

**The National Trust
for Welfare of Persons with Autism,
Cerebral Palsy, Mental Retardation
and Multiple Disabilities
Act 1999**

(Training Module)

**(A TOT Project Supported by Aus AID)
Human Rights Law Network**

HRLN
Human Rights Law Network

TRAINING MODULE ON
(UNDERSTANDING
THE NATIONAL TRUST ACT FOR THE
WELFARE OF PERSONS WITH
AUTISM, CEREBRAL PALSY,
MENTAL RETARDATION AND
MULTIPLE DISABILITIES, 1999.)

Developed for
The Human Rights Law Network



By Radhika M Alkazi

HRLN Vision

- To protect fundamental human rights, increase access to basic resources for marginalized communities and eliminate discrimination.
- To create a justice delivery system that is accessible, accountable, transparent, efficient, affordable and works for the unprivileged.
- Raise the level of pro bono legal expertise for the poor to make the work uniformly competent as well as compassionate.
- Professionally train a new generation of public interest lawyers and paralegals who are comfortable in the world of law as well as in social movements, and who learn from the social movements to refine legal concepts and strategies.
- Work towards an increased awareness of rights as Universal and Indivisible, and their realization as an immediate goal.

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(During the training it would be important for every participant to have a copy of the law and the Rules and Regulations with them so that they may refer to them for easier understanding. The module does not follow the law sequentially and constantly refers to the rules and regulations, as they are an important part of understanding the law. The training module will also refer to the UN CRPD as well as to the Persons With disabilities (Equal Opportunities, Protection of Rights and Full Participation ACT Participants will also take part in certain activities.)

PART ONE : INTRODUCTION TO THE LAW

Laws reflect the thinking and understanding of a society at a particular time in history. Before 1995 there was no comprehensive law emphasizing /outlining the rights of persons with disabilities in our country. Some aspects of disability were covered under different laws.

For example, Physical disabilities that resulted from injury in the workplace were and still are covered under Acts such as the Workman's Compensation Act or the Employees State Insurance Act.

With regard to mental disability we had the Indian lunacy Act.

This law dealt with the Institutionalization of people with mental retardation and mental illness. It made no differentiation between the two conditions and treated them as one. It was repealed and in its stead came the Mental Health Act in 1987.

In an effort to separate the concerns of people with mental retardation and mental illness, the Mental Health Act is only for people with mental illness. It deals with the institutionalization and guardianship of persons with mental illness.

It deals with:

- 1) The setting up of Central and State level mental health authorities
- 2) Establishment of psychiatric hospitals and psychiatric nursing homes - how they are to be set up and standards for their maintenance
- 3) Admission and detention of mentally ill persons in psychiatric hospital or nursing home - including admission under special circumstances.

- 4) Appointment of Guardians and managers of property of persons who are mentally ill.
- 5) The law also calls for the protection of the human rights of persons with mental illness.

A reflection of our understanding of mental illness and what is to be done with them, the Mental Health Act does not deal with issues such as education, employment or any kind of affirmative action or social security for persons with mental illness.

The Asia Pacific Decade of Disabled Persons which was launched in 1993 - adopted the proclamation on Full Participation and Equality of Persons with Disability in the Asia Pacific Region. Many countries in the region framed laws that specifically supported the rights of persons with disabilities.

In India, much debate and discussion led to the framing of the first comprehensive law for the rights of persons with disability. The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 was the result of India's active participation and endorsement of international declarations on the human rights of persons with disability.

The Persons with Disability Act outlines the rights of disabled people. It also outlines the responsibilities and obligations, which are placed on the Government of India, State Government and other local government bodies for the realization of these rights.

This law, for the first time clarified who a person with disability is in the country. According to the PDA Act persons with disabilities are people with;

- 1) Blindness
- 2) Low vision
- 3) Leprosy-cured
- 4) Hearing impairment
- 5) Loco motor disability

- 6) Mental retardation
- 7) Mental illness

For the first time in India, people with mental illness were recognized as people with disabilities in our country and also as holders of the rights given under the law, not just as people requiring medical care and institutionalization.

THE NATIONAL TRUST FOR WELFARE OF PERSONS WITH AUTISM, CEREBRAL PALSY, MENTAL RETARDATION AND MULTIPLE DISABILITIES ACT 1999

Even though the PDA Act of 1995 was seen as a comprehensive law, there was a feeling among disability activists that it did not take into account the very special needs of a group of persons with disability; namely people with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. While people with mental retardation and cerebral palsy are part of the PDA, people within the Autism Spectrum and people with multiple disabilities are not included under this law.

It was felt that many members of these four groups of people needed extensive care taking and protection throughout their lives. This protection and support needed to be there in the law. Their parents were very worried about what would happen to their children once they were no longer there to look after them. They were also worried because people with mental retardation are not seen as having the same legal capacities as other people.

The National Trust Act came into as a result of strong advocacy from parents groups in the country.

This law envisages the setting up of a trust, which will be managed by a Board of trustees. This board will be the body that decides matters related to the implementation of the law.

THE AIMS AND OBJECTIVES OF THE TRUST

Activity

Discussion; 10 to 15 minutes.

Think of all the people with disabilities like Cerebral Palsy / Mental Retardation / Multiple Disabilities that you know. What does independent living in the community mean in the context of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities? What are the life situations that would facilitate independent living? What are the barriers that people with disabilities face and the worries of their families?

As members share, the trainer can put down some of the major points that come out. The trainer can discuss with the group about some of the most important enabling life conditions for people belonging to these four disability groups.

As the group talks the trainer can note points that are reflected in the objectives of the National Trust ACT.

The Aims and Objectives of the Trust

If we look at Chapter three, Objects of the trust, we find that the law aims at enabling people with disability in some important ways.

For persons with disabilities it aims;

- (a) To enable and empower persons with disability to live as independently and as fully as possible within and as close to the community to which they belong;
- (b) To strengthen facilities to provide support to persons with disability to live within their own families;
- (c) To extend support to registered organizations to provide need based services during the period of crisis in the family of persons with disability;
- (d) To deal with problems of persons with disability who do not have family support;
- (e) To promote measures for the care of protection of persons with disability in the event of death of their parent or guardian;

- (f) To evolve procedure for the appointment of guardians and trustees for persons with disability requiring such protection;
- (g) To facilitate the realization of equal opportunities, protection of rights and full participation of persons with disability; and
- (h) To do any other act which is incidental to the aforesaid objects.

Comment

There are two major thrusts in the objectives of the National Trust. One is to enable people to live independently within their families and communities and the other is to find measures for the care and protection of people in these four disability groups. The ideas of inclusion within the community are also equally important and reflected in the objects of the National trust when it emphasizes the importance of the person with disability living within their own community.

Article 19 UN CRPD

Article 19 of the UN Convention is titled 'Living Independently and Being Included in the Community'. This Convention that comes seven years after the National Trust Act echoes the some of the sentiments behind the objects of the National Trust. The focus on Independent living within the community and inclusion is clear in both the Convention as well as the National Trust Act.

"State Parties to this Convention recognize the equal right of all Persons With Disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by Persons With Disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons With Disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with other and are not obliged to live in a particular living arrangement;
- b) Persons With Disabilities have access to a range of in-home, residential and other community support servic-

- es, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to Persons with Disabilities and are responsive to their needs."

PART TWO : GUARDIANSHIP

The other major objects of the Trust focus on care and protection and evolving procedures for appointment of guardians and trustees for persons with disabilities requiring such protection.

What is Guardianship?

What are the kinds of Guardianship under the National Trust Act?

Why do we require the provision of Guardianship?

What is Guardianship

Activity

In this exercise people experience the different kinds of feelings we have when we have to take responsibility for another person or control them in any way. People also experience the different feelings when we are in the care of other people or controlled by others in any way. This has parallels in the situation of guardianship where one person has power over the other person to take decisions on his behalf.

The group divides into half. The trainer explains to the group that one half of the group (group A) will choose various spots in the room and stand with their eyes closed. The other half of the group (group B) each person chooses a person with eyes closed and from behind person indicates by touching then where they have to move. A tap on the left shoulder means turn right and move towards the right. A tap on the right of the shoulder means turn to you right and a tap in the middle of the back means move straight on. The exercise is done in total silence with the no one allowed to speak. Members of group B have to keep members of group A moving continuously and members of group A cannot stop and must try to keep moving at their normal pace of walking.

The activity should be continued for three to four minutes. The members of group A are asked to open their eyes and Describe their experience

What did they feel?

- For themselves
- About the people who were leading them

Why did they think that they felt this way?

Members of group B then
Described their experience

What did they feel?

- About themselves
- About the people they were leading

Why did they feel this way?

As participants share the trainer keeps putting key words on the board. The feelings and experiences of group A and B are written separately. The trainer then draws parallels between the feelings of group A and B and the experience of being the person with disability (group A) and the guardian (group B). The members of group A may come up with positive and negative feelings. These are real feelings that people feel in such situations. If they do not come up with positive feelings, the trainer can draw the attention of the group to feelings such as trust, not having to take responsibility, feeling cared for etc.

Why is Guardianship required?

Guardianship is an issue that needs to be discussed. There are many strong views on the need for guardianship. One of the reasons why we have to have guardianship for persons with mental disability in our country at this point is because of their situation under the law.

All of us need care and protection to some degree in our lives. However some persons with disabilities, particularly persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities have been seen to require extensive care taking and protection. This care taking and protection is sometimes so extensive that people with disabilities may require another per-

son to represent them and take decisions on their behalf.

Guardianship has been seen as an essential protective measure for members of the four disability groups. Guardianship refers to the legal control of one person over another. The person who is a guardian has the legal authority to take decisions on behalf of the other person and represent the other person in all matters. Guardianship is also often referred to as substituted decision making.

If we think of some major life situations that most of us go through; getting a job, getting married, opening and operating our bank accounts, handling and managing properties... we find that in all these situations we are entering into legal contracts. We will often get our marriage certificate or open a bank account without even questioning our own capability to do so. However, it is not the same for people with disabilities....particularly people with mental disabilities. People with mental disabilities are not seen to be competent to make rational judgements. They are often then not seen as being competent to enter into contracts.

In law, in general, there is a term 'of unsound mind'. You will find this term in many different laws in the country. This term is usually interpreted to include people who have mental illness as well as people with mental retardation.

When a person is seen as of unsound mind they are not seen as having the ability to be able to take decisions and enter into contract. For most of our life situations we have to enter into contracts of one kind or another. For example, we enter into legal contracts when we:

1. buy or sell property
2. take up a job
3. rent out a house
4. enter into marriage
5. open bank accounts and in many other of our dealings.

Legal contract are governed by The Contract Act of 1872 are extremely important to us since, for many important life situations we have to enter into contracts.

In this ACT A person of 'sound mind' is defined as: " A person is said to be of sound mind for the purpose of making a contract, if at the time when he makes it, he is capable of understanding it and forming a rational judgment as to the effect upon his interest."

Under the provisions of The Contract Act 1872 'a person of unsound mind' cannot enter into contract. Such a person may not be seen as capable of understanding the contract or making a rational judgment.

Although the condition of mental retardation is not specifically mentioned in the above definition, it is usually interpreted to include it. The person therefore is legally unable to enter into contracts.

The possible exclusion of the person with mental retardation from being able to enter into contracts means that there has to be someone else who actually looks after these matters for her/his for her/his whole life. A person with an average intelligence is automatically able to take these decisions once they turn 18 and become an adult! Again, a person with severe mental retardation may require help in dressing, undressing, eating, bathing activities. She/he would require someone to look after him/her for his/her personal needs. In other words, this person would require a guardian to look after legal and financial matters as well as personal needs.

This is one major legal reason why guardianship is required for people with mental disability. There are other reasons too. The most important of them has been the big question that families constantly face. What will happen after me?

Different kinds of Guardianship

There are also different kinds of guardianship. One of the most significant aspects of the National Trust Act is that the law recognizes that all people do not require guardianship.

Section 14 of the ACT does point out that guardianship should be given only if a person requires it. The law also recognizes that all people with disabilities will not require guardianship for all aspects of their lives.

Under The National Trust there are two kinds of guardianships. Section 15 of chapter VI of the Act outlines the duties of the guardian;

"Every person appointed as a guardian of a person with disability under this chapter shall, wherever required, either have the care of such person with disability and his property or be responsible for the maintenance of the person with disability."

This means that a person with disability may have a guardian for;

1. their care and property
2. their maintenance

For example, a person with Cerebral Palsy may need support for caring out activities such as bathing, eating, wearing clothes, going from one place to another etc. She may be able to take her own decisions regarding the sale or rent of her property, operating her own bank account etc.

On the other hand a person with mental disability may be seen as requiring someone to take charge of all aspects of their lives, from the daily needs, their education, to signing on a legal paper or entering into any form of contract.

Although the Act uses two different words i.e. 'care' and 'maintenance' they seem to have been used to mean the same thing. This is further clarified in the regulations of the Trust.

13(7) of the Regulations of the Trust tells us that the application for guardianship for personal care and maintenance shall be accepted to cover the following areas, namely,

- a. food, clothing and shelter needs
- b. health care needs,
- c. religious needs
- d. Education, training and employment needs.
- e. Leisure and nutrition needs
- f. Protection from exploitation and abuse.
- g. Protection of constitutional and human rights.
- h. Medical and surgical needs.

Rahul is 21 years old, a young man with all his life ahead of him and many dreams to fulfill. Sitting all day long in his wheelchair can be confining and Rahul has spent a lot of time trying to communicate with others. He is not able to speak and contractures in both hands (elbows and wrists) have bent them so that it makes it very difficult to write. When he does write it has to be with help. Someone has to support the wrists and help Rahul hold the pen. Then slowly the words start to flow. Not everyone can help Rahul write.

For this and because he is unable to speak; most people (sometimes even family members) find it difficult to believe that it is actually Rahul writing! They find it hard to believe that he has the kind of intelligence that his writing shows. He is able to move his hand from one part of a communication board to another but it takes time. He is able to nod his head with a clear 'Yes' and 'No'...when he wants to communicate.

Those who know Rahul understand that it may take him time to communicate and that at different times he will use different means of communications. Others often lose interest and politely wander off.

Rahul is going to need some one to be with him and help him to eat, dress, bathe and all other activities throughout his life.

As a person with Cerebral Palsy (Spastic Quadriplegic), he is unable to sit on his own or use his hands and legs.

When he was young, it was easy to carry him from one place to another.

Now at 21 he is a young man and the wheelchair does not reach many places. Rahul's family is well off. There is no shortage of money or gadgets. But what worries his parents is the every day. Who will bathe him, help him eat, change him, take him to the doctor if he needs one? Will he be alone all his life? How can they make sure that their son's life is happy and a satisfied one?

One answer seems to be the appointment of a guardian for Rahul.

Note : *The trainer can initiate a discussion on these questions.*

- Do you think that Rahul needs a guardian?
- What kind of a guardian would Rahul need?
- Who should decide and how should this guardian appointed? What does the group think?

The National Trust Act attempts to answer some of these questions.

PART THREE: HOW IS THE LAW IMPLEMENTED

The National Trust (as the name suggests) is a trust set up by the Government of India. The Trust is governed by a board of Trustees. This board takes all the major policy decisions for the implementation of the Act. The board of trustees is headed by a Chairperson.

Local Level Committees

The Local Level Committees are the arms and the legs of the Board. They have the vital function of granting guardianship and monitoring it. Before the National Trust Act this very important decision was taken by the courts. Parents had to approach the courts to get guardianship of their children after they had reached the age of 18. This process was often a long one and parents have shared that sometimes it took up to two years to get guardianship. With the National Trust Act, this decision has now shifted from the Judicial to the public domain.

Composition

Local Level Committees (Chapter VI)

All-important matters of guardianship are dealt by local level committees. The local level committees are constituted by the Board.

Local level committees consist of three members:

- (1) An officer of the civil service of the Union or the State, not below the rank of District magistrate or a District Commissioner of a district.
- (2) A representative of a registered organization
- (3) A person with disability as defined in clause (t) of section (2) of the (Persons with Disabilities Equal Opportunities, Protection of Rights and full Participation) Act 1995 (PDA)

According to clause (t) of section 2 of the PDA

"Person with disability" means a person suffering from not less than forty percent of any disability as certified by a medical authority"

The different conditions that are included are;

1. Blindness
2. Low vision
3. Leprosy cured
4. Hearing impaired
5. Loco motor disability
6. Mental retardation
7. Mental illness

(Each of these has been further defined in the PDA)

Note: *The trainer can ask participants here what they feel about the composition of the committee. Do they see it as significant in any way?*

The Working of the Committee

This committee, once constituted shall work for a period the three years. The Board will have the power to either reconstitute the committee after three years or to allow it to continue; working even after three years. According to the law the LLC must meet once in three months.

The work of the LLC is to:

- Receive applications for guardianship
- Process these applications
- Take decisions regarding appointment of guardian.
- Receive accounts of property and assets of persons with disability from the guardian.
- Receive applications regarding removal of guardian.
- Take decisions regarding removal of guardian.

Who can become a Guardian or ask for appointment of Guardian.

It is important to remember that guardian can only be appointed for a person with disability after s/he is eighteen years old. Before that, (as for all people) the parents are the natural guardians of the person.

The people who can take the initiative to have a guardian appointed or become guardians themselves for a person with disability are:

- 1) Parents
- 2) Relatives
- 3) Registered organizations

Sec 14 of chapter VI states that a parent or a relative of a person with disability can ask for a person of his choice to be appointed a guardian. It also mentions that the application of guardianship will only be entertained once the consent of the guardian is obtained.

A registered organization may also ask for the appointment of guardian for a person with disability. Organizations working with or for persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities are able to register themselves with the National Trust. They are then able to support the activities of the National Trust, be part of decision making in the trust and also run some of their schemes. These organizations may be associations of persons with disabilities, organizations for persons with disabilities and parent associations.

Comment

What is extremely important to note here is that, this provision brings the issue of guardianship into the public domain. It is normally assumed that guardianship and care taking are issues within the family situation. By giving registered organizations the responsibility for guardianship, the law puts an element of greater accountability on these organizations. It also makes very clear provisions for people with disabilities who may not have families.

According to section (11) The Trust Regulations, 2001

1. Both the parents may jointly, or, in the event of the absence of one due to death, divorce, legal separation, desertion or conviction, may singly apply for guardianship of their or as the case may his ward beyond the age of 18 years.

2. In the event of death, desertion, conviction of both the parents, the siblings (including half and step siblings) jointly or singly (reason of singly application to be explained separately) may direct a registered organization to make an application for guardianship of a disabled member of the family.
3. In the event of non-application of sub-regulations (1) and (2) above, a relative may make an application for guardianship.
4. In the event of non-application of sub-regulations (1), (2) and (3), any registered organization may make an application for guardianship.
5. The Local Level Committee may direct a registered organization to make an application for guardianship in case of a destitute or abandoned person.

While the regulations of the Trust give us a range of preferences about who should be a guardian. The parents are the first choice and joint guardianship is encouraged. Then come sibling and other close relatives. Registered organizations will take charge if the person is a destitute person, or abandoned. The actual implementation of guardianship has thrown up many more situations and questions. A booklet published by the National Trust titled 'Frequently Answered Questions' gives many more answers to questions about guardianship.

Appointment of Guardian

If we look at the first three of the functions of the guardian i.e. to receive applications, process these applications and take decisions regarding the appointment of the guardian, we find that the law elaborates more on this.

Chapter VI section (3) of the ACT states that when the local level committee considers an application for guardianship they would have to consider:

- (1) "Whether the person with disability needs a guardian"
- (2) "The purpose for which the guardian is required for a person with disability".

Comment

Taking a decision to give guardianship is a very big responsibility that the local level committee has. The magnitude of the responsibility comes from the fact that earlier a decision to make a person a guardian was taken by the courts.

Also as the law clarifies that not every person with disability will require guardianship and it is the duty of the local level committee to take these decisions. There is also the very important decision of what kind of guardianship a particular person with disability requires. In our earlier discussions we talked about these areas.

Because of the importance of this decision, the Regulations of the National Trust (13) 6 also further clarify that the person with disability must be assessed by the Local Level Committees to determine the genuineness of the need of guardianship. In order to do that it shall be open to the LLC to seek assistance of technical personnel or their services to determine the need.

In fact some local level committees have done this and used the services of others in the community to support their work.

Monitoring Guardianship

The relationship between a Guardian and a person with disability can be a benevolent and enabling one. Similarly the fact that one person has total control over another person can turn a relationship into an abusive and violent one also. The other three functions of the local level committees are to receive accounts of property and assets of persons with disability from the guardian, receive applications regarding removal of guardian and take decisions regarding removal of guardian.

Section 16 of the law obliges the guardian to give an inventory of the property and assets that belong to the person with disability and to continue to give an account of the monies and property belonging to the person on a yearly basis.

Removal of Guardian

There is always a very thin line between protection and abuse. Checks and balances are always required when a person takes important decisions about another person. It is a well-known fact that persons with disabilities are extremely vulnerable to abuse, and to neglect. Non-disabled persons may not be aware of signs of distress or that a person with disability is being abused. Persons with communication difficulties as well as persons with severe disabilities may not be able to communicate their distress and extensive care taking may lead to situations of abuse.

The local level committee has the further important duty of also monitoring the guardian and removing the guardian if need be. Further section 17 of the law also states that a guardian can be removed if the person if a parent or relative or a registered organization finds that the guardian is;

- Abusing or neglecting the person with disability
- Misappropriating or neglecting the property of the person

The Rules of the National Trust give us the procedure for the removal of guardian and they also define what is meant by abuse or neglect.

Rules 17 (1)

- i) The local level committee upon receiving an application for removal of guardian from a parent or a relative of a person with disability or a registered organization on the grounds specified in clauses (a) and (b) of sub-section (1) of section 17 of the Act shall appoint a team of investigators consisting not less than three persons.
- ii) The team shall consist of one representative of parent organization; one representative of the associates for the disabled and one Government official associated with disability not below the rank of Assistant Director.

The following section elaborates on what is meant by abuse and neglect.

Rule 17 (1)

- (vi) The following acts of commission or omission shall constitute abuse or neglect on the part of the guardian, namely:-
- a) Solitary confinement of person with disability in a room for longer period of time.
 - b) Chaining of the person with disability
 - c) Beating or treating a person with disability resulting in bruises, skin or tissue damages (not due to his injurious behaviour indulged by the persons with disabilities).
 - d) Sexual abuse.
 - e) Long deprivation of physical needs such as food, water and clothing
 - f) No provision or non-compliance of rehabilitation or training programmes as specified by experts in the field of disability rehabilitation.
 - g) Misappropriation or mis-utilization of the property of the person with disability, and
 - h) Lack of facilities or no provision of trained or adequate staff for meeting the training and management needs of the persons with disabilities.

The Board of the National Trust

Composition of the Board

The Board of the National Trust is headed by a Chairperson.

This Chairperson

1. is appointed by the central government for at least 3 years.
2. has expertise and experience in the field of Autism, Cerebral Palsy and Mental Retardation.

Among other things, the Chairperson is responsible for

- a) proper functioning of the trust
- b) Proper functioning of the Local Level Committees
- c) Ensuring the implementation of the policies and programmes of the trust.

* Chief Executive officer (Rank of Joint Secretary Government of India).

Registered organizations are also an important part of the Board. The Board must consist of

* 9 members from registered organizations

- 3 persons from voluntary organizations
- 3 persons from parent associations.
- 3 persons from association of persons with disability

* 8 members of Joint Secretary and above rank of The govt. of India

* 3 members nominated by the Board representing the Associations of Trade, Commerce and Industry.

In carrying out the aims and objectives of the trust, the law permits the Board to invite people whom it thinks could contribute in any way. These people cannot take decisions but they can assist the board in its activities.

Powers of the Board

Among other things the law gives the Board the authority to create programs and schemes that would further the aims and objectives of the trust. Registered organizations can apply for funding to carry out the schemes and programs. The nature of these programs is also specified in section 11 of the ACT. These programs can be:

- (a) Any program which promotes independent living in the community for persons with disability by:
 - (i) Creating a conducive environment in the community.
 - (ii) Counseling and training of family members of persons with disability.
 - (iii) Setting up of adult training units, individual and group homes.

- (b) Any program, which promotes respite care, fosters family care or day care service for persons with disability.

- (c) Setting up of residential hostels and residential homes for persons with disability.
- (d) Development of self-help groups of persons with disability to pursue the realization of their rights.
- (e) Setting up of local level committee to grant approval for guardianship.
- (f) Such other programs which promote the objectives of the Trust. (Chapter IV)

In the implementation of these programs preference will be given to

- Women with disability
- Persons with severe disability
- Senior citizens with disability

Some of the important schemes of the National Trust that further the objectives of the National trust are as follows.

1. State Nodal Agency Scheme (SNAC)

To provide coordination assistance for NT to implement its activities at a faster pace to reach maximum number of people specially parents and siblings of persons with disabilities, smaller rural organizations through strong State level organization of reputed with technical expertise and to increase coverage.

The responsibilities of SNACs will be to function as

- (a) Information Centres
- (b) Project Mentors,
- (c) Training Centres
- and (d) Networkers.

2. Institutional Care (Samarth - Center Based Services Scheme (CBS)

The Scheme is for residential services - both short term (respite care) and long term (prolonged care). It includes early intervention, special education or integrated school, open school, pre-vocational and vocational training, employment oriented training, recreation sports etc..

3. Training of Care Givers (Community Based Caregivers Training (CBCT))

Aimed at relieving the burden of care on families which is costly, tiring and stressful over time by

- building pool of trained caregivers who may be hired on permanent or temporary basis by families that need it
- providing employment opportunities to deserving unemployed persons.
- providing services of care giving at a reasonable rate and to BPL persons with autism, cerebral palsy, mental retardation & multiple disabilities, free of cost. It would be done in this way that trained caregivers would be deployed at the organizations registered with the National Trust who would provide need based services to the persons with disabilities. -

4. Supported Guardianship Scheme (SGS)

Aimed at giving Rs. 500/- pm to families of 10 very severe and needy persons with disabilities for welfare. This scheme is only applicable in 75 select districts.

5. Publications & Newsletter

Awareness creation is vital if the law is to be known and implemented successfully. The National Trust has been extremely proactive and created low cost materials to disseminated throughout the country. 26 types of books, CDs, Video Cassettes, Brochures and posters have been developed. These books are often distributed for creating awareness and sensitization. This material is immensely popular among parents, professionals, students and Government personnel alike and it is very useful.

The National Trust also publishes a Newsletter. The thought behind the latest Newsletter of 2005 was Empowerment of the disabled. It covered success stories of persons with intellectual disabilities who are successfully employed in the open market.

Important aspects of the law and its implementation that enable the person with disability and uphold their dignity.

The person with disability is at every level of decision making in the conceptualization and implementation of the law. They are represented in the Board as well as in the Local Level Committees and are party to all the important decisions in the implementation of the law.

Decisions that were earlier made by the courts (judicial bodies) are now made by non judicial bodies.

Local Level Committees are supposed to be in every district of the country. A network of LLC's at the district level with representatives of persons with disabilities can be a tremendous force in creating awareness and achieving the rights of persons with disabilities.

The law recognizes that not all people in the four categories of disability need guardianship and therefore gives space for people with disabilities to develop their abilities. Some people with disabilities may be able to move from requiring a guardian to not requiring one.

The thrust on independent living and inclusion enables the person with disability in many different ways.

With the implementation of this law there is a growing awareness within the country about the abilities and needs of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. Without a change in perception and attitudes it is difficult to implement the law.

What the law does not do

What the law fails to do is to give the person with disability for whom a guardian is appointed a voice in the decision to appoint or even to remove the guardian.

How does the National Trust support families of persons with disabilities?

The National Trust Act does much to strengthen the family and parent associations in the country.

In the absence of well-developed services families have often taken the lead in creating organizations providing services and advocating for persons with disabilities. A strong, active network of parent associations exists within the country.

Of the nine members of the board who do not belong to the government, three members must belong to associations of parents of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability. This empowers parents association to be decision-makers in the implementation of the law.

The composition of the LLCs also strengthens the family and parent associations. Registered organizations can be parent associations and therefore part of the local level committees.

The Rules of the National Trust also provide for active participation of parent associations in the monitoring of guardianship. For example; If a guardian is to be removed, the local level committee must appoint a team of investigators of at least three people. One of these must be a representative of a parent association.

Although the provision of guardianship does not really answer the biggest question parents confront is "What will happen after me?? It enables the family to get guardianship much more easily than earlier and to access services and programmes as well as schemes on behalf of the person with disabilities.

The very existence of the National Trust Act and the various programmes it supports has encouraged the formation of parent associations and associations of persons with disabilities in the country.

One of the biggest advantages of having a guardian has been in the management of property and assets of the person with disability.

What the law does not do

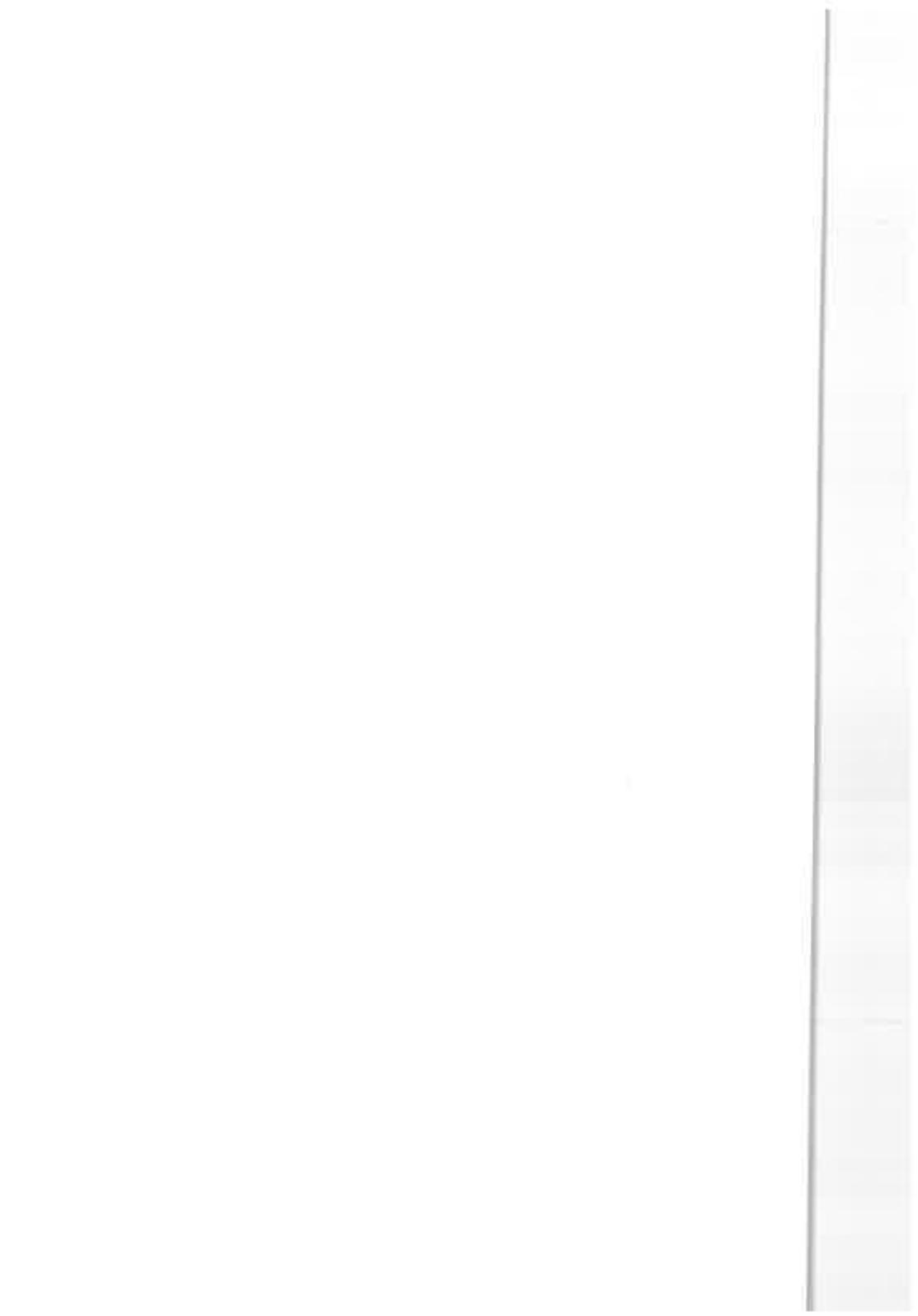
What the law does not do is fully answer the biggest question that parents have in their minds. What will happen after me? In today's world when joint families are shrinking into nuclear families, families are finding it difficult to find people who are willing to be guardians. Families are finding it difficult to think of people who they can trust to be guardians. Families still worry about their children being abused.

All over the world today people with disabilities have spoken against the concept of someone taking decisions for them. During the discussions on the drafting of UNCRPD people with disabilities, including people with mental disabilities argued that they should have the right to take their own decisions. They argued that decision-making is not always independently done and that all people are interdependent on each other. They could be supported in the taking of these decisions to the extent that it is required by them. Many people argued that the very provisions that were aimed at protecting them have actually led to a lot of abuse.

Article 12 of UNCRPD recognizes that "Persons With Disabilities enjoy legal capacity on an equal basis with others in all aspects of life".

Conclusion

While there are no easy answers, the development of abilities, support structures and changing images of persons with disabilities is one part of the answer. It is important that we constantly refer to the objectives of the Trust and interpret them in the light of the rights of persons with disabilities and the new Convention that sets out a new paradigm of human rights for persons with disabilities.



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