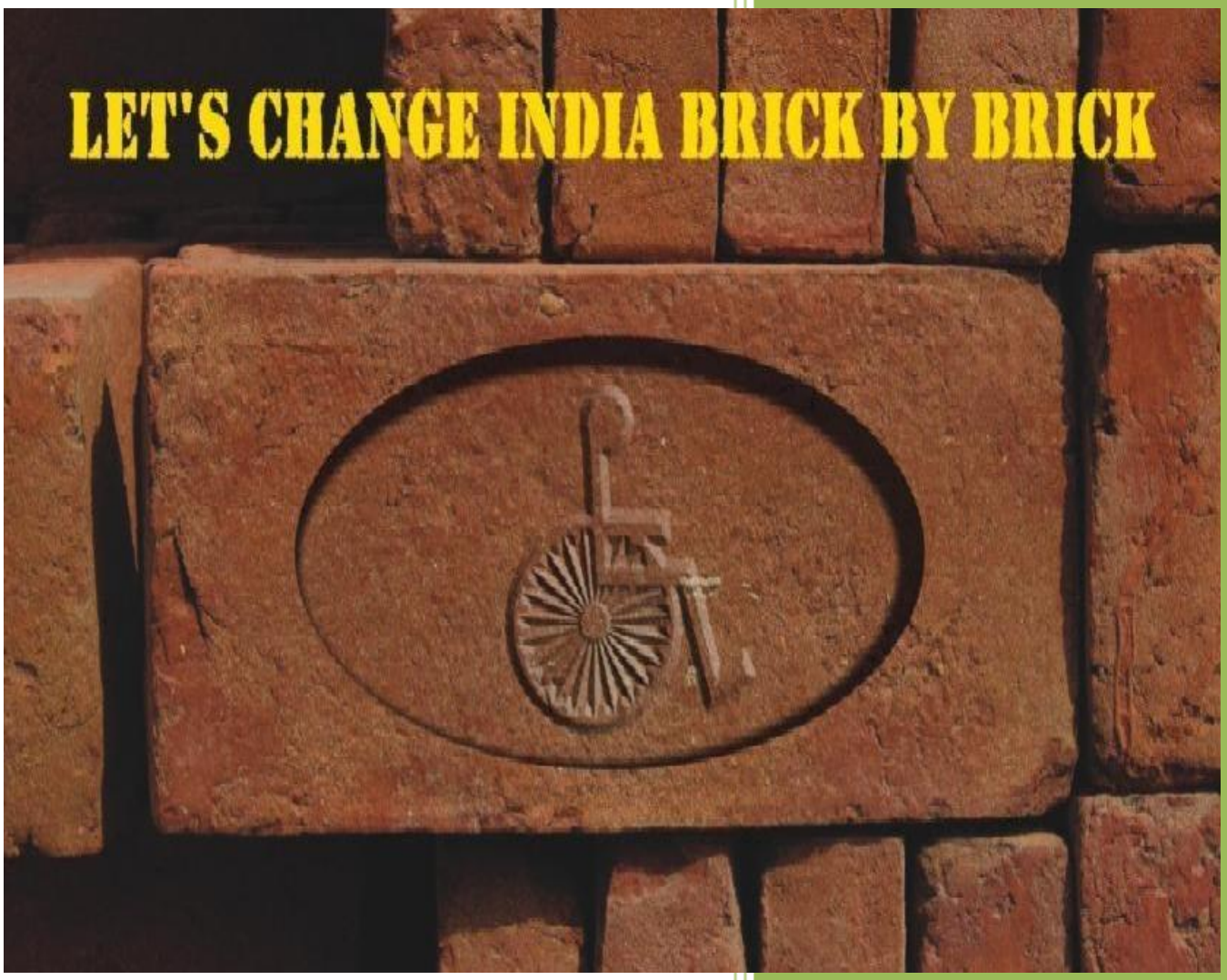
A Model Programme for Support and Rehabilitation of Adult Mentally Challenged Persons



Submitted to:
State Planning Board
Govt. Of Kerala

Report of Expert Committee on Assisted Living

Preface

The State Planning Board, Govt. of Kerala, with reference to the 12th Five Year Plan 2012-2017 for preparation of a Model Programme for Assisted Living for Adults with Disabilities, set up an Expert Committee for preparing a detailed project report. The TOR and composition of the Committee is in ***Annexure - I***.

The Expert Committee has been extremely excited about this very progressive move of the government of Kerala. At the National Trust, we have been keen to develop such models for a long time. This will be a pioneering work and will also show the way for dismantling large impersonal institutions which function at present in many states and have been getting a very bad reputation for neglect, abuse and over-crowding. These institutions were formed because of many people with disabilities being abandoned on the streets. However, these institutions lack capacity in supporting such persons or help them develop.

The assisted living programmes across the world are an answer to deinstitutionalisation and community living.

The government of Kerala has been the first in the country to think of a state-wide programme specially for adults with intellectual and developmental disabilities. This marks a first step in India where we are still struggling to set up residential facilities for adults with disabilities-- most are for children.

It has been a pleasure and sense of fulfilment for me personally to Chair this Committee. I do hope that the model we have developed and the plan do get executed at the earliest.

(Poonam Natarajan)
Chairperson
Expert Committee

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Preamble

An internet search for assisted living in India shows up assisted living programmes for senior citizens. This seems to be the new commercial activity, in the service sector. However, there is not a single one for people with disabilities.

The private sector has a number of facilities for people living with mental illness, these are regarded more as nursing homes and institutions not assisted living programmes.

The difference between a "Nursing home" "Home or institution" and an assisted living programme for people with intellectual and developmental disabilities are listed below:

S.No.	Homes/Institutions	Assisted Living
1	Large numbers/ faceless residents, counted by numbers not names. No individual treatment	Small group, not more than 10-12 people living together in a home like environment and as a small community.
2	Closed gates. Cut off from the neighbourhood or community	Within the community, with good healthy interaction.
3	Residents live to a rigid timetable	Daily routine flexible and open
4	Top down decisions on all aspects of living , even aspects like menu, clothes, washing, work , activities of the day	Each one has an individual plan and support. (Supported decision making) This will be both short and long term. Decision taken in a group or as individuals.
5	No long or short term goals, will live there a lifetime, no exit policy	Go out to work each day. They have an exit policy, if needed
6	Generally seem to have poor health conditions – residents prone to communicable conditions, like scabies, lice etc. Hair has been shaved off, no right to choose hairstyle, all residents wear clothes of uniform colour, size and shape. They even have common toothbrushes.	Each one has their own wardrobe and personal belongings – clothes, soap, toothbrush, bed sheet etc. Good hygiene and nutrition.
7	Non descript smelly & dreary	Not a dreary, smelly institutional feeling
8	May identify a handful of residents for specific skill development as status for organisation e.g. Special Olympics, or trips abroad	One size does not fit all – so individual needs in all areas, vocational job seeking, leisure time indoor / outdoor, developing skills like learn to draw, dancing, painting, potteries etc. Friendships to be encouraged, participating in community, courses, lessons etc.
9	No individuality is possible.	May be allowed to keep a pet

Table 1: *Difference between a "Nursing home" "Home or Institution" and an Assisted Living Programme*

Table 1 illustrates the difference. The former traditional institutions that are bleak and dreary are the main reason that parents agonise over the question as to "What will happen to my child when I am no more". Therefore, every parents organisation only dreams and plans on how to set up a living arrangement where their children will be able to live in a safe and happy environment.

Understanding Disability

There has been a paradigm shift in the thinking about disability. While earlier it was a charity or welfare subject, now it is thought of as a development and human rights issue.

Earlier a `cradle' to the `grave' living in an institution was considered the way to protect and care for people with disabilities. They were supposed to be the passive beneficiaries of welfare measures, with their lives decided and controlled by professionals. In India, though, as there were not many institutions, very much the same treatment of being passive and invisible happened within the family.

Though there are not hundreds of institutions, however, there are some in every state. In Delhi State at the moment there is a reform process going on, for one of the largest homes for adults with intellectual disability, and this is due to a public interest litigation. In Maharashtra a committee setup by the High Court to look at homes with children with disabilities has found children living in abysmal condition and very poor amenities.

Now, people with disabilities, are looking for autonomy and more control over their own lives. Disability is regarded as part of the human experience and human diversity.

The United Nations Convention for Rights of People with Disabilities (UNCRPD) is the first treaty signed by India and is a path breaking document, which has been worked out, after two decades of debate, dialogue and listening to the voices of people with disabilities. India has signed and ratified this document and is committed to many of the new ways of thinking about disability.

While developing models of assisted living it will be appropriate to flag some of these new concepts included in the UNCRPD.

a) One of the **general principles** is that the evolving capacity of people with disabilities and their right to preserve their identity are recognised.

   This is particularly important, when we focus our services on adults with intellectual disabilities (mental retardation). Intellectual and developmental disabilities in our country are regarded as "arrested mental growth". It is assumed, that people with low IQ's cannot learn and think logically. However, this `myth' has now been challenged. People with intellectual disabilities may need to be explained in plain language but they also learn and `evolve' like all human beings, throughout their lives. However, they may learn in a different way.

   The `stigma' attached may force families to hide a member with mental disabilities. However, people with disabilities are now advocating for their identity to be accepted as a person with a disability.

b) **Definition** – Persons with Disabilities include those who have long term, physical, mental, intellectual and sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis as others. It is important to consider physical, social, and attitudinal barriers.

c) Interdependence is not a lack of independence. People with disabilities have been able to clearly enunciate the concept of interdependence. `Independence' over generations has been a patriarchal way of thinking, where needing of support, in any way, is considered `dependent' and therefore contrary to any assertions for autonomy or choices in one's life. People with disabilities have busted this myth, by propagating universal interdependence where no one is an island.

d) **Supported decision making** : People with intellectual and other disabilities want to make decisions about their lives. They want to decide and have a choice of where and how to live, what to eat, where to work and chose their friends. They, however, may need more support and explanations, before they can take a decision, about each aspect of their life. The argument is for the right to make decisions, whether in traditional `wisdom' these may be right or wrong.

e) **Legal Capacity**: This led to inclusion of Article 12 of the UNCRPD, which has been most discussed and debated. It recognises all people as equal before the law.

f) Living and participating in the community on an equal basis as others. This means going to same schools and colleges, working together and using the same facilities. This requires dismantling large and faceless institutions and setting up community based facilities.

g) **Accessibility**: The concept has been enlarged to include not only physical barriers, but also barriers in communication, technology, social, attitudinal and access to justice.

h) **High Support Needs**: "High Support" means support which may be needed by individuals who require ongoing intensive support for activities of daily living; independent and informed decision-making; accessing facilities and participating in all areas of life including education; employment; family and community life; treatment and therapy; recreation and leisure. The need for High Support often arises due to significant disability in a single area or multiple or cumulative disabilities in cognition, communication, sensory-perceptual processing (not including blindness), emotional regulation, socialization, behaviour and mobility in interaction with attitudinal and environmental barriers;

i) "Support Plan" means a plan which is suitable for life situation of persons with disability respecting their individual preferences and enabling them to exercise their legal capacity and enhance their community participation specified in the Second Schedule;

j) "Support Network" means a group which supports a person with disability in carrying out his or her life activities and may be made of family members, friends, friendship forums/associations, service providers and others who have a personal connection and are in a trusted relationship with the person with disability;

k) **Reasonable Accommodation**: The United Nations uses this term in the Convention on the Rights of Persons with Disabilities. Denying it is defined to be discrimination. In the convention "Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure that persons with disabilities enjoy or exercise on an equal basis with others of all human rights and fundamental freedoms.

Assisted living is new concept. In our study we found many of the models more institutional and top down. Assisted living means creating a living arrangement, which provides for people with intellectual and developmental disabilities to have opportunities to live in the community, make decisions for themselves and develop their complete potential and lead a fulfilling life.

Chapter – 1

Some Learning's from Recent Studies in India

❖ Status of Persons with Disabilities and their Supported Living Needs

Started in 1969 the Rural Development Trust (RDT) is based in all 63 blocks of Anantpur district, Andhra Pradesh. It works with dalits, tribals, weaker sections and disabled persons in the areas of education, community health, housing, ecology, livelihood development and empowerment of women.

RDT has recognised over the last few years that families, communities and institutions where it works find themselves inadequate in providing necessary support to adolescents with severe impairments. It also came across disabled persons abandoned by their families unable to provide care due to poverty and lack of services. This was when RDT learnt about the concept of "supported or assisted living" as a service that addresses the needs of people with severe impairments with active participation and ownership of disabled people, support organizations, care givers, communities and the government.

RDT contacted a number of agencies and individuals in different countries to learn about supported living programs, but could not find any appropriate programs or guidance. So it decided to commission this study.

Salient Learnings

The study covered 455 disabled people.

1. People with multiple disabilities, were enumerated as physically impaired.

2. Most services benefit people with mild impairments. A person with high support needs may have access to benefits, but to make use of these, he/she may require financial aid for a personal assistant or an accessible environment.

3. Majority of respondents in the study were primary caregivers as the participants with disabilities had inadequate communication skills or training in the use of Alternative & Augmentative Communication methods.

4. Activities of Daily Living (ADLs) remained the main problem with families and persons with disabilities who were not independent in carrying out self-care.

5. There was no communication skills developed among some surveyed.

6. Besides the primary care taker, other family members also offered support to the person. But there were also few instances where only the primary care givers (the immediate family) had concerns regarding the needs and problems of the person with disability. Other family members remained indifferent or negative. In such situations, the level of anxiety amongst the primary carer was very high-- they had serious concerns for the future of the person after their death.

7. Community Self Help Groups (SHG's) facilitated access to pension and other benefits. They felt that persons with disabilities had equal rights and should be given equal opportunities in education and employment equal share in the family property. Women with disabilities, it was felt, had lesser security in the community and were more discriminated against than men.

8. Impact of SHG on the lives of its members: The group provided its members a conducive atmosphere where members received mutual emotional support and help.

9. Many disabled persons with severe impairments are unable to achieve their potential in life because they are dependent on their family members for any movement inside/outside the house. There are persons with severe impairments requiring high support who have done wonders by utilizing the services of a day-time or live-in personal assistant. They help manage education, job, leisure, social relationships etc. This arrangement also provides livelihood to another person.

10. The report recommends on alternatives for long-term care and support. These are based on an understanding that has emerged from the study that the long-term care and support needs of disabled persons are not just dependent on the severity of their impairment. They also depend on the attitudes and accessibility/inclusivity of family, community and state resources. In fact in the absence of appropriate capacity building support and presence of barriers within family and community, even a person with mild-moderate impairment may require maximum long-term care with much less quality of life.

❖ **On Needs Assessment for Development of a Model For Assisted Living Program for People With Disabilities**

The study undertaken by the National Trust conceives a plan that would be a model of Assisted Living, which will be piloted and then replicated and up scaled.

I. Objective of the Assignment

This assignment focuses on those persons covered by the National Trust Act -- those who have Cerebral Palsy, Autism, intellectual disability or multiple disabilities. Thus while the general term persons with disabilities is used in this document – the reference is to the four disabilities mentioned above. The specific objectives of the task undertaken were:

- To comprehensively study the existing scenario in India on the ability to promote the concept of independent living for Persons with Disabilities.
- To study the development of various existing global models of Assisted Living.
- To offer recommendations on the way forward.

In this early stage of model building the key methods followed were:

- Desk review of research studies, relevant documents to understand the global experience.
- Field visits to sites that offer lessons on Assisted Living for Persons with Disabilities in India.
- Interviews with persons with disabilities, and secondary stake holders (either face to face / email / telephonic)
- Focus Group Discussions with families taking care of Persons with Disabilities and members of associations of Persons with Disabilities and experts.

Finalising the Tools for Data Collection

After the first round of desk review an overall Needs Assessment Framework was developed. This framework formed the basis of developing an interview guide. The interview guide was field tested with some parents and experts. ((Refer to annexure 1)

About the Report: This report provides key findings from the field visits and the Indian experience. This section is further sub divided to offer insights into the various components that would be significant to model building. Key lessons learnt from the models visited, their strengths and challenges are provided at the end of the section.

The next section provides the key Findings from global experience and lessons from individual countries.

And finally a set of recommendations are provided on the way ahead.

In the initial sections of the report the reader is likely to find that there is an underlying assumption that the model building will take place around group homes. However, as the study progressed, the author was introduced to many people and their perspectives which challenged this notion and pushed the idea of diverse meanings of assisted living. It is hoped that the reader will be able to see the transition by the end of the report.

There are different perspectives that emerged while speaking to different stake holders with regards to how an intervention on assisted living should be implemented. From the parents perspective it meant a safe place for their children after they passed away, for the professionals it meant applying the principles of the UNCRPD, others spoke of using the Conventions' principles but ultimately arriving at a practical solution that is governed by a strong sense of ethics, respect and dignity for all.

Internationally there is a conscious move to de-institutionalise, and move away from the bio medical approach to disability. There is a strong shift towards community based solutions to rehabilitation and care.

Key Findings

1. All human beings are social beings and have to depend on one other for their existence. Hence, the point made was that the concept of "independent living' should not be a goal, but how "inter-dependence" with mutual respect is defined for different people.

2. In the context of persons with disabilities, they need adequate support systems to function like any other citizen. Every citizen has a right to a barrier free life, access to public institutions and facilities like banks, railways, road transport, entertainment, shopping, etc. Living independently also involves the ability to express one's opinions, receive and give love. These notions guide the meaning of "assisted living".

3. In the study people with disabilities felt that ideally the age of entry should be between ages 25-35. At this age the individual is open to adaptation and learning new skills/behaviour. As the person gets older, adaptability reduces and adjusting to a new residential place stressful. However, most parents would like to look after their wards till as long as they can.

4. Most of the respondents wanted a group home to have mixed categories of intellectual disabilities staying together. It was expressed that they would actually complement roles in supporting each other. Men and women could stay in the same campus but should have separate living quarters. Most felt that there should be no need to segregate on religious grounds.

5. On the class parameter, there were more diverse views. Some family members felt that some basic minimum criteria should be fulfilled with regard to hygiene, care, emergency care, food quality and maintaining respect and dignity of others. Some parents and experts felt that there could be different categories from which families could choose based on their ability to pay. For instance, some felt that their family members who were used to eating say in one way-- either in the Indian way of sitting on the floor or eating at the table-- might find it difficult to adjust to the other way. Similar would be the case for toilet types. Others defined assisted living as "simple, safe and comfortable" minus class distinctions.

6. With regard to language, most felt that a common spoken language would help while others were of the opinion that as long as there was respect for other forms of communication it did not matter and that other languages can be learnt.

7. The unresolved issue remains for persons with autism. For them being with the others causes difficulty and hence the nature of support they require in assisted living is going to be different. Similarly, for those who suffer from multiple conditions -- who are severely and profoundly disabled -- and for those who

require specialised medical care, living in groups and independently may be special decisions that families and group home managers would have to take on a case basis.

8. It would seem that there is a trade off between being 'as close to the community' and 'having open space' especially in urban areas. The respondents of this study offered ideas such as mandatorily keeping specific spaces and housing stock during urban planning. In rural areas, the housing schemes should have specific allocations for persons with disability. These places should be accessible and rules about who can access, pricing should be worked out.

9. One of the important aspects to be considered would be the additional costs and care required as residents grow older.

10. With regards to management almost all stated that residents should be involved in daily routine management tasks and decision making.

11. There has to be a set of dedicated professionals who will be responsible for the overall management of the home keeping in mind the support required. Laying down set standards would be difficult as according to the UNCRPD guidelines every person with disability would need individualised support to ensure "a barrier free life". But the key aspect that should be taken care of is an adequate ratio of care-takers and residents. Parents or family members should be involved in decision making and ideally the community should also play a role which will lead to better integration.

12. The extent of awareness among the community is still quite limited in terms of what persons with disability can do, hence currently the responsibility of looking after them falls largely on the family. As awareness spreads, one of the aims should be that the community becomes more involved and community mechanisms are evolved to look after those requiring special support.

13. The issue of availability of care givers with requisite training was of serious concern. Although there are courses meant for them, the education criteria for admission was seen as too high and the training too long. Some suggested that shorter duration courses should be developed, while others felt that this may not be adequate training. The National Trust is aware of the shortcomings of its Sahayogi (care giver) scheme and has proposed several changes to address the limitations. Some of the barriers to professional care -giving services are:

- Lack of standard pay scales
- The caste system based on notions of purity which labels personal care work as undignified.
- No career growth
- Family members of persons with disability assume that the care- giver is available for other household work.

The culture of formal individual volunteering is not very strong in India though it is gaining momentum.

14. Persons with disabilities face many barriers to find and keep work. Just like other individuals, they have diverse talents, interests and abilities. These should be taken into account while devising livelihood options.

15. A related aspect of work for adults would be having a personal bank account. Currently there are challenges to opening accounts for persons with intellectual disabilities. Supported decision making should keep this particular function as a priority as this will help the persons who are working to have control and access to the money they have earned.

16. Each one of the respondents said that any kind of home for persons with disability should have leisure time activity in the group home.

How a group home should function (key components)

1. Set a daily rhythm but not a rigid one.

2. Provide accessibility
3. Solve minor problems and offer first level emergency care.
4. Activities as per skills/talents and interest should be offered to engage the residents.
5. Persons can be involved in the daily upkeep of the place as per their abilities and should be supported to become responsible for the management.
6. It should be a place where everyone prays together, eats together, works together and celebrates together.
7. Not more than two-three persons should share a room.
8. Attached or adequate common toilet or bathing facilities conducive to their needs should be provided.
9. Ventilation should be adequate.
10. A garden space will be useful.
11. A compound wall and a manned security gate should be there especially in urban homes – more from the point of view of not letting outsiders come inside and not as much as to keep the residents inside.
12. Common kitchen and a dining place, provision could be made for a small kitchenette in case the people residing want to prepare something of their choice.
13. Adequate design aspects like tactile tiles, hold bars, sliding doors etc should be paid attention to with inputs from architects, engineers, planners. However, the basic thrust should be to "adapt" not construct the most "ideal" home with the best design aspects and standards. Such a building is likely to stand out in the surrounding and will send the message that highly specialised spaces are required for persons with disability. Moreover such an alien building is unlikely to make the people from the surrounding areas feel "at home".
14. Some of the concepts such as 'freedom', 'barrier free', 'quality of life' were explored. It was felt that ideally there should be no difference between the meaning for persons with disabilities and those without. Nevertheless, these concepts will evolve as persons with disability gain greater voice and it will be they who will define its meaning for themselves. One has to therefore be careful about making generalised statements such as "persons are most happy when they are with the family and are getting quality care." There could be a host of reasons why the family may not be the best place.

Emerging Issues

- There is a huge role of sensitising the community and spreading awareness about the rights of persons with disability. Just offering a service without community involvement will not lead to sustainable solutions.
- While Indian sensibilities will have to be kept in mind, at the same time, the country will have to undertake affirmative action to meet the goals of UNCRDP. Thus while dealing with caste and religious issues, the implications of living together will have to dealt with. The stigma associated with care giving will have to be replaced with a highly professional approach.
- While it is extremely important to centrally involve the organisation of persons with disability and activists from the sector, there will have to be other mechanisms through family or supported decision making to include the concerns of those persons who are severely profoundly affected. There is a continuum of needs that have to be addressed and there can be no one size fits all approach.
- There is a lot of scope for convergence among the various government bodies that can play a role in developing assisted living and National Trust could be the hub to ensure this convergence.

❖ **Impact Evaluation of Samarth Scheme**

- The study findings indicate out of the total 1952 samarth residents, 1259 (64.5%) residents are male and 693 (35.5%) are female. Further, age-wise break up reflects 389 residents (19.9%) are below 10 years of age. Similarly, 1189 (57.3%) residents belong to the age group of 11 to 18. This is followed by 382 (19.6%) residents between 19 to 35 years of age, 46 (2.3%) residents between 36 to 50 years of age and only 16 (0.8%) residents are above 50 years of age.

- The study also intended to assess the severity of disability of the residents. The findings reveal the disability of 107 (5.5%) residents are profound in nature, followed by 838 (42.9%) cases have severe disability, 784 (40.2%) have moderate disability where as 223 (11.4%) have mild disability. Further, it was also observed out of the total residents, 657 (33.6%) are from the middle class family, 634 (32.6%) are from the lower class family and 661 (33.8%) are from the family of below poverty line.

Chapter - 2

Models Identified in India

❖ Disabled People Led Model

People With Disability Promoted Model

Assisted living is an area that has /is being debated in a number of platforms. The group that is very vociferous about it is the parents group. The parents eternal worry "what after me?" has led to this discussion, but this debate has invariably discussed "homes" a more passive placing of adults or children in a sheltered place.

Over the years, and particularly after India's ratification of the UNCRPD, the growth of the disability movement, professionals, parents and persons with disabilities are now looking at the concept of Independent Assisted Living.

This shift from a passive "home" or institutionalization to a concept of independent living in the community is a reflection of new ideas that are emerging.

To quote Gerard Quinn and Michael Stein: "This right to legal capacity, acknowledges that people with disabilities have an innate capacity to decide their destinies for themselves – where to live, who to live with, what education or employment to pursue – and to have those choices respected. And if there is to be an intervention on the part of the State, the primary impulse should be to support a residuum (class of society that is unemployed and without privileges or opportunities) of capacity and to intervene to support people to make decisions for themselves, with appropriate safeguards".

This statement is particularly relevant to the idea of Independent Assisted Living promoted by the government of Kerala.

People with disability led model of Assisted Living

To get the views of persons with disabilities for their idea of an Assistive Living model a number of focus group discussions were held.

The size of the focus group was 4-6 people at a time. There was one discussion with only two people with disabilities and one where it was a one on one discussion. The discussions were with people with multiple disabilities, one with a person with visual impairment. There was no one who had hearing impairment.

The results / outcome was very interesting. They started with some:

Philosophical thoughts:

The decision / choice of going into a home should be in consultation with the person with disability. It should preferably be the last choice and the exit policy should be insured even when entering. Re-entering should also be allowed.

Physical environmental:

It should obviously be an accessible building and preferably divided into cottages. It should be cheerful, well ventilated with light walls. The construction / infrastructure should ensure privacy, but at the same time make sure that the area can be accessed if the person gets locked in. The cottages / rooms should have specified spaces for individuals. And definitely separate cupboards. Each person should have a key to the house and his room.

Residents:

There can be 30 in a home, divided into groups of 8 & 10 in each cottage (depending on floor area). It should definitely be a mixed group, that is, both genders and a mix of disability and the severity. Privacy has to be ensured. These smaller groups can work with 2 -3 care givers.

Emotional Environment:

Decision making is the prerogative of the residents where ever required. Flexibility in time, freedom of movement, freedom of religion, freedom of choice for leisure has to be ensured. The house should have music, TV, Games etc., and medical support on call.

Work:

Separate work place from home. If work has to be at home – choice of work in relation to age, cognitive ability and if possible, interest, has to be ensured. If the person with disability gets a salary they should contribute to the home. Choice of work should be left to the person with disability.

Leisure:

The residents have the right to choose the leisure activity. The activity is planned in such a way that it is age appropriate. Also encourage the development of activities like hiking, dancing, gardening etc.

Monitoring:

Monitoring is important. The Monitoring committee should be made up of people with disabilities, parents and professionals. The majority number in the committee should be people with disabilities.

Meetings:

Regular meetings of the monitoring committee has to be ensured and a grievance cell to be set up at various levels. Action should be taken as fast as possible if there is any abuse.

To summarize: The people with disability came up with the following non-negotiables.

- Security / secure environment
- Freedom of movement
- Separation of work / vocation from home
- The option to have religious freedom
- Accessibility in all areas
- Independent / supported decision making
- Entertainment / leisure
- Diversity

❖ Group Home Model

Swayamkrushi in Hyderabad has set up six group homes within the community. These group homes are located in apartments within larger complexes. Each unit houses six women with intellectual disabilities and a care giver.
Before starting a unit, a sensitization of residents in that complex happens over a cup of tea. This has helped to integrate and have complete acceptance. Residents of these units do all the household chores and also go out to work. They have an active social life within the complex and have been trained to budget and shop. This has been an unique experiment in our country and some of the learnings are important.

a. The ultimate aim is not just to care for the persons with intellectual disability, but to integrate them into society's fabric with status and self respect.

b. The social environment and culture being so diverse, the training of persons should be tailored to suit geographical, linguistic and social mores.
c. Training can be imparted in post-school programmes.
d. Such training must be imparted with the active interaction and appreciation of the parents. It has to be dynamic in nature and requires a good review mechanism.

A feeling of participation is encouraged through the following:

1) A normal rhythm of the day such as going to bed and getting up, getting dressed and eating as other peers.
2) A normal routine of life such as living in one place, working or attending school somewhere else and having leisure activities.
3) Experiencing the normal rhythm of the year with holidays, visiting the family and vacations away from one's home.
4) Having an opportunity to undergo normal developmental experiences which help grow and flourish with choices respected.
5) Experiencing normal economic and financial privileges which promote personal use of money through realistic social training and fostering of independent use. Work in open employment or in sheltered workshops or within institutions should be paid for accordingly.

❖ Foster Care Model

Persons with Neuro-Developmental Disorders (NDD) need proper care and individual attention from childhood for their all-round development. Though it is advised that such persons live with their families, often due to varied socio-economic reasons parents of Children with Intellectual Disability are not able to provide the much needed systematic training to their wards.

The purpose of providing Residential Care/ Foster Care is to provide a temporary safe placement for children with NDD so that they can be groomed and trained for independent living, also indirectly preparing them to be contributive members in an assisted living environment**.**

We do accept the fact that natural parents are the best care givers. Generally children with Mental Retardation and other Developmental Disorders stay with their parents and are provided with inclusive or special educational facilities. However, our experience has been that though these children are being cared for and trained by their parents within their own family set-up, when they reach 18-20 years of age parents look for an alternative residential shelter as they find it difficult to handle their behavioural problems and lack of independent living skills. It has also been found that 60 per cent of siblings of persons with disabilities (PwD) are not ready to accept the behaviour of the individual. (The unfortunate fact is that at the age of 18 years when we try to separate the PwDs from their families, it often causes immense mental / psychological trauma for them).
The "Ashraya Model" of foster care homes attempts to address several of these issues. It provides girl children with NDD Residential Facilities (Home away from Home) where they receive love, care and all sorts of facilities which are essential for their all-round development. They can also spend time with their parents and siblings during holidays and attend all important family functions. By the age of 18-20 years they achieve all pre-requisite skills needed to lead an independent adult life within their family, and above all, they can take care of their aged parents.

If such foster care homes, managed by dedicated NGOs, are made available throughout the country, parents can be free from their primary anxiety – "what would happen to our child when we are no more".

In order to achieve the objectives of the foster care programme the number of members in each home should not exceed 25-30. It is also better to have separate homes for boys and girls, with interaction programmes for them once a week or fortnight.

Each district could have 3-4 such foster care homes based on the needs of parents.

- **Ashrya** is a Residential Rehabilitation Home located in Kollam District for children with physical and mental disabilities from economically, educationally and socially backward communities. Its mission is to mould each child into a self-reliant, confident individual.

Ashraya provides the following services:

- Takes over the responsibilities of looking after girl children, which allows the mother the much needed freedom and opportunity to work.

- Provides employment to graduate women with disabilities by training them to be Special Educators.

THE ASHRAYA FAMILY

A girl child with NDD walks into the warmth of a family which consists of

- A mother (a single woman 45-50 years of age)
- An elder sister/teacher (a qualified special educator who lives on campus).
- Eight siblings with multi-abilities who compliment each other with their skills.
- Grandparents (senior citizens who are ready to utilize their wisdom/ life experience

ASHRAYA- ACTIVITIES

Ashraya extends a comprehensive rehabilitation services to girl children. It provides hygienic surroundingas, a well balanced diet, medical intervention and well rounded services.

INFRASTRUCTURE:

Ashraya is not an institution, it is a Home. Ashraya's building is totally disabled friendly, with great emphasis given to the atmosphere, such as bright and soothing colours on the walls, decorated with paintings, proper ventilation and lighting. It is designed to achieve maximum utilization of space. It provides dormitory facility with attached toilets at the same time providing the much needed privacy.
To run the present Residential Rehabilitation programme for 25 children, i.e. 3 families, Ashraya requires a sum of `100000 /- per month including expenses for students, welfare activities and staff salary.

ASHRAYA- A SUCCESSFUL MODEL

Senior children are now acting as caretakers/ sisters/teachers of the younger siblings. Hence Ashraya does not face any problem when a staff member leaves the home. Ashraya children are totally independent and are able to not only look after themselves but can take care of others as well. Independent Assisted Living has helped them achieve this.

❖ Social Therapy Model- Assisted living for adults with disabilities

Introduction

The Social Therapy Model for Assisted Living for adults with disabilities practised at Campion Hill Bangalore hinges on peer group companionship. The rehabilitation of the individual is addressed primarily through social therapy by way of involvement in housekeeping, kitchen work, maintaining the farm, vocational training, leisure, art and cultural activities.

The model is suited for people within the age group of 18 to 40 years with any or multiple disabilities. It involves 12 friends coming together to live under one roof along with one house parent and five co-workers. It would be best if both genders were included in the composition, with mild, moderate and

severely disabled being incorporated in the same home. Below Poverty Line Assisted Living homes would need to be sponsored.

MANAGEMENT

a. In each house, it is the responsibility of the house parent to oversee and supervise infrastructure and monitor progress.

b. There will be five co-workers in each house, both short term as well as long term. Their task is to support individuals with disabilities in ADL, in personal care and mobility at all times. They are trained to work on the farm, conduct workshops, cook, execute housekeeping, keep night watch and engage with the residents in outdoor activities, celebrate festivals and share meals.

c. There are day workers who teach pottery, weaving, tailoring, clay modelling art and work on the farm. The cooks are assisted by co-workers and residents. One of the co-workers is a driver.

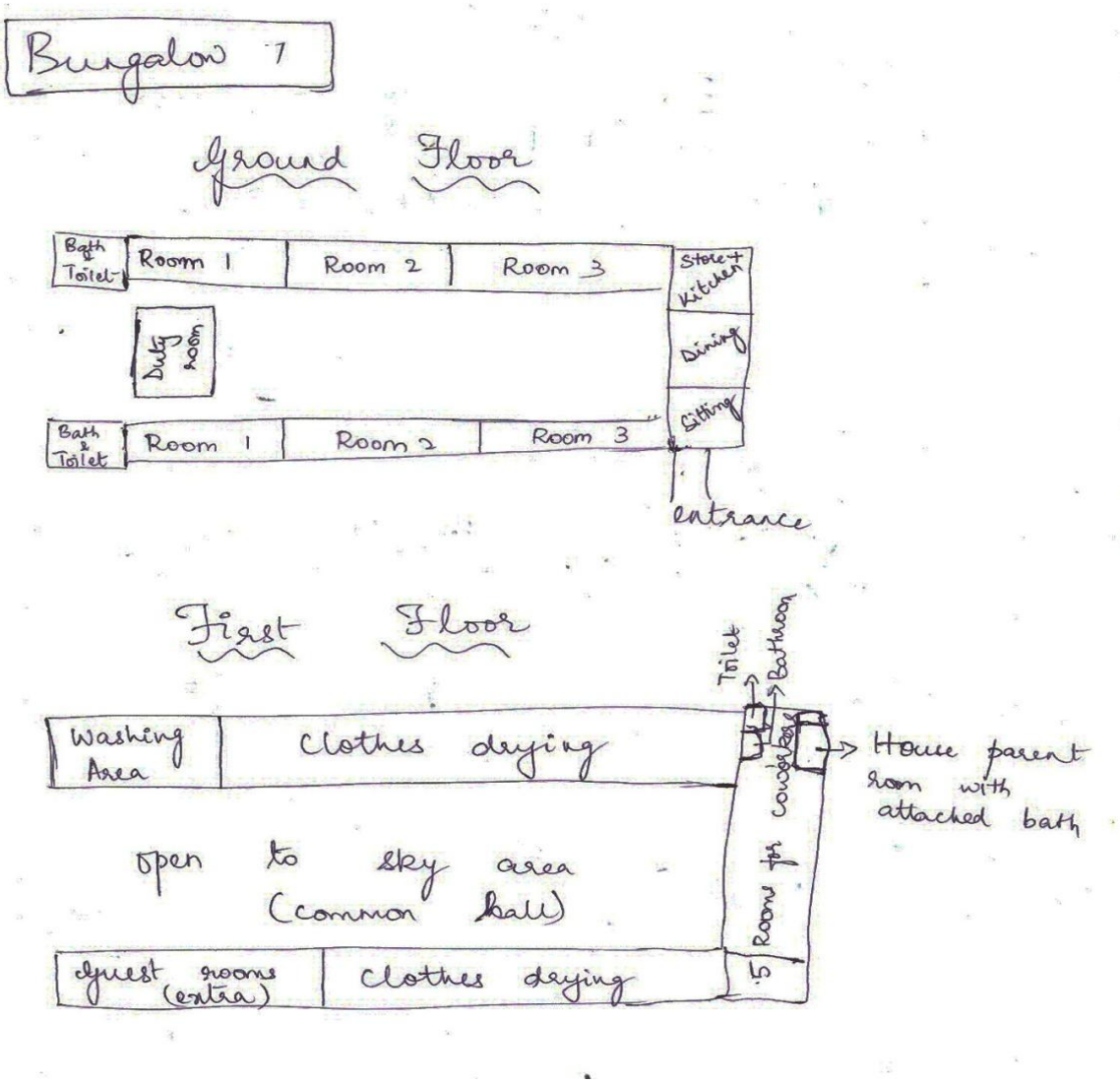
d. Weekly and monthly interactions with parents, guardians and guests are organized.

INFRASTRUCTURE

The infrastructure and architecture is designed to enable a healthy and barrier free environment.

The Campion Hill campus has two independent bungalows separated by a Vocational Training Unit Block. It is surrounded by a garden and a farm.

BUNGALOW 1



The ground floor is a T- shaped, rectangular plan, with an open courtyard on the horizontal access and three rooms on either side of the courtyard housing two people in each room -- six men and six women.

There is one duty room with a 24 hour co-worker on the job.

At the two ends of the living rooms, there are bathrooms on either side for men and women. They consist of one Indian closet and two western closets, both having design adaptations and accessibility for wheelchair users and others.

Three shower rooms with hot water and cold water facilities and three wash basins outside the shower rooms at different heights complete the bathroom set ups.

Three quarter doors with latches that swing into lock and unlock position are there with no bolts.

Handle bars are provided in all rooms. Switch boards are at wheelchair level.

Flooring is without any obstacles and grip tiles.

The vertical part of the T-shaped room will consist of three portions:

One big common room for relaxing, indoor games, music, reading and prayers.

One big dining room with table and chairs to accommodate 18-20 people. The room has a wash area and cupboards to stack crockery and miscellaneous items with a lock and key. All utensils (plates, tumblers, spoons, etc) are of stainless steel, some stylized for easy use.

The dining room leads to the kitchen, with a small wash area with double sink, one for dirty dishes and one for washing. A fridge, a gas stove and a locked store room are additional features.

The two floors are connected by a ramp

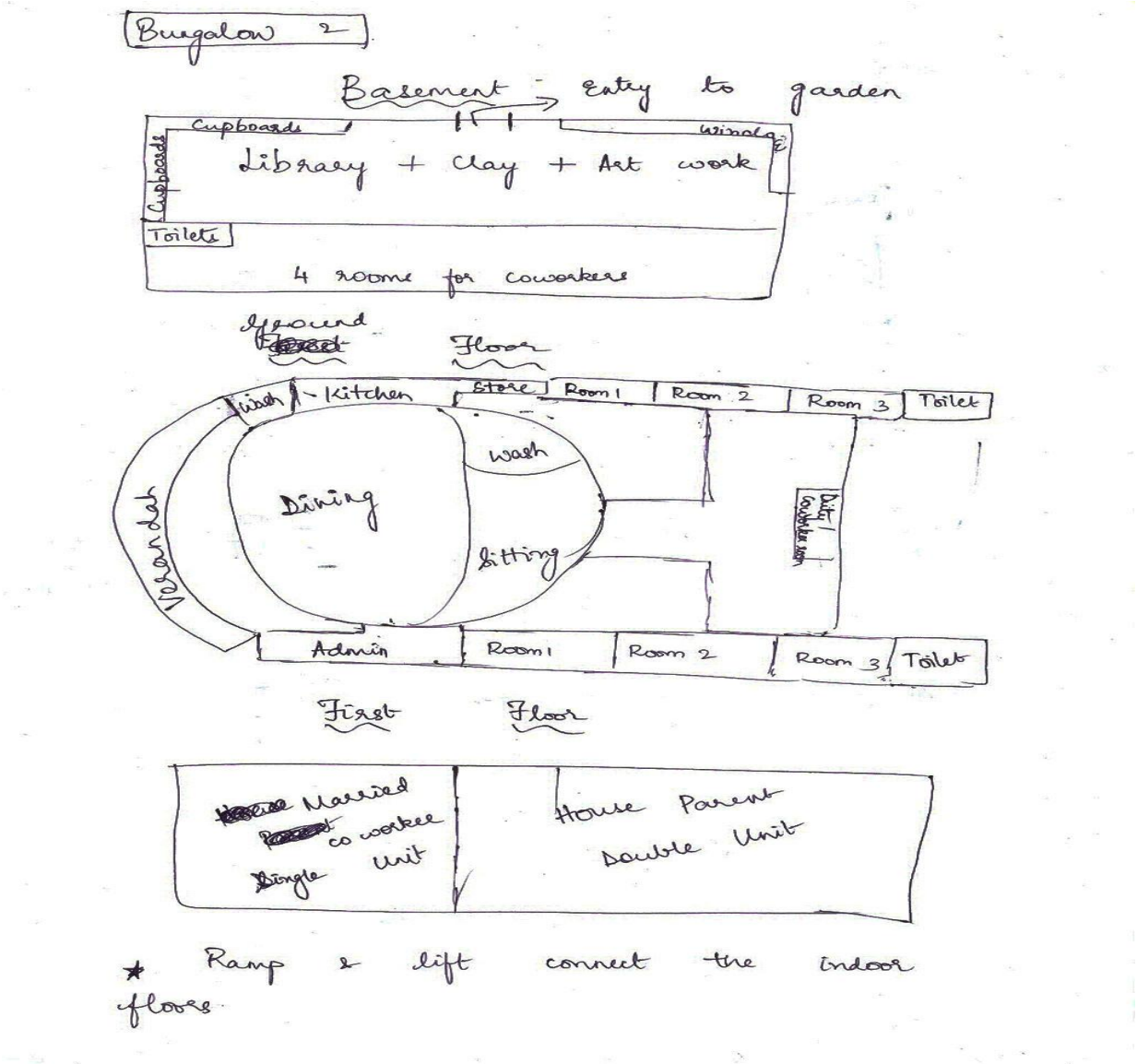
First Floor

On the horizontal wing, there is a room with three washing machines and an open space for drying clothes. Facing this room are two extra guest rooms.

On the vertical plane, there is one double room with an attached bathroom for the long stay house parent.

Adjacent to this, there are five rooms for co-workers. The corridor has two toilets and two shower rooms.

Bungalow – 2



This consists of three levels – basement, ground and first floor.

BASEMENT

The basement is a rectangular room with a huge meeting room used for various purposes including as a library, for clay work, art work, reading and house meetings.

On the adjacent side of the meeting room, accommodation for 4 co-workers are provided with two western toilets, two shower rooms and two sinks.

The toilets can be accessed by people who come for activities or meetings.

A ramp connects the basement to the ground floor. Steps connect the meeting room to the garden outside.

GROUND FLOOR

The ground floor comprises rectangular floor space with circular walls to be used as dining space and a sitting room.

On one side of it is the administration office. Facing the office, leading from the dining room is a common kitchen with a store room fitted with a wash area.

The kitchen has a solar stove, a fridge, platforms, two sinks and wall mounted cupboards.

The sitting room leads to an open courtyard. On either side there are three rooms for men and three for women, each for two people. These rooms lead to common toilets on either side.

There is a duty room for the co-worker in between the living rooms of men and women. Bathrooms and living rooms are designed according to the specifications given in the first bungalow.
A semi-circular verandah runs all along the dining room with overlooking bay windows.

FIRST FLOOR

A ramp connects the ground floor to the first floor which has a huge open terrace. There is a lift that can carry two wheelchair bound persons at the same time. The rest of the design for indoor leisure activities is similar to the first bungalow.

The first floor houses two quarters, one for permanent house parents and one for married co-workers. The quarter for the permanent house parent comprises two bedrooms with dining cum sitting room, kitchen, toilet and bathroom. For the married co-worker, a single bedroom with a small kitchenette and dining cum sitting room, toilet and bathroom are provided.

OUTDOORS

The outdoors is designed for leisure activities -- a swimming pool, hand ball court, a field for racing and other games. Rest of the land is an organic kitchen garden. There is a shed to house cattle and a garage with parking for two vehicles. There is one family car and one van for shopping and transportation.

VOCATIONAL TRAINING BLOCK

The vocational training block is hexagonal with a doorway in the front, a room on each wall, a toilet and a common conference hall. Activities such as pottery, weaving, tailoring and mat making are conducted here. The roofing is of Mangalore tiles with sun windows to allow light to the central conference room.

Summary

Life in the house is geared towards a healthy social life so that the community may contribute to one another towards a healing effect on everyone.

❖ Parivaar Model

PARIVAAR – the National Federation of Parents' Associations (NFPA) was formed in 1995. It is the apex organization at the national level that speaks for the rights of persons with Mental Retardation, Autism, Cerebral Palsy and Multiple Disabilities and their families. Parivaar is a full member of Inclusion International, a world body of parents' associations of the above disabilities in over 200 countries.

In India it is a federation of over 150 Parents Associations and NGOs in 27 states and a grassroots organization with 70 urban, 42 semi-urban and 38 rural parents' associations. Almost all the associations plan to set up living arrangements for their children, which will take care of their needs when they are no more. Most of the parents' associations are also members of the National Trust and some run the Samarth and Gharaunda programme.

To understand the models being developed by the parents' associations, the Expert Committee sent out a questionnaire. Five organisations responded, two of which are part of National Trust's Gharaunda scheme and one part of the Samarth project.

We present one example here from Thane, Maharashtra:

Assisted Living Centre at Nirdhar Pratishthan

Objectives:

- A model assisted living facility with vocational training and a sheltered workshop.
- A model of Agro based vocational training for residents and day care students from adjoining rural/ adivasi areas
- Create strong group of care givers, vocational trainers for agro-based vocational training.
- Build awareness among parents about government pension and health care provisions.

Target Group:

- Assisted living – 48 residents. Care givers 8.
- Counselling and home based vocation for 100 persons in rural/ Adivasi areas.
- Awareness and Advocacy : 360 guardians and well-wishers for implementation of pension, health care, legal rights and right to receive special education and therapies.

Answers to Expert Committee's questionnaire

Facilities provided

Dormitory type accommodation, hygienic food, toiletries, clothing (optional), non-prescriptive medicines, appliances for accessibility, reading material, sports facilities, vocational training and recreational facilities.

What is the Admission and Exit policy.

- Persons over 18 years with mild to moderate intellectual disability
- MR, CP-MR, Down syndrome
- Should be more or less ADL independent
- Self mobile during admission
- Should not have violent/ disruptive characteristics
- No contagious disease
- Care is provided for life time
- Exit is only due to persisting non acceptable behavior which can cause self injury or disruption to peaceful living of other residents.

1) **Vocational training and employment :**

SewiSewing, arts and crafts, weaving, pager bag making, cooking, training as watchmen, care givers and agro-based voc s and agro based vocation.

❖ National Trust Model

Samarth Scheme

The Samarth Scheme was launched in 2005 as a residential facility for 30 residents both girls and boys of all ages. This scheme was preceded by a pilot called the Reach & Relief Scheme. The Samarth Scheme is given to the registered organisations of National Trust, the funding is minimal as a tapering grant for nine years. The main aim is to help NGOs to become independent in running residential facilities. In fact, most of the project holders will be completing nine years either this year or next year. We have already given the learnings from Samarth programme in the earlier chapter. We would like to give one example of PASS which is both a member of National Trust and Parivaar in Guwahati.

There are 120 Samarth projects across the country and in terms of quality of services, it is a variable range.

1. Centres that are doing well are those which have explored and created newer opportunities for its residents. They have been able to raise funds to sustain and at the same time support skill-development of residents many of whom are earning members today.

2. Organisations that do not have a strong foundation in running services have had limited growth and not been able to diversify their services or create wider opportunities for their residents. These are mainly in remote or rural areas. Access to training facilities both for the staff and the residents and funding opportunities are limited.

3. Centres that have not been able to establish themselves are those who had to rent space for the project. They also lacked capacity is raising funds and running residential services for adults and preferred to run it for children.

PASS - (An organization of Parents for welfare of Persons with Intellectual and Developmental disabilities), Birubari, Guwahati-781 016

Facilities provided:

1. Provide all beneficiaries the required services without any discrimination.
2. Enable the beneficiaries to become self reliant in daily living to the best of their abilities. They are encouraged to assist in taking care of cooking, gardening, cleaning and recreation activities etc.
3. Involve the residents in planning and decision making. They are encouraged to work as a team following an approach of mutual support.
4. Provide facilities for vocational training.
5. Provide opportunities for outdoor activities---recreation, sports, art, music, celebration of festivals and social interactions.
6. Encourage the participation of Parents/Guardians.
7. Manage the residential complex in a homely atmosphere.

A. <u>Admission to Home-cum- Care Centre (Samarth Centre)</u>

The resident should have attained 18 years of age. Hostel accommodation is provided to those below 18 years who are from outstation, to avail special education services at Shishu Sarothi, a special school.

At the time of admission the following documents are required:

1. Disability certificate
2. Legal guardianship certificate
3. Medical reports from specified medical centre as well as previous medical history reports.
4. Support network of minimum 3 members (family members, relatives, friends etc.) residing in Guwahati.
5. An MOA (memorandum of agreement) is signed between PASS and the parents/guardian.
6. An initial trial period of maximum 1 month is kept as observation period during which either party i.e. PASS or the parent/guardian may withdraw admission giving adequate reason/explanation for the same.
7. Parents/guardian would be required to intimate the resident's existing assets if any and his/her inheritance rights. PASS shall be duly informed if there is any change in the resident's assets or inheritance rights (e.g. due to a WILL etc.).

GHARAUNDA

The National Trust launched GHARAUNDA - a scheme for Lifelong Shelter and Care. Its objectives:

1. To provide an assured minimum quality of care services throughout the life of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities
2. To encourage assisted living with independence and dignity
3. To facilitate establishment of requisite infrastructure for assured care system throughout the country
4. To provide care services at an affordable price on a sustainable basis.

PARTNER HOOGHLY - RESIDENTIAL CARE SERVICE

No of residents: 3. Healthy food, medical attention and other facilities are provided. There are two care givers. Vocational training, workshops and recreational activities are provided.

Admission and Exit policy:

Life-time/monthly payment option. Each boarder is kept on 3 months trial before final enrollment. To leave, 60 days prior notice is required.

Monitoring mechanism

Three parent member sub-committee monitor the day to day activities and look after the maintenance and proper running of the residential care unit.

KARNATAKA PRARENTS' ASSOCIATION FOR MENTALLY RETARDED CITIZENS [KPAMRC], VISHWASHANTI NIKETAN,

(Group Home Rehabilitation Complex)

No. of Residents : 34. Number of care givers: 6
Age : Between 22 years to 60 years
Sex : Male – 22; Female – 12
Class : 27 Lower Middle Class, 02- Upper Middle Class, 05 - BPL

Facilities provided

Long term residential care, short-term care, quarterly medical checkups, vocational training, day care, periodical outings, participation in sports and games competition and cultural events.

Rules :

i) Parents should be a member of the Association.
ii) Admission is for persons who are 21 years and above.
iii) Parents / guardians can take back their children at any time of their choice after three months of admission giving 30 days notice.
iv) Parents/guardians to provide required medicines, clothes etc., for their wards except those from BPL category.

Monitoring Mechanism

Core group consisting of two representatives from parents of persons who are residing at Vishwashanti Niketan and two from the Governing Council of KPAMRC.

Monthly meeting held on Second Saturday of the month for parents of residents staying at Vishwashanti Niketan.

Monthly meeting of governing council of KPAMRC held on 3rd Sunday of every month.

Prayas, Kolkata, West Bengal

The Project undertaken by Prayas Community Living Centre(PCLCT) towards Assisted Living is "SWAPNANEER" where people with disabilities will live under one roof with their parents.

Project "SWAPNANEER" thus comprise of three components:

(a) The Living Component comprising of Residential Units in the form of small living-cum-bed rooms with attached bath and a small balcony, separate dormitories for male and female residents with disabilities. It functions like a commune with a common kitchen and dining area. People with disabilities will be looked after by other parents once their own parents are no more.
(b) It has a pre-vocational centre and a full-fledged vocational training centre.
(c) Remedial education, assessment and counselling centre.
(d) Parents counselling centre.
(e) Centre for early detection of disability and intervention.
(f) One normal lift and a larger Lift (for carrying ailing residents on a Stretcher).

The Project has been planned for 25 families in the first phase. The care giver ratio is 1:5.

ADMISSION AND EXIT POLICY

As per the system of community living as conceptualized in this Project, the resident member shall live in the Swapnaneer complex as part of a joint family. Parents wishing to join the project have to enroll themselves first as members of the Society with the details of their child. There is a period of time when the new members get to know the earlier residents and a mutual decision is taken on whether they will fit into this community.

MONITORING MECHANISM:

In-house monitoring within the building will be through CCTVs to be fixed in various strategic places/rooms/dormitories. The monitoring will be done from the control room by a batch of Resident Members on a roaster basis. Surprise visits to various places will also be another mode of monitoring.

❖ Self Help Group and Local Self Government Model

RDT is a non-government organization based in Ananthpur district of Andhra Pradesh. This program is the implementation of a study mentioned earlier.

In 2009 RDT recognized that its program with disabled people also needs to include services for adolescents and adults with profound degree of Cerebral Palsy, Intellectual Disability, physical Disability and Multiple Disability.

Based on the recommendations of the Study, RDT designed a community based program called "Supported Living Program". The rationale of this design is its strong base in villages and its approach of community organization.

The key principles of this new initiative are:

- A community based initiative led by disabled people, their families and their organizations.
- A life span approach.
- A multi-sectoral focus

Entry point for implementation of this program is SHGs of persons with disabilities at the village level and Federations at the mandal level. The strategy adopted by RDT is facilitating SHGs and Federations (Disabled Peoples' Organistaion (DPO)) to take ownership of the program and ensuring future sustainability.

The general perspective of the facility, rules and regulations:

The engine that drives this program is disabled people's organizations. RDT's role is to facilitate DPOs to initiate and implement the program. The DPOs plan and implement the program. Almost all the resources are provided by the DPOs (caregivers and money) augmented by RDT with other services i.e. infrastructure, technical assistance.

Day Care Respite Centres function from already existing RDT school buildings, or where it is not available, alternative space is identified. The centres provide recreational facilities.

The village level caregivers are preferably members of SHG or a sibling/parent of person with disability in need of high support. There are two care givers (a man and a woman) in each village. They work in the centres primarily to assist people with disabilities to improve abilities and they work at home providing care.

The caregivers get honorarium on par with NREGA (National Rural Employment Guarantee Act) rate.

DPOs select caregivers and supervise their day to day work. If caregivers are not found in the SHG then they are engaged from the village. Caregivers are trained on the job according to the specific needs of the people being cared for. RDT conducts generic orientation and training programmes.

Funding:

RDT provides a one time grant to DPOs for income generation as a rolling fund. The DPOs lend this money to its members on interest. The DPOs have decided that they will contribute 50% of the interest earned on the loans given to members for the honorarium of the caregivers and the rest of the salaries are provided by RDT. The DPO members also contribute a one time of RS 50/- to 200/- at the commencement of the program. All this money is kept in a separate account by the DPOs.

In addition the interest that is returned by banks on the loan taken by members after 9 months of regular payment is also to be use for this program. It is planned that the care givers and mandal rehabilitation workers attend the DPO meeting every month.

Monitoring:

Planning and monitoring are carried out jointly by the staff and DPOs, both at the village and mandal levels. The caregivers maintain a roaster which is submitted to the mandal level rehabilitation workers. The DPOs verify and make payments to caregivers.

SHGs are responsible for monitoring the caregivers day to day work, and MS is responsible for monitoring the total program.

Chapter - 3

Model developed by Expert Committee in Assisted Living

After understanding all the models, the Expert Committee has evolved a model for Kerala State. (If accepted, we can find a specific name for it).

The Govt. of Kerala will set up 500 such units, across the state.

1. **Size of Each Unit**: Each unit, will be for 10-12 residents, and if space allows perhaps 1-2 residents for short term stay traditionally called Respite Care.
2. **Location**: Units will have to be located within the community, and not in an isolated or far off place, as is generally done for homes and institution. Units can be located within villages, small towns or could be an in an apartment building in the city.
3. **Composition**: Each unit can house both men and women, with separate living arrangements and common spaces eating, socialisation, leisure time activity. Depending on the situation, it can also be decided to have single sex units. However, the former is preferred, to support mainstream living which has been found to be therapeutic.
4. **Typical unit**: Each unit will house adults with intellectual and developmental disabilities (autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities). Each unit will have at least 2 residents with high support needs.
5. **Culture of the Unit** : Each unit will have a unique personality, reflecting the likes and dislikes of the residents. It will have a home like atmosphere, where each resident will contribute, by being responsible for any one task. Decision making in the unit will be a collective exercise, especially for menu, cleanliness, decor, leisure time activities and working out a broad rhythm of the day. Each resident will go out to work, which may be a job in the community or an enterprise which a group among them has started.
6. **Protection Policy**: A policy against violence and abuse will be formulated from the guidelines developed by National Trust on his website. Each member of the staff and resident will need to sign a code of conduct.
7. **Women with disabilities** : Since women face double discrimination it is important for the entire project to keep in mind the special need and vulnerability that women face.

The residents will collectively decide on outings, celebrations and inviting community members over, just as it is done in a family.

Entrance Policy: The following criteria should be followed for admission:

1. A person who has no family support.
2. A person whose family support has diminished because of death or illness of parents and breakdown of the joint family system e.g. siblings live separately and do not want to keep the person with disability. (However, as far as possible living with the family should be encouraged).
3. A person with high support needs, due to profound disability, epilepsy or behaviour issues.
4. A person who would like to move out of his/her parental home and look for skills, training, livelihood and may want to return to the family after having acquired the skills.
5. A person who would like to move out of his parental home, to live an independent life but many need support to live independently.

Exit Policy – All residents will have individual short and long term goals.

1. A resident may like to return and live with parents or siblings once they have learnt the required skills or have a livelihood.

2. A resident may like to move out and try and live independently in the community, once he/she has the ability to earn a living wage.

   If he/she does not succeed, the individual must be given the opportunity to come back to the assisted living facility.

3. A resident may want to get married and raise a family.

All Exits will have to be planned by the manager and the residents in consultation with the Management Committees.

Implementing Agencies : Kudumbshree & NGO's

Wherever needed if an NGO is commissioned to run a unit, norms for accessing the capability and credibility of NGO's will be laid down but may broadly be the following

1. The NGO must have a proven track record of not less than 10 years working with persons of the above disabilities.

2. It should believe in the philosophy of assisted living as against a top down institutional set up.

3. It should be accredited by Credibility Alliance or any other recognised agency.

Manpower – The ratio of caregivers can be 1:4 – e.g. for 12 residents we can have 3 live in staff. (1 amma – 2 chechis) and 1 Social Worker or Manager of the unit, who will be a non resident. The Manager / Social Worker will be responsible for the day to day administration of the unit.

Sensitising the community in the neighbourhood – Before setting up a unit, there must be a programme to sensitize the entire neighbourhood.

The Manager (Social Worker) will identify key people in the neighbourhood, not just elected leaders, but active opinion makers. They will be invited for a cup of tea and explained in detail about disabilities and the philosophy of assisted living. This can be done several times with larger gatherings each time.

This will also help, to identify volunteers and a community committee of 5-7 people.

- Rapport with the families of the residents.

- Day to day decision making (collective one).

Support Plans – Each resident will have an Individual Plan for the skills he or she may need to learn in ADL, household skills, social skills and vocational skills leading to livelihood or employment. Each plan will have both long term and short term goals. The long term goals may also change, as the person grows and evolves. Therefore, they will need to be revisited at least twice a year.

Each resident can also develop a circle of support, over a time. A circle of support or the first circle of friends are people who support for different aspects of one's life for e.g. what to wear, choosing a health treatment, choosing a leisure time activity, how to use one's money etc.

Volunteers – The Managers will look for volunteers from the community, who may like to come in for leisure time activities like – Yoga/Music/Theatre/Art/Pottery etc.

Local Doctors and other special requirements will have to be arranged.

Care givers : Training of caregivers will be essential and they will be taught day to day therapy, specially needed for any resident.

Livelihood Manager / Social Worker

For every 5 units there will be one Social Worker to work on Livelihood and Employment for the Residents. He/she will need to do the following:-

Resource Mapping :To locate opportunities for employment in the neighbourhood and matching them with the skills of each resident, supporting residents to get a job, travel to work and also keep the job.

Job Coach – The social worker may need to help residents to learn the skills needed for the job and also skills for keeping the employment.

Micro enterprises – In case, appropriate employment is not available, residents may join a self help group of Kudumbshree if they enjoy the livelihood work that group is doing.

They may also set up their own micro enterprise. ARUNIM of National Trust may be one possible link (see linkages).

Therapists – For every 10 units there will be at least two of the following:-

- Physiotherapist
- Occupational Therapist
- Speech Therapist
- Communication Therapist

They will visit each unit in rotation, at least one of them once a week. They will also be on call. Specific day to day therapies will be taught to the caregivers

Initial Pilot

It is suggested that we pilot the model in three places – south, central and north Kerala for a period of ten months in 2014-15.

This will require that the Department of Social Justice locates the buildings where this could be piloted. It would be beneficial to have one in a rural area, one in a small town and one in a city.
As we have identified Kudumbshree as the implementing agency, it can help with the planning and implementing of the pilot.

1.Sensitising the community – this will be done using the module that has been developed by Manjula Kalyan and NIMH. This will also help us to identify the beneficiaries for the pilot.

2.Training: in order to train caregivers, we will need to first train Master Trainers who are chosen either from Kudumbshree or another NGO. This is important as the caregiver training programme will have to be done in Malayalam. Master Trainers must have experience of working in disability for at least five years.

3.We will also need to sensitize Govt. officials, panchayats, parents and members of the Local Level Committee. This can be done by the Members of the Expert Committee.

4. We will need to recruit at least four social workers. Three will be the managers of each of the pilot units and one can help with resource mapping, employment and livelihoods or setting up of micro enterprises.

5.Mid-term review by the Expert Committee in seventh month and end term review in the 10th month must be carried out before rolling out the rest of the programme.

It is also suggested that a pilot could be initiated for a half way home : The main objective would be to understand and help settle down prospective resident, with the following difficulties. This will be before admitting them into a permanent home

a) Persons who have been abandoned
b) Have serious health or psychiatric issues.
c) Have high support needs, which need careful planning.

Staffing suggested:

1 Social worker, (full time) 2 Care givers (residential) and 1 Medical practioner (part time)

Chapter – 4

Guidelines

❖ ASSISTIVE DEVICES FOR INDEPENDENT LIVING

Article 19 of the UNCRPD provides that people with disabilities have the right to live independently in the community. Community living refers to persons with disability being able to live in their local community as equal citizens, with the support that they need to participate in everyday life. It also states that persons with disability have access to aids, devices and adaptations as per their requirements. It further states that the disabled have the right to support for living independently. Throughout the convention we see an acknowledgement and recognition of the right of the people with disability to a full range of support – from mobility aids to personal assistants; from access to building and public spaces to access to information. They may also require support to make decisions.

Therefore supported or assistive independent living does not mean a lack of independence; rather it reiterates the concept of interdependence and promotes it. And so assistive independent living is about having the autonomy to make decisions and having control over their choices. If support is required, to make this possible, it has to be provided.

In India, models for independent assistive living for multiple disabilities are very few – if none at all. One of the main reasons could be the complete lack of Assistive devices or access to assistive devices.

However, there has been an effort to develop indigenous aids and also to acquire and to list out the aids that are required.

In the model that is promoted by the Government of Kerala, it is crucial to make access to assistive devices available

This Chapter explores this under three headings:

1. Personal
2. Environment and
3. Community

Personal:

a) Communication aids
b) Daily living aids
c) Clothes

Environment:

- Home environment
- Work environment

Community

- Access to public spaces

1. Personal :

Communication Aids: If the person is non-verbal or has limited ability to communicate, it is essential to give him a communication aid. As Daniel Webster puts it *"If all my possessions were taken away with one exception. I choose to keep the power of communication, for by it. I would soon regain all the rest".*

In any living environment it is crucial to be able to communicate with each other. If one of the family members is non-verbal it should not be assumed that the person has nothing to say. A communication device has to be made possible for that person.

Communication aids can be high technology – that is using technology for accessing voice output devices. They can also be low technology – which is using charts, gestures and signs.

India today has developed a large range of communication aids which are cost effective and suitable for our culture and environment. They are all cited under the Isaac (International Society for Augmentative and Alternative Communication aids) India website: www.isaac.india.org

Daily living aids:

Daily living aids would address the persons' needs during the day. From tooth brushes to diapers: from eating and drinking aids to being able to make tea for oneself. National Trust: (address 6B, Bada Bazar Marg, Old Rajendra Nagar New Delhi-110060,website: www.thenationaltrust.in) has compiled all aids developed in India for living independently . These are showcased under the name of Sambhav and can be viewed at: AADI – Action for Ability Development and Inclusion, 2, Balbir Saxena Marg, Hauz Khas, New Delhi-110016, (www.aadi.org.in)

For more information a brochure is attached:

Clothes:

Clothes can be make in such a way, that they are attractive, but also gives the person the independence and privacy that is required. From simple things like using velcro and elastics to having an attractive "loop" to a zip. Today there are saris which can be put on like a skirt. Care should be taken that after an adaptation the clothes should enhance the personality not demean it.

Environment:

To further state. The UNCRPD also talks about the Right to movement for the person with disability. If this right has to be exercised the environment at home and in the community has to be made accessible.

2. Home environment:

From flooring in the house which should be non slippery, to step, stairs, and ramps – which should have bright contrasting colours;. There has been extensive research in this area. The details can be found in (Samarthya: website: www.samarthyam.org).

Adults with disabilities may also require motorized wheelchairs to make mobility efficient and effective.

Bathrooms; washbasins; switches and socket position should be accessible from a wheelchair .The window and latches should be at a height that a person with disability can use.

The kitchen counter should be at a height where the people with disability can access (All information in Sambhav brochure).

3. Community:

For people with disability to live independently and be included in a community the community needs to be accessible. From public spaces, to buses and the pavements, have to be constructed in a way that accords a person with disability liberty and dignity .

Leisure:

Leisure possibilities have to be made possible for people with disabilities. Inclusive parks, accessible cinema halls, restaurants, malls have to follow the guidelines laid down for access (www.samarthyam.org).

Inclusive Café's for people with disabilities should be encouraged (www.vidyasagar.co.in)

Employment Opportunities :

In a focus group discussion it was stated that the work place for person with disability has to be away from the home.

Transport and access in offices and public spaces is mandatory. It has to be ensured that the person is provided or can access public transport by themselves.

An accessible taxi service has been started in Bangalore. This service has been a great relief to the person with disability as he /she can now access leisure or employment independently.

(Taxi service website: www.kickstartcabs.com)

Conclusion:

To promote the right to independent living, it is necessary to remove the barriers that hamper it. The government of Kerala is working towards making a policy change towards this direction. They would need to address barriers that stem from stigma, inaccessibility, social structures and lack of support.

The government in Kerala is also addressing policy reform which has budgetary implications. They are also involving multiple stakeholders, other development groups, the local authority and the community.

The model that is developed will naturally be an evolving and dynamic one. If this proves to be a success; the road to recognizing the right to legal capacity, the right to live independently within the community with dignity and adequate support – will become a reality.

For detailed information on measurement, sizes, architecture and access to public spaces, please look up:

Isaac India Chapter: www.isaac.india.org
National Trust: www.thenationaltrust.in
Sambav: www.aadi.org.in
Samarthya: www.samarthyam.org
Vidya Sagar : www.vidyasagar.co.in
Taxi service: www.kickstartcabs.com

Public spaces:

www.chennaicityconnect.com,
https://go.itdp.org/display/live/Chennai
www.accessability.co.in

Sambhav Brochure – Annexure - V

❖ Guidelines for Personnel and Manpower

The caregiving model that has been chosen for the project is replicable. It will ease.
Functioning, Execution, Assessing, Monitoring, Reporting

The objective of the programme is to support the adult disabled to live with dignity, as independently as possible, in thought and action, in a safe environment.

An overall balance in relation to the freedom of the individual to do what one likes and the smooth running of the residence without infringement on others freedom, has to be achieved.

LEVELS OF THE PROGRAMME

1st Level

1) Government to identify the area for pilot study and the temporary building for the pilot study, while the residence is being constructed.
2) To invite members of Kudumbashree to interact with Expert committee members, for sensitizing them to the vision and proposed task that has to be brought into the community ,for sharing the importance of UNCRPD concepts ,so as to create and support the Assisted living.
3) They will share with the committee, the pros and cons of that particular community, so as to mutually understand the cultural background and sensitivities of the community for further planning.
4) They can help to meet the local panchayat and other community members and focus groups(eg parents and to be residents),for initial sensitization
5) They can help identify the following helpers:
    a) Caregivers - Senior and peer group people
    b) Mentors
    c) Volunteers

2nd Level-identification of staff

1) CARE GIVERS - identified from community by Kudumbashree

a) Entry criteria

- To have previous experience of care giving: either as professional, or as a relative(mother, wife ,daughter etc)of medical disability
- Will be agreeable to the need of having physical health check up and psychological assessment
- Should be able to read and write to a certain extent
- A pre test assessment to gauge the candidate's aptitude about care giving
- To attend orientation workshop
- Post workshop assessment, to decide what areas of the groups understanding needs to be worked on further
- ID proof and address verification by police, to check for any criminal records
- A personal letter why the candidate seeks this job
- 2 references from previous work place or from members of the community with regard to the candidate's reliability and skills.

GUIDELINES

Certain guidelines to immediate care givers have to be instituted for the interests and safety of the residents. The guidelines have to be in such a way that the care givers understand that this is for their own safety as well as the residents. If self discipline in the service of the disadvantaged individuals is not put in place then monitoring, execution and follow ups will be difficult. Thus the ultimate beneficiary in various geographical areas must be protected and supported uniformly. However, even in a home the parents have certain amount of discipline.

The guidelines are:

- Must have bath prior to working with residents, and must be personally hygienic; must be ready for work by 7:30 am
- 2 Sundays off in a month for their well being – by turns.
- Cell phone conversations restricted to post lunch siesta and night after 9:00 pm. All mobiles to be left with S.W during day time.

- Relatives and friends meeting them at work place by prior appointments and permission of S.W and only during S.W office time.
- Allowed to leave residence only on days off.
- Must learn to liaison with all levels of people:
    - Colleagues
    - Social Workers
    - Therapists
    - Mentors
    - Volunteers
    - Answer phone calls
    - Receive people

ROLE OF CARE GIVERS: To train as per care givers model given below

- Everyone's rights should be taken care based on UNCRPD during orientation- this must be made to understand.
- Must be able to participate in the informed decisions regarding health and rights of the residents.
- Must be able to counsel parents with the right information and share with them the goals of the residents, so as to reassure their apprehensions.
- Assist and support the residents in:
    - Personal care and hygiene
    - House keeping and menu planning
    - Any other help they may need
    - One care giver to be allotted to the 2 profoundly disabled by Rota
- Daily meeting for ½ an hour so that social worker understands the happenings the night before and will be able to liaison with the mentors and volunteers.
- Must accompany the residents to health services and help them understand information being provided to them.
- Should assist in maintaining compliance of treatment regimes, i.e. medication, physio, yoga, sun-bathing etc.
- They must partake in leisure activities and outdoor games so as to build the comradeship and wellbeing between them and the residents.
- Must not take over the personal tasks of the residents but must be supportive and encouraging to help them complete their tasks whether it is ADL or other activities, e.g. shopping.
- Must instil the right way of lifting, mobilizing and change of position as taught by the physio in the use of assistive device, wheelchair assistance and supervision to prevent pressure sores.
- Must eat along with residents.
- Must be able to report to social worker, observations of changes in the resident's health and wellbeing like skin care, sleep, bowels, urination, mood swings, behavior changes, seizure episodes, etc.
- Must earn the trust of the residents so as to be able to relate with ease and come to them for conflict resolution and abuses. It is important for caregiver to exercise utmost patience, serve with love, compassion and reverence.
- Must be able to understand any communication devices used by the residents so as to maintain communication.
- Must learn to ask for help and advice.
- Must understand legal capacity, decision making.
- How to practice advocacy on behalf of the disabled.
- Confidentiality of resident's personal lives must be taken care of constantly and not discussed as an object.

Master Trainers from KUDUMBASHREE: To choose master trainers who will later train caregivers sensitize social workers and Govt. servants and the community.

Since all the training will be in Malayalam, local trainers will need to be developed. The Expert Committee with the help of Kudumbashree will identify ten master trainers who will be trained for all the courses and sensitization programmes.

The National Trust Sahyogi programme master trainer programme is ideally for one month. This is for a training Sahyogi (Caregivers) the other sensitization training will take two weeks. The master trainers programme will be for six weeks

Qualification required to be a master trainer:

i. Experience of working with Intellectual and Developmental Disabilities at least ten years

ii. Should know good Malayalam

iii. Should have experience in training staff at different levels

The Sahyogi caregiver training is for 5 months, with one month face to face training and four months of practical work with the careseeker.

Therefore, the pilot programme can start one month after the caregiving training started so that at least some of the caregivers can do the practical work directly in the assisted living unit.

VOLUNTEERS FROM COMMUNITY

Volunteers will have two week training on disability and how to be a support person.

They will do the following:

1. Help with recreational activities
    - Reading daily news
    - Sharing story telling
    - Games
    - Needlework
    - Music: Learning vocal and learning instruments
    - Gardening and kitchen garden- to help with any infrastructure repairs.
    - Art/ Yoga/ Music
2. Give assistance in travelling
3. To accompany groups and outings
4. To support micro enterprise
5. To help a therapy
6. A volunteer may become part of a support plan or first circle of friend in the persons support network

Guidelines for livelihoods and employment:

There are two different types of employment and livelihoods.

Open placement:

In this model we are planning that one social worker will serve five assisted living units. Therefore, typically she will be giving services to 50-60 people with disabilities.

She will do the followings:

1. Functional analysis skills and interest of each of the residents. **Annexure - IX**

2. Resource Mapping of the Community
3. Identifying appropriate jobs in the community
4. Matching the skills with the residents with the jobs

Once a resident agrees to the job

I. Task Analysis of the Job
II. Training of the resident on the job
III. Acting as a job coach. A job coach will help the person with disability to settle down in the job and will stay with the person until all the skills are learnt including traveling independently. Then the job coach will slowly fade away.

Self employment / micro enterprise: ARUNIM (see linkages) provides a Business Plan Format for anyone wanting to start a small venture / enterprise. (Please refer to CD Business Plan Format)

Resource Mapping

Resource Mapping - Participatory Identification of Resources

It is generally a participatory process for identifying and understanding various resources available in the villages. The people themselves will do the PIR for specific purposes.

PURPOSE:

The purpose of the PIR is to understand

- Existing skills and in the village
- Existing resources in the village and nearby areas
- Opportunities available in the village

PREPARATION FOR PIR

1. Inform the people in advance about your visit to the area.
2. Find out their convenient timings and arrange for organizing people.
3. Prepare the objectives of PIR exercise.
4. Make a list of topics that you is to be studied and the data that is to be generated from the mapping.
5. Have white and color powder, chalk pieces, seeds, chart papers and markers to be used in exercise in the village.
6. Divide the responsibility among the team members like those of Facilitation, Organizing, Process observing and Recording information.

HOW TO CONDUCT

1. On entering the village, greet the villagers whom you meet.
2. Seek their co-operation in organising people - women / men / children, youth club, fan club representing different parts (streets / colony) of the village.
3. Ensure target population are present during exercise
4. Choose a spacious and flat place with the involvement of the villagers.
5. Do a round of introduction
6. State the purpose or objective of the exercise.
7. Facilitate people to start with their map without interrupting them often.
8. Start off with the roads and other landmarks and proceed further.
9. After drawing the general outline of the map like roads, rivers, ponds, canal or other landmarks and other infrastructures and tell them to keep appropriate symbols / objects that are locally available.
10. Ask probing questions to find about the details omitted.

11. Ask villagers to present their map and make corrections if any.
12. Ensure that a copy of the diagram of the map on the ground is made.
13. Present the results to the whole group and make alterations if pointed out.

TIPS FOR MAPPING

1. Do not select too small a place for mapping exercise.
2. Do not choose a spot where the exercise will be interfered or interrupted.
3. If the village is too large divide the area to be mapped.
4. Do not seek information that is irrelevant.
5. Have energizers if you feel that mood of the group is waning.

USE OF PIR

- Identify areas of specific problems.
- Recognize potential for improvement.
- Identify the coverage and linkages with service providers
- Understand various aspects of development as people perceive it.
- Identify resources developed by various schemes
- Gain insights into the ways in which people think & their priorities. Locate the appropriate places for installation of certain infrastructure facilities.
- Monitor the status of infrastructure facilities.

RESOURCES (Infrastructure)

Electrified houses, Houses having TV, Radio, Vehicles, Carts, Roads, Tube wells, Open wells, Wells (not in use) Hand pumps, Streetlights, Community hall, Post office, Library, Community vacant places, Anganwadi centre, Sub centre, School ,Play ground, Places of worship, Burial ground, Grazing land ,Shops - provision shops, Petty shop etc. Fair price shop, Toddy / Arrack shop, Barbers shop, Dhobi shop, Blacksmith, Bus stop, Tank, ponds, Natural resources, Types of soils, Trees, Details of field and land usages, PHC, who does or does not use PHC.

Occupation

Agriculture, Bonded, Dais, Entrepreneurs, Shop keepers, Traditional / Trained Dais, Traditional / Herbal medicines healers.

RESOURCE FLOW

DEFINITION

It is the study of flow of resources from the village to outside and vice-versa besides the consumption of resources within the village.

PURPOSE

- Resource flow exercise is used to understand the inflow and outflow of various resources pertaining to a village.
- Resources can include products, skills, services, cash, etc.
- This exercise is a useful starting point for understanding the village economy and planning development interventions.

HOW TO CONDUCT

1. Gather a group of people.
2. Select a suitable spot to conduct the exercise along with the people.
3. Do a mutual introduction.
4. Explain the purpose of the exercise to the group of people.
5. Request them to represent through meaningful symbols, all the resources that are

coming in, going out and consumed in the village. For e.g:

- What is coming in or going out.
- In what form.
- Approximately how much.
- Approximately of what value.

6. Analyze the diagram, discuss issues and opportunities.
7. Present the final output to the community.
8. Record the final output on paper without making changes.

USES AND APPLICATIONS

- It helps to create awareness among the community about their resources.
- It gives us an understanding of the utility of resources.
- It enables us to know the economic situation of a village.
- It encourages income possibilities.
- To understand the prospects for marketing.
- It helps to do a village budget planning.

Status of Livelihood Capitals

Human Capital

Labour Force Participation
Literacy Rate among the Population
Education
Health Status

Natural Capital

Private natural capital-Land Holding - Livestock
Common Property Resources

Physical Capital

Community Owned Physical Capital - community hall,

Financial Capital

Savings
Debt

Social Capital

Participation in SHGs
Participation in Grama Saba

Chapter - 5

Monitoring Mechanisms

DRAFT FRAMEWORK OF

- **STATE ASSESSMENT AND ACCREDITATION AUTHORITY FOR ASSISTED LIVING FACILITIES (SALF)**

Introduction

Assisted Living Facilities (ALF) constitute an establishment to provide residential facilities for individuals with disabilities who need continuous care and assistance in daily activities. These facilities are established as per the approved models set by the Social Justice Department and operated by Non-governmental agencies (NGO) who have the resources, expertise and commitment to cater to the needs of people with disabilities.

The Need for Standards

It is required to have norms for assessing the capability and credibility of the agency that comes forward to establish and operate ALF. Additionally norms are needed for the personnel, infrastructure, operating protocol for the facility so that care of the personnel is done as per the minimum standards required to maintain the basic quality of living.

This is all the more important because the individuals who require assistance are often not able to voice their needs due to their physical and mental limitations. The rights of persons and welfare of persons with disabilities cannot be compromised on the basis of lack of or limited resources. Standards are necessary to ensure that the project holders, with the support from an authorized accrediting agency of the state government, deliver quality services to persons with disabilities.

The standards ensure protection of the residents and safeguard the health, welfare and quality of life of the persons with disabilities living in these residential Centres.

SALF: The Definition

The State Assessment and Accreditation Authority for Assisted Living Facilities (SALF) is constituted as an independent agency authorized by the Kerala State Government to conduct initial evaluation for approval of the organization as well as periodic inspection for grading of the facility depending on the performance

The Core Principle of SALF: Standards to Uplift NOT Putdown

While standards are required for maintaining quality, there is a danger of pointing fingers, ordering shut down, or penalizing the agency or people who are found to be below standard. This may be okay in a regular production industry, but can be counter-productive in the case of a field such as assisted living for the individuals with disabilities. As such it is difficult to find genuine individuals or groups or organizations who want to organize and operate such a facility for a group of people who place high demands of care giving.

In such cases, the standards should not be an instrument to search out the ill-equipped organizations and used as basis to terminate support. The State Monitoring Agency, SALF in its capacity, will support project holders in meeting the standards. At the initial implementation, existing project holders who do not meet the standards will be given opportunity to improve, or opt to voluntarily close down if they believe they cannot or do not want to comply with these standards. At the periodical inspections, there should be a mutually agreed set of recommendations to improve the facility. There should be specific time limit set to improve the conditions and enhance the facility. There should be minimum standards set for the services provided. SALF and its peer assessment team should discuss with respective project holders what to do with existing residents in event of closure.

Structural Framework of SALF

SALF should have a structural framework to operate. This structural framework should define its mandate, funding mechanism, and constitution.

Mandate

SALF will be the central agency that will implement the evaluation and rating of the ALF across the state. SALF will have the authority to constitute multiple expert committees consisting of experts with a track record of objective analysis and reporting. The approval and rating will be done based on the reports submitted by the expert committees after visiting the ALF and providing grades for different criteria as laid out by the SALF.

Funding

The SALF will be funded by a mechanism that will ensure the independent nature of the agency (as worked out by Government policy on such agencies which needs to have the framework and freedom to work objectively)

Constitution

The SALF will have an executive council (SALF Council) that consists of Chairperson, Vice-Chairperson and Expert Advisors (EA) who are responsible for the operation of the agency. The EA will represent each district of the state and will be nominated based on specific criteria laid out. The initial SALF council will be set up on the recommendation of the Expert Committee for Assisted Living. The committee will set up criteria for nomination into the SALF council and qualification for the position of Chairperson and Vice-Chairperson and Expert Advisors. The tenure of service and other terms of reference of the SALF council also will be as per guidelines set by the existing Expert Committee for Assisted Living.

Operational Framework of SALF

The number of facilities are expected to exceed 500 across the state since each facility may not house more than 10 to 12 people and each Block may have a facility or a few adjoining blocks may have an ALF depending on the need as well as availability of funds.

The SALF will be a central agency to set standards, criteria, monitoring and coordination. The SALF itself will not do any evaluation by itself.

The Peer Inspection Team (PIT)

The individual inspection will be conducted by a Peer Inspection Team (PIT) consisting of three experts authorized by the SALF council.

The SALF will create a database of peer professionals from across the state after careful evaluation of their background, expertise and work history. The qualifications of the professionals should not be limited to degrees and years of experience but also reputation, objectivity, integrity, hard work, and team work. The peer professionals can be experts who have expertise in setting up and running ALF previously.

The state will be divided into three regions – North, Central and South – for the purpose of inspection and monitoring. Database of peer professionals will also be prepared and categorized region wise.

The Expert Advisors

The SALF council will have Expert Advisors (EA) who will each be responsible for one district of the state. Two EA's will team up to work on two districts with the understanding that they will be back to back substitutes for both their districts.

The Inspection Visit by PIT

The Expert Advisor (EA) for a district will set up, depute and authorize PIT to perform peer team inspection of ALF and obtain reports on the status of ALFs. The report will be prepared based on specific criteria laid out by the SALF council. The peer team will allocate scores for the specific criteria as per the

guidelines from SALF council. The SALF council will review the report and allocate grade for the ALF. The grading will be applicable for specific period after which the ALF will be reviewed.

The EA will select three professionals for each peer team inspection visit from the state database. The condition for selection will be a) there is no conflict of interest with the ALF to be inspected 2) the peer team member resides and works in another region other than where the ALF is located.
EA teams consisting of two EA (other than the EA responsible for the district) will perform random surprise visits periodically to ALF where peer inspection reports have been submitted. The EA team will verify the accuracy of the report and scores. This will serve as a check & balance for the SALF.

The expenses for the PIT visit

The expenses for the PIT visit will be borne by the ALF. The expense accounts for each PIT visit will be reported to the ALF and the same will be reviewed by the SALF council while considering the report from PIT. Specific criteria will be set for the travel expense, honorarium, and stay expense of the PIT team which will be adhered by the ALF. PIT will not receive any extra remuneration, gifts or other gratuity or perks from the ALF as this could be influence the objectivity of the exercise.

The Criteria Framework of PIT Visits

The following criteria may be included in the accreditation process for initial induction and awarding of rating for the ALF under consideration:

Organization/Management

- Office location details
- Hierarchy – Officers, workers details
- Financial status – Audited Accounts for at least two previous years
- Evidence of Expertise and Experience in Assisted Living Management

Personnel – Caregivers and Support Staff

- Number of people and their qualifications, pay, experience, geographical location etc.
- Duty Hours
- Ongoing training
- Checks and balances to ensure accountability
- Feedback mechanism
- Grievance Redress mechanism

Infrastructure

- Physical area, number of rooms, furniture, toilet facilities, kitchen, dining, common area, visitors area, entertainment facilities, library and reading room, consultants rest and work area, caretakers area, training space
- Outside grounds, general ambience, proximity to other neighbours, proximity to shopping, proximity to medical and therapy facilities, nearest recreational facilities
- Involvement of inmates in daily routines, keeping place clean, gardening, cooking
- Internet, electricity, water, sewage, waste disposal
- Maintenance routine, frequency

Operations

- Daily routines – Hygiene, Food, Cleaning, Schedules
- Recreation
- Engagement in activities
- Facilities for Medical Emergency
- Treatment for illness
- Documentation
- Established Systems
- Interaction with the community
- Accounting, Auditing
- Consulting schedule for Psychologist, OT, PT, Physiatrist, Social worker

Innovative Methods

- Unique features
- Stimulation of senses through activity
- Utilization of expertise/experience of inmates
- Community involvement

Grading

The PIT will be given guidelines so as to score the marks and grade based on the inspection. Each member of the PIT should independently score and the average should be taken to arrive at the final score. A weighted average of all the scores will give the grading for the ALF under consideration. This should be further categorized from best, good, satisfactory and unsatisfactory as Grade A, Grade B, Grade C or Grade D. The grades should be available for public viewing and the criteria should be published on the website so as to make the process transparent.

Dismantling Institutions

SALF should also form PIT teams to smoothly dismantle institutions that decide to close down operations. This could be due to SALF ordering a shutdown in case the project owner doesn't comply even after repeated warnings and cautionary notices. Alternatively an agency may decide to voluntarily close its operations due to its own reasons.

In such a case there should be procedures set to

- Transfer the residents to another facility as per informed choice as well as based on the need of the resident decided by a doctor or a social worker or care giver as may be appropriate.
- Transfer the assets to another facility or project holder who is willing to continue the operations.
- Be an assessor to determine the assets and liabilities of the organization and a mediator who will ensure smooth transition
- Be a liaison agency which can provide counselling and advisory support to the parents and immediate family.
- Provide information to the community leaders, volunteers and other stake holders

Continuous Local Monitoring Group (CLMG)

In addition to the SALF at the State level accrediting and monitoring through a set of PIT that visits annually or bi-annually, there is a need for a continuous monitoring of the upkeep of the facility and quality of service to the residents. This can be achieved only with the inputs from a Continuous Local Monitoring Group (CLMG) set up at each location. Although CLMG will be constituted of people from the local community, the reports they furnish should be copied to the SALF and kept on record along with the PIT reports. The CLMG can monitor, advise, take steps to maintain certain minimum standards. With the joint efforts from the CLMG and SALF it is possible to provide the quality of service and life to the residents of the ALF across the state.

CLMG guidelines should be to cover infrastructure maintenance and Operations of the ALF. The CLMG should consist of parents of residents, local self government (LSG) representative, and one or two professionals. The CLMG can form task groups who will visit the facility on a rotational basis so as to avoid overburden. Detailed guidelines need to be written down for CLMG.

Conclusion

This framework should be expanded to fill in the details as required. The important feature of SALF should be the independence and objectivity of the body and continued maintenance of quality. This can only be ensured if the leadership team constituted for SALF Council is a group of dedicated professionals who have a passion and personal commitment in a system that will take care of persons with disabilities.

❖ MINIMUM STANDARDS FOR RESIDENTIAL FACILITIES – NATIONAL TRUST AS ANNEXURE - VII

Chapter – 6

Training Module

THE CAREGIVERS COURSE CURRICULUM

Objective of the course:

The objective of the course is to mobilize and develop a cadre of caregivers from the community and maximize their potential by giving them skills required to ensure well being and safety of people with disabilities, taking into account the legal capacities of the persons, and working within the framework of autonomy and inclusion in the community. This course will also impart to the caregiver, the importance of having the right attitude of service: utmost patience, reverence, compassion and love.

The modules of the course (for details refer to the main document above)

Module 1: Pillars of care giving

Developing perspectives, the right attitude and an understanding of inclusion.

Module 2: Establishing trust and relationships through interaction with people

Developing the skills of communication and listening and to interact effectively with persons with disabilities.

Module 3: Understanding needs of people with disabilities

Module 4 : Ensuring safety and protection

Training in developing intuition and observation (in an anthroposophical way)

Giving an overall knowledge of first aid, Imparting knowledge about monitoring physiological parameters of (temperature, pulse rate, BP, blood sugar levels)

Module 5 : Implementation of care plan for movement, mobility, personal care, hygiene and nutrition

Module 6 : Supporting everyday lives of people with disabilities

Module 7 : Implementation of plans on leisure and recreation

Module 8 : Developing skills of functioning within the community

-identifying and using community resources for support (supplementary services on a limited basis to compliment the work of the care givers-mentors and volunteers from the community)

Module 9 : Care givers support

Information to care givers about available services

Assistance to care givers in giving access to supportive services

Individual counselling, organization of support groups, caregivers meeting-once every 3 months-(i.e. - meeting of caregivers of ten residences), care givers training to assist caregivers in making decisions and solving problems related to their roles

Respite care – to enable care givers to be temporarily relieved from care giving responsibilities

Training of Social Workers for resource mapping and livelihood, micro enterprise and as job coach for open placement

- **Module in Annexure- IV**

- **Sensitising of Community**

GOAL:

Sensitization of the community, to focus on understanding different levels of care to people with different degrees of disabilities, and how to evolve and extend appropriate support to the residents.

WHY:

To support the co-existence of the residents in the community to achieve a state of mental, physical and emotional well being.

HOW:

- Through films and TV advertisments
- Through posters
- Through discussions and brainstorming sessions
- Games,excercizes,role plays-experiential learning
- Through street plays/skits
- School visits-to enlist support of 11^{th} std students and teachers(for peer group interactions and latently might also help to detect disabled in the community.)

WHAT:

1)Disability vs handicap

2)Barriers (mental, physical, social)

3)Dispelling myths and superstitions,and co-relating with scientific evidence

4)Understanding perspectives:human rights,legal capacities

5)Inclusion,as a necessity into the community

6)Community participation (forming committees to be mentors,volunteers,supporting residential co-existence,addressing greviences,ombudsman)

WHERE:

- community identified places,which could be : under a tree/panchayat office/school building

WHEN:

Prior to choosing the community workers by Kudumbashree

WHO:

-Kudumbashree,to help co-ordinate on all these fronts (identify people,place,focus groups,mentors,volunteers,and give feedback of the inputs)

-NGOs

-School students and teachers

- **Sensitising of Govt. Officials - National Trust Panchayat Training Module as Annexure - VI**

Chapter – 7

Linkages

❖ Kudumbshree

The Mission of Kudumbashree

There are two distinguishing characteristics to Kudumbashree which set it apart from the usual SHG model of empowerment. These are

1.The universality of reach – from its very inception Kudumbashree has attempted to bring very poor woman in the state within its fold, as a consequence of which today Kudumbashree is present in every village panchayat and municipality, and in nearly every ward, colony and hamlet. The sheer spread is mind boggling, and it is only because the local community of women drive the system that it has managed to persevere.

2.The scope of community interface in local governance – the functioning of Kudumbashree is tied up to the development initiatives of the local government be it for social infrastructure, welfare or right based interventions or for employment generation. From food security to health insurance, from housing to enterprise development, from the national wage employment programme to the jagratha samiti, every development experience depends on Kudumbashree to provide the community interface.

It is using these opportunities that Kudumbashree strives to convert a microfinance led financial security model into a more comprehensive model of local economic development.

The Mission Statement

"To eradicate absolute poverty in ten years through concerted community action under the leadership of local governments, by facilitating organization of the poor for combining self-help with demand-led convergence of available services and resources to tackle the multiple dimensions and manifestations of poverty, holistically."

The Vision of Kudumbashree

Kudumbashree strives to develop the model of a micro finance led financial security process into a more comprehensive model of local economic development under the aegis of local governments. This would hopefully sustain the transformation of the local governance agenda from welfare to entitlement. Such a transformation does not come about easily and requires rewriting established administrative and development practices. It requires the community acquiring voice and being heard. It requires institutionalizing processes that allow for participation and meaningful contribution. And when we speak of community we speak of the people for whom government is a palpable entity influencing the quality of their lives, as well as of the people on the periphery, both social and physical, for whom manifold deprivations have snuffed out hope of change. We speak of the women who are finding, through collective endeavours, the stepping stones leading from participation to citizenship in its truest sense. It is through the realization of citizenship that Kudumbashree would be able to significantly address issues of equity and justice.

❖ ARUNIM

Association for Rehabilitation under National Trust Initiative of Marketing (ARUNIM)

ARUNIM is a pioneering and path-breaking innovation for creating livelihoods through entrepreneurship, with a special focus on persons with developmental disabilities

Background Information

As on date, there are about 900 NGOs registered under the National Trust. Majority of them have set up sheltered workshops, which focus on vocational training and on making products. However, various

formal and informal studies undertaken about the functioning of these workshops revealed that people with disabilities engaged in these workshops did not have sustainable work and income. They were unable to leverage the potential of the real-world markets. There was lack of proper training, access to resources, business skills and marketing expertise. To address these issues of sheltered workshops and to convert them to micro enterprises, ARUNIM was set up by National Trust.

Introduction

ARUNIM (Association for Rehabilitation under National Trust Initiative of Marketing) is a path breaking initiative of National Trust which is a statutory body under the Ministry of Social Justice and Empowerment. ARUNIM is registered as a non-profit society and was launched by Dr. Abdul Kalam on the 22nd Sep 2008. It is an independent Marketing Federation which works towards Economic Empowerment of persons with moderate to severe disabilities employed in sheltered/supported work environments particularly those covered under the National Trust Act. Its key objective is to facilitate livelihood and capacity building through the promotion of market driven products and services.

Vision

Persons with disabilities are empowered to be active partners in contributing to the growth of the global economy

Mission

ARUNIM builds an entrepreneurial approach towards economic empowerment and self reliance for Persons with Disabilities and other marginalized groups, with a focus on developmental disabilities.

ARUNIM will enable Persons with Disabilities to say I AM…I CAN!

Core Focus Area

ARUNIM's mandate is:

- To strive for minimum wages for persons employed in sheltered/supported work environments
- Innovative product designing and entrepreneurship skill development
- Introducing adaptations and mechanization where appropriate and feasible
- Working towards building 'ARUNIM' brand for chosen products
- Standardizing quality
- Marketing products using sound strategies in Packaging, Pricing, Placing and Promotions
- Establishing web based initiatives
- Setting up retail outlets across the country

Details of the Project and its Beneficiaries

ARUNIM's strategies include building the membership base across the country and networking with financial sectors, Corporate sectors and the various Government bodies and Ministries that promote micro enterprises, and building a brand. Its activities range from **policy level interventions to providing information, training in product design, introducing technology based solutions and marketing opportunities to all its members** and to providing intensive support to sheltered workshops, individual with disabilities, Self Help Groups, which could be inclusive of parents, siblings and persons from other marginalised group, for incubating micro enterprises. ARUNIM works with **235** NGOs, and individual entrepreneurs, as members across 24 states in the country. It reaches out to more than 3,000 persons with disabilities. ARUNIM training on Micro Enterprise, Design Workshops and Product Evaluation Programmes have been attended by more than **1000 trainers and participants** from across the country since its inception.

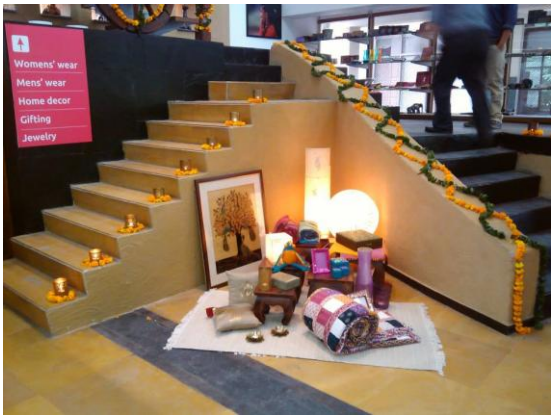
Marketing and Branding

ARUNIM's products are categorized under six business verticals.

1. Life style and Décor
2. Handcrafted Gifts and Souvenirs
3. Food products
4. Festival and celebrations
5. Stationery
6. Printing and Packaging

Currently the marketing channels are-

1. 4 Retail outlets in Delhi through which products are sold.
2. Participating in mainstream Exhibitions and Fairs and creating Corporate campus fairs opportunities
3. Bulk orders through Institutional sales from Govt bodies, Corporate and other organisation.
4. Participating in International Fairs and initiating export orders.



ARUNIM has networked and converged with other Ministries (Textiles, MSME, Environment, Labour & Employment, etc) for mainstreaming persons with disabilities and benefit from their schemes which would enable and include them to be part of the society.

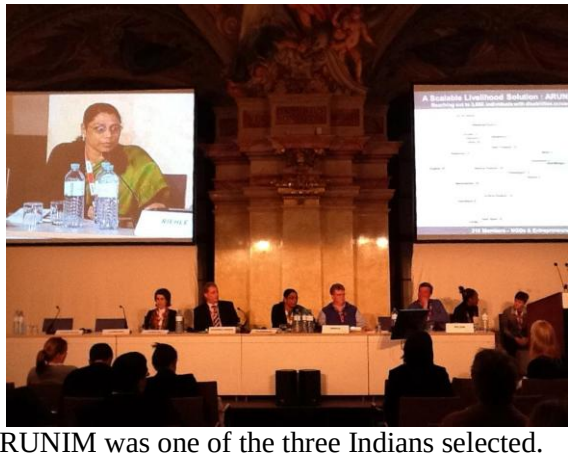
Key achievements 2008 – 13:

1. ARUNIM has member base of 230 NGO & individual entrepreneurs with disabilities pan India covering 29 States.
2. Conducted more than 60 Capacity Building Workshops - 14 Awareness & Product Assessment trainings, 24 Product Development trainings and 22 trainings on Microenterprise Skills to enhance better understanding of their business and make it more sustainable. We have trained more than 1000 master trainers and producer members so far.

3. ARUNIM launched the E3 (Economic Enterprise and Empowerment) Challenge 2010, a business plan competition as a first ever unique programme for persons with disabilities in partnership with NSDC, NT and UNDP to scale up participation. ARUNIM received 21 business proposals from 8 States and selected 6 projects for incubation and mentoring to convert them to business models especially focusing on people with developmental disabilities. These 6 projects were given close mentoring in every aspect to convert the sheltered workshops into micro enterprises.

4. A Pilot Project: ARUNIM installed a semi automated paper bag unit for production of paper bags as a pilot project. This has helped our members in mass production of paper bags in competitive rates. The automated paper bag project, has trained 46 people with disabilities and people from marginalised group so far.

5. ARUNIM has facilitated producer member sales from Rs. 3 lakhs (2008) to Rs. 70 lakhs (till November 2013), which is a sign of improved product quality and market response.
6. 128 member NGOs got an opportunity to participate in Shilpotsav organized by the Ministry of Social Justice and Empowerment in Delhi, Mumbai, Kolkata and Chennai. Members also participated in number of corporate fairs, India International Trade Fair, Blind Relief Association, and International Conferences
7. ARUNIM is registered with Fair Trade India
8. ARUNIM was recognized in the International platform as one of the Innovative Practices for "Promoting Micro Enterprise & Entrepreneurship for persons with disabilities" by Zero Project. The zero project is the Essl Foundation's project which advocates a new and innovative approach to the rights of persons with disabilities internationally. Its mission is working for a world with zero barriers. More than 71 experts from 30 countries took part in the Zero Project by nominating outstanding and Innovative Practices and a total of round 120 nominations were submitted and only 40 were selected and ARUNIM was one of the three Indians selected.



ARUNIM's Key objective is to create a Marketing Federation and facilitate Entrepreneurs with disabilities to become "Contributors and Job Creators".

Further information and reading:
http://www.arunim.in
https://www.facebook.com/ArunimIndia

A 'Different' Market, The Hindu - http://www.thehindu.com/todays-paper/tp-national/article3402558.ece -.T6vTjC6JoFM, 10 May 2012

Annexure - I

PROCEEDINGS OF THE MEMBER SECRETARY
STATE PLANNING BOARD, THIRUVANANTHAPURAM

(Present: Dr. Anuradha Balaram IES)

Sub:- 12th Five Year Plan (2012-17) – Preparation of a Model Programme for Assisted Living for Adults with Disabilities - Constitution of Expert committee- Orders Issued.

Read:- 1. Budget 2013-14 for Social Security and Welfare Sector.
2. Minutes of the workshop on Assisted Living for Adults with Disabilities held on 21/06/2013.

ORDER No. 288/ SSD/ 2013/ /SPB Dated: 13/08/2013

As a State initiative programme for the rehabilitation and welfare of adult mentally challenged persons, a scheme has been included in the budget 2013-14, Viz. "A model Programme for Support and Rehabilitation of adult mentally challenged persons". As per the proposal the State Planning Board jointly with the Social Justice Department and Education Department would take a lead role to work out the detailed project and implementation plan after constituting an expert committee. As per minutes read as 2nd above the State Planning Board had conducted preliminary discussion regarding the models to be worked out and decided to constitute the expert committee for preparing the detailed project report.

In the above circumstances, the expert Committee is here by constituted with the following persons as Chairperson/Members.

Chairperson: Smt. Poonam Natarajan

Members:

1. Smt.Manjulaa Kalyaan, Director, Swayamkrushi, Hydeabad
2. Smt. Rajul Padmanabhan, Director, Vidyasagar, Chennai
3. Dr. Veera Panch, Neuro Rehabilitation Centre, Chennai
4. Sri. R.Venugopalan Nair, Kollam
5. Director, Social Justice Department
6. Executive Director, NISH
7. Principal, State Institute for Mentally Retarded Children
8. Executive Director, Kerala Social Security Mission

Member Convener: Smt.Shila Unnithan, Chief,
Social Services Division, State Planning Board

Terms of Reference

1. To identify the most suitable and effective model/models for Assisted Living of Adults with Disabilities and prepare an Action Plan.
2. To prepare the detailed project report of the model/models identified.
3. To prepare draft guidelines for implementation of the model programme and provide necessary guidance to the implementing agency to execute the programme.
4. To support the implementing agency for developing a monitoring mechanism and training modules.
5. To explore the possibility of linkages with the programmes run by the LSGs.
6. To recommend policy changes needed in the area of assisted living for adults with disabilities.

The Chairperson is authorized to co-opt additional members in the committee with the clearance of SPB and invite experts in this area of disabilities to the meeting, if necessary.

The detailed project report (draft) and related documents will be submitted to the State Planning Board for approval on or before 30th December 2013 positively. After approval of the Board the project report will be transmitted to the concerned implementing agency for execution.

The non-official members of the committee will be entitled to travelling allowances as applicable to class 1 Officers of the Govt. of Kerala. They are also entitled to honorarium/ sitting fee as per rules. The local non official members will be eligible for TA/DA as per rules. The Class 1 Officers of GOI will be entitled to travelling allowances as per rules if reimbursement is not allowed from Departments. The expenditure towards the functioning of the committee will be met from out of the outlay provided under the head of account 3451-00-101-93 -Surveys and Studies of SPB, during 2013-14.

(Sd/-)
Member Secretary (i/c)

Forwarded/ By Order

Chief (Social Services Division)

To

The persons concerned

Copy to

1. P.S to Vice Chairman
2. P.A to Member, Shri. G. Vijayaraghavan
3. P.A to Additional Chief Secretary, Social Justice Department
4. P.A to Member Secretary
5. CA to Sr. Administrative Officer
6. SS, Accounts for drawing and disbursing amount
7. The Accountant General(A&E), TVPM
8. The Sub Treasury Officer, Vellayambalam
9. Stock / Spare

Annexure - II

Study Report on Supported Living Project (PDF)- Given in DVD

Annexure - III

On Needs Assessment for Development of a Model Assisted Living Program for People Living With Disabilities

Questionnaire

1. **How do you conceptualise independent Living?**

2. **What would it mean for persons with disability***?*
   (pose the question and the following points to be prompted if needed – in terms of mobility, being able to do basic personal care on their own? Being economically independent/ productive? – or would it be something very different from these concepts? How would this be different for people with different kinds and different levels of disability?

3. **What should a facility that offers "assisted community living" look like? Would it mean a separate location? Where would that be? Describe the key elements of such a facility. Should it be an integrated community?**

4. **What would be the infrastructural requirements of such a facility? How would the concept of "barrier free" be applied? What would be concerns of safety that such a facility should take care of? What would the safety violations that should not be permitted at all? How would this be different for people with different kinds and different levels of disability?**

5. **Who would such a facility cater to? Can a facility that offers "assisted community living" be mixed in terms of religion? Class? Caste? Language? Gender? What would be other factors that need to be considered while developing such a facility? Would it matter if this facility were to be open for people with different kinds and different levels of disability? How should this be addressed?**

6. **Who should be responsible for setting up such a facility? Should it be private charity/ government/corporate? Joint ventures? What else?**

7. **How should such a facility be managed in the long run? Community managed? How would the persons with disability be involved in the management/governance? Should it be jointly managed with professionals being an integral part of the management? What should be the role of government be in the management?**

8. **What would be the economics of such a model ? Would you consider user fees? Self sustaining/reliant? How would these concepts be applied and what could be the challenges in applying them? Or should it be entirely donation/grant based? Should it provide some kind of remuneration if the persons with disabilities produce items for sale at the workshop/crafts/bakery etc?**

9. **How would the need for care takers/ specialised service providers be met for such facilities? How would this be different for people with different kinds and different levels of disability?**

10. **How should such a model address ageing for persons with disability? In terms of medical care, physical support, costs?**

11. **How do you envisage the involvement of the larger community at such a facility? What kind of volunteering?**

12. **Would you think that use of art/folk culture/music/physical activity such as gardening/agriculture should be an integral part of daily routine at such a facility? How would this be different for people with different kinds and different levels of disability?**

13. **How can one ensure that minimum standards are followed at such a facility in terms of overall ambience, daily care safety, emergency care, service providers, access to technology or other aspects?**

14. **What would be the role of persons with disabilities be in defining minimum standards/ implementing these standards and legislating standards and norms? Who are the others who should be involved – professional service providers, government, academicians/researchers, any one else?**

15. **Could assisted living mean that people who are living in mainstream communities should be assisted on a regular daily basis by specially trained service providers for their tasks? How would this be different for people with different kinds and different levels of disability?**

16. **How would one apply the meaning of "ensuring quality of life" for persons with disability? What do you/they do to enjoy life? What more needs to be done to lead a joyful life? How would this be different for people with different kinds and different levels of disability?**

17. **How would you apply the concept of privacy for persons with disability in India? How would this be different for people with different kinds and different levels of disability?**

Note: Depending on the person being interviewed (in terms of the stakes they represent) some of the questions would be posed slightly differently in order to bring out their perspective more sharply.

Annexure - IV

Sahyogi training Programme – Given in DVD

Annexure - V

Sambhav – Assistive Devices Brochure (PDF)- Given in DVD

Annexure – VI

Panchayati Raj Training Module (PDF)- Given in DVD

Annexure – VII

Minimum Standards for Residential Facilities (PDF) – Given in DVD

Annexure – VIII

Movies on Group Homes- Given in DVD

- Arunima: Group Home in Dehradun
- Independent Living: Group Home in Delhi

Annexure – IX

Vocational Assessment Tool – Given in DVD

Annexure – X

Self Employment / Micro Enterprise (Business Plan) – Given in DVD

References:

1. **Ms. Vandana Bedi** : Status of Persons with Disabilities and their Supported Living Needs
2. **Ms. Jahnvi Andharia** : On Needs Assessment for Development of a Model for Assisted Living Programme for People with Disabilities
3. **Ms. Shabnam Aggrawal**: Impact Evaluation of Samarth Scheme
4. **Ms. Asha Bajpai** : Executive Summary Status Report of Homes for Mentally Deficient Children in Maharashtra