young woman with intellectual disabilities. However, the outcome and recent developments have made many decision makers and activists in the women's movement, think again about the rights and capacities of people with intellectual disabilities.

- A large rural NGO in India wrote to the National Trust about its concern of people with intellectual disabilities, specially adolescents and adults, being abandoned by their families at bus stops and railway stations.

This NGO works in a large district of South India; in their area they had identified at least 2300 persons with intellectual disabilities, who are at risk of being abandoned by their families. They wanted to find a solution. Discussions and meetings with families, grass root workers, disability consultants and National Trust led to some important learnings and drawing up of a road map. The NGO is now undertaking a survey and study to draw up a concrete plan of action.

What is important here is the move away from the easy route of institutionalization to working on an Action Plan that will create the opportunities for people with intellectual disabilities to train in skills leading to employment and participation in the community. In keeping with the mandate of UNCRPD, the action plan hopes to focus on capacity – in all ways and accepts the importance of Article 12.

I quote this example, because in the meeting, it was inspiring to see that discourse in the area of enabling people with intellectual disabilities is moving towards acceptance of legal capacity.

- Badhte Kadam (Steps moving forward) : A National Trust Campaign over 13 states in India in November, 2009 took the mandate of the UNCRPD to over 60 destinations and more than 20,000 people.

The campaign consisted of a cavalcade of eight vehicles, which were “flagged off” by the Hon’ble Minister for Social Justice and Empowerment. Two vehicles each, travelled in four pre-determined directions, carrying a team of advocates and materials for distribution.

The aim of the campaign was to:

- Provide information on the UNCRPD
- Provide understanding of NT-focused disabilities and
- Celebrate Diversity

The materials custom-made for the campaign included a mobile exhibition, and a bilingual booklet which demystified the UNCRPD, for distribution.

The most important impact was the presence of people with disabilities, who spoke about their experiences and the journey to getting an education, a job, marriage etc. Using “role models” as a strategy, helped many people with disabilities and their families to understand the possibilities and the rights.

3. Harmonising the National Trust Act with the UNCRPD

On the legislative reform front we were faced with the following key questions: Should the NTA continue to be a legislation for the four named disabilities alone or should it extend to all persons with disabilities? Should the NTA be reconstructed from a paternalism heavy legislation into rights dominant one by inducting the paradigm of universal legal capacity with support into the NTA? Can the provisions relating to substitution be replaced by support for all persons with disabilities? If yes then what kind of mechanisms would need to be put in place to ensure that such support is not abused? Also what kind of support needs to be put in place and how should the support mechanisms be activated?

The National Trust in its law reform efforts has been trying to obtain consensus on these critical questions.

This law reform process was initiated with a concept paper which suggested that both for promoting cross-disability solidarity and to recognize human interdependence the NTA should like the CRPD opt for an all inclusive definition of person with disability. This paper also made the link between legal capacity and capability development and asked for the recognition of the legal capacity of persons with disabilities in order to challenge the stereotype of inadequacy and incompetence.

In the civil society consultations, a number of parents organization expressed their opposition to the suggestions made by the paper; even as self advocates expressed their support for the new paradigm. In the main the consultations were contentious and conflict ridden and we could not reach any consensus on the nature of law reform required. The paper however introduced the concept of universal legal capacity with support in Indian socio-legal discourse.



line with the principles suggested by the paper was initiated, even as pilot projects to explore the establishment of support regimes were inaugurated. It was realized that a law which suggested both the induction of an inclusive definition of disability in the NTA and sought the induction of universal legal capacity with support would generate unbounded controversy. It was consequently decided that the question of an inclusive definition should be deferred and the law reform effort should concentrate on inducing the new paradigm of legal capacity in the NTA and the other questions arising from it.

Consequently, the first draft amendment to the NTA only recognized the legal capacity of the four designated disabilities and recognized that those persons with disabilities who required support to exercise legal capacity had a right to such support, and the accessing of support in no way negated legal capacity. The norms by which the support had to be provided were specified.

The duty of creating support regimes was placed proactively on Local Level Committees, which were to be personned along with other local level functionaries, by persons with disabilities. These support regimes were to be subjected to periodical audits by zonal technical resource teams, again consisting of persons with disabilities.

It was significant to note that in comparison with the concept paper this draft of the NTA obtained large support from parents' organizations and persons with disabilities already covered by the statute; even as the dissatisfactions of those not covered by the statute continued.

In the next stage of the reform process the second draft amendment to the NTA introduced an inclusive definition of persons with disabilities. Consequently the statute was now called "The National Trust for the Legal Capacity and Support of Persons with Disabilities Act. This draft enhanced the resources available with the Local Level committee. And whilst the need for safeguards was addressed; the law primarily concentrated on creating support regimes. In order to assist in standard setting and design making, it established a high powered technical committee, which would create appropriate models of support.

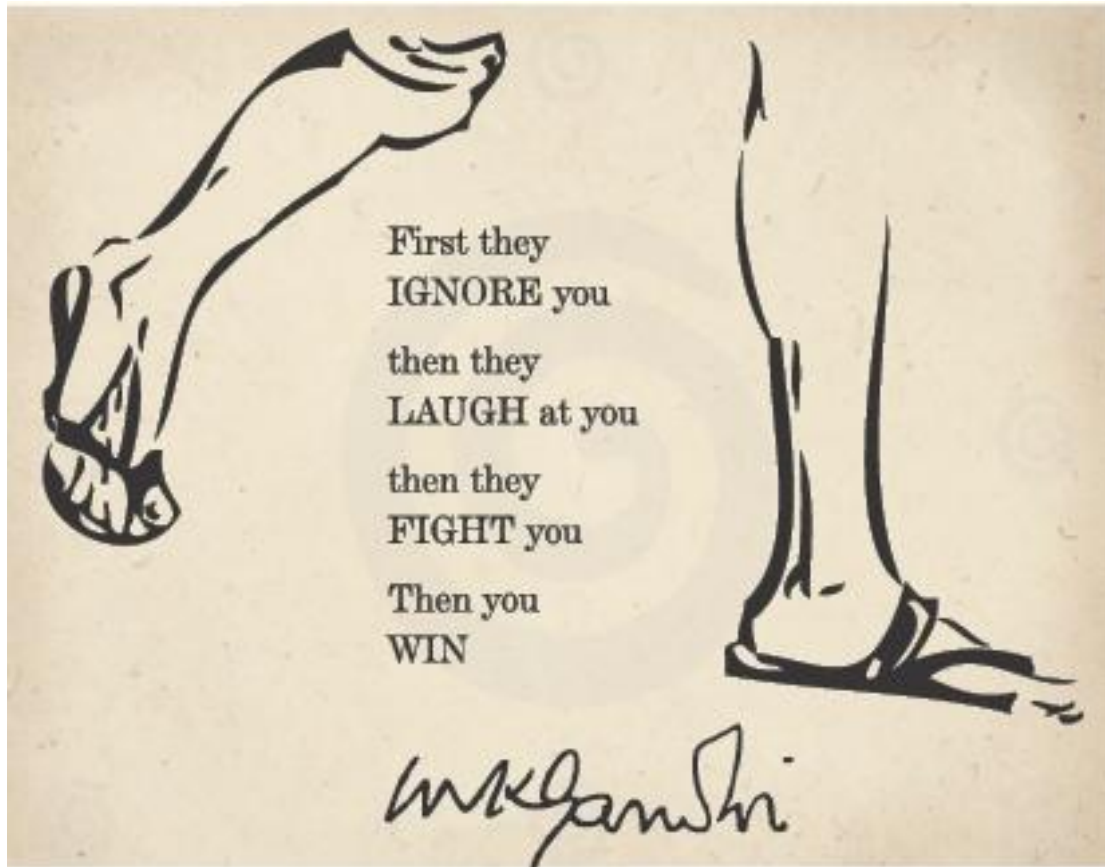
The new draft of the NTA has received wide ranging support and there is slow consensus emerging on the need to address legal capacity and support as a question of capability development and human interdependence. However the consensus is slow and uncertain. The anxieties surrounding abuse of support remain; and people are unwilling to totally dismantle guardianship. It is being suggested that NTA should repeal plenary guardianship but allow limited guardianship. Apprehensions on making the National Trust available to all persons with disabilities are also expressed. However despite these queries, what is significant to note is that from a time where deliberations were based on an unquestioned acceptance of the incapacity of persons with intellectual and developmental disabilities; discourse today is driven by a growing acceptance of legal capacity and support.



The mandate of article 12 cannot be only fulfilled by changing the law. It is also necessary to create the services to back the law and to build the capabilities of various personnel who will need to implement the new paradigm. The National Trust is now engaged in teaming up with the training academies in the country in order to undertake capacity building exercises. The Trust is also ready to launch pilot programs in order to understand what manner of skills and resources would be required by the various implementing bodies in order to render the paradigm of legal capacity with support functional in fact. It is with the learnings of these pilots that the rules, regulations and guidelines of the CRPD consonant NTA shall be made.

Conclusion

In conclusion, the National Trust has employed article 12 as site of struggle; a platform for reasoned deliberation. Just as the Trust requires that the NTA should be a rights informed legislation; it has used the process of law reform to raise awareness on the legal capacity and capabilities of persons with disabilities amongst governmental bodies, civil society and the disability community. Our strategy is to keep saying that which we think is right so that we can slowly persuade those who were ranged against us to join us.



Ms Poonam Natarajan
Chairperson, National Trust
(Ministry of Social Justice & Empowerment, Government of India)
16B Bada Bazar, Old Rajinder Nagar, New Delhi 110 060
Tel.: 011- 43187800; email: nationaltrust@nic.in;
Website: www.thenationaltrust.in