

Early Intervention in Inclusive Education in Mumbai

The 'Why' and the 'How'

Manual 1

Policy makers at National
and State level



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Foreword

The '*How to Series of Inclusive Education*' is a set of manuals that have emerged from a study undertaken by The Spastics Society Of India, Mumbai in collaboration with UNICEF and supported by the Canadian International Development Agency (CIDA).

The title of the project is *Inclusive Education Practice in Early Childhood*. It is an action research project involving both intervention and research on a large scale covering 6000 families based in the impoverished areas of the Mumbai slums. Six hundred children, both disabled and non disabled, were placed in Demonstration Learning Centres within the community where an enrichment programme and a need based intervention was given over a two year period. The intervention strategies were carefully documented and the progress of the children tracked by external researchers not connected with the intervention team. The aim was to study the mechanism or *intervention* strategies needed to put *children with disabilities* into existing programmes being run by Government and non-Governmental agencies and the barriers that came in the way to accessibility and participation.

From this evidence based research emerged a series of instructional resource material: the '*How to Series of Inclusive Education*.' These manuals are relevant for any organisation, or agency, working to address the crucial need of bringing *children with any disability* into inclusive settings. They recommend *a whole community approach to inclusive education*, and although the research was carried out in India it can be used anywhere in the world.

Who is this manual for ?

The manual is for those involved in policy-making and organisation of early childhood education:

- National level policy-makers and administrators
- State level policy-makers and administrators

What issues are addressed ?

- General principles - the concept of inclusion
- Why include?
 - ✓ A social justice issue
 - ✓ Educational benefits
 - ✓ Social benefits
 - ✓ Economic benefits
- What are the barriers to inclusion?
- The SSI-UNICEF project - brief overview
- Examples from the project of HOW barriers can be overcome
- Examples from the project of the benefits of inclusion
- What YOU can do to make inclusion a reality

What do we mean by Inclusion ?

Inclusion means enabling *all children* to access early childhood education in regular schools and nurseries by removing the barriers to their participation. This means, not only children who are **disabled**, but others who experience barriers to their participation in schools and nurseries - **socially disadvantaged** children, such as those living in the slums, and girl children.

Education for **All** must include **ALL** children

Why include ?

There are a number of very good reasons for the inclusion of all children in regular schools and nurseries.

• Social justice, entitlement and legislation

The Government of India has already passed a legislation for provision of education for children with disabilities and to promote the inclusion of pupils with disabilities in mainstream schools. The Persons with Disabilities Act, 1995 states that the Government will ensure that:

Every child with a disability has access to free education in an appropriate environment until he attains the age of 18 years. The appropriate governments and the local authorities shall endeavour to promote the integration of students with disabilities in the normal schools.

Sarva Shiksha Abhiyan (SSA) or 'Education for All' has been endorsed by the Government. India is a signatory to the 1990 United Nations World Declaration on Education for All, which reaffirmed the right of all children, including disabled children and those with other educational needs to access to education and to the principle that all should be educated in regular school settings.

The follow-up to this: the 1994 Salamanca Statement and Framework for Action reaffirmed this position and set out some ways in which it could be achieved. These called upon governments to:

- Improve access to education for all
- Adopt the principle of inclusive education
- Provide early intervention for children with disabilities
- Facilitate participation by parents, communities and people with disabilities in decisions about service delivery
- Ensure that teacher-education programmes give teachers the skills and understanding to provide education in inclusive settings.

The 93rd Amendment to the Indian Constitution affirms the Government's commitment to Education for All, and in the preamble it states that this includes children with disabilities.

Thus, there is a recognition, at Government level, of the rights of children with disabilities to receive an education, and for this to be offered in a school alongside non-disabled peers.

• The educational benefits of inclusion

There are benefits for inclusion for **all** children - those who are socially disadvantaged, those with disabilities, and girl children, as well as for children in general. *All learn better together. Classmates help each other.*

A child who is disabled may be able to help a classmate who is able-bodied, but less talented at a particular subject, such as mathematics. Able-bodied peers will help their less able-bodied classmates with other aspects of the curriculum, such as practical science.

Teachers become more skilled at using a variety of teaching techniques to address a variety of learning needs. This will benefit all students, not just those with learning difficulties or disabilities. *Teachers become more creative and lessons are more interesting!*

Therapists and other experts in particular disabilities, such as teachers of the deaf or the blind, become skilled at handing on their expertise by training teachers and support workers to deliver therapy and teaching programmes. This means that their scarce skills can be shared and learned by others working with children, so more children can be helped.

- Studies have shown that ALL children in inclusive classrooms make good progress, both academically and socially.
- Research shows that **EARLY INTERVENTION** is a key factor for disabled children making good progress.

• The social benefits of inclusion

All students benefit socially from inclusion. Disabled and socially disadvantaged children mix with their peers and this *raises their aspirations and self-esteem.*

Peers learn to accept those who may appear 'different' in some way and *social barriers are broken down.*

Families feel supported and less isolated: because their children are not rejected, but are part of the mainstream.

The community benefits from learning tolerance and learning to value the contribution that all can make to society, no matter what their background or disability.

Professionals find a new role in supporting teachers and community leaders, and breaking down the barriers between services and the community.

• The economic benefits of inclusion

Inclusive education is more cost-effective and makes good use of scarce resources. Education brings benefits to individuals and to society. It teaches independence and self-reliance. This is more likely to happen in inclusive settings, where all are challenged to achieve their potential. Educated persons will contribute to society by becoming good citizens and having the ability to earn a livelihood and contribute to society.

What are the barriers to inclusion ?

If inclusion is so beneficial, why is it not more widely practised in India?

There are a number of barriers that are put in the way of moving towards a more inclusive education system. These are:

- Structural
- Cultural
- Attitudinal

• Structural barriers to inclusion

Currently, the education of children with disabilities is not part of the remit of the Ministry of Human Resource Development, which deals with the education of all other children in India. The education of children with disabilities is the responsibility of the Ministry of Welfare. This immediately creates a barrier for the inclusion of all children into regular schools. There is an urgent need to relocate responsibility for children with disabilities to the Ministry of Human Resource Development, so that Education For All can become a reality.

There are a number of negative consequences of the handing of responsibility for the education of children with disabilities to the Ministry of Welfare:

- It promotes the segregation of children with disabilities into special schools, through a system of grants to voluntary organisations.
- The focus of many interventions offered by voluntary organisations is on rehabilitation and not on the education of the whole child.
- There is not sufficient population coverage, and many disabled children do not receive any education.

This undermines India's commitment to Education For All.

Education is a right for ALL India's children, and should not be seen as a charity provided by voluntary organisations.

Notwithstanding the national legislative framework, it is possible for education departments at the State level to organise their schools to become more inclusive. There are many examples across India, in a number of States, where children with disabilities have been successfully integrated into mainstream schools. Following are two examples of success.

Ayush attended a special school till Class or Standard Four. His needs were carefully analysed. He was dependent on others for care and for his daily needs. He needed specially designed furniture for seating, a wheel chair to move around and a writer for written work.

Observing his overall progress Ayush's parents' together with his teachers from the special school felt that Ayush would benefit from an inclusive setting. A school close to his house was selected.

The intervention involved a series of meetings to convince the Principal to include Ayush. Ayush was given a test. The Principal agreed to include him in Class or Standard Five and to give him the available concessions. The other interventions were that the parents took the responsibility of coordinating with the arithmetic teacher of the lower class and the special school. The parents appointed an attendant to drop and pick him from school and to look after his toileting needs in school. His peers and their parents took turns to copy notes for him.

The result was an inclusive environment in which Principal, teachers, peers and support from the parents resulted in the confidence Ayush now has in his new school. He is well accepted and does not want to go back to the special school.

Namita uses a wheel chair to travel to her college. When she was included in a mainstream school in Std VI, the classes were held on the higher floors. The school had neither a lift nor a ramp. This could have become a barrier to her inclusion, as carrying her up everyday would have been difficult.

The principal was supportive of the parents' decision to admit her in a mainstream school and decided to shift her class to the ground floor. Her friends helped with copying notes and Namita graduated from school with a first class!

• Cultural barriers to inclusion

India is a country of huge cultural, linguistic and religious diversity. The culture stresses the important role of the family in caring for its weaker members. Disability is often accepted as 'fate' and even as something to be ashamed of. Thus, at the political level, there has never been a strong lobby to improve services for disabled people. Children with disabilities are 'invisible'. They do not figure in the policies of national and local planners. This has led to over-reliance on a 'charity model', leaving the responsibility for provision to voluntary agencies.

• Attitudinal barriers

Attitudes to the provision of services for disabled children reflect the prevailing culture. Historically, there have been a number of models, or ways of thinking about disability.

- Disability is a punishment for past misdeeds
- Disability is a personal tragedy, not the concern of policy-makers
- Disabled people are in need of 'charity' and it is a duty to help them
- Disability is a medical problem and 'treatment' is needed to 'cure' their impairments.

These kinds of attitudes locate the problems of disability within the individual and suggest that individualised solutions to problems can be found. The attitude is that disabled people and their families cannot decide for themselves what services they need, but that professionals, working within a charity or medical model, will decide what's best for them.

• A new way of thinking - a 'social model' of disability

People are disabled, not because of their physical or mental impairments, but because of what society decides for them.

Attitudes towards disabled people are changing in a modern society. It has been realised that old attitudes and practices created problems which meant that people with physical or mental impairments were handicapped by their environment. For example, by buildings which were not accessible to people in wheelchairs. Or by schools which reinforced separation and difference instead of supporting inclusion and acceptance.

• Disability as a 'human rights' issue

We are moving away from the old attitudes and ways of thinking about disability towards a 'human rights' framework. This relies not on an individualised charitable view, but on a belief that all members of society have a right to participate fully in the life of the society. This means that social and educational policies should not marginalize or separate certain groups because of their perceived 'difference', but should seek to promote their full inclusion into the life of the society.

Policies and practices within the education system should be based on the premise that all children have a right to education in regular schools with their peers, regardless of sex, race, language, religion or impairment.

Inclusive Education in Early Childhood Project

The Project was an *action research study* based in socially disadvantaged areas of Mumbai. The title of the research was *Inclusive Education in Early Childhood* and involved demonstration, research, evaluation and analyses. The methodology was a mixture of qualitative and quantitative research. Six inclusive pre-school classes of socially and educationally disadvantaged children under 5 years had been selected as sites of the demonstration child-care and learning centres.

• Typology

The term inclusive education refers to not only the education of children with special educational needs but to *all children facing barriers to learning, regardless of gender, class, caste, religion, disability*. The project focused on families living in extreme poverty with their disabled child in the inner city slums.

It also looked at children who are disabled and non-disabled but who, for many reasons, are not within the educational system. Therefore inclusion of children in this context refers to three barriers caused by:

- Poverty
- Cultural bias against the girl child
- Systemic exclusion of the disabled child.

The words disabled children are used to include all disabilities, impairment, handicap or disability, as a generic term.

• The Critical Five years

The frame of reference for the study was children in the 0-6 year age group. The rationale for the research is the Critical Five Years, there being major evidence, that the optimum learning of basic skills for a child is the 0-5 early years, and that children who are socially disadvantaged or disabled in some form or other suffer greatly scholastically, linguistically and educationally in this period.

• Critical for disabled children as well

This argument holds true for 'all' children, including disabled children. What comes across strongly from the studies and research done is that intervention for children with disabilities should begin as early as possible, and, that if a disabled child is left without proper management and care, there is a high probability of secondary effects developing which are disastrous for the child. Today the education of disabled children has become statutory, and legislation, backed with fiscal support in some countries, has empowered disabled children and their families to seek legal redress, if they find services not complying with the law or discriminating against them. This is a major shift-in attitude. Researchers had emphasised the paramount importance of integrating them in appropriate environments, suited to their special needs, but the new approach now recommends access to a common schooling for all children.

Inclusive education has taken centre stage as being the most cost effective way of dealing with exclusion.

A holistic programme combining education and treatment under one roof was provided. Facilities for identification, assessment, provisions for education and treatment were designed specifically to the needs of the families in the poorer areas of the city of Mumbai.

This innovative educational experiment involved 6000 families and drew from the experiences of a team of professionals from the Spastics Society of India, Mumbai.

Appropriate teaching aids, need - based modifications for children with disabilities, low cost appliances, use of recycled material, were incorporated into the intervention strategy. Pedagogic issues were addressed as an intervention strategy incorporating child-centred programmes. Training was given to teachers and helpers empowering them to deal with children with disabilities.

A project evaluation was conducted using both quantitative (structured questionnaires, interviews and data) and qualitative (observations, in-depth interviews and focus groups) techniques.

The Aim of the Research

The aim was to study the mechanism or intervention strategies needed to put children with disabilities into existing programmes being run by the Government, so that Inclusive Education can take place within the Government's framework of services. The following areas were examined:

- Social skills
- Emotional development
- Self-help skills for independence
- Problem-solving ability
- Language and communication skills
- Health status

The training interventions included the training of the following :

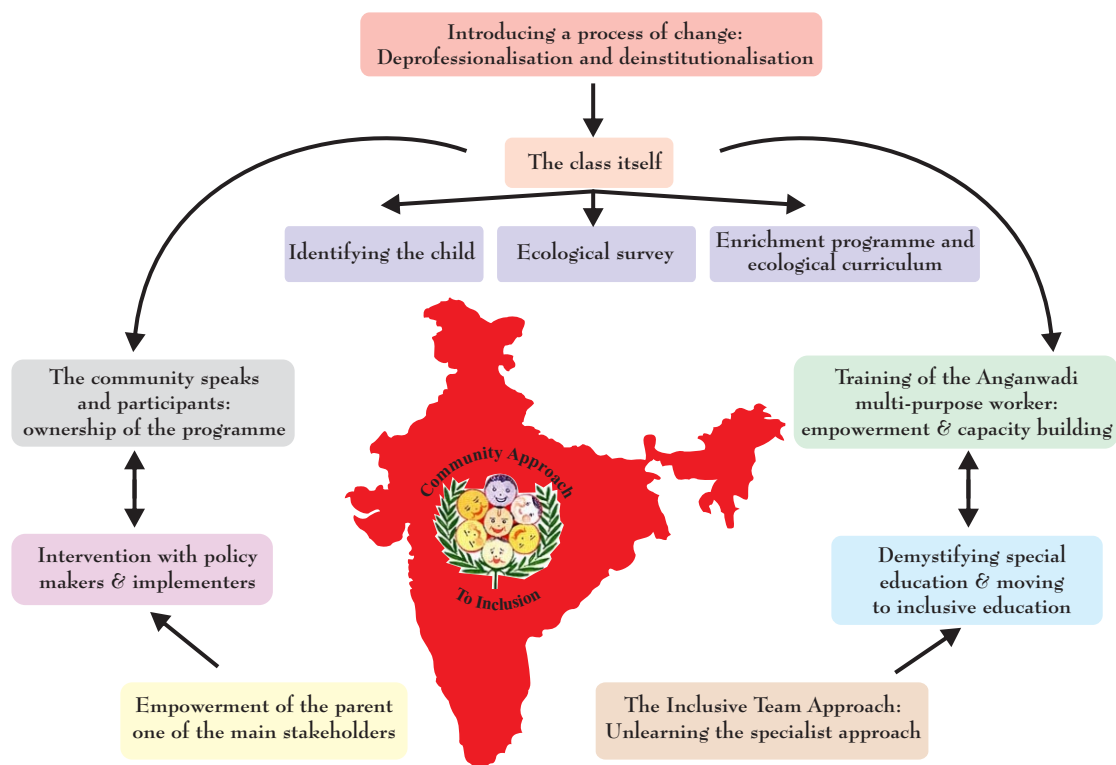
- Anganwadi workers
- Parents of children with disabilities
- Parents of children without disabilities
- Community voluntary workers (BMC workers)
- ICDS supervisors (Bal Sevika officials)
- Mahila Mandal leaders
- Community nurses
- ICDS street level bureaucrats and administrators

The project brief was:

- To document the factors that need to be addressed to get children with disabilities into the neighbouring schools.
- To measure change of attitudes within the community.
- To measure children’s change in their perceptions of disability and their social interaction.
- To measure whether learning is taking place with a simple pre and post test.
- To disseminate best practice in development of inclusive pre-school provision by providing manuals so that the projects can be replicated in other similar community settings.

The manuals show how a community can be built up to accept children with disability as a part of their lives, and how they too can avail of existing services.

Examples of HOW barriers can be overcome



The SSI/UNICEF Project included all members of the community at all levels in the implementation process. A range of strategies was used to involve all and to overcome resistance and barriers to inclusion.

Overleaf are some examples of barriers and how they were overcome.

Barrier 1: The professionals

'I am a professional... I know the problem of the child'

Inclusion of children need not only be carried out by professionals and institutions, but it usually is. There is a trend, which is widely reported, that specialist teachers tend to move into regular schools and assume a hierarchical position. This position is 'I know the problem of the special child' 'I am the professional' 'I will tell you how to go about it'. Not everyone does this, but such an attitude prevails. This creates a barrier to inclusion. Such an attitude has been shown not to work. It leads to the teacher in charge feeling deskilled. The teacher does not take ownership of her role as teacher in relation to the child who may need additional support to learn and develop.

How to overcome the Barriers

Deprofessionalise and Reprofessionalise

To introduce a more cooperative and collaborative partnership instead of an authoritarian and hierarchical one, the professionals involved in this project had to be provided with the skills needed in the new context and culture in which they were going to operate. The process of reprofessionalisation involved - retraining, relocation and redeployment of time.

Formal and informal sessions and discussions were held around these issues making the Resource Support Team aware of such implications. It was critical for the team to understand that inclusion of seriously marginalised impoverished children needed a change in personal awareness. Training to be sensitive to the community involved some identifiable skills and characteristics including humility, modesty, openness, and engagement skills.

The 3 new R's for reprofessionalization

Retraining

...into a new context and culture of the community

Relocation

...away from the institutional- base to the community meant developing more community based initiatives

Redeployment of time

...several jobs were changed and another set of priorities was introduced

Deinstitutionalise

Many trained specialists have a bio-medical approach, too dependent on rehabilitation tools and rehabilitation tools to address the idea of inclusion. They are used to well-resourced rooms, beds for examinations, and technical aids, and find it difficult to shed their aura of professionalism. Professionals moving from an institutional base to a community base needed training in order to understand that the usual well-resourced, institutional-based equipment was never going to be available in places where there were no services for anyone.

Training to be Sensitive to the Community

Humility

..... that the hardship of people who have been described as the poorest of the poor was immense, their resilience in the face of such poverty immense...and needed to be recognized and understood.

Modesty

.....that we were there in the community to learn and not just to teach.

Engagement

.....that the dress should not be too ostentatious and they must be able to sit on the floor and have a cup of tea if offered

Friendly open attitude

.....that sensitivity means not to get put off by the grinding poverty.

Status

.....that people who were from the community...and working on the project must be given status...they were always pushed to relate their stories and teach us

Results

Professionals learned to listen to the voices in the community before giving advice. They became less arrogant and hierarchical and forgot about their professional designation. They learned to leave their egos behind and listen more than speak. A change in the balance of influence took place with a more equal approach resulting.

Our work in the community indicated how a process of reprofessionalisation and deinstitutionalisation helped to develop a participatory approach involving all actors needed to implement inclusion, and this has reaped rapid results.

Barrier 2: The Anganwadi Worker

'How am I going to cope with the disabled child?'

Process of addressing the Barrier: An ethnographic participatory approach

Discussions took place to find out what kind of fears Anganwadi workers had about including children with disabilities in their classes. The Anganwadi Multipurpose Worker (AMWs) main fear was how to cope effectively with children with disability. This is a universal fear around the world, and may be even more so in the under-developed countries.

The following strategies were developed to empower and give them the skills they would need.

A Disability Identification Tool

An Ecological Survey

A new ethnographic approach
in developing a knowledge base

An Enrichment Programme

A collaborative participatory approach
in developing curriculum

Results:

The creation of the role of the Anganwadi Multipurpose Worker: a community-based individual who understands all the various elements of teaching in an inclusive manner, and has been given the appropriate skills for her role.

Barrier 3: The Community

'Disabled children are best in special schools'

These were the kind of comments that were made were from the Anganwadi workers and the street level bureaucrats. Initially the parents also were not fully convinced. They were apprehensive and fearful. A few had their reservations about including children with severe disability, intellectual deficits or epilepsy. They felt that at a very young age, the children without disability would be scared or upset when they watch a child getting a seizure, or the unusual behaviour exhibited by the severely challenged.

How to overcome the barrier: Information and breaking the myths

The apprehensions, the fears about the prejudices from the community was an important barrier to be addressed. Substantial work was done with key persons from the community.

Yatras, rallies and street plays focusing on childrens' needs and rights were presented. Information about inclusion was disseminated to houses in the communities.

Community Misunderstandings

'A disabled children can't learn together with other non disabled children.'

'Disability is due to sins committed in a previous life.'

'They don't treat disabled people as human beings.'

'Is Education for all important?'

Whom to address

Parents, Families & Joint Family Members

including grand parents, parents-in-law & aunt-uncle

Community Workers

(teachers/helpers), local leaders, local school principals

Health Officials

including community health volunteers, community development programme officials & paraprofessionals

Local, State Level Bureaucrats

from the BMC, ICDS, NGO's & Schools

A survey was administered at the same time which provided data about the attitudes of community members and local leaders. Informal discussions and questions brought out more about the attitudes of the community to children with disabilities and to the knowledge and mythology that people had about disability.

Results: Ownership of the project by the community.

The benefits of Inclusion

Many success stories have come out of the SSI/UNICEF project. Here we present a few of those stories to illustrate what has been achieved, and the benefits of inclusion for all who have participated:

- ✓ Children with disabilities
- ✓ Non-disabled children
- ✓ Parents and family members
- ✓ Neighbours and the wider community
- ✓ Anganwadi multi-purpose workers
- ✓ Teachers
- ✓ Health professionals
- ✓ Welfare and community workers

Acceptance by the community

Over the course of the project attitudes to children with disabilities changed among community members, parents and teachers. Children with disabilities were more readily accepted as friends and playmates by non-disabled children and their families. They were more likely to be sensitive to the emotional needs of disabled children and less likely to think that disabled children could spread disease. Most parents, both with and without disabled children thought that all children should go to the same schools.

One parent said: "In your Anganwadi school normal and disabled children learn together. This is good work, but my child not yet learn everything, so give more attention."

Involved parents said: "Children with disability should not be called [names] such as Langada, Kanna, Behra etc."

Parental involvement in their child's education

The active involvement of parents in their child's education is a key component of success. The project worked closely with parents and they became closely involved in what happened in school, and proud of their children's achievements. They also learned how to help their children at home.

One parent says: "Our children are doing well. My disabled child says a poem in English at home. He knows family members' names in English. He couldn't speak English before he joined the Anganwadi, now he has started to speak. Thank you teacher and the staff."

Another parent says: "Whenever teacher gives homework, I help my child to complete the homework, and he is doing well."

Children's learning

All children disabled and non-disabled, were tested at baseline, on entry to the anganwadi using a series of developmental scales¹ which measured the following aspects of the child's development:

- Social
- Emotional
- Communication
- Creative
- Motor
- Functional skills of independence.

Children with disabilities made the greatest gains in their scores in **functional skills for independence** (feeding oneself, dressing, toileting) and by the end of the programme were scoring as high as the non-disabled children. Other areas where disabled children made significant gains were in: **social skills** and **communication**. Thus, both their ability to interact with peers, teachers and parents improved, as did their use of language, comprehension and expression.

The major gains for children without disabilities were in the areas of **motor development** and **communication**.

Thus, all the children involved made significant gains in the main areas of development.

¹ See SSI/UNICEF Final Report 2003 ' **Inclusive Education Practice in Early Childhood in Mumbai** ' by Dr. Mithu Alur and Dr Marcia Rioux.

Removing barriers to inclusion

The project identified four main barriers to inclusion operating in the community. These were:

- Physical space
- Anganwadi Multipurpose Workers' attitudes towards the child
- Parents' attitudes towards education in general and inclusion.
- Classroom activities which were inappropriate or too demanding

A Barrier to Inclusive Learning (BIL)² scale was developed to measure these and was administered at baseline, mid-term and end term.

The end term scores showed a marked reduction in barriers to learning as a result of the behaviour of the Anganwadi multi-purpose worker. Lessons were modified to allow greater participation by disabled children.

How can Inclusive Education be implemented ?

Policy consists of policy **formulation** and policy **implementation**. These processes are like two sides of one coin. For policy to be implemented effectively, the policy objectives must be clearly stated.

In the case of children with disability very frequently we find that policy documents may state that a particular programme is for **all** children, but when it comes to implementation **all** does not include children with disability.

It is therefore critical for policymakers to include the clause that:

all means children with disability as well.

The manuals included in this package show how children can be included and the various segments of the society that need to be reached.

After an in depth examination of the situation in India, we find that what is missing is the **HOW of implementation**.

² See SSI/UNICEF Final Report 2003 '**Inclusive Education Practice in Early Childhood in Mumbai**' by Dr. Mithu Alur and Dr Marcia Rioux

These manuals show **how** children with disability can be included anywhere where there is little service provision and where there is little or no professional expertise. The manuals provide a package of training for both **policy formulators** and **policy implementers**.

The manuals can be used by policy-makers at National and State level to provide a framework to assist local implementers to set up and run successful inclusion projects.

The following areas are covered:

How can children with disabilities be put into existing services?

- What kind of tools are needed to identify children with disabilities?
- What are the modifications that need to be made within the classroom which will ensure the children's participation, within the class?
- What kind of sensitisation programmes have to be done within the community?
- How are the staff trained?
- What kind of capacity building has to be done to get children with disability IN?
- What kind of training is to be given to street level bureaucrats and local policymakers?
- What kind of awareness spreading has to be done to see that the community is accepting children and families with disabled children?
- What kind of changes are necessary in Government's community teacher training syllabii to ensure that teachers are addressing the question of disability?

Who should be involved in providing an inclusive education programme for Pre-school children?

