

TOWARDS
PERSONAL
INDEPENDENCE

BY
Bhadrashanker Pandya

SOCIETY FOR THE WELFARE
OF THE MENTALLY RETARDED

Society For The Welfare Of The Mentally Retarded

Ahmedabad

This is an association of the parents of mentally handicapped persons in Gujarat State. The Association membership is open to parents/guardians of the mentally handicapped persons and Institutions working in area of special education, vocational training, vocational habilitation and welfare of the mentally handicapped; patron members and donor members.

The activities of SWMR are as below:

- Parent, sibling and family counseling.
- Promote special education.
- Promote vocational training and habilitation.
- Socialization and social awareness about mental handicap.
- Provide equal opportunities and participation through cultural, educational, entertainment and social programs.
- Publication of information, biannual magazine "Mansi" and books about mental handicap.

Association also plans for following activities in future to.

- Provide residential hostel for mentally handicapped.
- Provide guardianship to orphaned mentally handicapped'
- Provide services for cottage industries.
- Providing marketing network.
- Provide home service for self employment.
- Provide field-workers to bring awareness amongst new parents of mentally handicapped child.

Ahmedabad
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Vrundavan Shah
Editor Mansi. SWMR

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Towards Personal Independence

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Towards Personal Independence

The final objective of all institutions working in the area of development of persons with disability is to achieve personal independence, provide a life worth living. Most physically handicapped persons achieve the same to more or less extent. However in case of mentally handicapped persons the achievements are no where near the target except a few isolated cases. There may be over fifty Associations of parents of M.R. persons, one National Federation of Parents Associations and over one thousand institutions, special education schools, vocational training and habilitation centers, and government agencies all over the country, working towards development, education and training of mentally handicapped individuals. The amount of efforts, expertization, funds and men power is large enough though not adequate to meet with total need. Mentally handicapped persons even after years of training in renowned institutions hardly develop necessary functional and work skill. It may be helpful to look at the entire structure of development of a mentally handicapped from the very foundation to top or from root to fruits. Unlike physically handicapped persons initial delays in developmental

process of mind do irreversible damage to the child with mental/sensory developmental problems, the mental-handicap set in before they become fully aware of the problem and probable solutions. Mental retardation is neither an illness nor a condition but it is a regressive process. The process can be checked and controlled even when it can not be stopped. The only persons to first identify the problems are doctors. Gynecologists, pediatricians and general physicians who are aware of the therapeutical treatments, can guide parents in addition to the medical treatment of illness. Early intervention and family awareness can be a good foundation for further work.

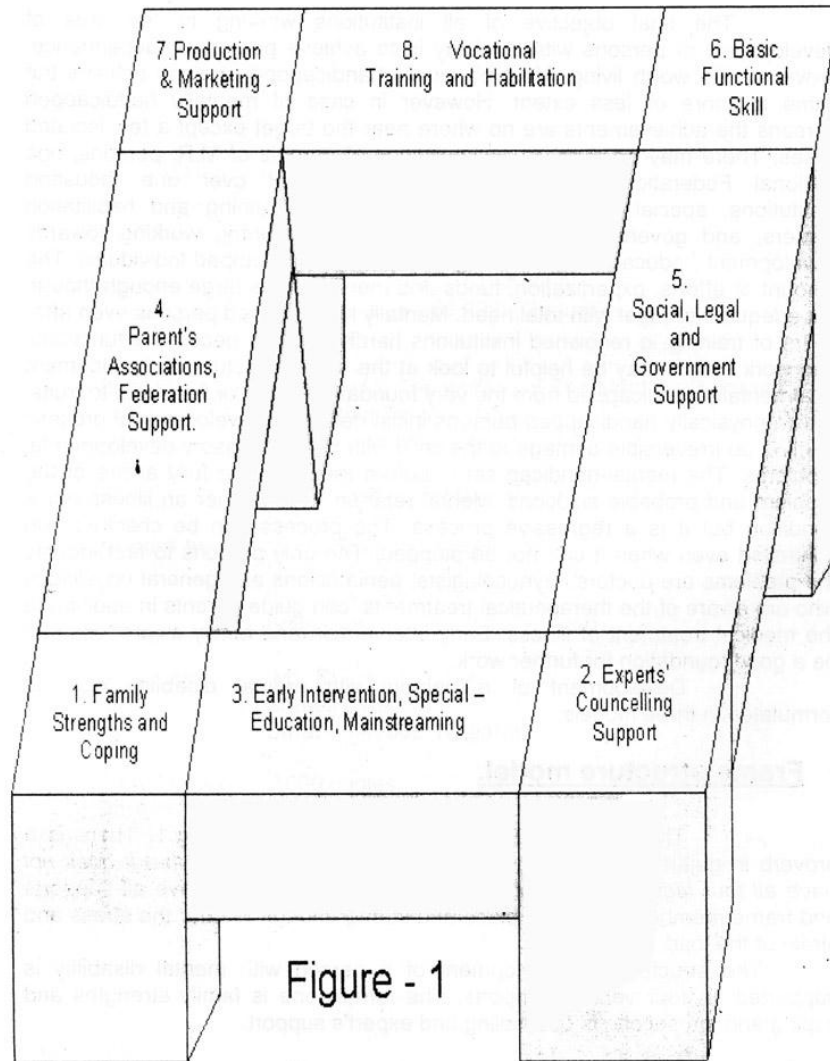
Development of a person with mental disability can be formulated in three models.

I Frame structure model.

This model is diagrammatically displayed in **fig.1**. There is a proverb in Gujarati which means "The defect with the cot is that it does not have all four legs ". Like a cot frame, all structures should have all supports and frame members at proper place and strong enough to bear the stress and strain of the load.

The structure of development of a person with mental disability is supported on four vertical supports. The former one is family strengths and coping and the second is counseling and expert's support.

Figure – 1



Early intervention, special education and main streaming are supported by these two initial and former supports. Unless these three frame members are in proper place and strong enough the frame can not even be erected, stability comes only after erection. The third vertical support "Basic functional skill" can be achieved with help of early intervention, special education and structural connection of social-legal-government support. The fourth support is "production management, and marketing network "for the vocational habitation. Parent's associations can support these activities for successful vocational training and habilitation leading towards personal independence, through employment opportunity. The details of each of the eight frame members are as follows:-

1. Family strengths and coping ability

A family on arrival of a child with disability undergoes stages of confusion, lack of information, emotional shock, shame, loss of support, social restraints, extra need in terms of finance, extra time; mental worries, care of other children, helplessness, anger, feeling of guilt and strained family relationship. All persons overcome such feeling slowly even without any expert counseling. But if the compromise with the situation is done either as acceptance of bad fate; curse of god; punishment of own sin or with false hope that everything will be alright with time, with blessing of guru or some religious ceremony, miracle, and so on; the family remains under a false illusion for long. This initial period of childhood is crucial for development of a child with mental disability. The child sets in irreversible process of brain damage. The first five years of childhood are most important for development of basic intelligence and sensory-motor coordination developments. In case of child born with mental disability the intervention can start as early as within a month of birth and not later than the second birthday. Delay of every month reduces the possibility of achieving better results. If the damage to brain occurs at a subsequent stage either due to brain trauma or viral infection or any other reason the intervention must start immediately with the medical treatment. The family has to remember the slogan "Manushya Yatna, Ishwar Krupa" meaning "God help those who help themselves".

With proper counselling family shall be able to overcome the negative initial impact and develop coping ability. Love for the child, acceptance of the limitations of the child and faith in god are good basic coping skill. These basic strengths of family will result into self determination of action and preparedness for struggle. It will mould into a decision to workout solutions by getting all information, struggle without expecting miracle, come out from confusion and helpless wondering, and avoid passive ignorance or neglect of reality. It is of worth mention that faith and superstitions are divided by a very thin porous divider. One may cross the limit without knowing. Passive resignation is not faith in god. Prayer for getting strength to cope up is faith and prayer for miracle is crossing the line away from faith, and into superstition.

For need based family intervention parents and professionals may refer to NIMH publication "Understanding Indian families". Author Dr. Rita Peshawaria.

2. Expert's and counseling support

Medical treatment in case of persons with mental handicap is useful only to the extent of handling the illness, infection, or physiological disorder. A few neurological disorders can also be medically treated. The functional disorder, psychological problems and developmental problems of brain can be only treated therapeutically. These are treatments which need specialized skill, patience, and perseverance over a very long period; may prolong to life time work. The early intervention program can be best implemented at home by parents and family members. Help of psychologists,

occupational therapist, special education teachers, speech therapists and a family counselor can be taken for proper implementation of the program. A few guide line principals for taking help of experts will be helpful to parents and family members.

- Do not follow blindly. Try to understand.
- Do not contradict or challenge an expert but always ask for more information, study and raise questions where you get stuck-up.
- In case of need to confirm diagnosis or method of treatment do not hesitate to get second opinion. However do window shopping for information and purchase only from reliable shop. Do not change therapists and treatments just with expectation of quick miraculous results.
- Experts do not hide facts, do not give false promises, do not give totally negative picture and boast about his own ability, do not make hasty decisions, and do not neglect the case history or family need. Expert will fully understand the problem, confirm what he understood, ask for more details if required, keep the conversation open and if necessary under observation for required period of time. He will also discuss alternatives keeping various options open. He will recognize your ability and supplement the same without adverse comments. He will give necessary intervention program and monitor, review and modify as the development progress area wise. Parents and family members like grand parents, uncle, aunt can participate actively in the implementation of early intervention. Sibling and neighborhood are of great help in developmental progress.

NIMH have published number of books about development of mentally retarded persons in different areas like, gross motor skill, fine motor skill, self help, toilet training, social skill, communication skill, and behavioral problems. The author of this article have compiled these information in a book titled "**Light a candle instead of cursing the darkness**". This book is likely to be published soon.

3. Early Intervention Special-Education and Main Streaming

Early intervention is the first step supported by family coping skill and expert therapists. Unless the primary functional skill in sensory-motor, fine motor, perception-motor, self help, toilet training, socialization, communication, and awareness about privacy, develops to a level of healthy interaction with peers, teachers and unfamiliar persons, schooling is not possible, even in play group or K.G. with other normal children. There are very few special education schools or institutions who undertake early intervention program for infants. It may be difficult to handle child with mental handicap even during early childhood or late childhood at such institutional level if the basic function skill is not developed. The best teacher and therapist for early intervention is therefore a mother, a grand mother, or any elderly person in family who can do such functional mothering. With proper awareness siblings are also of great help in

inducing functional skill in the child with mental handicap. Any expert who refuses family involvement in the planned development program should be kept away.

The second ply of this frame member is schooling. Depending on the available facility of special education, level of development of functional skill and actual age of the child he can be admitted in special education school, play group or K.G. Main streaming is education of a child with mental, retardation of marginal or minor level in normal school with other normal children following a normal curriculum. Children with mental handicap admitted to normal school without development of basic functional skill of pre-primary level is likely to be rejected, have frustration and fall back in development. Many mentally handicapped children meet with this tragic fate. During schooling either in special education school or in main streaming the child with marginal or minor retardation can do well. Child with moderate retardation will not be able to cope up with the class. At both levels, children will have a socialization and mutual interaction training. Expectation of too much or under estimation of the child's ability to learn basic functional skill is both harmful to his progress. These special children need special attention without expression of the same. In no case they need special and differential treatment. The efforts are to be stretched to best possible level but not up to yield point.

4. Association of Parents of mentally handicapped

This is a valuable support for organizing family counselling, parent and family education, early intervention program, special education, vocational training, rehabilitation and guardianship, coordinating N.G.O and government efforts, help parents about financial problems. Parents' organizations can also centralize purchase, marketing and production activities of rehabilitation institutions. Provide hostels for orphaned mentally handicapped persons.

Objective of all activities of parents Associations should be; planned developments of infants and very young children; and provide protected habilitation to adolescents and adults. Most parents Association follow the second objective only. The reasons are (i) Families of infants and young children do not have information of parent group activities (ii) Parents Associations have much less information on early intervention programme. Most parents do not even distinguish between acceptance and over protection. It is rightly brought out in the NIMH book "Understanding Indian Families" by Dr. Rita Peshawaria that sincere and concentrated efforts will have to be made in developing constructive and meaningful parent professional partnership " .

5. Social-Legal and government support

The parents Associations, N.G.O and active professionals can bring social awareness and acceptance of mental handicap. Social acceptance of their equal right to opportunity and participation will help their confidence and development. Government can also be moved to provide

them legal status and protection. The National Federation of Parents association and NIMH are very active on this front. They need overwhelming social support to achieve their goal.

6. Basic Functional Skill

In the structural diagram fig.1, the supports 1, 2, 3 are base to achieve the objectives in 6, 7, 8. The basic functional skill is an important support of the super structure.

Enrollment to vocational training needs some basic functional skill as pre-qualification. Candidates enrolled without these skills hardly make any progress during training. Those who got early intervention and some exposure to special education or main streaming atleast up to primary level are likely to have attained this skill fully.

(A) Pre-Qualifications for vocational training

(i) Self help skill

- Toilet training. Ask for leave if necessary and use toilet appropriately. Maintain privacy.
- Can take food in appropriate quantity. Have socially acceptable table manners.
- Maintain cleanliness and appropriate dress.

(ii) Communication skill

- Ability to communicate with co-trainees and instructors in acceptable manner. Use non verbal expressions, gestures where verbal communication is not possible.
- Awareness and ability to communicate locations of residence, and place of training. Know address and telephone numbers of both places.
- Ability to use public telephone, public transport between residence and training center. Awareness of traffic and risk on road.
- Ability to read letters, numbers and understand instructions. Remember and follow instructions once given, in appropriate sequence.
- Ability to handle cash in small amounts.
- Knowledge of time, day, date, month.

(iii) Social skill

- Begin with appropriate greeting and enter into meaningful conversation.
- Co-operate with others, request help if necessary in appropriate way.

- Protect own things and request for permission appropriately to use others things. .
- Remain self controlled and disciplined.
- Avoid conflict. Express displeasure appropriately. Neglect provocative situation and stay away from same.
- Express personal problems and private matters to appropriate person at appropriate time in appropriate manner.
- React appropriately to feeling of others. Maintain appropriate behavior with co-trainees and instructors of same sex and opposite sex.
- Argue logically and avoid contradiction.
- Draw attention appropriately depending on urgency of situation.
- Firmly refuse inappropriate demand.
- Listen patiently without interruption.
- Maintain appropriate distance and tone during conversation.
- Cut humorous jokes appropriately and laugh appropriately on such jokes.
- Ask questions only to get additional information or clarification.
- Maintain concentration and patience.
- Do not hesitate to accept and correct own mistake.

(iv) Motor skill

- Ability to climb up and down normal steps and slope without support.
- Ability to fill up water in bottle pouring from small nozzle without spilling.
- Ability to cut simple shapes from thin card-board using a pair of scissors.
- Ability to ride bicycle.
- Ability to hammer a nail in soft board.
- Ability to drive screw in drilled hole using a screw driver.
- Ability to tighten bolt with hand or with use of a spanner.
- Ability to catch a tennis ball thrown at him from a distance of 10-20 feet. If candidate fulfils 90% of self-help and 50% of the other pre- qualification skill he may do well at vocational training. During training 100% self help and over 80% of the other skills are required to be achieved.

(B) Work Skill and Work Culture

Work culture imparted during early childhood by family, play important role in development of work skill in any person. Work culture is induced by imitation of family members doing their part of work; encouraging and entrusting work to all children in home according to ability; making

each child responsible for specific work at home and appreciation of their performance. Works like sweeping, moping, washing small clothes, folding dried clothes, peeling peas and grams, cutting to vegetables, preparing tea, making toast, noodles, soft drinks and service guests can be taught during childhood. Elders may help initially, then supervise from distance and finally allow independence to work.

With improvements in sensory-fine motor skill stitching buttons, fixing hooks, and eyes, thread needle embroidery, patch work stitching of bed sheets, pillow covers can be mastered. Fixing and small jobs done with use of hammer, screw driver, pliers, spanner, drill, scissors, saw can be taught step by step. The first five skills of list below is the result of work culture. The other work skill can develop only with the work culture in back-ground.

- Pride and joy of doing work.
- Work responsibility and quality consciousness.
- Awareness of sequence of operation, use of proper tools, materials and time.
- Concentration in work on hand.
- Awareness of punctuality, discipline, safety.
- Habit of keeping tools, material at proper place.
- Acceptance of change of work, place, instructions.
- Avoid disturbing others during work.
- Obey instructions with awareness and draw attention if any change is necessary.
- Ask for clarification only if necessary.
- Ask permission of leave if necessity arise.
- Report completion of work or obstruction if any in work progress.
- Awareness of his motor ability and risk of acting beyond ability.
- Draw attention of superiors about defective equipment and act fast when safety is jeopardized.
- Awareness of risk involved in electrical live circuits and open connections.
- Awareness of risk involved in wet floor, moving components of equipments,-sharp pointed, unstable and loosely supported objects.
- Awareness of risk involved in steam or compressed air operated equipments likely to be ejected or shot.
- Awareness to take quick steps for safety in emergency without panic.
- Awareness of conservation of materials, flow of raw materials and finished products without crowding and waste.

These pre-training and post-training functional skill, work skill and safety skill can only make a trainee eligible for vocational habilitation and employment. It is observed that in most of the vocational training and habilitation schools, institutions, sheltered workshops; the pre-training qualification

are either defined or fulfilled. As a result, further training and achievement of work culture, work skill and safety skill do not reach socially acceptable standard. Purposeful employment opportunity does not become a reality. Parents and professionals have to jointly work towards achieving these high standards to best possible level. These standards are ideal work skill even for normal employees. Same are also expected from mentally handicapped persons.

7. Production Management and Market Support to Vocational Habilitation

Vocational habilitation is largely dependent on production of marketable goods at competitive price, unless subsidized. The sheltered workshops supported workshop, and habilitation units are not legally industrial production units or handicraft, that attract any subsidy. Parents associations and N.G.O may move government under P.O. act 1996 in this direction. To develop good employment opportunity in any class of those described in para 8; the vocational habilitation shall need to follow three basic requirement of industrial strategy.

- (A) Need based market survey and selection of product; selection of product for which need can be created. Training in production of such items can only ensure employment after training.
- (B) Production management to control the quality, cost and production, efficiency of men and machinery.
- (C) Marketing network to sell the product. Purchase management for the purchase of raw materials and other inputs.

The personal management aspect of industrial strategy is not applicable as personals are trainees or beneficiaries.

(A) Market survey

At present most vocational centers for persons with mental handicap are engaged in manufacture of office files, envelopes, greeting cards, wax candles, coir door mats, cotton carpets on handloom, patch work on bed sheets, pillow covers, thread needle embroidery etc. A few are engaged in tailoring other than dress or manufacture of eatables like papad, pickles, spices. All these are good marketable products with implementation of production and marketing management described in (B) and (C) below. Very few institutions have tried and are planning plastic moulding, industrial product assembling or packing works; off-loaded by industries to such vocational habilitation institution, irrespective of higher cost. However opportunity for employment out side the institutions on completion of training is out of reach; including self employment. They do not earn enough to even support themselves. There appears to be three hurdles in the path of this obstacle race.

(i) Objective

The objective of training centers is not clear before parents and institutions. Parents of mentally retarded adolescents and adults helpless with passive resignation want their M.R off spring to be in some institution so that they can do their job and give time to other children. The institutions wanting to help M.R persons not knowing what to do and how to manage, start an institution with help of parents, donors, and own efforts. Some affected parent is mostly behind such institutions. Enrollment is open for all. No separate training is devised for M.R persons having different level of functional skill. They say the M.R persons have a "feeling of doing some thing" The objective of pride, earning responsibility and personal independence are absent. The following objectives are required to be aimed at.

- Self employment or employment in family business and production work.
- For persons unable to achieve the functional skill and work skill of required standards parents associations can run cottage industries based on local agriculture crop pattern, local market need, or house hold need. Most of the products listed in forgoing para are good.
- They can be supplemented by tomato catch up, pickles, spices, dried vegetable products, bottling mango juice, and preserved green peas-grams, papad.
- Training to develop work skill to engage the trainees in house keeping in own homes, hospitals, suitable homes, child care and baby sitting. Over twenty percent of total men-hours are engaged in home keeping and house keeping. Cooking training can be a very useful vocational training.
- Decorative items made from bamboo, cane, grass, palm leaves, coir, and jute; find good market in hotels, clubs, offices, luxurious homes with good returns.
- Those that have good awareness and sensory motor developments can learn fine arts like painting, sculpture, drama, folk dance etc. All these training and work skill can be imparted by family at home, in cooking class or by engaging craftsman by parents groups. The theoretical objective of placement of trained persons with mental retardation in industrial setup or public office appear non workable even for persons with mild M.R. They can be easily mislead into addiction, financially-morally-sexually exploited, and physically assaulted in industrial environments, or large office set up.

(ii) Market survey of demand and resources

Market research, market survey, Marketing strategy, Marketing network are high sounding Words when applied to multinational and national industries of large magnitude. The words need not be associated with the multimillion rupee budget of such companies and with the hi-fi technology. The tribals in Kerala make hut roof of coconut leaves, tribals in Central India make hut roof of palm leaves or grass and tribals in Himachal make the same of slate stones. House walls are made of mud or bricks in plains and of stones in hills. Market research is as simple as that. Milk producing villages, vegetable

producing district had to sell their products at cheaper rate where as they were in short supply and costly at places far away from these production places. Collection of milk, vegetable and other agricultural products in a systematic way and arranging proper distribution system has now changed the entire structure of price and availability. Handicraft, handloom and many other products are now on export list. Marketing strategy and marketing network is as simple as that. If the parents associations undertake collecting and marketing responsibility of the small vocational habilitation units for centralized marketing, even through commissioned agents or N.G.O the marketing network will come in existence. Need is flexible and change from place to place and time to time. It can even be remolded through canvassing. Soap, shampoo, creams, detergents, washing powders are good examples. Cotton textiles demands changed to woolen, silk, synthetic fibers, blended fibers and have come back to pure cotton fabrics. Any item becomes most modern and latest by something herbal in it. It is initially said that it is herbal, cheap and harmless. Then price increased beyond non herbal products. When every item was hand made, machine made items were in demand and were costly. Now again hand made products are in demand and costlier. This is the market strategy to be adopted for products made by the vocational habilitation centers. Do it in a different way. Give something different. Project advantages to purchaser, to society and to environment. Do not attract pity or sympathy, project quality and merit. Avoid selling goods as made by M.R or handicapped persons. Always say they are hand made, herbal, direct from farm product, and so on. The persons with mental disability do not have to do all this; parents associations and the N.G.O have to do it.

(iii) Product selection by cost analysis

Cost of any product consists of ten main components.

- Cost of raw materials, including wastage.
- Cost of equipment's and tooling.
- Cost of land building and interest on investments.
- Cost of development / design.
- Cost of production labour.
- Cost of supervision.
- Cost of energy. Electricity
- Taxes.
- Agency commission / marketing cost.
- Management over heads.

Detailed analysis of each of these components is subject of production control in the next para. It may be assumed that two main components "cost of land building, interest on investments " and " Taxes " can be neglected, as funds will be raised by donation and tax exemptions can be availed for such institution. The product may be selected in such a way that equipment, tooling, energy cost will be low. The over head will be negligible as it will be managed by voluntary organizations. The product should need high labour, cost of semi skilled workmen as compared to cost of raw materials. Also the raw materials should be locally available cheap if purchased in bulk. That will give good return on labour even with lower efficiency. The product should also have a wide margin of acceptable quality, so hat rejection is very limited. The list of products, in para (i) fulfills all these requirements. The industrial product market is highly competitive and have very narrow margin of quality acceptance, as compared to handicraft and farm based products. Both these products groups can also have decentralized cottage level production without adverse effect on cost, quality or productivity. The workmen who are not able to stay away for employment get the employment where they stay in smaller units.

(B) Production Management

Production management will control the production process by maximization of output per unit inputs. Inputs in form of capital, space, equipments, raw materials, labour, energy and over heads. Since the selected products have labour and raw materials as main inputs they need maximum conversation.

(i) Conversation of raw material's cost

Maximum efficiency can be achieved by minimum raw materials cost per unit.

- Purchase management, will achieve control on purchase cost.
- Rejection control by production quality.
- Alternative use of raw materials not used in main production. Control on surplus and obsolesce.
- Cost realization of byproducts and waste materials.

(ii) Labour cost control

Labour cost can be minimized per unit of product by introduction of following measures.

- Workmen training and perfection for specific operation.

- Avoid on-job instructions. Supervisor may brief the workmen before the work starts and if any correction is needed, brief at the end of shift or collectively once in a week. These briefing sessions may not be a fault finding or rebuking time but a part of training for perfection.
- Time and motion study. Use stop watch and log-sheets to note the time involved in each activity and between two activities. Find ways to reduce time and increase production.
- Renovate methods, tools, tackles.
- Find out ways to get more production in less time with same workmen and same tools.
- In process involving cutting, pressing introduce safety methods so that process remains safe inspite of increase of speed. Production should not suffer due to fear.
- Make all hand tools, equipment operation levers comfortable, easily approachable and smooth enough to reduce operation time and fatigue, e.g. coir craft becomes comfortable if coir is moist and hurt the workmen less then dry coir. Coir roll can be suspended on spindle so that it can be pulled as required. All wooden handles, clamps, holds should be polished smooth and small enough for hand grip and so on. Metal handles should have knurling to avoid slip of grip. Metal handles should be fitted with plastic knob for better hold and comfort.
- All clamps, fixtures, chucks, holds, limit stops, should be quick fit-quick open type. Use of cam and lever, snap fix, spring loaded release can make operations real fast and reduce fatigue.
- Repetition of operation is unavoidable in any production. Yet operational fatigue can be cut down, by breaking the monotony.
- Give workmen change of job to be conversant about more then one operation. But do not change frequently enough to reduce his speed and efficiency.
- Provide safety guards on all moving, rotating, sharp cutting edges. Protect all electrically operated tools to avoid short circuit and accidents. All workmen must be trained to meet with any emergency either due to sick workmen, defective equipment, defective operation or electrical shock.
- Since the employee / workmen have lack of quick thinking and they also lack emotional control, supervisors should be easily available in case of real need and not so easily available to create interruption in work. Supervisors should keep a distance but close watch. They have to master the special supervision skill for these special workmen.

(iii) Equipments, tools, space, investment cost control

It is observed that every one wants to do everything. Any vocational training and habilitation centers will have at least half a dozen items and trainees working randomly. No trainee is specifically marked for specific training and some of the equipments-tools-space just remains ideal and unused. This is not what de-centralization means. In fact such units are short of funds, space and instructors. No outlet is yet set up for products. Different items need different raw materials. Purchase of raw materials in small quantity is very costly. The cost of production goes high with all these increased variety. It is necessary that rehabilitation centers concentrate their production activities on specific area with change in product due to seasonal demand or seasonal availability of raw materials.

• **Design, developments, engineering and supervision controls.**

These are cottage industries decentralized for production and centralize for purchase, production controls and marketing. The technology is not as difficult as the words sound. No consulting engineers and business managers are required for this purpose. In a sports club in an industrial town of south Gujarat they employed a local fisherman as swimming instructor. He proved to be good swimming instructor inspite of his inability of social interaction and knowledge of communication limited to tribal language. For work like bamboo, cane, palm leaves craft the local workers in the trade are best instructors cum consultants. All things may be made small, simple, easy, cheap, flexible, convertible for common people to understand and implement. Work skill and simple imagination are more useful than imaginative and big buildings. Let the trainee know what he is able to do to

The mentally handicapped persons are encountered when their abilities are projected in form of their work, and when they get paid for their work. The building up of self esteem will be a very sound base for personal independence.

(C) Marketing network and purchase policy

(i) Purchase of consumables, raw materials, spare parts, equipments, job works, is an important factor in cost control. Purchase technology has five parameters; Purchase cost, purchase order quantity, quality, selection of source, payment and delivery terms. The cost includes taxes, transport and inventory carrying cost. Purchase can be planned at bulk order cost with staggered delivery over a period to each cottage industry. This can reduce inventory carry cost, deterioration and surplus. But less than minimum quality purchase will increase transport cost. Purchase of perishable local raw materials like tomato, vegetables is better decentralized. Bulk purchases of materials from far away places and from wholesale market is advantageous even with increase of transport cost by way of redistribution cost. All this theoretically complex systems are very simple if looked at with imagination and common intelligence. In the preface of a hand book on purchasing and inventory control the author has written that "without any formal specialization and training a house wife is the best purchase manager" she effectively controls all five parameters of purchase management. She do not insists on lowest price or best quality. She knows what to purchase at

what .price in what quality and accordingly make bulk purchase; monthly, weekly and daily need purchase.

Parents Associations has to do all it in the same way.

(ii) Sales promotion, market network and marketing strategy are also high sounding words for simple system. There are four ways the products of habilitation centers can be marketed. Presently the visitors of institution and parents of the trainees purchase out of sympathy or with intention to help the trainees.

(a) Parents organization may have a sales counter in the organization's place for all vocational habilitation centers, where products are sold on no profit no loss basis. The actual expenditure of managing the sales counter may be added to the cost of production.

(b) In all seminars, workshops, annual programmes and on public product sales exhibitions, parents' organization must keep a stall for products of all member institution. Organizers of exhibitions can even be moved to provide such space free of cost for such purpose.

(c) House to house sales by volunteers of parents' organizations can be organized.

(d) House to house sales can be entrusted by parents organization on commission basis to agencies/students/siblings of mentally handicapped.

(iii) Marketing will be possible if the following marketing need is met with in production.

- Quality of product.
- Assured supply of market commitments in case of bulk orders.
- Competitive price. Even if the purchaser prefers the purchase from such production centers and purchase without inviting tenders such deal will not last long if prices are too high or quality is inferior compared to price.
- Product information and marketing arrangements to be made available to prospective purchases. Public awareness through media and frequent exhibitions.
- Collective efforts instead of individual management.

Blind man's Association Ahmedabad, have fulfilled all above parameters.

8. Personal independence through employment

The final objective of all efforts is the self supported personal independence of mentally handicapped persons. They can earn the same through work skill, social skill, and remunerative employment. Employment to give financial self earning. Employment can be classified in the following groups.

(A) Employment in sheltered or supported workshop.

(B) Employment placement after vocational training in (A) above.

(C) Competitive open employment after vocational training in (A) above.

(D) Employment in co-operative or parents association managed production units.

(E) Self employment or employment in family business/ production /industry.

[A] Vocational training and habilitation in sheltered workshop. Supported workshop.

These are only training centers with the objective of increasing employment opportunity. Most institutions under this scheme give stipend for initial period of two years. The trainees do not get any other benefit. The stipend is discontinued on completion of the specified period. If trainee continue for further period he may not get any useful training as also do not get stipend. Trainee who could not achieve the work skill during original training period due to lack of basic functional skill is not likely to develop it there. He need a different training. This is where parent's interest only to keep the index person away from home when they are busy with something else comes in way.

[B] Employment Placement

The basic concept of employment placement on completion of training and habilitation in sheltered / supported workshop for persons with disability is workable to some extent for physically handicapped persons. For persons with mental handicap the idea of employment placement has not worked even for person with mild mental retardation and even legally normal persons achieving I.Q. above 70, after successful intervention programme. The environment in industries and large office setup are hostile to these persons. They can hardly retain their job even if they can do their duty well. They can be misleading into addiction, moral-financial-sexual exploitation, and behavioral problems and physically harmed. Their reaction of good behavior or reaction of others' bad behavior always put them in wrong box. Social evils are more then match for these lovable, simple open-minded sensitive persons.

[C] Competitive open employment

No person with I.Q. below 70 is likely to get such job even if fully competent for job requirements. The employers face legal problem in employment due to the confusion of law regarding status of M.R person's right under industrial dispute, workmen compensation, minimum wages and contract act as also the labour laws. Other conditions remains as in [B] above.

[D] Employment in cooperative or parent Association organized cottage industries

These types of employments are discussed in earlier paras.
Additional advantages are as stated below.

- (i) Majority employees are persons with disability. Normal employees working with them are well aware of their limitations and abilities. Normal employees have accepted to work with persons with disability to help them.
- (ii) The industry is either managed by parents, grand parents or sibling of handicapped persons. The management therefore knows limitations to be taken care of and abilities to be best used in useful production.
- (iii) **The** product selection, process selection, tools and equipment operation and job allocation are done according to ability of the employee. The co-employees, instructors, supervisors know how to interact mutually.
- (iv) The industrial laws and acts are not applicable as these units may be registered as co-operative, non profit parents habitation centers or charitable institution. The workmen are either members of cooperative or beneficiary or habilitation trainees. This is required to be made clear in registration of cottage industrial unit.
- (v) The parents Association or co-operative may also act as guardians and custodians of those persons with mental retardation who do not have natural guardians and whose I.Q. is below 70. The constitution of the parent's Association may have a sub committee for guardianship with legal authorization for this purpose.
- (vi) Such training cum production units of parent's Associations ensure long time functional service as they are managed by affected families.

[E] Self employment

Persons with mental handicap who are educable with primary or secondary level education or trainable with pre - primary or primary level education; have achieved functional skill by early intervention and special education; are likely to be successful in self employment without or with help of family members. This is the most appropriate and workable alternative for middle class families, lower income group families, families in rural areas and small towns and even for large cities. Many physically handicapped and some mentally handicapped persons are fruitfully self-employed. The choice of self employment is such that it is labour oriented, need semi skilled few persons to operate and marketing is easy. It does not have more variety and complication in handling cash transaction. A few self employments practicable and actually practiced are given below.

- (i) Telephone S.T.D. booth, with general management help of a family member.
- (ii) **Xerox** copier booth with management help of a family member.
- (iii) House to house sale of washing powder, soap, incense stick and other consumables. News paper distribution.

- (iv) Sale of peeled peas-grams, vegetables cut and made ready to cook. Working woman will be glad to pay for this time consuming work. Business like this can be within neighborhood areas.
- (v) Manufacture and sale preserved food stuff, like pickles, spices, dried vegetable, tomato catch-up, mango juice, fruit jams, and papad and so on. Training can be available at any cooking class for special items.
- (vi) Embroidery, patch work, tailoring of other than dress, button hole, buttons, hook and eyes.
- (vii) Hair dressing.
- (viii) Home service for old and working couple. Service for electricity bills, telephone bills, post office work. Cash handling of large sum may be avoided. Help in serving sick persons at home or at hospital.
- (ix) Baby sitting for appropriate babies in appropriate families and residence area.
- (x) House keeping, normal daily cooking in own house or appropriate employment.
- (xi) Participation in family business / industry or work with independent responsibility and appropriate remuneration.
- (xii) Drama, folk-dance in entertainment group if such ability and appropriate group is available. Painting, sculpture if such ability and training is possible.

From all alternatives [A] to [E] the last alternative gives full personal fruitful independence. Family management help can be extended just for beginning and can be reduced and withdrawn as self management ability of the handicapped person develop. For persons with lesser ability alternative [D] is best.

The objective "Towards Personal Independence" achieved by individuals can be classified in three levels. The efforts should be to reach total independence, and not to stop at less than the maximum possible.

(A) Total Personal Independence.

Individuals who are educable and have academic education up to secondary school level; who can read, write and handle money and material, can reach this level. They can have self employment or can have a remunerative job. Few achieve this level.

(B) Partial Personal Independence.

Individuals who are trainable; who can have only pre-primary level academic skill can reach this level. They need close supervision and help of family members in management. They can have remunerative employment in protected environment. They can earn enough to support themselves.

(C) Toilers.

These individuals do not support them-selves except managing their daily routine. They are employed to have feeling of doing work. Their functional skill is below the trainable level.

II Root-Fruit Model.

The development of a mentally handicapped child is compared to the growth of a plant. The first to grow from seed is roots. Next comes stem and leaves. Stem takes the shape of trunk and branches and more roots and leaves are supported on trunk and branches. The last to come are flowers and fruits. This is represented diagrammatically in fig.2

1. Roots

Unless roots grow from seed, development can not start. Development of roots need, soil, water and fertilizer. The first need for the development of any child is lovable family. Intervention, professional support, acceptance and special education are additional need of a child with mental handicap. As the roots of early intervention get these nutrition the awareness, motor skill, cognitive skill, self help and functional skill will develop like leaves of a plant. Receptive communication, non verbal communication and speech as well as mobility will also develop. In development of a plant and also in development of a mentally handicapped child the first two, roots and leaves; intervention and functional skill are important throughout the life time development.

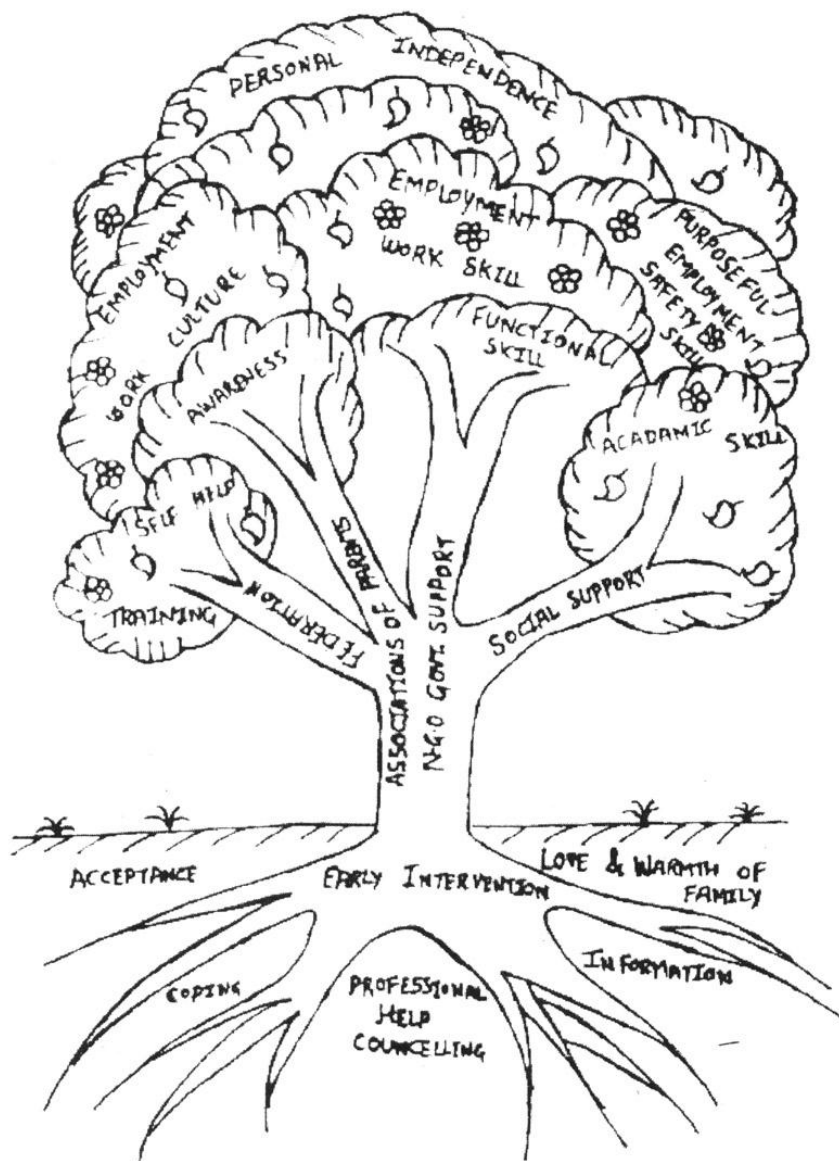
2. Trunk and Branches

As the plant develops into a tree the middle section, trunk and branches comes into existence. The function of trunk and branches is to support stems, leaves, flowers and fruits. The parent's Associations, N.G.O government and social support are like trunk and branches. Their function is to support the basic objective by organizational, production, market support for vocational habitation. Also organize parent counselling, family counselling, special education, guardianship and other services.

3. Flowers and Fruits

The objective of a tree is fruits and the fruits in development of a mentally handicapped are personal independence. With the nutrition and support described in (1) and (2) a grown up tree will have flowers

Figure - 2



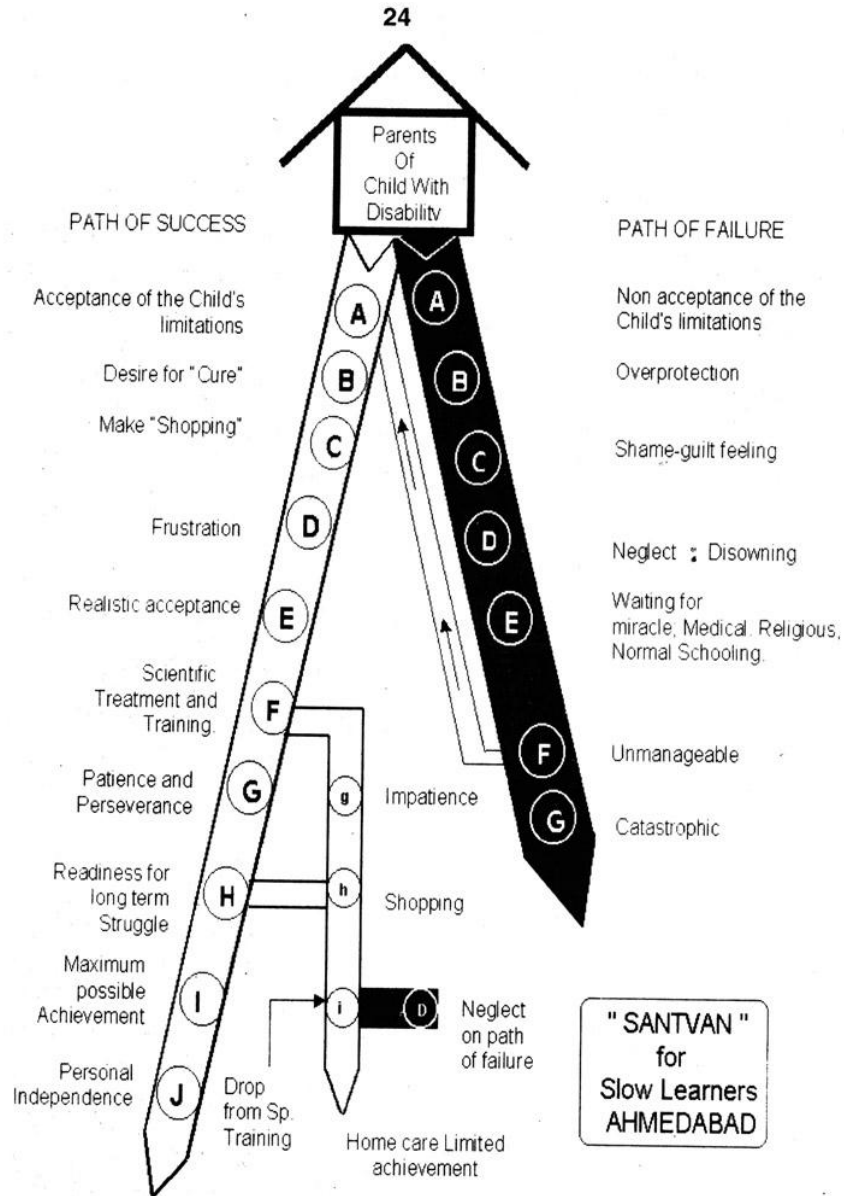
of employment and result in purposeful personal independence. No one can expect fruits to grow on branch without roots and leaves. Over protection, neglect, passive resignation, expectation of miracle, feeling of shame and guilt are obstacles in healthy developments and are required to be over come very early.

If trainees are enrolled for vocational habilitation institutions without functional skill, like sensory-motor, self help, socialization, communication skill and work culture; they are trying to grow fruits without roots. There are plants that grow roots and fruits below ground, but no fruits grow without roots and leaves.

The basic functional skill, work culture and work skill described in para 6 of model-I are the essential pre-training and post training qualifications to be imported before and during training to have

fruitful employment and personal independence. Employment is fruitful only when it provides enough remuneration for independence.

Figure -3



III Choice of Path Model.

This model is developed by "Santvan" for slow learners. A small integrated special education and therapeutical school at Ahmedabad. The model is diagrammatically displayed at fig.3. The diagram shows two paths for parents of child with disability. A path of failure and path of success in Managing Child with Disability.

1. Your child :

- (a) He/she is not a disabled child, but a child with different **ability**.
- (b) Like any other child, needs love, affection protection and **opportunity** for development.
- (c) Since he/she has limitations, needs better understanding, more responsibility a “challenge’.
Face it with courage and determination.

2. Acceptance of the child :

- (a) Child has limitations.
- (b) He/she needs specialized scientific help.
- (c) Such help to be offered as **early** as possible, progress is possible but slow in nature, hence lot of patience is required.
- (d) Avoid shopping (moving from one specialist/organization to **other all the time**).
- (e) Non-Scientific approach or religious ceremonies may be done along with scientific help without disturbing the special training program of the child.

3. Special Training :

This consist of development of functional skills required for everyday living i.e. self help, play, communication, social & emotional skill, pre-academic & academic skills etc. Therapeutic consultations to understand the physical and psychological needs are important considerations in planning such training for development of functional skills.

4. Parent Education :

- (a) Consistency and continuation of training input at home are important for speedy and satisfactory progress.
- (b) Parents involvement to understand necessary attitudes, opportunities, and needs of such children through actual demonstration by the person offering specialized training/treatment are important considerations.
- (c) Every member of family has to share responsibility of needs of the child.
- (d) Development of child may be compared with his own past progress and not with others. All children develop at individual pace.

5. Integration :

Healthy and meaningful participation of such children with family members, neighbours and other members of the society through social occasions, normal schooling, recreational and religious

places along with necessary special training; helps in community awareness & acceptance of such children and make them equal, productive and happy member of the society.

6. Facilities:

- (a) Parents should be aware of specialized services available in the city, state and country and its nature.
- (b) Parents should avail of economical concessions offered by the government and should be united to take responsibility to press Govt. and other agency for protection & equal opportunity for such children as equal citizen of the country.

In case of the child who has successfully completed above mentioned 1 to 4 stages with the help of parents and grandparents who accepted his limitations, studied and implemented the necessary special training program with patience and perseverance, finally resulted into the rarely achieved stage "Integration" at the age of 6/7 yr. only. The quality of achievement is encouraging for the professional input in such children.

Model **III Choice of Path**, included with express permission of "SANTVAN".

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About the author

Shri Bhadrashanker Pandya is an electrical and mechanical engineer. After retirement as chief engineer from Gujarat State he practiced as chartered consulting engineer for about seven years.

To help his grand daughter born in 1992 with Down's Syndrome he studied and practiced early intervention.- special education and occupational therapy. With active participation of SWMR he published his Gujarati book "Dev-na-Didhel" in 1997 which was based on his study and work with his grand daughter. He further studied life time need of mentally handicapped and their families. He has compiled a book "**Light A Candle instead of Cursing the darkness**" which is likely to be published soon.

Shri Pandya during the course of his study observed that institutions and organizations working in the area of vocational training and habilitation need information about basic work skill, safety skill, work culture, production management and purchase and marketing management techniques. He also considered that home industries, cottage industries and self employment opportunities are better for mentally handicapped than the industrial placement.

This small booklet is compiled by Shri Pandya to furnish all these details to parents and non engineer professionals, in the field of vocational training and habilitation.

SWMR has published this book to help the mentally handicapped persons towards personal independence.

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15-03-2000

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NIMH/Acad.2(28)/00/6860

22 February 2000

Dear Shri Pandyajji,

It was a real delight to receive your completed work of the book 'Towards Personal Independence'. I think that I can safely say that you must be the first grandfather to have written such a book in the country. Hence my heartiest congratulations to you for your constructive contribution. I appreciate the ideas you have put forward in the book in your own individual style and I think this book could be useful to many a parents and teachers of special children.

I did consult our Director, Dr. D.K.Menon regarding its publication and as suggested by him it will be good if you could pursue your idea of getting it published from Society for the Welfare of the Mentally

Handicapped at Ahmedabad. Looking forward for greater contributions from you and wishing you a very, healthy and long life

With kind regards and best wishes.

Yours sincerely,

(Dr. Reeta Peshawaria)

Shri Bhadrashanker Pandya

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