

## THE NATIONAL TRUST ACT, 1999: AN OVERVIEW

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The National Trust for Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act was enacted by the Parliament in December 1999. Earlier the Persons with Disabilities Act, 1995 came into force with effect from 1996. The Trust Act has a very progressive objective, namely, to enable persons with disability to live as independently and as fully as possible within and close to the community to which they belong. The idea is not to push people out of the society and keep them in residential institutions such as what has happened in West, but to encourage them to live within their family. They have the right to live within their family. But there are people with severe disabilities who may not be able to move. Thus, there could be a possibility of a therapist visiting home and providing rehabilitation services in the home. The main objective is to provide need-based services during the period of crisis in the family of a person with disability. Crisis comes very frequently particularly when we have nuclear families. Let us take a situation where husband gets an episode of mental illness, gets admitted into hospital and remain there for a period of three to four months. In such a situation who will look after him if the wife also works. Thus, there is a need for providing temporary respite to the family so that the person could go and live somewhere else, and once the family is reunited he can come back. In other words, there is a need to recognise diverse needs of the families to retain a person with disability within the family system.

The next issue is about the persons with disability who do not have family support. We do recognise that there could be occasions when such persons have grown up, they have one parent who dies, or both the parents die. In such a situation who will look after the child. In the joint family system the next side of the family may look after this person, but difficulty arises when the families are disintegrated and no family support is available. In this situation it becomes a responsibility of the state to provide the guardianship or look after the person with disability. Thus there is a need to have a provision to take care and protection of persons with disability in the event of the death of the parents or guardian. It is appropriate that they should have proper homes to themselves and they are looked after by the state in the above situation. As of today people with mental retardation either end up in Juvenile Homes, or they end up

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in mental hospitals, or they end up in jails. These are the places where they go and this is what the state does. None of the three places are appropriate where people with disability should go.

The next objective is to evolve procedures for appointment of guardians and trustees for persons with disability requiring such protection. This is again a progressive piece of objective where we do understand that parents in their own life time have an aspiration. If one dies, he could leave aside some property for his child and he could appoint somebody as a guardian. Now what happens is that in a family if the natural guardian, whosoever is the head of the family becomes the natural guardian, and he is supposed to look after the property which is inherited by person with mental retardation or persons with multiple disabilities and is unable to manage his or her own property. In that case parents may have a safeguard of appointing somebody as a guardian or appointing somebody as a trustee to look after the person with disability.

And the last objective is realisation of equal opportunities protection of rights and full participation of persons with disability. Section 11(2) provides that for the purposes of subsection (1) approved programmes means what could be the programmes which can be taken up under the National Trust Act, 1999. Today the rules have not been framed. They are still in the pipeline, and perhaps once the rules are notified then a greater shape for the implementation of the Act can be given.

The Act also provides for creating conducive environment in the community and also envisages counselling and training of family members of persons with disability. The idea is that the person should not be pushed out and persons should be able to live within the family. In other words, we are looking for family support services, or need based support services to the family. Now different families may have different kinds of needs. And ideally when we are talking about family support services, it could be in terms of information needs of the family or it could be financial needs. Financial needs are tremendous. For example, a family is unable to send a child to a school or special school because they do not find facilities for transportation from home to school.

It is envisaged that the National Trust could be able to fulfil this kind of a need of the family where transportation costs are met by the Trust. Similarly, another support to the family could be that if a person is unable to send his child for physiotherapy or occupational therapy outside the endotherapy centre, therapists are specially educated to come and visit the home and provide home based training programme to the child. This is what we call intra-net services and the family could be given support by the National Trust to purchase or seek itinerant services from teachers or therapists.

Another important aspect is training and counselling. Counselling and training to members is inevitable and necessary because family

members may not have appropriate perceptions about the capabilities of a person with disability. Sometimes family members overestimate the capabilities of a person with disability, sometimes they underestimate or sometime they think that the person is useless, he is a burden. In these cases, the person considers himself as not capable of living with the family. Hence, there is a need for extending support to the family in terms of counselling so that the persons with disability could have the right to live within the family. Another aspect of the programme is setting up of adult training units. Now adult training units are expected to come up because if they live within the family people who are adults would like to go and have some kind of remunerative employment and the remunerative employment concept is the key issue here. They need training to be productive and to be useful members of the society. The concept of individual and group forms started in the foreign countries at a time when they are dismantling the residential homes and placing people with disability in residential set ups. There, the county or the local municipal authority takes on rent a building where people with disability who can live independently. The criteria is that the person should be able to make a choice of what kind of clothes to wear, what to eat, what to cook, and also should be able to go to market and purchase a thing and also commute on his own without getting lost. These are some of the criteria where people can have group homes or individual homes in the community, they are supported partly by the municipal authorities or by the state government or the local self-government.

We now come to the programme of respite care, foster family care, and day-care services. Now respite care is necessary when parents go for work. And there are occasions when parents join together and leave the child in each others neighbourhood. The respite care sometimes may require some professionals to be appointed. In that case the salary of the professionals could be met by the national trust and similarly the foster family care is a concept that a family could adopt a person with disability and the national trust could give money like eight hundred rupees per month or nine hundred rupees for keeping a person with disability in that foster family. Besides the day care services for persons with disability, there could be respite care, there could be social places or socialisation, there may be place for training, there may be place for special education created by the Trust. So diverse kind of situations are envisaged where people with disability can purchase the service and the money could be spent by national trust. Quite apart from this, it also provides that family members could bequest the property to the trust in the understanding that the trust will look after the person with disability and also there are provisions for setting up local level committees which could assess the need for appointing guardian and supervise the functioning of the guardian, and also review the appointment of a guardian.