

# COMMUNITY-BASED REHABILITATION FOR AND WITH DISABLED PEOPLE

## **INTRODUCTION**

This compendium is meant to be of use to people with disabilities, their families, their organizations and all those who care to improve services and promote human rights in Latvia. It stems from a dialogue with Velku Fonds (a national NGO) and Star of Hope International, Sweden and draws on experience of Einar Helander, Karl Grunewald, Ture Jönsson, Anita Mossberg and my own from Sweden, Eastern and Central Europe and many other countries around the world, where we have been involved in disability programmes. An article by Anna Lindström and Anders Eklund in OrthoLetter has also been used. The focus is on Community-Based Rehabilitation, CBR, and inclusion at school, at work and in the society.

Parents, friends, carers: Rely on your own strengths and capacities and start with what you have! Find the resources available, and use them!

## **DISABLED CHILDREN, ADULTS AND THEIR FAMILIES – NEEDS AND RESOURCES**

People with disability (PWD) have the same needs as other human beings, and additionally they may have specific needs related to the disability.

They want to

- live with their family,
- take care of themselves,
- move around (at home and in the surroundings),
- go to school,
- take care of their home,
- have a job, and
- take part in social activities.

Specific inputs, then, can be:

- Care –like nursing care;
- Functional training –part of rehabilitation in a narrow sense like exercises;
- Special education –sign language for the deaf, orientation to find ones way for the blind, communication training and social training; and
- Vocational rehabilitation –to prepare the PWD for a vocational training or a job.

Once the specific needs have been met, PWD-s should have access to regular services for everybody to obtain:

- Income generation (possibly additional counselling);

- Social participation;
- Human rights; and
- A life in dignity like everybody else.

It is well known, but worth mentioning here, that health is deteriorating and the life expectancy decreasing in Eastern Europe. Tuberculosis can be taken as one indicator and suicides as another. The birth rate has been declining since the 80-ies. One can assume, that disabilities increase parallelly. The mother of a visually disabled girl complained: “/Nowdays/ You have to be rich, successful and beautiful. A disabled child does not fit into that picture.”

The social welfare office at municipal level has been assisting families with disabled children, but very often, they have too little knowledge of rehabilitation. There are about 30 NGO-s for parents of children with disabilities. Although there is some cooperation between them, they are not well coordinated. Many of these NGO-s have been providing services to the children and their families and also training for staff. They have put less emphasis on lobbying, advocacy and awareness raising. This reflects the lack of experience of voluntary work, which is not centrally directed. The authorities are also reserved and not supportive of such initiatives.

The process of privatisation has been intensified and resulted in the private sector commanding the bigger part of the GNP. The transition to a market economy –according to the World Bank– has lead to ”an increasingly inequitable distribution of income and a significant increase in the number of people who are vulnerable, impoverished, demoralized, and forced to cope with profound and rapid changes with very little assistance...”

Perhaps three per cent of all inhabitants have a disability which would require an immediate, rehabilitative action. In Latvia, that means 150,000 people with disabilities, of whom 50,000 children and youth. Prior to 1990 disabled, so called defect persons or invalids were kept away from society and institutionalized. In the case of a child with disabilities, the parents were encouraged or convinced to give it away. Therapy and rehabilitation were indeed provided, and the number of rehabilitation specialists, both medical and pedagogical was high, but the bottom line was segregation. For the deaf, oral communication was proscribed and sign-language all but unknown. Severely disabled were branded non-educable and they did not receive rehabilitation but were taken care of in institutions also called sanatoria.

My impression is, that during Soviet times persons with disabilities were generally ignored or denied, i.e. segregated. While high quality rehabilitative measures could be provided for those who were assessed as hopeful cases, people deemed ineducable were confined in homes and institutions and just kept alive with more or less loving care. The selection to institutions was done by expert committees but still arbitrary, in that many were missed and many were kept in spite of their condition having improved. Children at risk by birth could turn out to be completely normal after a year or two, but at that time they were abandoned by their parents and had to remain in the institution. The existence of these institutions is an important factor to consider in analysing the present and planning for the future, which is reflected in the section below “Institutions as resource centres”.

Yet, counter currents did exist as ideas of equality and modern pedagogics like Makarenko’s and Vygotski’s, and also advanced habilitation techniques like that of Vojta or Petö. The ethos underlying the Soviet system was made up by some kind of New Man ideals, mechanistic behaviour modifications and an extremely medical concept of rehabilitation. A characteristic of Latvia from pre-1990 was its isolation from the international debate about disability issues like *empowerment* and *equalisation*.

The new law on "Social care and social service" stipulates that the municipalities bear the responsibility for all inhabitants including PWD. That calls for policies, programmes and a mobilization of local resources, which is an additional argument for the CBR approach. There is a need for accurate demographic data on age and sex-distribution in Latvia, the same in the school system and finally the same in the disabled population, before one can proceed to draw up a comprehensive, national plan. However, the base-line data on needs and resources should be collected according to CBR methodology (as explained below).

One must also bear in mind here, that the needs of disabled women are not always identical with those of disabled men, nor can one mechanically transfer experience from rehabilitation or special education for boys to the same activities for girls. It is true, that more than 3/4 of all specialists –educational and medical— are women and so are, naturally, the majority of those caring for disabled family members. Still, it is questionable whether this dominance of women contributes to gender equality.

## **DISABILITIES AND ACTIONS**

Almost all societies have specific terms and conceptual categories for individuals who have difficulties, and these terms and concepts reflect cultural and social conditions. Organizations of disabled people have opposed the dominant *medical model* of disability, which put the blame on the disabled individual for his/her difficulties and provided solutions by medicines or surgery. According to them, the limitations and difficulties experienced by PWD-s are related to physical and mental phenomena in the environment rather than to their own functional shortcomings. In a *social model* impairment was followed by disability as the social consequence. In line with this thinking, they have forwarded *equalisation of opportunity* as the solution to those limitations and shortcomings rather than prevention or (medical) rehabilitation.

Conventionally, when considering a disabled person, people have focussed on his/her shortcomings and limitations instead of the capacities and resources which he/she may have.

The United Nations (UN) World Programme of Action for People with Disabilities from 1982 gave definitions to important terms such as prevention and rehabilitation. The concept and principle Equalisation of opportunities was established to express, that people with disabilities should have the same opportunities as others. This was the very theme of the International decade of people with disabilities 1983 - 1992. The mid term review of the decade (in Stockholm 1987), however, revealed that although there had been some progress it was too slow. There was a need for new efforts.

As a consequence, the Standard Rules on the equalisation of opportunities for people with disabilities were approved by the General Assembly of the UN in 1993, and this legal instrument is about to be upgraded to an international convention.

### **What is disability – terminology and definitions**

A sometimes inflamed debate has been going on in the disability area since the seventies: which words to use and how. While the public in general are totally unaware of the problem and talk gladly of "the handicapped" or even "invalids", for leaders of the disability movement they are those "not yet disabled" who by ignorance or prejudice create the barriers which make life difficult.

The WHO international classification from 1980 encompassed both the medical and social aspects and the whole process by stating that a disease or injury has three possible outcomes, namely recovery, death or a remaining limitation of some kind –a chronic condition, long lasting

or irreversible: an *impairment*. That is the first phase of what has been named the *disability process*, a process divided into the three stages *impairment*, *disability* and *handicap*. An impairment must be present to begin with, and the other two stages may follow in a sequence or separately.

– Impairment then, denotes a partial or total loss of an organ or a lasting (more than six months) disturbance in its function, such as an amputation, a brain damage or a reduced capacity to produce insulin.

– Disability is related to the individual as a whole, meaning his/her functions. In the CBR manual disabilities have been divided into eight groups, largely on the basis of how the disabled person or his/her environment experiences them: *difficulties learning* (like in mental retardation or intellectual disability), *difficulties moving* (because of weakness, deformities or amputations), *difficulties speaking and hearing* (this includes deafness) and *difficulties seeing* (this includes blindness). *Abnormal behaviour* can be used for chronic mental illness (psychoses, schizophrenia); *Lack of feeling* in the hands or feet (polyneuropathy from diabetes); and *fits* can be used to describe epilepsy. *Allergies and chronic respiratory diseases* may limit a person considerably, forcing him/her to be very careful, to avoid certain activities and making him/her constantly tired or even exhausted. *Migraine and chronic heart conditions* can also restrict the mobility of a person. There are other groups of disabilities, and for each CBR-plan they should be found out.

Although disability has gradually become part of the social justice concept in Western nations since the seventeenth century, and is a current worldwide social concern, it is in no way as readily definable or determinable as race, gender, age or even poverty, other issues of social justice. It remains a relative term. The question is: “How can a disabled person be distinguished from one who is not yet disabled?” One answer is: “Do not make any distinction!”, because a disability should not characterise a person, and such a label causes discrimination. Another answer is: “We have to find out, but it is extremely difficult to draw the line”, because that label is what entitles a person to a rehabilitation programme, technical aids, and benefits or allowances. But how many dB reduction of hearing should constitute a hearing deficit and how many degrees of restriction in a joint should be considered a mobility disorder? Where should the line be drawn between a normal IQ and mental retardation?

– Handicap is seen as the result of an interaction between an individual with an impairment or disability and barriers in the social, cultural or physical environment, which hinder him/ her from fulfilling his/her role in a given society, a disadvantage. Prejudice and negative ideas can be mental barriers..

The Swedish Institute has an interesting definition: “The environmentally related concept of handicap, originally introduced by the active and strong movement of people with functional impairments, plays a central role in Swedish disability policy. This means that a handicap is not viewed as a characteristic of a person, but as something that arises when a person with a functional impairment is confronted by an inaccessible environment. This approach lays responsibility on all organisers, both public and private, to ensure that the activities they run are accessible to all.”

Impairment, disability and handicap correspond to remedial measures of *prevention*, *rehabilitation* and *adaptation of the society*.

Many impairments and disabilities can be prevented, but those who remain with an impairment or a disability must get rehabilitation. For those who can neither get rid of their disability through training nor compensate for it through assistive devices, an adaptation of the environment is required.

Figure 1. The disability triad with the accompanying measures and their goal, originally formulated for the Inter-national Year of Disabled Persons, 1981. All of rehabilitation is inside, but prevention and adaptation of the society are partly outside the disability context.

The terminology here exposed was gradually accepted by rehabilitation professionals but not by organizations of disabled people. They have for instance objected to primary prevention as a component of disability programmes, since it leaves out those who already have disabilities. In the same way, access and democracy are for the whole population, and such adaptations of the society cannot be limited to disability programmes alone.

Respecting a person with a disability, we should recognise his/her character and qualities as a human being instead of being fixated on that single characteristic which appears to make him/her different from ourselves, a limitation or defect. Burnett goes on,

“The disability is not what prevents participation, the barriers that exist outside of the individual prevent full participation... The central goal of rehabilitation, your mission, is to empower those with disabilities to take charge of their own lives to the greatest extent possible.”

“Professionals tend to exaggerate the importance of anatomical and physiological factors related to disability while ignoring or underestimating such as ignorance and prejudice in the environment or mere physical obstacles to the functioning of a person with a disability. Rather than subjecting a disabled individual to our therapies, we as professionals must empower him/her to make his/her own choices.”

After two decades of use, the International classification of impairments, diseases and handicaps (ICIDH) required a revision. Since its adoption by the World Health Assembly in 2001 –including Latvia– it provides a common framework for understanding the dimensions of disablement and functioning at three different levels: body, person and society. The new International Classification of Functioning, Disability and Health (ICF) specifies on the one hand attributes-experiences of individuals and on the other hand the situations-circumstances in which they find themselves. The complex is presented as a multidimensional relationship between *impairment*, *activity* and *participation*, whereby the health condition and the so-called contextual factors can interact with each other and with the other factors.

The interaction is described as both horizontal and vertical. There is a dynamic process which can move in both directions, whereby disturbances in body functions can reduce activity and participation or the other way round, an increased participation can improve activity and even body functions. This all is influenced by environmental factors facilitating or hindering just like personal factors such as motivation or hopelessness.

The concepts and terminology here described explain the why medical rehabilitation is correct for treating body functions and structure, and social interventions for enhancing participation, integration or *inclusion*, which is a little more. Inclusion is the opposite of exclusion or segregation. Inclusion in this context covers two situations: one has to do with the disabled individual not being discriminated and one with disability projects not being kept separate from mainstream development cooperation. Having been sown as a seed in the educational sector, this idea of inclusion has taken root in the field of disabilities and project planning too. It is a further development of the principle *A society for all* and has been applied to project planning . Inclusion also means to plan infrastructure, roads, streets, and public buildings so that everybody can use them. (In Sweden, the word integration is still used for lack of a good translation.)

## **CAUSES OF DISABILITY AND PREVENTION**

### **Diseases**

Many diseases can lead to impairments and disabilities some examples:

- Stroke –reduces mobility, causes difficulties communicating and understanding;
- Heart and circulatory problems –reduces mobility, limits the general physical capacity;
- Rheumatic conditions –causes pains and aches and limits mobility; and
- Cataracts –causes visual deficiency if not operated

### **Accidents**

- Traffic accidents all too often have their origin in alcohol consumption; and
- Accidents at work can be due to insufficient protection or too much stress;
- For children, the biggest risk apart from road traffic are accidents at home like falls or burns.

## **Congenital**

Injuries may be caused to the growing organism already in the womb, by the mother's smoking or drinking or by pollution and toxicity in the environment. Chromosome disorders also belong here, and all these can lead to deformities, mental retardation or cerebral palsy.

## **Poverty**

In several ways, poverty may be a direct or indirect cause of disability:

- Poor people have less possibilities obtaining rehabilitation or to assistive devices;
- Children in poor families are more exposed to infections, malnutrition, diseases and accidents; and
- They risk to get less stimulation for their psycho-motor development.

In Latvia, the socio-economical instability affects large sectors of the population, but particularly PWD-s and their families belong to the poor sectors. There are studies showing, that a families with disabled children are poorer than others, and an aggravating factor is, that women/mothers are forced to be the breadwinners.

## **Primary prevention**

Primary prevention is part of health care and safety measures of different kinds for the population in general. Water, food, social and material welfare as well as medical services in this order are indispensable prerequisites to maintain health.

Services for safe motherhood as well as immunisation campaigns can be organised by the health structures, but measures for road safety, occupational health and sanitation require participation of the social sector and many other authorities.

Genetic counselling can be used to inform parents, especially those with hereditary diseases, on the risk of having children with defects. It is possible, that the incidence of such hereditary diseases as muscular dystrophy and hemophilia could be reduced, but there is a risk that genetic counselling carries an element of coercion. Even if we could agree on which characteristics are desirable for a human being and which are not, it is not at all proven, that these techniques can help bringing them about.

While primary prevention is for the whole population, secondary and tertiary prevention are directed at disabled people.

When the primary preventive measures have not been sufficient, a disease or an accident with injuries occurs. But even the largest programmes of primary prevention will fall short of eliminating all diseases and injuries. One can talk of a disability constant for conditions like cerebral palsy: There will always remain a proportion of children with disabilities. One reason is, that a better standard of living and better health care saves children who would otherwise have died at birth, but they can have brain injuries and deformities. This is the disability constant.

## **Secondary prevention**

Therefore, efforts and resources will always be needed to hinder a permanent impairment and disability. That is what can be called secondary prevention. Curative care, surgery, physiotherapy and other measures belong here. Examples are: medical treatment of diabetes, correction and fixation of fractures, keeping the joints mobile and in good position after burn injuries, maintaining range of motion in joints affected by burns, early detection and early

stimulation for mentally retarded or deaf children. Moreover, training the arms for a person whose legs are paralysed and the provision of a wheel-chair, teaching sign language to a person who is deaf.

The distinction between secondary and tertiary prevention is not very neat.

### **Tertiary prevention**

Tertiary prevention then, can be taken as a synonym for rehabilitation in a narrow sense like medical rehabilitation with training, the provision of assistive devices and long term medication (like in epilepsy and diabetes). It can, however, also be taken to cover adaptation of the society and equalisation of opportunity. In this case, manifold interventions like legislation, publicity, urban planning, social security etc. will be included.

Above all, it must be understood, that medical interventions cannot prevent handicap. Social and environmental measures are also called for.

Example 1. Wheel-chairs may be given for free to poor disabled. Still, in a rough terrain or in congested cities full of physical obstacles and traffic hazards, they will make little –if any— difference in the life of a PWD. The roads, traffic rules and buildings must be modified.

Example 2. In Sweden, a pedestrian entering a marked crossing has priority in that cars have to stop.

Example 3. A spastic child can receive any amount of habilitation by specialists; it cannot develop to adulthood as long as an overprotective parents restrain it from using or developing its capacities. The parents must be made aware and get involved.

People with disabilities, particularly children and mentally retarded, are at risk for exploitation in general and sexual abuse in particular. Their parents and wardens need education and they themselves can be trained in self-assertion so that they can defend their integrity and withstand pressures.

## **REHABILITATION**

*Rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualisation (Helander).*

Rehabilitation means to give back the ability or capacity to someone who has lost it. One can speak of *habilitation* when meaning the acquisition of abilities and capacities which the person has not had before, like in the rehabilitation of children with disabilities from birth or mentally retarded adults.

Some professionals, policy makers and clients equate rehabilitation with medical interventions only, but it is more appropriate to regard a broad spectrum of pedagogical, social and medical activities for and with disabled people as rehabilitation. Rehabilitation should then encompass the defence of disabled people's legal and human rights as well as their empowerment, which in turn can be promoted by their getting organized.

## **HUMAN RIGHTS AND DEMOCRACY**

Fundamental human rights belong to everybody in a society, and the more developed it is, the better it can provide those rights like health, jobs, education, housing and security. Evidently, democracy is closely linked to such development, and it is logical therefore, that PWD-s are enabled to take part in the political debate, organizations and elections. One could measure the level of development of a country by how well it covers the needs of its weakest members.

People with disabilities have for a very long time been dependant on others, been objects of care and charity. They now begin to organize themselves and demand to be heard, to be subjects (rather than objects) and to be empowered under mottoes such as “Nothing about us without us!”. Organisations *of* disabled people and not *for* disabled people are today leading the development in this area and forcefully demand their human rights.

### **The UN Standard Rules**

The United Nations (UN) World Programme of Action for People with Disabilities from 1982 gave definitions to important terms such as prevention and rehabilitation. The concept and principle *Equalisation of opportunities* was established to express, that people with disabilities should have the same chances as others to have a good life with friends, work and leisure. This was the very theme of the International decade of people with disabilities 1983 - 1992. The mid term review of the decade (in Stockholm 1987), however, revealed that although there had been some progress it was too slow. There was a need for new efforts.

As a consequence, the Standard Rules on the equalisation of opportunities for people with disabilities were approved by the General Assembly of the UN in 1993:

“States should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution.”

“States, ... have the responsibility to cooperate in and take measures for the improvement of the living conditions of persons with disabilities...”

See also the reference to the Standard Rules in relation to institutions and in relation to education below.

There are moves to upgrade the Standard Rules to an international convention making them even more decisive and binding for governments and authorities world-wide.

## **COMMUNITY-BASED REHABILITATION**

Community-Based Rehabilitation, CBR is a way of delivering services at community level. CBR reduces or eliminates physical, psychological and social barriers for people with disabilities. CBR uses and builds on the resources of the community, including the disabled people themselves, their families and their neighbourhood. CBR increases their material resources as well as their knowledge and capacity to improve their situation. CBR is a contribution to community development.

### **How it developed**

CBR is based on rehabilitation procedures that have naturally developed among disabled people themselves, their families and other people in the community. The methods have then been further elaborated by WHO and collected in a manual. In the 1970s a team consisting of a rehabilitation doctor, an occupational therapist and a physiotherapist visited a series of countries

studying how PWD-s were assisted and supported. They collected good examples of spontaneous rehabilitation like mothers and fathers training their child, assistive devices being fabricated at home, and innovative ways teaching deaf or blind people. Did these examples have something in common apart from being informal and successful? Yes, the community (parents, other family members, neighbours) played an active role. The WHO team were convinced, that this kind of rehabilitation could be further developed and spread, so that many more people could benefit. Contacts were established with ministries, national and international organizations, associations of disabled people, professionals with rehabilitation, community leaders, parents' associations, womens' associations, and in fact nearly all kinds of individuals linked to people with disabilities. With united efforts, the implementation of the CBR strategy could start and pilot projects could be set up.

WHO thus developed CBR to ensure that rehabilitation services are available to PWD-s in their communities. CBR is built on the idea that family members, assisted by a CBR worker with basic knowledge of rehabilitation, are often the best resource for training the disabled person. Through this approach, as many as 70 per cent of the people with disabilities can receive meaningful rehabilitation in their own communities. The conventional rehabilitation services, such as hospitals, physiotherapy departments, special schools and centres, will have a different but important role for specialised interventions and for training the personnel. The CBR strategy, thus, encompasses medical, social and educational services on different levels complementing and reinforcing each other.

## **Technology**

The exercises should be simple and easy to repeat regularly during a period of time. The manual is the tool to use, after it has been adapted and translated to local conditions. It has a simple and formalised language. Through a systematic filtering, the vocabulary has been reduced to some 1,800 different words only. On the other hand, there are 2,000 instructive line drawings in the manual. Thus, the manual can be used by uneducated people and it ensures, that the training is carried out in a predictable way.

The CBR-worker should follow-up the training, and after some time –as planned— carry out an evaluation. It is the CBR-worker who should know when and how to refer a disabled person to specialised services and how to receive the person on his/her return. An amputee, for instance, cannot usually be supplied with a prosthesis in the village. The CBR-worker will contact the nearest workshop where the appropriate appliance can be produced. When the amputee returns, the CBR-worker should be able to give advice on training and on how to adapt the home so that the amputee can move around safely. In this way, the CBR-worker will be of great help to the orthopaedic technicians too. The referral system works from the community to more specialized centres for specific problems and back to the community for continued training and integration, a *two-way referral* system.

The WHO team also concluded that the technology to be used a carefully designed service delivery system with programmes for training personnel, provision of equipment and assistive devices and facilities for transportation.

## **Service delivery and management**

It must be kept in mind, that the University clinic or rehabilitation centre in the capital are not decisive for ordinary people, even if professionals and academicians may be proud of their top institutions.

**The quality of rehabilitation in a country or society is that what an average disabled person gets.** (Helander)

Likewise, the number of millionaires in a country is not an indicator of either development or affluence but the number of poor, sick and disabled is.

**A society that discriminates its disabled citizens is a disabled society.** (Grunewald)

The service delivery should have a good quality and reach as many persons as possible in a cost-effective way.

The participation of the family is crucial to have success, but PWD-s integration into the community cannot be reached unless the community itself takes responsibility.

Conventional rehabilitation services are often provided by specialised professionals who see disabled people merely as *objects* for their interventions. Gradually, however, it has become clear that people with disabilities, as well as their families, being experts on their own conditions can *actively participate* and thus become *subjects* in their rehabilitation. This is a characteristic of a CBR programme proper. Together with the CBR-worker the PWD decides what should be done and when. In Sweden the so called "individual rehabilitation plan" is even regulated by law.

A CBR-worker will be related to a population of some 1,000, and one of his/her first tasks will be to visit all families to identify and register PWD and find out their needs. Having done this, he/she should suggest the training material most suited and link with the person who will be responsible for the exercises, often a family member.

*Local facilitators* (LF), corresponding to Community Health Workers, are those who carry out the work in the field together with disabled persons, their families and local people. They detect and register persons with disabilities, listen to their needs for rehabilitation, select training material, find a trainer, follow-up the rehabilitation with assessments and records, assist the person to reach other services (if available) when needed and finally receive them back again to live and work with other people in the community. In some places the LF-s are volunteers from the Red Cross, religious organizations, guides and scouts or similar, and – in the successful project of Bangalore – they are called "champions". Elsewhere they are employed more or less formally by health or education authorities. The question of remuneration and incentives is frequently asked, and there is no general answer. It should be sought in the socio-cultural conditions of each particular community. In all events, the local rehabilitation workers should be answerable to the community. The solution found will have a relationship to the possible rate and incidence of *drop-outs*. This phenomenon, however, is not so detrimental to a well planned CBR project, where rehabilitation workers may leave the programme but still remain in the community. They will keep a positive attitude and they will transmit knowledge and experiences apart from applying them informally in their own family environment. Drop-outs, in this way, can be seen as *drop-ins*.

Depending on the time available for them, each LF cares for 10 to 30 clients at a time. The intermediate level is normally managed by a corresponding *intermediate level facilitator* (ILF) or *multi purpose rehabilitation worker* (MPRW). The MPRW may be rehabilitation assistants, nurses, therapists, social workers, teachers and others with an appropriate training. They in turn train LF-s, support therapeutic procedures and monitor training and interventions with PWD. One MPRW could take on 10-30 Local facilitators.

CBR is a programme that belongs to the community; this is where the PWD are found, as well as many of the resources that can be mobilised for rehabilitation work like neighbours, local artisans, committed teachers et al. In order for a CBR-programme to be rooted locally, a *community rehabilitation committee* is set up. It consists of community leaders and others interested in taking part. One must keep in mind the necessity of involving and stimulating the cooperation of NGO-s present in an area.

In all of the above mentioned activities men, women, boys and girls with disability remain in their own communities. They have access to the regular services for others like education, health, social assistance etc. and get any extra support needed through them. They can take part in all decision-making concerning themselves. In Sweden, the rehabilitation staff are required by law to set up an *individual rehabilitation plan* with and for the disabled person.

Services linked with CBR are particularly well suited for active participation by people with disabilities. They can learn, apply and control much of these services, thereby reducing the dependency on external professionals. Such services will furthermore be helpful for disabled persons to meet and get organized. As a matter of fact, in the CBR strategy the role of professionals is mainly to share knowledge, teach and facilitate. They help PWD discover their own capacities and how to meet and solve their own problems. PWD and their families are helped to become aware, learning from each other and supporting each other and becoming self-reliant. Learning can be greatly enhanced by team-work in a group situation, in the community.

Training is crucial for CBR-staff. Once again, it is the responsibility of specialists to demystify and share their knowledge and experience skilfully (we must stop considering our knowledge as private property to be exchanged for privileges, status, carriers and higher salaries), so that the CBR-workers can carry out their tasks. This does not mean to say, that the specialists will be replaced by CBR-workers or less qualified personnel. Rather, in the CBR-set up, there are specialists of different kinds, who all of them support each other and sharing knowledge and information. Individual therapies are –to a certain extent— supplemented by teaching, showing and demonstrating. A CBR-worker will not become another physiotherapist or special teacher, but he/she will know which physiotherapeutic or didactic methods to apply in specific situations. Yet, it should be kept in mind, that CBR-work demands specialised skills too! CBR is being taught at universities. At some of them on a post-graduate level.

Yet, the training of trainers is an opportunity to practice the same problem based approach as in the training of PWD.

By management we mean the day-to-day running of the programme, a system for monitoring and evaluation, planning and policy making. There should be managerial components to ensure proper planning, organization and administration of programme, including the necessary co-ordination and co-operation and a budget. This all should have be covered by legislation and have a full public involvement.

According to a declaration by the EU Persons with disabilities should well be recognised and acknowledged as genuine actors in society through their full participation at all levels of elaboration, implementation and follow up of the inclusive policies. This practice is expected from member states.

An *evaluation* methodology has been designed and tested for measuring quality and quantity of the CBR-services. There is a computer based instrument elaborated at the UN Development Programme (UNDP) for monitoring CBR-projects. Another description of how to evaluate CBR has been published by WHO. A typical element of CBR project evaluation is, that PWD are

among the evaluators. Parameters used are such as a) the number of disabled children integrated into regular schools, b) the number of disabled adults gainfully employed and c) the creation of organizations of disabled persons. Efficiency and effectiveness are measured both in relation to individuals and to communities.

CBR has been more widely tested and evaluated than most rehabilitation approaches, and it has been shown, that CBR improves attitudes in society towards PWD-s and promotes equal opportunity. The training and therapeutic or assistive inputs from CBR have also proven effective and efficient.

### **Institutions as resource centres**

The term institution refers to one or more buildings that are separated from their surroundings, in which many people live together, divided into some kind of diagnostic groups. Institutions for persons with intellectual disabilities can be called boarding schools, residential homes or hospitals.

Today, the institutions are the last remaining manifestation of past, collective ideologies, that gave the state the right, and the power, to separate certain people from the rest of the community and limit their freedom, participation and life in general.

There is evidence that no people with disabilities need to live in institutions, no matter how profound their disabilities are. And more importantly: To live in the open society leads to an increased degree of independence and personal development.

No other group of people has been subject to the same levels of encroachment on their integrity, as well as prejudiced abuse as children and adults with intellectual disabilities. Despite the fact that the human rights include people with disabilities, it is still considered acceptable to deny them access to the open society and confine them in institutions. In general, the negative effects are less severe when the institution is modern and small scale. But even in small institutions there is a marked difference compared to inclusive living.

In Sweden and Norway all institutions for people with intellectual disabilities have been closed. As a result, destructive behavioural patterns have diminished or disappeared altogether to a degree that no one could have foreseen. Prejudices have been torn down, the solidarity with people with intellectual disabilities has been strengthened and the humanitarian forces in society have gained influence.

The trauma of being involuntarily separated from one's parents, friends, and familiar home environment creates a fundamental conviction of being unwanted and powerless, of being an object, rather than a unique individual.

The institutional environment in itself creates additional handicaps that will mark the person for the rest of his or her life. It is primarily the emotional and social development that is hampered.

As a result of the research on the psychological effects of living in an institution, two terms have been coined: *social deprivation* and *taught helplessness*.

Emotional maturity is not dependent on the degree of disability. A person may be relatively intelligent, but emotionally immature, while someone with severe intellectual disabilities may be relatively mature, emotionally. The fact that a person with profound intellectual disabilities has difficulties in expressing his or her feelings does not preclude a developed emotional life.

The overarching idea is that children, youth, and adults with disabilities should be given access to living conditions and everyday routines that are as similar as possible to those of ordinary citizens.

Parents should be given support so that their children and teenagers can remain in the home. Only under inordinate circumstances should they be given the opportunity to live in a foster home or a pupil home.

Adults should be offered support so that they can live in a way similar to other adults or in a group home.

By living like other people one will develop a personal daily rhythm as regards getting up in the morning, eating at regular hours, having work hours, leisure time, and bedtime. In addition, this will lead to a normal weekly routine with opportunities to participate in cultural or other activities in one's neighbourhood, depending on one's individual interests.

A normal living situation will ease the contact with one's parents, relatives and friends, due to both social and geographical reasons. Having one's own apartment as part of the group home will make it possible to have control over one's own social life.

Just as for ordinary citizens, all residents of the group home and the pupil home should partake in daily activities-children should attend school and adults should have jobs to go to.

Within the frames for age divisions there should not be any divisions based on sex or degree of disability.

The only groups of people who should live together because they share additional handicaps, apart from their intellectual disabilities, are deaf people, because they need staff who master sign language, and persons with autism, due to special treatment programs.

The staff at inclusive homes feel greater responsibility for the living facility, they show more involvement, they like their work place and their work structure is focused on the individual. Each of them is responsible for one or more residents, concerning everything that involves these individuals in the home. Their input can be adapted to the needs of each individual.

A group of people with disabilities that live together should be no larger than that they can develop personal, lasting relationships with each other and with the staff. Because their communicatory skills, as well as their ability to predict different reactions, are limited, the group must be kept small.

A residence for a small group will blend in with the rest of the neighbourhood and the size of the staff will be kept down. In a small group conflicts, as well as routines, will be few and the participation in society will increase. Each individual will be given the support he or she needs

*Persons with disabilities are members of society and have the right to remain within their local communities. They should receive the support they need within the ordinary structures of education, health, employment and social services. (The Standard Rules)*

The highest number of intellectual disabled children and youth Sweden has had in institutional care is five thousand people. Today, we do not have any institutions. Out of 19,000 children and youth who are given special education, 1 400 live in pupils homes and a couple of hundred in foster homes. Out of 1 500 intellectually disabled children who are below school age, only 40 do not live with their families.

The number of available care units at residential homes and special hospitals in Sweden increased during the 1960s and 70s, so that all adults with intellectual disabilities who wished for

care could be accommodated. See figure. By the end of this period, there were around 125 institutions, one third of which were private.

The special hospitals were closed as the need for them diminished and the residents were transferred to residential homes. The residential homes were gradually replaced by group homes.

The number of group homes increased during the 1970s. At this time a large number of activity centres were opened too. Today, 60 percent of all adults with intellectual disabilities live in-group homes, 20 percent live independently and 20 percent live with their parents.

Sweden and Norway are the only countries that have closed their institutions for intellectually disabled people. Denmark has closed a large number of institutions. In the 1960s institutions were being closed in the U.S.A. too, but this took place without any measures being taken to provide alternatives and the disabled people were just abandoned.

In Sweden and Norway, on the other hand, parents were given personal and financial support, the right to free day-care and pre-school as support from local groups of experts, so-called habilitation teams. In addition, families were given the right to short-term relief from the care of the child (usually a few days at a time or a week per month) or to have temporary caretakers in the home (usually a few hours every week). For profoundly disabled children over the age of seven an additional regulation gave them the right to special education in training schools run by education authorities and transportation to and from the school.

Did this process from institutions for children and youth to pupil homes take place without any conflicts? On the whole, yes! Most of the protests came, understandably enough, from the staff. During the initial phase, parents of children in residential homes were sometimes sceptic as well, but they changed their minds when they saw the advantages with pupil homes.

The county councils, who owned most of the institutions and who were responsible for the pupil homes and the special education, accepted the new system. In the long run it was cheaper for them and it was better for the children and their parents.

The number of group homes increased during the 1970s. At this time a large number of activity centres were opened.

Approximately one half of the number of people who moved into the group homes came from their parents' homes and the other half came from residential homes. This decision was very important. At last, people with disabilities were given the chance to live like ordinary citizens! And this also included those who had very profound handicaps.

Today, 60 percent of all adults with intellectual disabilities live in group homes, 20 percent live independently and 20 percent live with their parents. Every year, a considerable number of people with intellectual disabilities move from group homes to apartments nearby, due to developments in social skills that they have made. One important advantage with the group home is the fact that it can easily be put to other uses or sold when it is no longer needed, as opposed to an institution.

The daily activities in the community or neighbourhood where the group home is situated are necessary for those living in group homes, with their parents or alone. These daily activities used to be limited to special activity centres, but they have been expanded with an increasingly work-oriented establishment. As a result, intellectually disabled persons, either in small groups or individually, take part in some type of service or production.

The loneliness that many feared would occur, as a consequence of inclusive living never became reality. However, it is necessary that staff encourages and support the individual in choosing activities, participation in courses, etc. As it turns out, many people with intellectual disabilities

possess great skills in making new friends and acquaintances. It is striking, the way they are able to, and enjoy, rambling in the community and many of them belong to different organisations or clubs. The general public's knowledge and experience of people with intellectual disabilities have increased and now they are not perceived as disturbing or threatening. Studies have shown that those living in inclusive homes were given better, that they felt safer and needed less medication. Aggressive and self-destructive behaviour decreased drastically. Those persons who had the most severe disabilities improved the most, in relation to their disabilities.

### **Steps that can be taken in Latvia**

Because of the decrepit condition of many institutions for intellectually disabled people in Latvia, renovations or the building of new institutions are necessary. Until that shift to group homes and activity centres is achieved, one could improve the institutions:

- Divide dormitories with low walls or curtains.
- Divide the residents into small groups that have their own staff and that live and eat together and have their own common room.
- Try to include persons of both sexes in the groups.
- Give all residents their own wardrobes by their beds and bedside lamps.
- Give everyone their own clothes and shoes so that they can get up and go outside every day.
- Provide everyone with meaningful daily activities in locations outside those where they live.
- Use large dining halls for something else.
- Increase the possibilities for individuals to decide what their day should look like and how they should use their money and spare time.
- Increase the staff and give them more responsibility for planning the day and the week for the residents they are responsible for.
- Give the staff increased authority to encourage contact with parents, siblings and friends.

### **The CBR-manual**

The main tool for CBR work in practice has been the manual elaborated by WHO. It consists of booklets which can be taken apart and used separately for the situation at hand. There is an introduction explaining how to apply the tool and giving a background to the whole reasoning about disabilities.

There are four *guides*, and the first one for local facilitators. They are helped to meet the community and find out the attitudes towards disabled community members. If there is a motivation to change things, the LF continues by seeking out PWD-s through a house-to-house survey, and the methodology is outlined. The LF proceeds by identifying the resources and obstacles for the PWD and then selects the training material to use from the manual. The LF can then read how to support the family member or other person who helps with the training, recording the progress, asking for advice when needed, referring to specialists when needed and recording the different steps up to an evaluation.

The second guide is directed to the community rehabilitation committee. Here, the community leaders are getting an explanation what are the reasons to assist PWD-s and how they in turn can support the development of the community. There is advice on how to make a CBR project sustainable and how to obtain and control funds for it. As an example, the local carpenter can be

asked to make a corner seat (for a child with spasticity) and other assistive devices rather than having it brought from outside, and that will keep the payment within the community, while the item may well be better suited to the local circumstances too.

The third guide is for the PWD-s, who are motivated to organise. Reasons are provided and explanations of democratic procedures within the organization of PWD-s. It is also shown how PWD-s can take part in and influence CBR activities. Based on local needs and resource as they are, such activities are particularly well suited to practice integration. As a result of this advice, there are organizations of PWD-s running production cooperatives which give meaningful jobs and an income to PWD-s while the organization also benefits.

The fourth guide, finally, is meant for school teachers. In many countries, they are the most widely spread, educated people belonging to an organization –the education system– and they can contribute to disability work. The guide makes them aware of children and youth with disabilities, who can be among their pupils unknown, and it is shown what the teacher can do to help such pupils succeed. The case for integration/inclusion is also clearly spelt out, and examples of measures which can bring this about listed. Some of them are very simple and yet regularly forgotten. The teacher should speak distinctly and not too fast, turned so that light comes on the face, use the blackboard, and that makes it easier for both visual and auditory disabled to understand.

The guides are followed by *training packages* directed at practical tasks common to disabled children or adults. Thus, *breastfeeding* is essential for all disabled babies, and it is explained why plus how to carry it out when the child is either spastic or floppy or has other deviations. As a matter of fact, breastfeeding is a kind of early stimulation particularly useful for a child with disability. Similarly, *play activities* are to be made available for all disabled children, but different measures may be needed for blind children (toys with noise and three dimensional drawings, for instance) compared to such with mobility disorders (provide a stable position or putting objects within easy reach). *Schooling* is described in detail under the heading “inclusion”, but the booklet includes not only training for the disabled individual but also advice on how to influence teachers and school authorities to accept him/her. In the pages devoted to *social activities* much can be said about the right to family life, and it has to be done in a way suitable to the socio-cultural circumstances where the package will be used. The same is true for *household activities* and *job placement* which concludes this series. Complementary texts on vocational rehabilitation –for example– can be added.

The remaining training packages are directed at specific disabilities, such as *difficulties hearing and speech*, *difficulties moving, fits (epilepsy)*, *difficulties learning (mental retardation)*, and *strange behaviour (psychiatric disorders)*. At a later stage it would probably be advantageous to add training packages for conditions like *allergy, cardiovascular* and others for Latvia.

Each training package contains an explanation of the disability and what a person with such a disability may need to do. Moreover, in addition to the original survey instrument in the guide, there are assessments of the nature and degree of disability of each type. The emphasis in the training package is on the exercises to perform, or –when more appropriate– instructions on the fabrication of equipment and assistive devices. The LF can see how to plan the course of rehabilitation, engage the PWD and/or others in it and –once concluded– to evaluate the results. This in turn makes it possible to continue the programme, change it or end it.

## ***INCLUSION***

Inclusive education and CBR represent complementary and mutually supportive approaches.

Children with special educational needs must have access to regular schools, because this is the most effective way of combatting discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all.

The fundamental principle of the inclusive school is that all children should learn together, wherever possible, regardless of any difficulties or differences they may have. The merit of such schools is not only that they are capable of providing quality education to all children; their establishment is a crucial step in helping to change discriminatory attitudes, in creating welcoming communities and in developing an inclusive society. Assignment of children to special schools –or special classes or sections within a school on a permanent basis– should be the exception.

Many forms of child-to-child approaches are being used in both developing and developed countries. Common to all these approaches is an attempt to ensure that children in a community or school have a chance to better understand persons who, for whatever reason, are different from themselves. They show that when they gain a little more understanding, children who have been cruel or feel uncomfortable with a child who seems different, can become that child's best friends and helpers. Peer buddies is a specific form of peer tutoring in which the involvement with other pupils is primarily non-academic. It might simply mean being with the pupil before and after classes.

Inclusive education in general can be to the advantage of all children in the classroom due to the efforts made to consider the difficulties experienced by disabled pupils, to cater for diversity and to improve the learning conditions. Creative and individualized pedagogical approaches enrich the quality of education and facilitate the learning of all children. It is also a common experience, that children with disabilities are not those who disturb most in the class-rooms, nor do they generally hinder the learning of their mates. Other children, who may be considered normal and even unusually intelligent, can be the ones who are aggressive, extremely egocentric and disruptive. The story of Martins is illuminating: Although he has severe physical and mental limitations, he enriches the life of his parents and even neighbours. Meanwhile, many superintelligent egoists who pursue their own careers and profits, make a lot of damage at school and at their work-places, not to mention society at large. After all, many of the brightest scientists worldwide develop weaponry for mass destruction.

Experience in many countries demonstrates that the integration of children and youth with special educational needs is best achieved within inclusive schools that serve all children within a community. It is within this context that those with special educational needs can achieve the fullest educational progress and social integration. While inclusive schools provide a favourable setting for achieving equal opportunity and full participation, their success requires a concerted effort, not only by teachers and school staff, but also by peers, parents and volunteers.

There is, unfortunately, no official definition of Inclusive Education and it is therefore a concept that might mean different things to different people, but basically Inclusion is about recognising and respecting the differences among all learners and building on the similarities. It is an approach that looks into how to transform education systems in order to remove the barriers that prevent pupils from participating fully in education. It is about developing good teaching strategies that will benefit all learners.

It is sometimes seen as a political strategy based on human rights and democratic principles confronting all forms of discrimination as part of a concern to develop an inclusive society and to ensure that some students receive additional resources and are not ignored or neglected. So time has come to find a new model where we change the school system instead so it can fit and be

open to all children. We can't any longer accept that some children are regarded or even diagnosed as "non educable".

Experiencing difficulties in learning is a normal part of schooling rather than an indication that there is something wrong with the child. In many instances there are reasons to believe that it is the school system and not the child that is handicapped, or "defect". No student ever fails in school unless the school itself has failed to help the student.

The starting point should always be what is best for the particular child. Emphasising Inclusive Education does not, however, rule out special schools or centres. They would still be required to cater to some children with profound and complex difficulties in need of more specialised and extensive help. They are, however very few in number. As many as 80-90% of children with or in special needs could get their education in regular schools and classrooms, if certain important preconditions are met.

It is necessary and important to reform existing school systems in order to make Inclusive Education a reality. This means e.g. changes in curricula and teacher training; developing support services to schools and classroom teachers; seeing parents as partners etc.

It will therefore be necessary to allow for flexibility in the methods and materials used to give these children the widest possible access to the regular curriculum. There is also an urgent need to change educational practices.

Curricula should be adapted to children's needs, not vice-versa. Schools should therefore provide curricular opportunities to suit children with different abilities and interests."(28)

"Appropriate preparation of all educational personnel stands out as a key factor in promoting progress towards inclusive schools..."(

It is of special importance to establish a system of special, Mobile Resource Teachers, who can assist the children, the classroom teachers and the regular schools as one of the most urgent and important support services in order to facilitate the introduction of Inclusive Education. Many of these teachers can be recruited from the earlier institutions, if they are motivated.

These resource teachers assist the regular classroom teacher with certain parts of both the regular and the special curriculum. Their assistance is especially important when a new topic is going to be introduced.

But "Special" education is not that different from good, ordinary education. It starts from where the child really is, regardless of age or grade, and from what he/she already knows. From there the teacher helps the child, step by step, often at a lower pace than the majority, but towards the same goal - to master some basic skills. These skills are important for the preparation of an adult, productive life in society. This includes not only theoretical, academic knowledge, but also, and perhaps more important, practical skills and a development socially, emotionally, physically, morally and spiritually, which the regular education too often seems to forget.

Other key functions of the resource teacher are to assist in preparing the material the disabled child is to work with, and to facilitate communication between the classroom teacher and the child. Another vital ingredient of this service is to assist with provision of specific resource material.

Advising parents, children, regular class teachers, headmasters, is also central to the resource teacher's work. And to have regular discussions with the class teachers about suitable educational programmes and activities for children with special educational needs. Even the parents of the non-disabled children must be informed so they understand and accept the idea of inclusive education, that it can provide better education to all students by being more child-centred.

The resource teachers are also playing an important role in various school-based in-service training activities by transferring valuable knowledge and skills to the entire teaching staff. The mobile resource teacher tends also to become the natural link between the school and other resources children with disabilities need, such as special schools, resource and referral centres, a CBR programme, social services, functional training, vocational preparation, etc.

In the UN Standard Rules on the Equalisation for Persons with Disabilities, rule 6.6 is of special interest in this case. It says:

*"To accommodate educational provisions for persons with disabilities in the mainstream, States should:*

*(a) Have a clearly stated policy, understood and accepted at the school level*

*(b) Allow for curriculum flexibility, addition and adaptation;*

*(c) Provide for quality materials, ongoing teacher training and support teachers."* A list of preconditions that have to be met before the dream can be a reality might therefore look like this:

Change of negative attitudes

Political will and support

School reform:

flexible curricula

revised teacher training

support services

parents as partners

To conclude: Inclusive Education does not simply mean to move children from existing special education services to an ordinary classroom. As we all realise there will be no proper Inclusive Education if existing school systems are not being reformed in a number of ways. If the main reason for excluding the children in the first place was that the regular schools were failing to meet their needs, it makes no sense to bring them back unless changes have been made!

It is however important to start taking the first steps on this long road: by setting up some demonstration projects where consideration could be taken to various local conditions;

by looking into national legislation and policies;

by revising existing curricula and teacher training programmes;

by changing public opinion and mobilising community support;

by initiating and supporting community-based activities and self-help groups, etc.

“Special” children should of course not be prevented from being “special”. The aim must be to respond to all pupils as individuals, recognising individuality as something to be appreciated and respected. Inclusive education responding to special needs will thus have positive returns for all pupils.

The European Commission agreed in 2000 to concentrate on the modernisation and improvement of the social protection, on the promotion of social inclusion, on the reinforcement of gender balance and on the strengthening of fundamental rights, as well as combat against all discriminations. Member states are required to promote the creation of a barrier free Europe for

people with disabilities. Each person with (a) disability/ies should be recognised and acknowledged in his/her expertise as a person, in order to guarantee his/her free choice of life. Social surroundings (families, professionals...) might provide their support as long as required (but not longer). Persons with disabilities should as well be recognised and acknowledged as genuine actors in society through their full participation at all levels of elaboration, implementation and follow up of the inclusive policies.

From all this, it should be clear that CBR and Inclusion practised in a country or community, will effectively improve the lives of PWD-s and their families and simultaneously contribute to a more caring society. That would be in line with the humanitarian ideals of Europe's Christian heritage. By strengthening local initiatives, participation and the growth of voluntary organizations, democracy would also be enhanced.

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