

**ESTABLISHING CBR FOR
PERSONS WITH MENTAL RETARDATION**

A task for the Sweileh Integration Project in Amman

Kent Ericsson

Proceedings from the International Seminar
“Changing Services in a Changing Society”
Amman, Jordan, 1998

The seminar was hosted by
IM/The Swedish Organization for Individual Relief, Sweden
Ministry of Social Development, Jordan
National Council for the Welfare of the Disabled, Jordan

This book has been edited by
Kent Ericsson
Department of Education, Uppsala University, Sweden

This book can be ordered from
The Department of Education,
P.O. Box 2109, SE-750 02 Uppsala, Sweden

The book is also available in Arabic and can be ordered from
The Swedish Organization for Individual Relief
P.O. Box 2378, Amman, 111 81 Jordan

Uppsala, Sweden
1999
ISBN 91-506-1362-6

FOREWORD

In May 1998 an international seminar was held to celebrate the 30 years of IM/SOIR (Individuell Människohjälp/The Swedish Organization for Individual Relief) active support to persons with mental retardation in Amman, Jordan. A written version of the proceedings is presented in this book. It is our hope that not only participants of the seminar but also a wider group of interested persons will be informed about the ideas put forward on this occasion.

I would like to thank HRH Prince Raad Bin Zeid and HRH Princess Majda Raad for their presence and patronage of the seminar. I also would like to thank the Minister of Social Development Mr. Mohammed Kheir Mamser for opening the seminar. My thanks also go to HRH Prince Firas Bin Raad, chairman of the CBR Committee of the National Council for the Welfare of the Disabled, who headed the Preparatory Committee. My most sincere thanks to this Committee and to the Seminar Secretariat, all members mentioned in a later chapter on "Speakers and Members of Committees".

I am most grateful to the international contributors who gave of their expertise at the seminar. In this way we have been presented with new facts which will broaden our ideas of how to organize our services to the benefit of persons with mental retardation.

Director Zeinat Abu Shanab and psychologist Patricia Ericsson have been active in organizing the seminar together with Dr. Wael Masoud and research psychologist Kent Ericsson, who made up the programme. Kent Ericsson has then taken on the task of editing the contributions at the seminar into this book. I thank you all for your efforts.

This seminar has been made possible through funds from Sida (The Swedish International Development Cooperation Agency) and SMR (Swedish Mission Council). Many thanks for your contributions.

The question for the seminar concerned the nature of community based services. I, together with the Secretary General of IM/SOIR, Mr. Stefan Holmström, hope that this book will assist in furthering development of good ideas and practices for persons with a disability so that they will be able to lead a good life.

Lund, Sweden in 1998

Örjan Ekman

President of IM/SOIR

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Words of Welcome:

MR. ÖRJAN EKMAN
President of IM/SOIR

It is a great joy for me as president of IM (Individuell Människohjälp), the Swedish Organization for Individual Relief (SOIR), to wish you heartily welcome to this seminar. We have called it "Changing disability services in a changing society: 30 years of IM/SOIR work in Jordan". It is a sign of the good Jordanian climate of cooperation that this seminar has been organized in cooperation between IM/SOIR and the Ministry of Social Development and the National Council for the Welfare of the Disabled.

What has brought us together here today? What is the strong link between all of us gathered from many countries in this hall today? It is the deep concern we all have for persons with mental retardation. As teachers, care-workers, as researchers, as directors in NGO:s and in the Ministries, as parents, we all want to open new possibilities for persons with mental retardation, to open structures in society which have been closed, and - not least important - we want to change common attitudes towards persons with a handicap.

All this is possible: our perspective of 30 years gives us an interesting outlook on changing attitudes and on a changing society in Jordan, in Palestine and in Sweden. This experience gives us an empirical background to this seminar, so our intentions and dreams for the future can grow from a fertile soil.

Please allow me to start in a very personal way. I would like to tell you why these questions are so important for me. With a background of working with vocational guidance in Sweden I came to Jerusalem in 1982 as new director for IM/SOIR:s work in Jerusalem, West Bank and Gaza. During two years I was in daily contact with the mentally retarded children and youngsters. I could follow the progress of the pupils at the special school and the children of the care-home. I could witness the astonishment of Rashed from Gaza, four years old, when he, for the first time in his life, could stand up from the floor and look at the world around him: is the world like this! The shock was big, as I can understand. I could meet parents, amazed by the development of their child. I

could observe changing attitudes among ordinary people, who could see the youngsters from the workshop take the bus back to their homes. Nobody close to these persons with mental retardation remains the same after working together with them. They give something to us, which enforces in us the strong motivation to be their advocate, working for their right to be integrated into the general life of the society - as it is expressed in the Jordanian law.

How did it all start for IM/SOIR in the Middle East? More than 30 years ago, in 1966, a request came from the Jordanian government. Could IM/SOIR start to work in Jordan for the mentally retarded children? There were difficulties in finding international NGO:s willing to work with the mentally retarded. The request was given consideration in Sweden. Should we? Could we? The geographical region was new for us. The answer was positive and the first initiative was taken in the form of a small care-home in Eastern Jerusalem, at that time a part of Jordan. The beginning of IM/SOIR:s work was dramatic. The care-home was inaugurated at Easter-time 1967. Six weeks after the opening the war broke out and the political borders changed. For IM/SOIR the consequences were that we developed activities both in the occupied territories and in Jordan.

In 1968 the work started in Amman, in small scale according to our working methods. From that period parallel activities developed in Jordan and in Jerusalem, the West Bank and in Gaza. That is why, among the participants today, we have a Palestinian delegation coming from Jerusalem and Gaza. Our friends and colleagues from IM/SOIR Jerusalem/Gaza, you are most welcome!

How did the work start in Jordan? I will not give you 30 years of history, but just some glimpses. What is the most essential thing when you start new work in the field of development? I think it is the choice of field-workers. The persons you involve in the work. Their skills, their willingness to listen, to learn, to understand the new cultural context, the capacity of respect and of empathy and of course the human depth.

IM/SOIR found that person and asked her to work for us, first in Jerusalem and then in Amman. Her name was Gunhild Sehlin. Her name is so closely linked to our history in Jordan that we want to remember her today with thankfulness and pride. Her deep intuition opened the doors not only to the children but to the families and especially to the mothers. I think that the mothers of the mentally retarded children felt when they met Miss Sehlin, here is a person with whom I can share my problems and my concerns, somebody with a wide open heart and mind. Heart and mind, I want to stress that. The two parts of us are both needed.

So the work started in a very practical and empirical way: the target group was given, the knowledge of their needs came through the per-

sonal meeting, and the activities were chosen out of these needs. It was like starting to draw a map without previous structures to rely on. The strength of the work was the closeness to the families concerned, the empathy, the pedagogical work to strengthen the skills of the child and to give self-confidence. To this we have to add; from the beginning the intention was to provide an example on how to work with persons with mental retardation in order to inspire others to do the same.

In 1975 the work had grown and all activities were gathered in Sweileh, where a new building had been constructed for the care-home, the special school, the vocational school and the sheltered workshop. The special school was meant to be a model. Later on, when other initiatives were taken in Jordan and new special schools were established, IM/SOIR closed the school in Sweileh and changed the target-group to be more exclusively for persons with severe mental retardation, these still being a group with few possibilities for training and learning.

The third phase of IM/SOIR:s work was initiated in 1995. The main issue was: how to integrate the services for persons with mental retardation into the Jordanian society? This seminar is held as a part of this integration project. The decision was made to work from a community based approach. Patricia Ericsson, psychologist and consultant for IM/SOIR, will later on give you the introduction to this project and its ideological context.

During this period of 30 years a growing competence has developed among the Jordanian staff. Today all our special teachers, our instructors, the entire staff are Jordanians, including the director. This has been a very important result, that persons from Jordan now have the professional skills to continue the work. From Sweden we can cooperate with you with some experts who can share their special knowledge and their experience, based on the longer experience of integration work.

When we come to Jordan, and I speak both for myself and for Stefan Holmström, secretary general of IM/SOIR, we feel very much at home, we feel we have close friends here and we work together with people from the Ministry and from other agencies who are strongly committed to persons with handicap. This is a very good feeling. The needs in the world are great. We can bring with us experience from other countries which often helps to suggest new solutions. I can tell you that IM/SOIR is involved in work with the Tibetan refugees in India and Nepal, with development work for handicapped children in Zimbabwe and Romania, for poor children and refugees in El Salvador and with social work in Sweden, that is with people who are unemployed, or who have lost self-confidence and human hope, and with youngsters coming from families with big social problems. Our work in more than 14 countries makes us aware of the unity of the family of man trying to work for deep human values which are often threatened and need to be protected, especially the human value of each individual person.

Dear friends, I hope this seminar will help us to find new ways into society for persons with mental retardation. I hope we will find ways of giving one another inspiration and knowledge so that we can put into practice methods of work based on current experience and research.

Words of Welcome:
HRH PRINCE RAAD BIN ZEID
Patron of the Seminar

It is my distinct honour on the occasion of the 30th anniversary of the establishment of the Swedish Organization of Individual Relief in Jordan to patronize this seminar entitled "Changing Disability Services in a Changing Society".

At the outset of this seminar, organized by both SOIR and the Ministry of Social Development, as well as the National Council for the Welfare of the Disabled, I would like to extend to you all on behalf of the NGO sector in the Kingdom my heartfelt welcome and say how honoured we are to host such an august group of pioneers and social scientists in the field of community-based rehabilitation (CBR).

I am confident your valued participation will assist us in evaluating the plans, approaches, methodologies presently available regarding CBR-related issues and in so doing help us determine our priorities in the field of rehabilitation.

The role of CBR programmes is becoming increasingly important with every day particularly in developing countries. Within this context, I would like to remind our participants that SOIR since its inception 30 years ago has left its indelible mark and positive impact on all matters pertaining to the mentally-challenged children in the Kingdom.

SOIR proved to be the pioneer in the field of special care and new educational programmes for the mentally disadvantaged children with unfathomable long lasting benefits. Prior to SOIR many of these children had to endure immeasurable hardship and lived in intolerable conditions in the Fuheis hospital with mentally disabled adults.

If credit has to be given to anyone no one deserves it more than its first director Mr. Gunnar Nickelson in 1968 and even more to its second director in 1970 Ms. Gunhild Sehlin who during her fifteen year tenure ushered in profound changes in the running of such specialized homes dedicated to the rehabilitation of the mentally-disadvantaged children; and having done so with such meticulous care, love, understanding; and inexhaustible reservoir of patience and goodwill. She has surely suc-

ceeded beyond anyone's dreams. She passed away quietly in 1996 at the age of 86. God rest her soul.

I believe many of our participants today would agree with me that all the NGO:s since her departure followed her sophisticated, educational and exemplary approach, culminating in the establishment in the last decade of a number of such centers throughout the Kingdom.

Here I would like to say that we should not forget the significant changes effected by the UN Decade for the Disabled on the lives of our friends with special needs. A conspicuous example of these changes is the adoption by the UN of "The Standard Rules on the Equalization of Opportunities for Persons with Disabilities" which calls for the promotion and adherence to the policies of integration, inclusion and total participation of persons with disabilities with the community as a whole and in all areas of human endeavour.

With the adoption of these standard rules, CBR programmes have become increasingly important as an indispensable tool at the grassroots level within the community. We in Jordan have witnessed some modest beginnings yet still have a long way to go. We have barely touched the tip of the iceberg. However with the support and cooperation with many of our friends in SOIR and other such organizations we will be able to reach our common goals towards the welfare, rehabilitation and integration of the mentally-challenged children.

Before closing, I would like to extend a warm thanks to Mrs. Zeinat Abu Shanab and her organizing committee of SOIR for its commendable efforts in the preparation and planning of this important seminar, wishing you all the success in your upcoming deliberations. God bless and God speed.

Words of Welcome:

MR. MOHAMMED KHEIR MAMSER Minister of Social Development

I am pleased to welcome Your Royal Highnesses Prince Raad Bin Zeid and Princess Majda Raad, and thank Your Highnesses for Your kind patronage of this seminar.

Dear guests from abroad, we welcome you warmly to our country Jordan, and we wish you a pleasant stay here. We are deeply grateful to the Swedish Organization for Individual Relief for initiating this seminar which is organized in cooperation with the Ministry of Social Development and the National Council for the Welfare of the Disabled. This is a noble and humanitarian initiative that aims at shedding light on the importance of directing services and support to the disabled within the framework of the local community.

Your Royal Highnesses, dear guests, we are very proud of the Hashemite leadership which has always taken the lead in directing attention and care to this group of citizens in our community. The leader of our country has expressed and summarized this by saying "the rights and duties that should be performed for this category is imposed on the society by their honest citizenship and their true belonging".

This leadership has been seen as a message to the workers in the government and to the NGO:s, which has been interpreted and implemented through the development of the legislation. It has become a duty incumbent upon them to find legal ways of handling all the cases in a civilized manner, based on both scientific and practical criteria. These efforts were crowned by the passing of the 1993 Jordanian Law for the Welfare of Disabled Persons, thus providing a guarantee for the rights of the disabled to become effective and productive members of the society.

The philosophy of this Law emanates from the principle of the equality of the disabled in terms of rights, duties and commitment according to the charters of international human rights, the spirit of Islamic religion, as well as the Jordanian constitution and the National Charter.

The services presented to the disabled have developed in quantitative terms in order to counter the increasing demand made on the providing

organizations. They have also developed in qualitative terms through a transformation to the integration of the disabled in public schooling, vocational training, employment and to an adjustment of the environment to facilitate accessibility for the disabled. In order to insure access to services and care for the disabled youth, coordination will be provided through the office of His Highness Prince Firas, the cultural consultant to his Majesty King Hussein, in order that all disabled students, whose averages exceed 65%, be accepted in the General Secondary stage at the Jordanian Universities, and that they be granted an exemption of 90% of the set duties.

In the field of employment, the law grants the disabled the right to perform any work which is appropriate to their abilities and qualifications, the rehabilitation of the disabled being one of the most important issues in Jordan and the fruit of a series of educational, social and economic advancements.

In the field of developing programmes and services available to the disabled, the role of the private sector, as represented by the General Federation for the Voluntary Societies, has to be mentioned. An example of the activity and participation of the voluntary sector can be seen in the opening of the special education classes made possible through support from the Ministry of Social Development in equipping the classrooms, providing supplies and teachers and in the provision of financial support to the voluntary societies.

The Ministry of Social Development is keen to develop these concepts and strategies by concentrating on services in the local community as the principle alternative to institutional services. This seminar will emphasize this point by its concentration on such services and presentation of them in the framework of the local society, and by reviewing the effects and consequences of this trend for children of preschool age and older students.

Before I conclude my address allow me to congratulate the Swedish Organization for Individual Relief on the 30th anniversary of its work in Jordan. We deeply appreciate the efforts and experience it has presented during the last three decades, and we wish this seminar every success in accomplishing the goals set, namely, the exchange of expertise and information between the participants in order to further the work for the disabled, to train and rehabilitate them and enable them to become productive citizens in the local society.

PREFACE

Kent Ericsson

DEVELOPMENT OF POLICY FOR DISABILITY SUPPORT

An international overview shows that a gradual development has taken place during the last 50 years regarding support to persons with an intellectual disability. The International League of Societies for the Mentally Handicapped, a worldwide organization representing a large number of organizations promoting the interests of persons with intellectual disability, published its Rights for Persons with Mental Handicap in the 60:s (1968). Today the organization has changed its name to Inclusion International, thereby pointing to what they see as their main task, namely to work for the inclusion of these persons into ordinary society.

The normalization principle, arguing for the normalization of lives of persons with a disability and an integration of their special services into those of the welfare society, was the concept developed in the Nordic welfare countries, especially Denmark (Bank-Mikkelsen 1964) and Sweden (Nirje 1969). Later these concepts were brought into the international domain in the 70:s and have since then been developed further. During the last 30 years social innovations in these countries have led to a number of new forms of support which are necessary to realize a more normal life for persons with a disability.

The shift in the USA towards a community life for persons with a disability took place in the 60:s and was manifested in the 1969 report from the President's Committee on Mental Retardation "Changing Patterns in Residential Services for the Mentally Retarded" (Kugel and Wolfensberger 1969). The changes referred to in the title was the transition away from institutional forms of services to those based in the community. The ideas presented in the report have since then been accepted, and even developed further, during the years which have followed.

The basis for UN in its work to promote the lives of persons with a disability has its roots in the human rights formulated by this organization during the 40:s. In the 70:s a number of policy documents were drawn up underlining the rights of persons to be part of their community. As a consequence the concept of CBR (Community Based Rehabilitation) was formed during this decade. The International Year of the Disa-

bled in 1981 was the occasion when this position became public. This was followed in 1992 by the start of the decade of the disabled. During this 10 year period work took place on preparing the Standard Rules for Equalization of Opportunities (UN 1994). This offered a global strategy to the international community on how to organize support and services to persons with a disability.

The European Union has recognized this development towards a policy based on the rights of persons with a disability to use the resources of the local community and to participate in the life it offers. It also adheres to the UN strategy of equalization of opportunities for persons with a disability as a means to achieve this (EU 1996).

Policy and real life

This development of disability policy is not just a matter of formal decisions by international organizations. Behind this one can find a large number of persons with an intellectual disability who have lived under poor and detrimental conditions. Some people, e.g. families, staff, representatives and the public, have found this unacceptable and worked to find better conditions of life for them. It is their efforts and experiences which over the years have been brought forward in local, national and international organizations to end up as brief statements of policy in the documents mentioned here.

This new policy has been based on the idea that persons with a disability are members of society and that they should have the opportunity to participate in the life going on in the community to which they belong. With a development towards community based services, intellectual disability becomes to an increasing extent an issue which demands involvement from families, from other people in the local community, from persons in services providing for the public, together with people from private and public organisations. Thereby its realization will be greatly dependent on the culture, and the conditions it offers, where services are being effected.

But policy is not real life! Work must take place to turn general ideas into a reality for the persons concerned. The development of community based services is a cumbersome process as their realization must take into account the realities of the community such as the interests of persons and groups, organizations and formal bodies, rules and regulations together with physical structures and local traditions. However, the community should not only be seen as a hindrance to these services. One will also find that many of these conditions contribute to development and a better life for the persons concerned.

Development in Jordan

Jordan has been open to the ideas of UN and the strategy suggested by this organization. There is a broad development going on towards non-institutional services in Jordan, which is illustrated by the presentation of the National Committee for the Welfare of the Disabled. In his chapter HRH Prince Firas Bin Raad, chairman of the CBR Committee of this body, presents the challenge of establishing services for CBR in Jordan. He thereby formulates the question for this book: what do we mean by the community based approach and how do we contribute to its success?

The issue of how a society should channel its support to persons with an intellectual disability has been put into focus in Amman, by the Sweileh Integration Project. The idea of this is the development of community based services so that persons who once received their support at the Sweileh Center, should be able to receive this in the community to which he and his family belong. As new services are being established, the institutional ones are being dissolved. IM/SOIR, a major contributor to the Sweileh Center, has thereby responded to ongoing international development when changing direction as to how to organise support and services. Patricia Ericsson, consultant to IM/SOIR in Amman through the Sweileh Integration Project, describes in her contribution the establishment of the Sweileh Center and the transition of services taking place when new alternatives, based in the community, are developed.

International development

When accepting a global strategy common ground can be formed by persons with similar and relevant experiences from various countries. This conviction was the basis for arranging the seminar from which the chapters of this book emanate. A number of international experts were invited to reflect on the concept of the community based approach, basing their views on their rich experiences.

Mehari Gebre-Medhin presents current issues and strategies relating to the child with disability in the family and the community, and thereby lays the basis for the presentations to come. Roy McConkey focuses the role of the family of the child with a disability, when working within the framework of a community based approach. He illustrates how support to families can be organized, with an example from an ongoing project in Guyana. Seamus Hegarty contributes to the clarification of the community based approach by discussing how this has evolved in the school setting. He points to what is characteristic for special education in the community and its consequences for the child and groups concerned, mainly parents and teachers.

Neil Ross gives an international overview of work which has taken place to apply the community based approach. He points to a number of projects which have taken place and in this way guides us to interesting

experiences. He finds not only positive results but also experiences which call for criticism and deeper analysis.

As IM/SOIR, responsible for the Sweileh Center and the Sweileh Integration Project, is a Swedish organization it is of interest to look into experiences of the community based approach in Sweden. This is done by myself as the last presentation.

The first day of the seminar was used for international presentations. During the second day participants of the seminar discussed what had been presented to them and summed up their conclusions in a set of recommendations. These are presented here as a chapter.

With this I want to thank these persons for their presentations at the seminar and for their contributions to this book.

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TOWARDS A NATIONAL STRATEGY BUILT ON THE CONCEPT OF COMMUNITY BASED REHABILITATION

HRH Prince Firas Bin Raad

This presentation has been prepared and submitted by the Committee of CBR in the National Council for the Welfare of the Disabled.

I. INTRODUCTION

The policies and programmes of Community Based Rehabilitation (CBR) are regarded as a new approach to reach higher stages of the following goals:

- 1: Prevention
- 2: Rehabilitation after discovering the disability
- 3: Equalization of opportunities
- 4: Integrating the persons with special needs in the local community. Programmes are implemented by the persons with special needs themselves, in cooperation with their families, and local communities represented by governmental, voluntary and non-governmental bodies.

We would like to comment here on the importance of using the concept “Persons with Special Needs” instead of “the Disabled” because we respect the individual and put the person before the “disability” (this paper does not use the concept “disabled” unless it is mentioned in official naming).

CBR means that governments and official organizations or bodies refer most of the responsibilities and necessary resources to the local communities. The local community itself becomes the responsible party in fulfilling the needs of the majority of the persons with special needs by identifying themselves and in offering rehabilitation and support to integrate these persons in public life. This concept came as an acknowledgment of the size of “the disability challenge” and the inability of the official and specialized organizations to face this humanitarian challenge.

It should be mentioned that CBR and institutional services are complementary to each other. In the best circumstances, according to the opinion of the persons who support this concept, any local community can rehabilitate 70% of those with a mild or a moderate disability, while the remaining 30% with a severe disability need to be referred to specialized rehabilitation institutions.

Table 1. In the following table we can see the role of each approach.

CBR	Institutional Rehabilitation
Persons with disabilities, volunteers & family members	Specialists
Can rehabilitate 70% of persons with disabilities	Serves 30% of persons with disabilities
Serves all areas	Serves limited geographical area
Changes attitudes, integration	Rehabilitation service to the person with disability.

It is clear that institutional rehabilitation, as a part of a national strategy for the care of the disabled, has an important role in facing “the disability challenge“. This role is represented in the following services:

1. Offers preventional advice and has an educational task.
2. Provision of specialized rehabilitation services for persons with severe disability.
3. Provision of some of the outreach services.
4. Participation in training the supervisors and the local volunteers, and providing the necessary technical references.

The policy and programmes of CBR that complement the institutional rehabilitation are many and varied. It is worth mentioning that most of the experiences gained has been in the “Southern“ countries. Some of them have had optimistic results, especially “Bangalore“ CBR in India, and CBR in Palestine. From the references it can be seen that they have increased as many of the United Nations bodies (World Health Organization, International Labour Organization) and other international organizations have taken the initiative of developing technical curricula in order to train local volunteers, supervisors, mothers and family members, and to implement CBR programmes in the field.

On the level of national policies preference is given to the establishment of a national committee for CBR, as some countries including Jordan have started in order to establish policies for CBR and to provide an “umbrella“ for different programmes of CBR, and to help in finding the necessary financier for the activities of different programmes. Regarding

the work at the level of governorates, the national committee can motivate the responsible persons to form local voluntary committees to help in the implementation of the programmes in the local communities.

CBR includes programmes with different directions and having different characteristics. Some programmes take the “medical approach” and work through the primary medical care. Some programmes are done through a “specialized” party, and concentrate on the application of home visits. Some programmes emerge from the local communities. They do not depend on specialized services, caring mainly for social development. They work on changing negative social attitudes towards persons with disabilities. Even such programmes have different approaches, but there are two common denominators among these programmes namely “prevention” and “integration”.

The main and primary goal aims at prevention of disabilities (auditory, mentally, physically and blind) caused by the following factors:

1. High levels of relative marriages.
2. Traffic, home and work accidents.
3. Poor health care during pregnancy and delivery and after delivery (prenatal & postnatal causes).
4. Hereditary illnesses which can be avoided through laboratory tests before marriage.

The secondary goal, “integration”, includes methodology and other subsequent goals:

1. Early intervention (postnatal).
2. Early prevention (postnatal)
3. Rehabilitation (physical & occupational rehabilitation/auditory & speech rehabilitation).
4. Health care.
5. Education.
6. Higher education and training.
7. Rights of persons with disability (equalization of opportunities/human identity).
8. Vocational Training.
9. Employment.
10. Free customs and duty exemption for assistance for persons with disabilities.
11. Following the building codes which meet the needs of physically, auditory and blind disabled persons.

In addition to these two goals, there is a common denominator. These are the “components” of the local community. These components interact in different degrees with the CBR programmes. The components are:

THE PERSON WITH A DISABILITY

Family members	Volunteers	School and teachers
Medical Centre	Local supervisor	Mosque and Church
Village Council	Specialists	Charitable societies

II. JORDANIAN APPROACH TO NON-INSTITUTIONAL PROGRAMMES

There are different experiences in Jordan concerning the care of persons with disabilities. Some of these are specialized institutional programmes, and some are field programmes within the frame of the local community such as outreach programmes, home visitation and CBR programmes. The following are some of the field experiences.

1. CBR programmes of UNRWA (First Experience)

The idea of CBR started in 1982 as a first pioneer programme in cooperation with the British OXFAM Society.

The beginning was in Souf Camp where clear ideas as to the goals of the programme had been given, for example the rights of the person with disability and the improvement of his standard of living through the support and responsibility of the community, through the rehabilitation offered to him by the local resources and facilities and later, integration into all aspects of life.

The years have passed and the ideas and thoughts have spread. A group of persons interested in persons with disabilities transmitted this experience from one place to another until the number of programmes became nine, each serving the same goals.

Although these programmes have all been established in the camps, with the exception of the CBR programme in Wakkas town, they offer services for other areas and villages surrounding the camps and the rehabilitation centres (table 2).

Here we shall refer to the many achievements which have been reached since the first CBR programme was started. The achievements are:

1. A number of rehabilitation workers (women) have been trained.
2. Local committees have been formed at all the camps, the number of the members being 9-11.

Table 2. Basic information about 9 projects.

Place (location)	Year of Establishment	No. of workers	No. of beneficiaries (boarding)	No. of beneficiaries (day services)
Souf	1982	13	116	65
Jerash	1985	14	58	65
Husson	1987	13	75	60
Baqa'	1988	24	243	185
Wakkas	1990	13	75	50
Hitteen	1993	17	130	106
Irbid	1994	12	88	75
Talbya	1994	12	55	35
Wihdat	1996	12	95	45

3. Coordination committees between the different programmes are formed.

4. Integration of persons with disabilities in normal schools has occurred, not less than 50 pupils.

5. On the basis of equalization of opportunities a number of persons with special needs have been employed.

6. A number of income generating projects have been established.

7. Communication has been established between the programmes and other institutions working for the same goals in order to improve the level of training of the workers.

2. CBR Programme in Mafrak (Second Experience)

The Jordanian Swedish Medical Association, UNICEF Fund, ADRA Association.

This CBR programme was started in Mafrak in 1992 under the patronage and support of HRH Prince Raad Bin Zeid, the head of the Jordanian Swedish Medical Association.

Prior to starting the first project, the first international conference on CBR was held where several specialists from Arab and foreign countries participated. After the conference, Mafrak governorate was chosen to be the centre of the project for the following reasons:

- Mafrak is the largest governorate.
- The lack of specialized organizations, either governmental or voluntary.
- Mafrak is a geographical area suffering from a lack of resources of different kinds making it among the less lucky areas.
- Mafrak could be regarded as an experimental area for CBR programmes in Jordan. Because of the lack of institutional services it can be seen as a model for such programmes.

After one year of work in the project, the second conference of CBR was held under the patronage of HRH Prince Raad Bin Zeid, organized by the Jordanian Swedish Medical Association. The conference presented the kind of CBR programmes serving persons with disability.

In the beginning the programme in Mafrak put an emphasis on the medical side, helping to carry out a field screening in order to know the number of cases of disability and to classify them. This screening identified 1.280 persons with disabilities.

After studying the results, five supervisors or local trainers received training in the philosophy of CBR and to qualify them as trainers or instructors for local volunteers. In 1995 the services of CBR expanded to cover eleven villages in the "Al-Hamra" area, in cooperation with the directorates of Health and Social Development. It should be mentioned that at the end of 1995 ADRA Society took responsibility for implementing the project. The work was concentrated to the "Al-Hamra" area and ADRA also adopted the "Al-Khaldia" area. The project has the following main components:

1. Changing attitudes of the local community, from a negative view of persons with disability to a more positive attitude which helps their integration and participation in the community.
2. Providing services and programmes concerning special education and rehabilitation to all ages of persons with disability, especially through continuous home visits.
3. Concentration on prevention programmes through counselling and advice for parents and the local community.
4. Evaluation of the practical needs of persons with special needs in the eleven villages.
5. Providing awareness to the local community about the concepts and philosophy of CBR.
6. Offering CBR and rehabilitation for persons with disabilities.
7. Continuous training for specialists, volunteers and families on the practical dimensions of CBR.
8. Documentation of the activities and achievements.

The Al-Mafrak programme has the following characteristics: The programme started under the supervision of a group of doctors, members in the Jordanian Swedish Medical Association. From an initial medical approach the programme took on a wider frame concentrating on the following three aspects:

1. Changing the attitudes of the local community towards persons with disabilities.
2. Providing rehabilitation services to the disabled person either at home or outside.
3. Creating awareness about prevention.

3. CBR programme in the South Governorates

A CBR programme started in Rabba town in Karak Governorate. The director of Mafrak CBR programme, through the support of Potash and Phosphate Companies, followed the same procedures in Al-Rabba. 12 female volunteers were trained. To identify persons with disabilities a primary screening study was carried out in the area. It is hoped that the programme will spread in the future in other governorates in the South.

4. Ministry of Health and Health Care: The Medical Approach (Third Experience)

The Ministry of Health adopted this approach through the departments of medical rehabilitation in cooperation with the World Health Organization. The medical approach started within the framework of CBR with the following steps and stages:

1. A field screening for persons with disabilities in Al-Mafrak and Aqaba governorates was carried out to identify disabilities and their types, and to prepare the necessary rehabilitation programmes.
2. Several workshops have been organized during 1989-1997 on the concept of CBR, and the role of the medical approach to improve this concept. 80 participants attended the workshops from the different governorates including doctors, nurses, physiotherapists and others from the local community.
3. Training courses, about CBR and its concepts, have been organized for staff working in medical centres.
4. The CBR plan came into action in Aqaba Governorate in the beginning of 1997. The project took the following directions: a) Field screening to identify the number of persons with disabilities. b) Establishment of a central committee in the governorate, and 8 sub-committees in eight different villages.

5. Outreach Programmes and Supporting Organizations in the Community

Some supporting and specialized organizations offer rehabilitation services and counselling to persons with disabilities in their living areas, especially for those in far rural areas, the aim being to give them an opportunity to participate and be integrated in their local community. The organizations participating in the programmes are:

1. Holy Land Institute for the Deaf (since 1982).
2. Al-Hussein Society for the Care & Rehabilitation of the Physically Handicapped (since 1990).
3. Swedish Organization For Individual Relief (since 1993).
4. Al-Diya Society for the Rehabilitation of the Blind (since 1996).
The service is offered by a mobile team of specialists in rehabilitating persons with disability and offering counselling to the parents and volunteers. Rehabilitation is offered by:

a) A specialized team in the outreach programme localized to different areas of Jordan such as Deir Abu Saeed, Al-Kura, Wadi Mosa/Petra and the villages in the middle of the Jordan Valley. This team concentrates on:

1. Medical assessment of persons with disabilities, preparing the necessary treatment programmes.
2. Home visits and school visits.
3. Organization of training courses for the volunteers and rehabilitation workers.
4. Referral of persons with severe disabilities to specialized organizations.
5. Integration of pupils with disability into the governmental and UNRWA schools.

b) A mobile clinic visits the distant areas and has the following task:

1. Offering rehabilitation and treatment services and assistance aids.
2. Organizing primary individual training programmes to mothers.
3. Counselling on disability.
4. Screening of disabilities in the area (statistical screening).

The difficulties and obstacles facing the outreach programmes are:

1. Lack of coordination among parties working in CBR.
2. Lack of statistical screening on disabilities in Jordan.
3. Lack of technical resources specialized in CBR.
4. Negative attitudes towards persons with disabilities.

5. Lack of services in medical care.
6. The lack of commitment and continuity in the work of volunteers.

6. The Programme of Auditories in the Specialized Centre in the National Girls School

This programme is not considered among the common CBR programmes, as it represents one of the programmes provided at an experienced educational school in Amman. We prefer to place this programme among the other approaches as it represents a programme applicable in local communities in different areas of Jordan. It concentrates on early prevention and intervention for children under the age of five years. In addition, it prepares the children to understand the vocal message. It is also worth mentioning that such methods are applicable in most of the local communities either in kindergartens, elementary schools or in health care centres.

The team from the specialized centre in Amman established the programme of early prevention and intervention for auditory problems in a normal school, Al-Hliya for Girls, during the academic years 1995-1998. During this period the programme developed so as to provide comprehensive services including early prevention and intervention with regard to all problems of hearing and language.

During the first stage, 1995-1996, the programme achieved the basic educational steps in order to improve the level of early intervention for those with auditory problems. The first step was administrative, to facilitate early intervention in the preschool stage by the use of questions concerning the causes of auditory problems beginning from pregnancy, through prenatal and up to postnatal stages. Other simple steps have also been taken to help identify the children in the classroom through the use of questions which help the teacher control the communication abilities of the children throughout the year.

In the second stage, 1996-1997, the programme applied the services of auditory screening by games (these taking place at the specialized auditory centre) according to the orientation of the American Association for Auditory and Speech (1982-1990). In addition examination of the middle ear and intervention in the classroom throughout the year is carried out by use of an Arabized instrument and by the provision in the first elementary class of a special vocal instrument to clarify and raise the level of the teachers vocal message.

In the third stage, 1997-1998, the programme implemented the auditory test and ear test by using modern instruments at the school itself. The programme also included early intervention, diagnosis and comprehensive speech intervention in the school. A class was provided with a sound instrument to clarify and raise the vocal message of the teacher. Another class in the kindergarten was prepared to test the degree of vocal reflections. The results of the programme, in its different stages,

indicated that 28% of the pupils in the kindergarten stage who suffered from weakness in hearing and speech, benefited significantly as this programme prepares a suitable classroom environment which helps the pupils to reach their real mental academic ability.

7. Home Programme for Early Intervention

PORTAGE is a means of early intervention through training the mothers of children under nine years. The programme trains the mother how to teach the child and to deal with him. In this way mothers are qualified to be the real teacher of her children through the support of weekly home visits.

The programme serves those children suffering from mild and moderate mental retardation. It also serves children suffering from delay in mental and physical development. Deaf and blind children are not included in the programme.

The first basic training course for PORTAGE was held during a month in 1997 in cooperation with the Arab Council for Development and Queen Alia Jordan Social Welfare Fund. 24 trainees graduated and 18 trainees are still working in the field.

The implementation of this programme began a month later, working from 4 units in the following centres:

- a.: Mota Centre for Special Education in Karak Governorate.
- b: Young Moslem Women Association, Al-Hussein Society, Association of the Parents & Friends of the Handicapped.
- c: CBR centre at Hitteen Camp, Shnalar.
- d: Home of Hope Centre for the Multiple Handicapped.

Under the supervision of Queen Alia Fund, these four parties offered services to 263 children through the four units and 164 children are presently registered in the different programmes.

8. Conclusion of the Jordanian Experiences

It is now clear that different programmes of CBR have developed in Jordan in recent years. These programmes have contributed to offering direct and indirect services for hundreds of persons with disabilities in different parts of Jordan. This number of persons could not receive such services if offered in the specialized centres. CBR programmes in some local communities in Jordan have formed a tandem for the specialized centres and the organizations of CBR.

The above mentioned programmes have positive and developing roles to play in creating awareness and identifying the rights of persons with disabilities and their families. The programmes have also offered medical, social and educational services, even if these have been relatively limited.

Many factors have contributed to the limitations of these services. Some of the most important factors is the absence of official and unofficial policy in adopting this concept on the national level, and in requesting its practical implementation by the executive party in the field.

III. LOOKING TOWARD A NATIONAL STRATEGY

The Jordanian experience in the care of persons with disabilities, although it is new and relatively limited, has positive aspects that cannot be ignored. But there are obstacles and difficulties that should be objectively analysed. Therefore the Council for the Welfare of the Disabled has decided to form the national committee of CBR to solve “the obstacles and the difficulties”, and to show the effectiveness of this concept, in order to spread it in different parts of Jordan in both short and long terms. The main aim of any national strategy is to create awareness about the importance of disability prevention and attitudinal change towards the persons with disabilities by members of the local community.

This emphasizes the equalization of opportunities, enhances the feeling of social justice and participates in achieving the required integration. To discuss the difficulties and obstacles, and to achieve the two main goals (prevention and integration), the local committee decided to adopt the following foundations within a national strategy for the care of persons with disability:

1. Prevention (for discussion in the seminar).
2. Early Discovery and Early Intervention.
3. Different Rehabilitation Methods.
4. Special Education.
5. Vocational Training.
6. Employment.
7. The Rights of the Disabled.

To concentrate official and unofficial efforts on the importance of these foundations, and putting them into effect, the national committee will draw on the central policies concerning CBR as the basis for any strategy for the care of disabled. The committee will participate in bearing the following roles in cooperation with the director and administration of the executive office of the National Council for the Welfare of the Disabled.

1. Financial Role

The committee shall seek to find the necessary finance to support the different programmes of CBR that help in making valuable and behavioral change by building good relations with local institutions and international organizations believing in the benefits and importance of

CBR. Examples of such organizations are the International Labour Organization, World Health Organization and the Italian MOVIMONDO.

2. Motivational and Planning Role

The National Committee, through its work with the executive office, aims to take the following steps:

1. Motivate the local committees, through local partners and development organizations concerned with disability, to adopt the different programmes of CBR.
2. Establish an information and knowledge base about all CBR programmes, and about the positive and negative aspects of the experiences gained. The National Committee will be a reference for all efforts and initiatives in this field.

3. Training Role

The National Committee will work to achieve the following goals:

1. Form a national team of specialists in the field of CBR in order to supervise and train the planners, supervisors, volunteers and family members working in various CBR programmes.
2. Adopt training manuals for workers in all fields of rehabilitation including the manuals of either World Health Organization or International Labour Organization, for regular use in the field.
3. Start special subjects in the CBR concept in the Colleges of Special Education, the educational subjects reflecting the need of social work.
4. Establish an academic college for the education of the necessary carers assisting in rehabilitation concerning speech, auditory, physical and occupational rehabilitation.

IV. CONCLUSION

This proposed paper has aimed at showing the importance of CBR - as a concept and as a means of facing what is called "the disability challenge" - and that CBR shall represent the core of all policies and programmes concerning persons with disability. These policies and programmes shall be about the concepts of CBR (in the curricula/subjects in the college of special education). Specifically the introduction of this paper is aimed at clarifying the concept of CBR and its importance. This paper also presents a brief summary over all the field programmes now being implemented by various parties. Finally, this paper has tried to point the way to CBR and to guide the National Committee toward building a national strategy for the disabled, built on the concept of Community Based Rehabilitation.

THE SWEILEH INTEGRATION PROJECT

Patricia Ericsson

THE EARLY YEARS

The establishment of IM/SOIR in Jordan

The Swedish Organisation for Individual Relief (IM/SOIR) began its present work for persons with intellectual disability in Amman at the end of the 1960:s. On the request of the Jordanian government a project for children had already begun in Jerusalem but because of the outbreak of war in 1967 and the change in national borders, it was decided to move to Amman. The service began on a small scale, on a personal and informal basis, the main emphasis then being placed on simply finding a situation of care for children whose physical and social needs, because of the lack of any form of support for them or their families, were found to be immense. The work begun 30 years ago can retroactively be seen as an extensive pioneer task where the services which gradually evolved came to include residential facilities, schooling and daily activities for at its most 150 persons from pre-school age to adulthood.

From simple beginnings in temporary rented premises IM/SOIR moved in 1975 to its present site, there establishing what has come to be known as the Sweileh Center, Sweileh then being a small township on the outskirts of Amman. The center came to consist of school buildings and training facilities for around 100 children with boarding facilities for 50, a group home for 6 young adults who had no family contacts and a workshop for approximately 40 adults. In addition to the administrative buildings, dining room and staff rooms, there are premises for the specialist staff such as various therapy rooms and a hall for sports. The grounds are extensive and include sports facilities, a house for social gatherings as well as staff accommodation, initially intended for Swedish staff members. Since the establishment of the center IM/SOIR has had a significant role to play in the provision and development of services for persons, especially children, with mental retardation, the service provided there being seen as exemplary for the later development of other services in Jordan.

A background in Swedish services

The establishment of IM/SOIR in Jordan took place at a time when new legislation regarding services for persons with mental retardation was being implemented in Sweden. The 1967 Act had for the first time given all children the right to schooling, irrespective of the severity of their disability, and had placed responsibility for the implementation of the services of the Act on society. These were to be made available through the establishment of special residential institutions, including boarding schools. The objectives and practices which were being established by IM/SOIR in Jordan were therefore based largely on the system of services then currently under development in Sweden (Ericsson 1993).

It is in this context that the center at Sweileh in Amman should be seen, its establishment being a reflection of the development which dominated the Swedish scene in the 1960:s and 1970:s. One characteristic of this period was a localisation to secluded areas and the concentration of the various disability services, as well as staff accommodation and administration, to one large facility. In Sweden this included the establishment of a series of modern residential institutions providing for all age-groups, comprised of both housing facilities and daily activities for children as well as adults. The Sweileh Center, apart from its adjustment to the Jordanian style of building, is in many ways based on the model of the residential institution being built at this time in Sweden.

Towards a community based approach in Sweden

During the early years the support of Swedish staff was considerable. Not only the director but many of the special teachers, nursing and care staff and specialists, for example occupational therapists, were recruited from Sweden. Their task however was not only to care for and train the residents and to support their families, but also to train Jordanian staff, providing opportunities for teaching and practical experience for these professional groups in particular. In retrospect one can see that many persons, both those receiving support, and staff who have also acquired training and experiences, have passed through the center during these early years. The Swedish staff were recruited because of their experience of similar work in Sweden and could therefore introduce working methods previously unfamiliar in Jordan. This in turn provided the Jordanian staff with qualifications which gave them new opportunities to contribute to Jordanian services being developed. With the increasing number of qualified staff becoming available in Jordan, the number of Swedish staff was gradually reduced and in 1990 the first Jordanian director was appointed and the role of the two Swedish staff members became primarily advisory in character.

During the same 20 year period developments were also taking place in Sweden. In particular one finds the beginning of the provision of schooling through special day schools, enabling parents to keep their

child in the home while receiving support in the local community. Initially many of the schools were regarded as being primarily for those with a mild intellectual disability whereas children with more extensive needs were still referred to the residential institution or boarding school. But a transition had begun to take place, from the residential institution to the establishment of facilities in the community where the child lived, and where other children attended school. This can be seen partially as a reflection of the general school reforms of the period and has with time successively led to the present situation where all residential institutions have been closed and all children with mental retardation receive the support they require through locally provided day services, educational and social.

DEVELOPMENT AND CHANGE

Persons with extensive needs

One can see that during the 30 years that have passed since the Sweileh Center was started much has happened in the field of services for persons with intellectual disability, in Sweden and internationally, including Jordan. The services at Sweileh have also varied in character during this period. From being primarily a residential center for children, with training and programmes for the family as part of the support offered, it became a center for all age groups with the provision of schooling, vocational training and sheltered work for adults.

For the children, and even some of the younger adults with a mild disability, alternative opportunities and services have been developed in the community. Many schools have now been established which can provide for these children, thus enabling them to live in their homes and attend on a daily basis. Some of these schools have been inspired by the experience gained through the work at Sweileh and staff trained there have been able to contribute to their establishment. As a consequence the pre-school, special-school and workshops at Sweileh have successively, during the 1980:s, admitted persons with more severe forms of disability. Staff have accordingly had to acquire new working methods suitable for meeting their particular needs.

This process of change was not without its problems, for the staff at the center and even for the families of those admitted. The earlier tradition of receiving persons with a mild disability often had the rewarding consequence of seeing immediate development and the child being able to leave the center after having acquired certain elementary qualifications and skills. The general practice had been that a child was admitted for a limited time, a "training period", during which the family was involved in the programmes being offered and a return to the home was the main objective. Following a period at Sweileh some children were then able to go on to other schools, others into adult life, having gone through the

vocational school at the center. When it was found difficult to find adequate daily activities for adults, a sheltered workshop, started in 1980, was available for the adults who had passed through the school and returned to live in their family home. But the objective remained that a purposeful daily activity outside the center was desirable, therefore the workshop maintained its tradition of training persons for a life in the community.

A need for reappraisal

The admittance of children with more severe disabilities throughout the 1980:s required not only that teaching and training methods needed to be revised but even the objectives and goals for the task of the center. But these issues had not been adequately handled. Most noticeable was the need to recognize and undertake measures to deal with the reactions of staff who considered either that they had not succeeded in training the child sufficiently, or that the child was unreceptive to training and therefore not worth being admitted to the center. It was not self-evident or automatic that all those concerned had the insight to understand and accept that a child with a severe disability was also in need of support, but in other forms, and that the support should be extensive and probably required throughout life. To achieve this the existing short-term training programmes would need to be replaced by other forms of supportive measures which could be provided on a permanent basis.

In this situation it became clear that there was a need for a reappraisal of the role of the center and of its working practices. From having been conceived of as a service for training and preparation for life in the community and thereby serving many as they “passed through” the center, wishes were being expressed that it instead be a place for long-term care, families feeling unable and reluctant to receive their child back into the home where no support services were available. As a consequence waiting lists had become a practice, and stagnation a fact. A choice was going to have to be made as to which direction future developments should take.

A review of services

Early in 1994 a study of the Sweileh Center was carried out in order to analyse and evaluate the work with regard to the goals set for the services being provided, and to assess the working conditions, as well as the working practices being used (Ericsson 1997). The conclusion drawn from this study was that the organization was in need of review, starting with the objectives for the services. If the center was to adapt to the policies being developed within other services for persons with intellectual disability, internationally and in Jordan, and to the needs of those currently seeking support, several changes needed to be made. It was also pointed out that if the reputation of IM/SOIR as a pioneer in the field of serv-

ices for persons with intellectual disability was to be maintained, the future service should be in line with the current international course of development. This indicated a move towards a community orientated approach where long-term systems of support, based on the individual and cultural needs of those to be served, are provided in their local community.

The study showed therefore that changes had to take place in several areas, starting with the formulation of goals and objectives relevant for the present-day needs of persons with intellectual disability, and their families, in the Jordanian society. This in turn required that working methods and approaches were developed which were consistent with the formulated goals. This necessitated that a choice be made between a continued emphasis on the personal care and training of the child with the possibility of long term placement at the center, or the introduction of a wider view of community based support, directed to and made accessible for the whole family within their local community. In either case new working methods needed to be introduced, partly in terms of forms and methods for support, but also more open and creative communication between various staff departments and levels within the center and in relation to other service providers in the community. A prerequisite for such change was a change in the existing administrative routines and the organisational structure of the center.

Alternative approaches

The review had shown that a standpoint had to be taken on future development. One alternative lay in the retention of the center, maintaining a centralised institutional system of care. This however, would have involved a modernization of the premises if the facilities were to correspond to current standards and to the needs of those seeking support, and an investment in the existing buildings would therefore have been necessary. Another issue of importance was the choice between a residential service or attendance on a daily basis, the later entailing an extension of the existing transport system. The study had, however, pointed to, and recommended, the choice of an alternative approach, namely the provision of services within the community to which the person with disability belonged.

The principles on which this approach is based are widely accepted, implying the right for a person with a disability to live in the ordinary society, there receiving the support needed. To a large extent there is an international consensus on these matters, especially with regard to the principles and goals for the services to be provided (Ericsson & Ericsson 1995).

Differences may occur regarding how and when these principles can be realized, but few dispute the right of these persons to be integrated into the life of their society. An acceptance of these principles is pro-

fessed in Article 3 of the 1993 Jordanian Law for the Welfare of Disabled Persons and is the central issue addressed in the adoption by the UN in 1994, of the Standard Rules for the Equalisation of Opportunities for Persons with Disabilities.

This alternative is based on the idea of maintaining the family home as the living unit for the child, while the family, and the child, are provided with various means of service, support or care during the day. Such service must of necessity be available within reasonable proximity to the family home so as to facilitate family participation in the daily life of the child. Such an alternative offers the child and its family a system of care based on the principle of integrated services and community participation. For adults with disability the alternative implies the provision of services and support, inclusive of housing and a home, within the context of the normal life of the society to which the person belongs. The consequences of the application of these principles for the IM/SOIR center in Sweileh was that the existing services be transferred to other areas of Amman, namely those where the child or adult had their family home. This was described as a question of integrating existing services into the community to which the person belonged. This alternative approach came to be termed "the community based approach".

The choice of a community based approach

If IM/SOIR, as a Swedish based organization, was to adhere to the principles established and developed during the last 20 years and for which Sweden is renowned internationally, the choice was obvious. The choice was also obvious if IM/SOIR was to maintain its role as pioneer of new approaches and methods. However, any process of change takes time for introduction, consideration and preparation before the task of implementation can begin. The realization of the ongoing process of change began for the Sweileh Center when the Board of IM/SOIR, at its head office in Sweden, formally decided, in January 1996, to embark on the alternative approach of developing a community based service to replace the existing service provided through the center at Sweileh. The recipients of the future service were to be the existing group of children and adults already attending the center, and the provision of support was to be guaranteed through the transfer of resources, human and financial, to the new services to be developed. This decision marked the start of what has come to be called "The Sweileh Integration Project".

THE SWEILEH INTEGRATION PROJECT

Preparation for change

Prior to this decision changes had already begun to take place. Based on the intensive ongoing discussions as to the future role of IM/SOIR, initiatives were already taken in the direction of the recommendations from

the earlier study. The administrative organisation of the center had been reviewed and changes introduced regarding the division and levels of responsibility. Discussions had also begun concerning further organisational changes required for the implementation of the community based approach and for the task of transition. A study-programme for staff had been started through which some of the critical issues taken up in the earlier study were addressed. These had included among other matters, questions such as who would be the future recipients of an integrated service, what will their needs be and what qualifications and competence will be required in order to meet these needs? How should these needs be met in their cultural context and what material requirements will be necessary? What community services do already exist which would be conducive to meeting these needs?

As a consequence of these discussions even some structural changes had taken place. The residential care-home to which school-age children had been admitted on a yearly basis, was for example closed. The new relationship was developed with the families of these children, and the day service they received was given the character of a regular school and negotiations started to have this service recognized as such by the authorities. Of necessity this required the development of the transport system provided by the center, a task which indirectly led to a greater knowledge and understanding of the persons' home, family and local community. The group-home for 6 young adults was further developed and discussion began as to how a future service should be formed to meet the needs of this group.

The objective of the project

During the years since IM/SOIR began its work in Amman the services provided through the Sweileh Center have given training and care to children and adults with a disability, support to their families and training to staff both within and from outside the center. Much effort, materially and in terms of the transfer of knowledge and working practices through the presence of Swedish staff, has been invested in the development of the center. The work has, however, until recent years, been built mainly on the institutional tradition where resources are concentrated to a specialised and centralised organisation. Experience of community based work was therefore limited and little knowledge existed regarding the provision of support through the ordinary services of society.

IM/SOIR has now, through its decision to embark on a further process of development in Jordan, taken on the task of developing the forms of support and expertise necessary to establish the new type of service. In the same way that an earlier institutional tradition was conveyed in the establishment of Sweileh, the experience of establishing community based services in Sweden is now being used to support the transition

which is taking place to establish services in the local communities of Amman.

The integration project begun in 1996 has as its objective the integration and dissemination of the existing services provided at the center to locations and facilities in the communities from which the persons come. This has been based on the understanding that those attending the Sweileh Center, irrespective of the extent of their disability, have a right to live their life in the community to which they belong and that the support and services provided should facilitate the realisation of this objective. In the Jordanian society today some experience has been gained regarding integrated schooling for persons with a mild mental retardation. However, this experience is still very limited, especially with regard to providing for the needs of persons with a more severe disability. The task which has now been embarked on is therefore a challenge for Jordan as well as for IM/SOIR.

Major issues to be addressed

The start of the project, based on the principles agreed on in the 1996 decision, required that some major issues be addressed. They concerned the need for more basic knowledge regarding the persons concerned and their local communities. Firstly, who were the group of persons to be provided with support through the new service, and what were the needs and wishes of this group and their families? Secondly, what was the character of the local community to which these persons belonged, and to what extent could existing services and organisations be found and identified as presumptive partners for the development of an alternative to the services currently provided at the Sweileh Center? In order to answer these questions two surveys needed to be carried out.

Knowledge concerning the persons with a disability was to a large extent already existent among the staff at the center. It was already known that those admitted to the centre were those whose needs were most neglected, namely those with a more severe form of mental retardation, some also with an additional disability. Usually, few services were available for this group. This had already indicated that priority should, even in the future, be given to this group. On the other hand little was known concerning the wishes and ideas of the families of these persons. In order to learn it was necessary to undertake a series of meetings with the families of these persons, partly as a means of informing about the changes taking place and partly to provide an opportunity for them to express their views concerning the family member concerned.

Parallel to this survey it was also necessary to acquire knowledge concerning the local community to which these persons belonged and the nature of any existing facilities or services of relevance for a future cooperation. As the extent of current knowledge on this question had earlier been recognized as very limited, a special study had been carried out to

describe the existing services in Jordan for persons with mental retardation (Jaber 1994). This material could now be used as a basis for surveying the situation in the geographical areas or districts from which the present group of persons came.

A characteristic of a community based service is that it provides support in close proximity to the person with disability but also in liaison with other ordinary services in the community, not just in order to share knowledge and responsibility, but also facilities and resources. Examples of such services are local health centres and other medical services, social services and community centres, and recreational facilities. Relations with such agencies need of course to be developed, this being part of general working methods in a community based service. Coordination with other services or agencies for persons with disability, national and international, also need to be encouraged.

To achieve this contacts need to be established with existing local bodies and organizations and steps taken to find ways of cooperation. Such partners can vary depending on the local circumstances, government bodies, private organizations or other NGO:s being possible associates with whom to establish working relations.

Other issues in need of being addressed as a prerequisite for the running of the project concerned organisational and managerial matters, including the appointment of a Project Manager and the reorganisation of the administration at the Sweileh Center. The nature of the project management was decided on and the first steps taken towards forming the management and leadership group, both for the existing work at the Sweileh Center and the implementation of the integration project. These matters were not however finalized until early 1997. The nature and extent of support and direction from the Swedish head office was also reviewed and a Swedish consultant appointed to provide support on a part-time basis.

Throughout the period when the need for change had been investigated and analysed, the necessity for further knowledge and the development of new perspectives and working methods had been constantly emphasized. This was therefore seen as a further major issue to be undertaken and plans were laid for a continuation and development of the ongoing study-programmes, these being held in the form of workshops, seminars and public conferences.

The period of implementation

In the decision to realize the Sweileh Integration Project it was estimated that it would extend over a 4-year period, from the appointment of a project manager in 1997. Based on the preparatory work already carried out it was therefore possible to accomplish the first relocation of services during the second half of 1997. Characteristic for a community based

approach is the location of services to places used by the public in the local community. In the case of this integration project one requirement for establishing an integrated service had however already been achieved. The persons attending the day-groups, the day-school classes and the workshops were already living with their families. The problem which remained was that their services were located to one place, Sweileh, which for most of those attending was far from their home. Staff are also recruited from considerable distances from the center.

The starting point for the development of the alternative service was therefore the homes of the persons to receive services, the integrated alternatives gradually replacing those now at the centre. The specialist team, presently stationed at the center, can through the development of other working methods serve various facilities and families in the community and in due course even be located outside the centre. In this manner the nucleus to a comprehensive community based disability service is created. Such a programme, starting as a limited project, is one way of providing experience and knowledge for the further development of services in Jordan.

Alternative services are established

Baqa

Following the surveys in which the needs of the children and adults, and the character of their local communities were identified, it was found that a considerable number of pre-school and young children attending the special school came from the Baqa area of Amman. It was also a fact that some teachers from the Sweileh Center were already very familiar with that community and had a significant role to play in the development of other services for persons with a disability in that area. A new community center had recently been opened, providing services for various groups of persons in need of support, including those with other forms of disability, for example a school group for deaf children. Living in this area, which is located some distance from Sweileh, had previously meant considerable travelling time and a transport problem for those attending the center.

Following discussions with the local committee for this community, and the community center in particular, and in agreement with the families of those concerned, it was possible from the start of the autumn term of 1997 to transfer two school classes to the community center and provide them with a corresponding daily activity there. The groups included a total of 15 children, 2 teachers from the center moving together with the children. For the teachers the transfer also meant a closer proximity between their home and place of work. Support to this initial group is still provided by the various specialist staff from the center and

close contact is maintained between the project group from Sweileh Center and the management at the community center.

Wehdat

A similar group of 12 children has, in March 1998, begun in the Wehdat area of Amman. 7 of the children in that group already attended the center whereas another 5 were children previously on a waiting list for admittance to Sweileh. In this case the group has been integrated into an existing pre-school, a day-care service for other children without disability and a small group of children with deafness.

The transfer of these 12 children to this facility has involved an extension and renovation of the existing premises, which is seen as a general improvement of the conditions for all children attending the center. In both these cases the new service is located to districts of Amman defined as camps, the population being mainly Palestinian refugees. The local committees of these camps are the partners with whom IM/SOIR has made the agreement for cooperation in the running of the service, while a representative for the handicap programme of UNRWA (United Nations Relief and Works Agency) has also participated in the negotiations and in taking responsibility for the running of the new service. Also for this group support is provided from the Sweileh Center.

Al-Salam Club

A third service has also been started during the spring of 1998, for adults who previously attended either the vocational school or the sheltered workshop at Sweileh Center. The initiative to this project came from a voluntary organisation called the "Al-Salam Club for the Handicapped" this being primarily a social club for persons with various disabilities, providing premises for both recreational and social activities. A group of 10 young people now attend the center which is also located in closer proximity to their home community. Seven of those participating, previously attended the Sweileh Center and are now continuing with the same vocational activities but in a new setting.

For several of these persons this development has led to a greater degree of independence as they now can travel to and from their daily activity on their own, with ordinary public transport. The other 3 persons in the group come from the vicinity and have previously not had access to any form of daily activity. The group's activities are supported by volunteer workers who themselves, because of a handicap, often physical, attend the center and by some other volunteers who have been recruited locally.

In the agreement met between IM/SOIR and the Al-Salam Club the relationship between the two partners is regulated in the same manner as with the two community projects. In addition to agreement regarding the

overall objectives the financial and administrative roles are regulated, as is the period for the cooperation between the partners. The supportive role of IM/SOIR is also specified and in the case of the Al-Salam Club the activities at the club are supervised regularly by staff from Sweileh Center who participate on a part-time basis.

In addition to support from staff at the center, IM/SOIR has, for a two-year period beginning March 1998, appointed a coordinator whose task is to provide support and coordination of the work being carried out within all the newly started projects. This appointment is made within the framework of the Sweileh Integration Project.

From these three examples of alternative services, established within the first year of the implementation of the project, it has been shown how change can take place and alternatives can be developed. They may differ in character and formation but each, in their specific way contributes to the common objective of providing adequate personal support, within the context of the person's own culture and local environment.

The society in which these services are now being developed has changed dramatically since IM/SOIR came to Amman 30 years ago. But there are still children and persons with intellectual disability in need of support and this needs to be provided in a manner which is consistent with present conditions.

The Integration Project as it is being carried out shows that IM/SOIR still has a role to play in Jordanian society. Taking the initiative to hold an international seminar is another way of contributing to the further development of modern services required by those who are dependent on support from others in order to live a good life.

CHANGING DISABILITY SERVICES IN A CHANGING SOCIETY

The questions of new policies, objectives, and the need for new working methods relevant to the needs of present day Jordanian society, have been central to the discussions of IM/SOIR during this period of change. Finding a relevant way forward has been seen as a major challenge for IM/SOIR. One way of meeting this challenge has been to arrange an international seminar at which invited speakers from other countries could address these topics by sharing and discussing their knowledge and experience. It has been felt that this would not only contribute to finding a way forward but also be a good way of celebrating the fact that the work of IM/SOIR in Amman began 30 years ago.

Throughout IM/SOIR's time in Amman there has always been close cooperation with the Jordanian Ministry of Social Development, this cooperation having been strengthened further during recent years when the questions of change and development have come to the forefront. In 1997 IM/SOIR held a national workshop at which its Policy Statement was presented and discussed. The workshop was opened by the Minister of

Social Development and a representative from the Ministry also participated and presented a paper on a suggested national strategy for the handicapped in Jordan. In the early discussions concerning the planning of the suggested international seminar it was therefore seen as natural that it be arranged in cooperation with the Ministry, and with the National Council of the Disabled, a body which has a central role and responsibility for these issues.

It is within this context and against the background of the 30 years of IM/SOIR involvement in Jordan that the seminar is taking place. The process of change has begun for the Swedish organisation and hopefully a new life is beginning for those receiving services through this organisation.

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THE CHILD WITH A DISABILITY, THE FAMILY AND THE COMMUNITY

Mehari Gebre-Medhin

INTRODUCTION

The world of the disabled child is no longer an isolated one. In the past children with a disability and their families were often kept out of society. In recent years, however, communal, national and international movements have begun to open their doors to them. The pattern of service provision to the child with a disability is changing. Schools, kindergartens and playgroups are encouraging integration of disabled children with non-disabled children. This approach is based on the philosophies of human rights and normalization and the Convention of the Rights of the Child. The concept of normalization evolved in Scandinavia in the 1960:s and is now spreading throughout the world.

WORKING FOR THE CHILD WITH A DISABILITY

These efforts to promote inclusion of children with disabilities and special needs into the regular life of non-disabled children, and the society at large, have highlighted the importance of minimizing the risks of stress and negative effects associated with the inclusion process. The disabled child, the family, the care setting with various professionals, and the community all need to make adjustments. This is the rationale for the focus on establishing linkages and workable transitions in our work among disabled children.

The child with a disability has to pass through a series of care settings and learning situations if his or her growth and development are to be ensured. These settings and environments constitute a chain of stations which begin in the home and link the disabled child and its family with preschool and school and with the community. In general, all these settings have different characteristics. The challenge is to find ways in which the various settings can be synchronized in order to maximize the benefits to the child and minimize the potential for stress.

The objective of the focus on transitions and linkages is thus to ensure appropriate experiences which will allow the child to have a healthy body, a capable mind and appropriate social skills. These needs of the child must be viewed in the context of the ordinary child health and social services that cater for health promotion, growth and development, disease prevention and treatment among children. None of these services can be carried out effectively without establishing well-functioning links between the child, the family and the community.

Supporting the home and the family

Parents of disabled children often suffer unnecessary hardship as a result of inappropriate reassurance. The realization that their child has a disability is a major source of stress. Among common manifestations of their grief are guilt and denial. It should not be held against the parents that they experience self-inflicted problems because, in their grief and feeling of guilt, they may seek multiple opinions and unorthodox treatments. Anger is common and is often directed at the care setting. Occasionally there may be rejection of the child. The family has to come to terms with its grief while simultaneously coping with a "difficult" child. Further, they have the additional burden of dealing with friends, relatives and professionals who they feel are not always sensitive to their needs. In all this the family needs support.

The family needs to be told about the child's disability openly, accurately and sensitively. Disability in children can be traced to origins in one of three sets of factors; a) prenatal factors, including genetic and chromosomal abnormalities, infections, drugs and toxins, b) perinatal factors, including hypoxia (lack of oxygen) around birth, trauma, infections and biochemical abnormalities, and c) postnatal factors such as trauma, hypoxia, meningitis, encephalitis and poisons.

Knowledge about the etiology of the disability in the child is important, as it provides a basis for accurate genetic counseling, prediction of the outcome, preventive strategies and parental support. It is helpful to grieving families to know why their child is disabled, and where doubt exists, to have a chance to discuss this openly.

Families with disabled children may suffer considerable social isolation. The arrival of a disabled child may imperceptibly lead to severed relations with families and old friends. Alternatively, the families may have difficulty in maintaining contact with relatives and former friends. A major obstacle in this context may be the cost of transport. In the same vein, financial difficulties may stand in the way of a range of social activities, including taking the child to parks, and other forms of entertainment outside the home. Many families live in substandard homes in overcrowded areas with inadequate space for child recreation.

The persistence of old community attitudes may lead to feelings of guilt and shame among the families. As a result of these feelings, and the consequent loneliness, the families may experience periods of apathy and overt depression. This may compound the difficulty in creating a stimulating care setting at home, leading to deterioration in the quality of parenting. All these negative feelings may in some instances lead to child abuse, which will further undermine the parent-child relationship and create distrust on the part of the community towards the family.

Particular attention needs to be given by the community to the singleparent family. It is understandable that intellectual and emotional stimulation may not be adequately provided in such families. The disabled child in such a setting is less likely to be given adequate toys or reading material in the early years. As a result, the transition from the home to a care setting may be rendered difficult.

Migrant families with a disabled child are particularly at risk. Settlement takes a variable period of time and most immigrant families may not feel accepted by or experience a sense of belonging with the receiving society. They often tend to move from place to place and are more likely to be unemployed. They change jobs often and in many instances are frustrated because they have to carry out jobs that are at a level below their true capacity. They will tend to segregate and form closed societies. This throws a particular strain on the child with a disability, who may not attend infant health centers, preschool centers, and other care settings.

Meeting the needs of the disabled child

The child with a disability needs protection from physical danger and must obtain adequate nutrition and health care. Protection from certain infections through appropriate immunizations is important. The family needs support in its efforts to create an atmosphere that is conducive to bonding. The home environment should provide language stimulation, opportunities for acquiring new motor skills, and a chance to develop independence. It is also the primary scene for support of the child's sense of self-esteem, for providing opportunities for self-expression and for encouragement of creativity. The home should promote self-reliance and development of personal care. The first step in learning to cooperate, both to receive help and to help others, begins at home. The motivation for and reinforcement of learning are imparted early in the calm and reassuring home setting.

Addressing transitions and establishing links

The multiple care setting and learning environment of the child with a disability consists of the home, preschool or school, and the community. These settings generally have widely different characteristics. The differences between these environments and between the processes therein are

a great challenge even for a family with a non-disabled child. These differences are greatly compounded in the case of a family with a disabled child. The challenge lies in making the child's transition between the home and care and learning environments as smooth as possible in order to strengthen the child's ability as it moves out into the world.

In the case of both the non-disabled and the disabled child, a long range of pitfalls lie in wait in the process of transition from the home to the outside world. The informal and spontaneous and more holistic form of communication and learning in the home abruptly gives way to more formalism and regimentation and the learning of specific skills. The disabled child is now thrown into a cultural milieu that is different from home. Whereas the child had free access to the family and occupied a central place in the home, the new care setting and the environment are shared with several other children. Herein lies a great risk of failure and marginalization. The new care setting therefore needs to adapt to the needs of the child with a disability.

Preparing the child

A number of measures can be taken to prepare the child for a care setting and learning environment outside the home without stigmatizing the home or the child. Such preparation should not create a sense of failure or devaluation in either the child or the family. Care must be taken to avoid focusing on deficits and look instead for possibilities. The preparation of the child for the future should not take place at the expense of the joy of learning now.

Adequate preparation means good health and nutrition and support in order to give the child the ability to handle basic cognitive concepts, and as far as is possible to communicate in everyday transactions, using the language of the school. The child should be able to relate with others, and be psychologically well assured, with a good self-concept, be able to work as independently as possible and be motivated to learn. In all this an integrated approach is needed without too much emphasis on individual skills.

Focusing on the care and learning setting

Cooperation between the home and the learning environment should achieve a more disable-friendly school and help bridge the gap between the home and early education and care.

Special training will be needed for teachers to help ease the transition into the formal and structured classroom situation. The school will also need to consider special programs that address the disabled child's requirements without at the same time creating a sense of failure and

punishment on the part of the child or the family. Such preparation should not undermine the work for long term support, which the child with special needs requires in order to succeed.

Creating a sense of partnership around the child

There is a need for partnership, dialogue, communication and synchronization of views concerning the needs of the child. Cooperation is required to ensure good nutrition and health in the care setting and learning environment. There is a need for flexibility regarding the decision about when the child should start activities outside the home. The teaching methods used should encourage an active learning process and should be less formal. Adjustments in the size of classrooms may be required and the curriculum and pedagogic structure should take into account the needs of the child with a disability.

It is of great importance to focus on effective communication among various people with influence on the life of the child, to build linkages between the child's home, the care setting, other learning environments and the school system. Continuous communication and consultation will help all those involved to anticipate and provide orientation for changes that will be faced by the child and the parents both at home and in the care setting. This joint endeavor and partnership will help the child to develop broad coping skills rather than preparing it for the one or other environment. Such an approach will help to identify means of supporting each child in his or her particular situation. The partnership will strengthen the parents in their role so that they are able to create more favourable conditions in the home and in the community for the development of the full potentials of the child. The success of such an endeavor is a function of the degree to which sharing of knowledge, experience and responsibility takes place on an equal basis among all involved in the care of the child.

The linkages in the work around the child with a disability have branches that go in different direction. Formal and informal communication between all the teachers who work with the child will be needed. Close links between the different learning and care settings will help to create a cultural environment that is conducive to good learning and development. This requires working on culturally linked models of care that will bring the views of the society and the home into the school. This will help the child advance in its learning and development at its own pace. It is possible that great gains can be made by placing the most able and highly motivated and qualified teachers at the junction where the child moves from home to the school and care setting. The community, the school and the care setting, as well as the family, should discuss ways of achieving an appropriate teacher-to-child ratio.

In summary, great benefit can be obtained by investing in a partnership between the home, the school, the care setting and the community in the care of the child with a disability. Such a child must be viewed as a shared responsibility. The resources of the various settings should be pulled together - the effect of the resultant sum is likely to be greater than that of the component parts. Parental involvement is mandatory, as the preparation of the child and its environment begins at home. Joint planning and communication on a continuous basis is essential, as is shared information on the progress made by the child.

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SUPPORTING FAMILIES THROUGH COMMUNITY BASED APPROACHES

Roy McConkey

Community based services offer a fresh approach to meeting the needs of people with disabilities and their families. They have three aims:

- The primary goal is to enable the person with a disability - whether a child or an adult - to lead an active life within their family and community.
- A second aim is to mobilise people within the family to support and guide the person with the disability and their family carers.
- Third, community based services aim to reach out to people with disabilities wherever they live, by bringing help to them in their own locality.

MODELS OF DISABILITY SERVICES

These three main features of community based approaches are in contrast to the model of service delivery which has been prevalent in many countries to date. Traditionally disability services have developed around the five features noted on the left hand side of table 1.

1. Disability Services

- | | |
|---------------|---------------|
| • Child | • Family |
| • Specialists | • Supporters |
| • Therapy | • Activities |
| • Groups | • Individuals |
| • Health | • Community |

The focus of attention is the child and in particular on deficits rather than on talents and competencies. The service relies on specialist workers who bring a particular expertise but who are rarely competent at dealing with the full range of 'problems' which certain children present. Moreover specialists depend on therapeutic procedures which only they are deemed qualified to administer usually in special settings such as clinics, hospitals or treatment centres. The service is usually designed to meet the needs of a particular group of clients; those with physical disabilities or hearing impairments or intellectual handicaps. Finally the service is usually delivered within a health setting; the ideal being to 'cure' the disability or at least reduce the handicap.

Failings of Traditional Services

This model of disability service has had some notable successes; especially in the rehabilitation of people - most often adults - who become disabled as the result of an illness or accident. With children and young people who are born with a disability or who acquire it early in life, we have come to realise that this model has three significant drawbacks.

- It has not helped the child's integration into their local community. Indeed in western countries we have evidence that it has increased their isolation and feelings of loneliness.
- Such services tend to reach only a minority of those requiring help. This is especially so in developing countries when it is the urban, more affluent families who tend to benefit from this model of service as specialist workers are reluctant to transfer to rural areas.
- The people working in the service are so pre-occupied with the people already in the service that they have little time or inclination to expend efforts on the prevention of handicaps through medical, social and educational interventions.

Community based approaches attempt to remedy these failings. To do so, they have had to adopt a different set of parameters as shown on the right hand side of the above table.

Features of Community Based Approaches

- The focus of attention is not just the child or young person with the disability but rather it is the family. The services must attempt to meet their needs.
- The emphasis is on supporting the client and the family by mobilising suitable supporters either from within the family and/or the local community.

- Instead of specialist therapy, the goal is to utilise the activities of daily living as a medium for developing the skills and talents of the person who is disabled; with the aim of helping them to become more self-reliant.
- People with a disability - even with the same disabling condition - are NOT all the same. Hence community based approaches attempt to treat each person as an individual by developing a specific rehabilitation plan tailored to their particular needs and circumstances.
- Finally, community based approaches recognise that people's needs cannot be met solely within a health setting. Rather education, social welfare, housing and employment to name but some, must also be involved. This must occur at the local community level as well as at a regional or national level. Few countries have achieved the latter.

SUPPORTING FAMILIES

The family of the person with a disability is at the heart of the community based approach. Why?

- They are the primary supporters of the person with the disability now and probably throughout their lifetime.
- Their attitudes and beliefs will profoundly affect the lifestyle and opportunities open to the person with disabilities in their community.
- Research has shown that nearly all families have the competence and potential to nurture the physical, social, emotional and intellectual well-being of children with disabilities just as they do with non-handicapped children. Burton-White (1984) for example, summarised the outcome of his research in promoting the development of 'at risk' pre-schoolers in the United States when he wrote:

“We came to believe that the informal education which parents provide for their children makes more of an impact on the child's total educational development than does the formal education system”.

How best can services support families? In recent years, experience and research from around the world has demonstrated the value of three types of help especially during the childhood years.

- Home Visitors
- Parent Groups
- Training Opportunities

Although these are considered separately in this paper, they are not meant to be alternatives but rather they should form a coherent response to family needs from as early in the child's life as possible.

Two further types of support are also beneficial. Although they fall beyond the scope of this paper they are mentioned here for sake of completeness.

- **Financial assistance:** In more affluent countries, Governments pay a range of financial benefits to families to assist them with the extra costs involved in caring for children or adults with marked disabilities.
- **Out-of-home care:** Families also benefit from their relative attending a day centre or school. This gives the family a break from caring and may enable mothers to participate in income-generation. In affluent countries a range of services funded by the State are available including those which offer overnight care. However in developing countries, families have come together in associations to provide these services for their members (see later).

Home Visitors

The role of home visitor is simply stated. They advise and guide the family on coping with the disability. This may mean informing families about the help that is available in the locality, such as hospital check-ups. They may recommend equipment or aids to assist the person such as a walking frame; or demonstrate exercises or learning activities, which the family can use at home to help the person acquire new skills.

By visiting the family regularly, for example every two weeks, the home visitor can build a trusted relationship with the carers — usually the child's mother or grandmother. Their role may then extend into one of counselling mothers; listening to their concerns and advising on marital difficulties, financial problems and hurtful reactions of family members or neighbours.

As you will probably realise by now, home visitors are not a new concept. The extended family or 'tribe' has often provided an advisor or confidante to new mothers with whom they can discuss their concerns. The home visiting concept builds on this tradition by introducing the family to a person who has particular expertise or interest in the disability. However societies vary in their tolerance of an 'outsider' becoming involved in family issues and services must be sensitive to this when recruiting staff to act as home visitors.

Equally the role can be demanding and the effectiveness of the home visitor will depend not only on their personal qualities but also on the training they receive; a topic to which I will return. (see Thorburn, 1995 for a discussion of the role of home visitors).

Recruiting Home Visitors

As table 2 shows; home visitors can be recruited from at least five different sources and projects around the world, invariably use some combination of these.

2. Home Visitors

- Existing Personnel
- Paid Workers
 - Community*
 - Parents*
- Unpaid Workers
 - Community*
 - Parents*

Existing Personnel: Re-deploying existing personnel to act as home visitors has been a popular option in affluent countries. Teachers, therapists and health workers have adopted this new style of working. The strategy has been successful also in developing countries. In one of the islands of the Philippines, teachers who previously worked in a special school for visually impaired children were retrained as home visitors and allocated to various districts where they visited the children at home or in ordinary schools to support the parents and teachers in their work.

Paid Staff: Many community projects have recruited, trained and offered paid employment as home visitors for people with disabilities. This is the concept underpinning the W.H.O. model of Community Based Rehabilitation (Helander, 1992). Although the original idea was to recruit people from the community, in later years an increasing number of people with disabilities or parent of children with disabilities have successfully been employed as home visitors. This strategy not only gives much needed employment opportunities but these individuals come with personal insights and motivation which can make them more effective and acceptable to families.

Volunteer workers: These form a third option. Once again some community services use family members as their primary workers an idea that is also prevalent in more affluent countries where parents work alongside professionals when families first learn that their child has a disability. However other community schemes have successfully recruited teachers, health workers among others to act as supporters for families. This is best exemplified in O'Toole's (1995) work in Guyana.

Although these options are available in most communities around the world, I would not like to underestimate the amount of effort which services need to expend on recruiting suitable persons and the inevitable turn-over which occurs with poorly paid or volunteer workers.

Parent Groups

A second strategy for supporting families is by bringing them together for regular meetings over a period of time. Such groups may grow into the development of local associations for parents and friends. Indeed in most Western countries, the formation of parent associations has been a major influence on the development of services. Groups offer four advantages to parents:

Emotional Support: Many parents feel isolated and shunned by society if they have a child with a marked disability. Having the opportunity to meet with others shows them that they are not alone and as their sense of solidarity grows they will be able to face the future more hopefully.

Advice and Guidance: Families can draw on their own experience when offering advice to others. Their recommendations may be more credible than that offered by professionals who lack the day-to-day experience of living with a child who is disabled.

Advocacy on Rights: An association can be a more effective promoter of rights than can individuals. The combined energies, expertise and experiences makes it easier to develop and sustain a campaign of persuading communities and even Government of the rights of disabled people and their families.

Services for Members: Groups through co-operative endeavour can offer services to one another. For example, parents may take it in turns to 'staff' a creche or a day centre so that mothers can have some free time. Many associations have opened resource centres for their members where they can meet visiting specialists; obtain information; borrow toys and equipment; and attend income-generating activities.

Often parent groups have grown out of the work begun by home visitors. They also offer an ideal setting for training courses.

Training Courses

The provision of training courses for parents and people from the community is a relatively new concept in disability services. Previously specialist courses often lasted three or four years; they were held in Colleges and Universities and people needed academic qualifications in order to take part in them. Such training was designed to equip the students with the skills and expertise to deal with many different disabling conditions in people of all ages and settings.

By contrast parental training has a different set of requirements. Parents need the skills and knowledge that is most relevant to their particular child at this stage in his or her development. Hence the training can be more focused and often of much shorter duration than the training courses taken by professionals. More crucially the training courses need to fulfil the following criteria:

- They should be available locally.
- The content should draw on family and community experiences and be applicable to those settings.
- Learning should take place through seeing and doing rather than by listening and reading. People with low academic attainments will learn better that way.
- Groups need to have a person to lead them through training.

These considerations have led my colleagues and I to develop an approach to parent training that is based around specially-made video programmes which are recorded in family and community settings. These programmes can then be shown in villages with a locally recruited person to act as course leader.

AN EXAMPLE FROM GUYANA

Guyana is one of the poorest countries in the Caribbean region of South America. The population of 0.8 million people is made up of three ethnic groups; East Indian, Afro-Caribbean and Amer-Indian. There are few specialist services for people with disabilities and those which do exist are located in the capital city of Georgetown.

The Community Based Rehabilitation programme was started some ten years ago by an educational psychologist, Brian O'Toole (who was a university teacher) and a government employed physiotherapist, Geraldine Maison-Halls. They aimed to recruit and train local community volunteers to act as supporters of families with young persons who had a disability; physical, sensorial or intellectual. The volunteers were mainly teachers and health workers although family members and retired persons also offered their services (O'Toole, 1996).

Their programme did not aim to provide a service to people with disabilities. Rather the goal of the programme was the sharing of skills and knowledge to families and communities so that they could better assist the persons in their own community. Implicit in this strategy was the objective of providing some assistance to all; rather than concentrating on providing a quality service to a few.

Developing a Training Strategy

Three elements made up the training strategy:

1. The production of 'training packages' consisting of resource materials for use with trainees and 'prescribed' methods for getting the messages across to the trainees. These packages were produced in the first instance for training family support workers but they have also been used as short courses with family members and community groups.
2. The use of available personnel to act as local tutors.
3. The training and support of local tutors to ensure training standards are maintained and their skills nurtured.

Production of training packages

Video was chosen as the main teaching medium and its advantages can be quickly summarised. It is visual; viewers can see new ideas and approaches in action. A variety of activities can be quickly displayed and viewers can watch the sequences a number of times to reinforce their learning. Local scenes depict the viewer's reality and emphasise that the messages are appropriate to the culture and that they are already being applied there. It is relatively easy to dub commentaries in local languages on to the video-programmes thereby making training more accessible to everyone (McConkey, 1993a).

Moreover, video cassettes can be easily taken or sent to any places which have video playback equipment. This is becoming more readily available throughout the world. Recorders and televisions can be battery operated. The programmes can be easily repeated with different groups of parents or community workers. Our experience has suggested that portraying families and children with disabilities on video can enhance their status within the community as the programmes focus on what the people with disabilities can do for themselves (McConkey, 1993b).

However, the video-programmes need to be augmented by handbooks for use by tutors and/or course participants. These will contain suggestions for group discussions, practical activities and assignments as well as giving checklists, forms and materials for further reading.

To date, nine training packages have been produced in Guyana covering topics such as enlisting community support, identification of disabilities, promoting children's development, integrating children with disabilities into mainstream schools and income generation (see Appendix).

Local Tutors

The figure to follow summarises the number of people in Guyana who have taken part in training courses over the past five years.

3. People Trained

• Community Volunteers	
<i>Initial Training (150 hours)</i>	175
<i>Specific Packages</i>	400
• Nursery and Primary School Teachers	350
• Families and villagers	
<i>Child Development</i>	@2,000
<i>Health Education</i>	@4,000

In Guyana, volunteers from the community receive around 150 hours training to equip them for their role as family support workers mainly with children who have disabilities. Originally, this training was provided by the project co-directors but this is now done by the regional co-ordinators using the ready-made training packages. In the past two years, six, 150 hour courses have been run concurrently in three regions of Guyana for over 170 community volunteers. The multiplier effect is obvious but the packages have the advantage of ensuring a common curriculum continues to be available and that effective teaching methods are promoted.

Experienced community volunteers have also organised local courses for various groups using specific training packages. For example, a new training package on integrating children into mainstream schools has been used by a cadre of experienced CBR workers to provide a 20 hour training course for teachers from nursery and primary schools in their areas. Nearly 300 teachers participated in local courses in one year.

Likewise a training package giving basic health messages - Facts for Life - was presented by local CBR teams to over 4,000 persons in the interior region of Guyana and two recently produced packages aimed at promoting the well-being and development of all children and hence preventing developmental disabilities - *A New Tomorrow* and *When There Is No Nursery School* - have been used with approximately 2,000 persons.

Successful Tutors

When we free our mind from the traditional image of 'trainers in disability' services; then we can begin to appreciate that the number of potential tutors could be very much greater if they were provided with suitable resource materials. Community staff; parents of people with disabilities; people with disabilities themselves - are but three groups who would be well motivated to undertake the task.

Experience in Guyana suggests that successful tutors tend to have the following attributes:

- they are very familiar with the local culture. If they are expatriate workers they have been in the country for five or more years.
- they may be trained and experienced professionals but they are able and willing to step outside their particular specialism to provide 'multi-disciplinary' training opportunities. Often they have been able to call on a network of contacts to supplement their knowledge and expertise of other disciplines.
- they are able communicators who form a ready rapport with the trainees.
- they are highly motivated to help people with disabilities and their families and provide inspiration to others.
- last, but by no means least, they have a clear vision of service goals and they have a detailed plan for bringing it about. Central to these endeavours is their direct involvement in the training of workers and families.

Training Outcomes

How do we judge the success of training? Traditionally training in rehabilitation has been focused on equipping people with knowledge and skills. However a community based approach to rehabilitation must take a broader view and ensure that the training offered to communities and families produces at least three other important outcomes:

- It engenders positive attitudes and increases motivation to assist people with a disability.
- It changes the behaviour of family members and the community towards people with a disability.
- It encourages the development of local services through the initiatives of local people and further promotes their capacity to be self-reliant.

Of course all these outcomes apply equally to persons with a disability which is why our training initiatives must actively embrace people with a disability as well.

SERVICE GOALS

Finally, how can we be sure that we are providing a good service to children who have a disability? This statement of rights (table 4) summarises succinctly three yardsticks against which we can judge all services for children with disabilities.

*A mentally or physically handicapped
child should enjoy a full and decent life
in conditions which:
ensure dignity;
promote self-reliance
and facilitate the child's active
participation in the community.*

4. Article 23: U.N. Rights of the Child, 1989

- Does the service promote the children's dignity and self-image?
- Does it promote their self-reliance?
- Does it facilitate their active participation in the community?

Sadly there are few services in my country which can realistically say 'Yes' to all three questions. We still have a long road to travel; one filled with many pot-holes and steep inclines. There may even be people willing to ambush us and stop us from making further progress. But I know from talking to you and visiting your country that you have already started on your march so I leave you with an Irish blessing: "may the road rise up to meet your feet".

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APPENDIX

TRAINING PACKAGES

1. Promoting Development
 - Hopeful Steps (Children with Disabilities)
 - A New Tomorrow (Children 'at risk')
2. Health Messages
 - Facts for Life:
 - Identification and Disabilities
3. Services
 - Community Action on Disability
 - When there is no Nursery School
 - Schools for all
 - Steps for Reading
4. Income Generation

TAPPING COMMUNITY RESOURCES: SPECIAL EDUCATION FOR THE 21ST CENTURY

Seamus Hegarty

As we reach the end of the century, people in all spheres of life are taking stock - looking back at the achievements and failures of the past, noting the lessons to be learnt and planning for a better future. Such reflection is important too where young people with disabilities and learning difficulties are concerned. There have been solid achievements but there is still much to do if these young people are to realise their potential and live decent lives. Your conference is therefore very timely, and I am both pleased and honoured to have the opportunity to share in your reflections.

HISTORICAL OVERVIEW

In the sweep of history the twentieth century will stand out as a time when people with disabilities came out of the wilderness. It was increasingly recognised that society had a civic responsibility, over and above any duty of care, to people with disabilities, as to any other group experiencing disadvantage. Provision of all sorts - education, medicine, rehabilitation, employment, housing - was elaborated, in many cases for the first time. While there is still much to achieve and access to social goods is very uneven, people with disabilities have moved from a situation of widespread marginalisation to one where their rights to social goals are at least acknowledged and, in some countries, considerable help is available to enable them to live as full members of their communities.

These changes have gone along with an evolution in attitudes toward people with disabilities. In outline terms, one can discern five stages in this evolution: rejection, neglect, care, elaboration of provision, and inclusion. Positing these five stages in the evolution of societal attitudes does not imply a strict, linear sequence which is the same in every country; the stages do overlap and they are embodied in different ways in different countries. What they offer is a framework for pulling together and helping to understand a very diverse set of phenomena.

Turning to education, we can discern a similar evolution in attitudes from rejection to inclusion. A Jordanian example illustrates this well.

Khuffash, Abu Ghazaleh and Shami (1981) state that in Jordan the attitude of society to the handicapped evolved in three stages:

- a negative stage where a handicap was regarded as beyond human control and the individual had to be resigned to the situation
- a development stage where rights to education and rehabilitation were recognised but services were very limited
- a dynamic stage where the importance of adequate services was recognised and efforts were made to build them up.

There have been two breakthroughs in recent years where young people with disabilities and learning difficulties are concerned. The first concerns their right to education and the acknowledgement that every child and young person can benefit from education. Education is a fundamental human right but it has not always been acknowledged in respect of young people with disabilities. This is now enshrined in much national legislation and also in international declarations from the United Nations Universal Declaration of Human Rights in 1948 through to the Salamanca Statement in 1994.

Laws do not of course guarantee change and legislative intent is no substitute for action. The significance of a supportive legislative framework should not be underestimated, however; as noted below, it assists in mobilising resources, challenging unhelpful attitudes and generally moving provision in desired directions.

The fact that children previously deemed ineducable are now being educated is singularly important. In Britain, for instance, the implementation of the Education (Handicapped Children) Act in 1971 meant that children who had attended training centres now went to school and the focus of provision switched from training to education. Other countries made this change at different times but the net outcome is a solid body of practice which demonstrates that even children with the most severe disabilities can benefit from education.

The second breakthrough relates to the kind of educational provision made and, in particular, the extent to which children with disabilities and learning difficulties participate in mainstream schooling. There has been a movement toward 'inclusive schooling' whereby mainstream schools seek to ensure that the educational programmes they offer are such that all pupils, regardless of disability, are included in the life and work of the school. This movement drew on a number of significant developments in social thinking from around the globe: the Scandinavian belief that everybody should be able to live as normal a life as possible; the North American emphasis on providing education within the 'least restrictive environment'; the notion emerging from the anti-psychiatry movement in Italy that large institutions were an unsatisfactory living environment; and the British concept of special educational needs and the

associated idea that learning difficulties are interactive in origin - children have difficulties in learning not simply because of innate characteristics but because of the interaction between these characteristics and the environment, including how they are taught.

Community based rehabilitation has been another influence on change. The principles underlying community based rehabilitation have had some albeit limited influence on special education. Community based rehabilitation seeks simultaneously to challenge the mystique of professionalism and to realise the potential contained within the community. Its principal focus has been health and social services as distinct from education, and education was not a major aspect of early CBR programmes. However, the key principles - family and community responsibility, diffusion of expertise, training, confidence building and empowerment - are no less relevant to the provision of special education services. In any case, its philosophy of supporting people with disabilities in their own communities is congruent with the ideology of inclusive education. A further, associated consideration is the fact that in many developing countries special schools have been channelling a disproportionate amount of the available resources into the education of a very small number of children; inclusive, community based approaches began to emerge as the only way of providing education on a sustainable basis for the majority of children with disabilities in a country.

PRINCIPLES GOVERNING SPECIAL EDUCATION

Special education is part of general education and its provision must be seen in relation to the education system as a whole. A UNESCO (1993) document has set out a number of strategic considerations governing the provision of special education. These cover: legislation; administrative support; the organisation of provision; early childhood education; preparation for adult life; parental involvement; training; research and development.

Legislation

Legislation is deemed important for three reasons: it can articulate and reinforce national policies on special education; it can help to secure resources or the effective deployment of existing resources; and it can help to change attitudes. Increasingly, the role of legislation in underpinning developments in provision is being recognised, and in many countries the legislative frameworks for special education and general education are coming together. The key elements of appropriate legislation are

- clear statement of policy
- coherent framework for provision
- attention to resources and how they are to be secured and monitored

- guarantee of consumers' rights
- arrangements for implementation.

Administrative support

The administration of special education poses particular challenges: it extends beyond education into health, social welfare and rehabilitation; and it entails a multiplicity of tasks, dispersed responsibilities and, in many countries, diverse sources of funding. Its importance is key, however. Not only does it provide the necessary co-ordination but it shapes the nature of the provision made.

The most usual arrangement at national level is to have special education run by the education ministry. This generally entails a separate department running parallel to the mainstream system, with modifications as judged necessary. Sometimes the administration of special education is subsumed under primary education, reflecting the main thrust of provision. A growing number of countries seek to administer special education as an integral part of general education, in recognition of the fact that integration at school level is facilitated thereby.

Organisation of provision

Historically, special schools were the principal source of special educational provision. Over the course of time special classes and other forms of support for pupils with special educational needs came to be built up in regular schools. This has led to a situation where in most countries special educational provision is a mixture of segregated and integrated provision. As an aside, one can note that the mixture varies greatly from country to country, with for instance segregated provision in one country for pupils who in other countries would attend regular schools; this suggests that the pattern of provision often reflects local tradition and circumstances rather than a rational assessment of pupil need.

Two main considerations here relate to special schools and regular schools respectively. The challenges facing special schools are discussed below. So far as regular schools are concerned, they have to face reform. Regular schools have generally failed pupils who have difficulty in learning, and major changes are necessary before it is sensible to place such pupils in regular schools on a wide scale. It is helpful to see these changes in the context of the school improvement measures currently being adopted by many schools. In outline terms, developments must be sought at two levels: the curriculum and the academic organisation of the school; and the professional development of staff. The former requires rethinking the curriculum, teaching approaches, how pupils are grouped for teaching purposes and so on. All this calls for major changes in teacher behaviour. Teachers and other school staff must acquire the attitudes, knowledge and skills that will create and sustain a new kind of

school where those previously excluded are included and where the learning community encompasses every child in the community. This is discussed in more detail under Training below.

Early childhood education

The importance of early childhood education is widely acknowledged. The absence of appropriate stimulation in infancy and early childhood ranks alongside malnutrition and poverty as a major source of disadvantage and retarded development. This is true of all children but especially so for children with disabilities.

It is particularly regrettable therefore that there is such a shortage of appropriate provision. UNESCO figures suggest that many countries have little or no pre-school provision for children with disabilities (UNESCO 1995). Where provision is available, it tends to be focused on those with overt physical or sensory impairments to the exclusion of those many other children who stand to benefit from it. It is also likely to be concentrated in urban areas with very little provision for those living in the countryside.

Lack of resources is not the issue here, however. Much of what good early years education requires is available in local communities, either actually or in potential. Some expert input is helpful, even necessary in the case of certain children, but the principal requirements are the time and attention of adults and older children in the community. They can provide the physical stimulation and the language enrichment needed by young children with disabilities - and are likely to be able to do so in far greater measure than institutional providers. What is needed is a means of mobilising these community resources and linking them with professional input where necessary and available.

Preparation for adult life

Schooling is for all young people a preparation for adult life. For many the normal school curriculum is not sufficient preparation, whether it be for the world of work or for independent adult living in an increasingly complex world, and specific preparation provided during the latter years of schooling and subsequently is extremely beneficial.

All this holds true in far greater measure for those who have disabilities or learning difficulties. Many of these learn more slowly than their peers and may have limited academic achievements by normal school-leaving age. More importantly, they are far less likely to be ready for independent adult living and, as a consequence, to need systematic preparation for it.

The two goals of action here are to help young people become economically active and lead lives that are as full and independent as possible. The curriculum must therefore focus on work, adult relationships,

personal autonomy and all the things that make up adult living. Careers education and guidance can play an important role in expanding young people's horizons and in facilitating the choices they must make. Needless to say, the teaching approaches used at this stage must take account of the fact that the young people in question are no longer little children but adolescents.

Parental involvement

Parents are the first and natural teachers of their children. This is all the more so if a child has a disability since learning may be more difficult and learning opportunities that arise naturally for other children may not be available. Parents are likely to need support in the role, not least because of the traditional attitudes of professionals who have tended to devalue the contribution of parents. Parents may well be diffident themselves about what they can do, and in any case will benefit from sharing experiences with others and learning specific skills to use in dealing with their children. This is discussed in more detail below.

Training

Developments in special educational provision are critically dependent on the quality of staff in schools. This in turn depends on the opportunities for training and professional development available to teachers and other school staff. The fundamental requirement for teachers of pupils with special educational needs is that they be good teachers. Teaching these pupils is not some arcane skill quite separate from teaching other pupils, and well trained teachers in regular schools have already many of the requisite skills. Additional training is generally necessary, however, to ensure that staff have an up-to-date understanding of why some pupils have difficulty in learning, have appropriate attitudes toward them and are versed in a number of specific assessment and teaching techniques.

This calls for new developments both in initial teacher education and in in-service education. If regular schools really are to educate pupils with disabilities and learning difficulties on an inclusive basis, every teacher must receive an appropriate introduction to the attitudes and competencies required in their initial training. In fact, some countries now require some coverage of special educational needs in all initial teacher education and a growing number provide it on an optional basis. Specialists are also required of course, and it is generally found to be advantageous to arrange advanced training for teachers who have some experience and can interweave such training with classroom practice. This training has to take particular account of the fact that these teachers are working in regular schools and not in a special school. Because the context and very nature of the work being done are different, the training must be correspondingly different.

Classroom assistants and voluntary workers, including parents, are a major resource for inclusive schooling. The contribution they can make is likely to be much enhanced if they receive appropriate training. Not only does this add to their effectiveness and make the task more rewarding for them, but it helps to ensure a coherent approach across the school - inclusive schooling requires that all staff deal with children in a consistent way and that the different interventions made are complementary.

Research and development

Educating children and young people with disabilities is a complex matter. It challenges much current thinking and practice, and it consumes a certain amount of resources. It is important therefore that the actions taken are well-founded and relevant to local circumstances.

It is for these reasons that research and development are important. Expenditure on research and development may seem a luxury when the underlying provision is limited and in need of expansion. Skimping on such expenditure can be a false economy, however, since R & D can direct and focus provision and ensure that it is built up in the most cost-effective way.

Much can be learned from research carried out in other countries but this does not remove the need for an indigenous R & D capacity. This is necessary in order to access information from abroad in a systematic fashion and interpret its relevance. More than that, however, each country or region needs to investigate its own circumstances and needs, shape programmes accordingly and evaluate them in action. Some investment in research and development is necessary to achieve this and is likely to repay itself many times over.

SPECIAL EDUCATION IN THE COMMUNITY

The provision of special education can benefit greatly from community involvement. I want to look at three aspects of this involvement: parents; special schools; and professionals.

Parents

Parents are an important, and under-utilised, resource in the education of children with disabilities and learning difficulties. The pity is that it has taken professionals and policy makers so long to realise it. There is a growing body of good practice, however, and many children and their families are benefiting from this.

So far as education is concerned, collaboration between home and school is the key relationship. There are five dimensions to such collaboration:

- *Information.* Collaborative working must be built on a basis of information exchange. Parents need information on the nature of their child's disability and on any educational implications it may have. They also need to be made aware of local facilities and particularly of course educational provision. Teachers for their part need to know about the family background and the child's behaviour and responses outside school. Communication between home and school can take a variety of forms - face-to-face dialogue, group meetings, school open days, home visits and written materials.
- *The curriculum.* Parental involvement in the curriculum can be school-based or home-based. Home-based approaches range from structured programmes such as Portage which involves parents and a range of professionals in a planned partnership to ad hoc and informal contact. A key effort here is to take account of the fact that these children need a highly structured environment so far as language and basic skills are concerned and to ensure that the child's experiences at school and at home reinforce each other. Parents can assist also in delivering the curriculum in school, by providing an extra pair of hands in the classroom and by implementing teaching and therapy programmes.
- *Behaviour problems.* For some children and their parents this is a major concern, and it is imperative that teachers and parents collaborate closely to ensure the fullest understanding of any reason for inappropriate behaviour and a consistent approach to it.
- *Personal support.* Children with disabilities bring joy to their parents, just like other children, but they can also generate stress and anxiety. An outside perspective can help greatly in relieving the intensity of feeling that parents sometimes experience. Contact with other parents and the sharing of common experiences are singularly important here. Teachers too are well placed to help: they are more likely than other professionals to have the confidence of parents, and can assist them to view their child realistically and accept his or her limitations.
- *Liaison with professionals.* Some families have dealings with a large number of agencies, an experience that many find confusing if not intimidating. Teachers can be a valuable link between parents and professionals. This can encompass everything from facilitating appointments to explaining parents' rights to them and interpreting official information and reports.

Special schools

Special schools have been the answer to the special education question for many years. At times it may have seemed an enlightened answer, possibly even the only answer available. In general, however, it is the wrong answer.

Save the Children supported a school for children with physical disabilities at Khemisset in Morocco for some 30 years until its handover to the Moroccan Ministry of Social Affairs in 1993. This was - and may well still be - an excellent school and provided high quality education and rehabilitation. Many of its alumni went to university and play active roles in society. Surely, a success story.

There is a downside, however. A frank evaluation by Save the Children and past pupils of the school listed serious drawbacks:

- The children were totally isolated from their families and communities and found reintegration difficult if not impossible
- When they attended secondary schools, they commonly experienced pity, ridicule, overprotection and isolation
- Family responsibility toward their child with disabilities was ignored and they received no support to keep their child with them
- The provision focused on the child and did not target the attitudes, policies and institutional barriers which prevent children with disabilities from receiving education
- The school consumed a disproportionate amount of the available resources, spending a great deal on each of its 120 pupils while an estimated million children with disabilities received virtually nothing.

The dilemma implicit here is a familiar one. It is also urgent to the extent that many, many children continue to miss out and their only chance of an education is slipping away. The radical response to this dilemma is to shut down special schools and spread the resources more widely. This is certainly necessary on occasion and in some European countries with very high levels of special schooling such as Belgium, Germany and the Netherlands it is a pressing requirement.

There is another way, however, and that is to change the nature of special schools and the ways in which they work. Given that they represent a major investment in staff and expertise, in buildings and equipment, in software and other materials - all the things that regular schools lack so far as pupils with disabilities are concerned - the effort should be to capitalise on what they have. Dispersing resources runs the risk of dissipating them, and it serves no good purpose if the net outcome is that nobody receives specialist support.

There are in fact a growing number of special schools which have evolved from being segregated institutions to providing outreach support to all the regular schools in their neighbourhood. The best of them have become powerhouses for special education support in their communities. Typically, they have direct responsibility for some pupils, possibly sharing them with regular schools nearby, but they also have a range of responsibilities for pupils in regular schools and more widely in their commu-

nities. This special school of the future has a multiplicity of tasks. It can (Hegarty, 1994)

- be a source of information on all matters relating to special educational needs
- conduct assessments, particularly in difficult cases
- provide advice, consultancy and support
- engage in curriculum and materials development
- evaluate software, equipment and other materials
- conduct research and other experimental projects
- contribute to professional development
- be a resource for parents
- provide counselling and careers advice for older students.

Such schools are no longer just schools. They are multi-purpose institutions with elements of an advisory service, a resource centre, a library and information service, an assessment facility and a training agency. This latter is particularly important since they are ideally placed to develop the attitudes of parents and school staff and equip them with necessary skills. Needless to say, such institutions need to be resourced accordingly. The investment is justified, however, since it is a powerful means of permeating schools and communities with an awareness of special educational needs issues and raising skill levels.

The role of the professional

Progressing community involvement in special education depends critically on the role of the professional. There has been a great deal of criticism of professionals in special education and the ways in which they have problematised disability, erected barriers of technical language and ignored the perspectives of people with disabilities and their families. Different professionals have moreover tended to work in relative isolation from each other to the detriment of the children they serve.

Though sometimes overstated, much of this criticism is justified, and there is a great need of new orientations on the part of professionals. The insight and expertise they bring are still necessary but the way in which they are deployed determines how useful they are. Professionals can ignore the resources to be found in the community and hinder community involvement or they can facilitate its development and underpin it in a variety of ways.

There are four dimensions to effective practice in this regard:

- Focus on the child rather than on disciplinary background. The requirement is to understand the child in his/her situation and devise interventions accordingly. Professionals must not be content for example to rest behind technical language which, though precise, is not readily translated into aspects of the child's everyday functioning.
- Interdisciplinary work. Assessment and intervention should involve the different professionals in a collaborative way. Psychologists, doctors, therapists and teachers need to work together to ensure that any interventions are well founded and that they all fit together in the child's interest.
- Work with parents. Professionals should regard parents as an integral part of the assessment team; they see the child in a wide variety of situations and, especially if their observation is guided, can make a unique input to the process. Likewise, they can help in translating assessment outcomes into programmes that reflect the child's everyday life. They can also of course implement relevant programmes outside the school or clinic if they are given appropriate guidance and support.
- Giving skills away. Professionals are not magicians and, by the same token, their effort must be to give their skills away and not to conceal them from an awe-struck public. They can do this formally by providing training for different groups. They will probably be more effective, however, if they adopt a sharing approach in their interactions with parents and fellow professionals, explain clearly what they are doing and the reasons for it, reinforce others' efforts at skill acquisition and always see themselves as part of a team.

CONCLUSION

A key characteristic of a civilised society is how well it provides for those who are less fortunate - whether the reason be physical disability or learning difficulty or something else. To the extent that we treat some of our fellow citizens as less than fully human, our own humanity is diminished. These are matters that transcend political organisation, economic situation and religious belief. Many countries who would regard themselves as highly developed in other respects fall down on this criterion of being civilised.

You have faced many challenges in this country in recent years. Ensuring that pupils with disabilities live full, valued lives in your communities is one more challenge, a challenge perhaps where the enemy is more elusive but also closer to home. We need to confront our own attitudes and the social structures that place obstacles in the way of people with disabilities. The work being done by IM/SOIR and its associates here is one way of meeting this challenge. I am delighted to commend it

and the new approaches to disability services that it is fostering in Jordan.

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COMMUNITY BASED SERVICES: SOME INTERNATIONAL TRENDS

Neil Ross

MAJOR TRENDS

In this brief overview I would like to contribute to the discussion about the community approach to the delivery of support to persons with intellectual disability, by giving some international experiences. I do this as President-Elect of IASSID, the International Association of Scientific Study on Intellectual Disabilities, a position which gives a unique view of present international development. Much of this text was co-prepared by Professor Trevor Parmenter who is the President of IASSID. Professor Parmenter is at the University of Sydney, where he is a member of that university's medical school in a newly created department, the Centre for Developmental Disability Studies.

Community Based Services, or CBS, is of great interest to our organization. Some of our members come from service provider organizations, others do research in this field in their respective universities and still others are administrators of national or regionally funded organizations, all with a relationship to the ongoing development toward community based services.

IASSID has several Special Interest Research Groups, or SIRG's, that meet regularly taking up the theme of CBS either directly or indirectly, such as the special interest groups on Aging and Quality of Life.

Valerie Bradley, vice chair and presiding officer of the US President's Committee on Mental Retardation recently observed (Bradley 1996):

“The success of the replacement of institutions and the development of community capacity is still elusive. It is contingent upon our ability to recruit and train support staff to maximize public as well as family and community supports to ensure adequate advocacy for people with intellectual disabilities in decentralized settings, and to persuade local and national policy makers that any restriction of financial supports is a false economy that may ultimately result in re-institutionalization and re-segregation. Safeguarding the future there-

fore means ... not only finding better ways of meeting the needs and aspirations of peoples with intellectual disabilities, but also engaging with the wider political debate about equality of opportunity and civil rights”.

In many industrialized countries the provision of accommodation services for people with a disability is facing a number of challenges. Both government and non-government agencies are continuing the process of downsizing accommodation facilities in favour of smaller single or multiple room accommodation.

The era of the initial de-institutionalization and community expansion movement began in a period of expanding economics and optimism, especially in the industrialized countries. The social reform movement was stimulated by ideological initiatives including normalization and social justice imperatives. But as Bradley points out the current landscape challenges us to do more with less. The expanding welfare state has given way to circumscribed benefits and services (Bradley & Knoll 1995).

A new way of thinking, or paradigm, is emerging, referred by some as a citizenship perspective (Ericsson 1996). This perspective is more in accord with “The Standard Rules on the Equalization of Opportunities for Persons with Disabilities” recently promulgated by the United Nations (1993). The person with intellectual (or any other) handicap is first of all a citizen like all others born into this society. The corollary to this is that the rights and obligations which apply for others are equally applicable to persons with a handicap.

The four major characteristics of the new paradigm are then:

- the primacy of the community;
- an emphasis on relationships;
- person-centred supports;
- choice and control.

It is possibly not surprising that our earlier attempts to provide community based living programs concentrated to a large degree upon the physical features, size and location of the accommodation. In our attempts to ‘right the wrongs’ of the institutional models we were heavily influenced by deviance theories of disability as enunciated by the writings of Wolfensberger (1972, 1975, 1992).

In the development of new approaches we are re-assessing what it means to be in the community, especially as it is becoming clear that the setting in which one lives may not be the major determinant in achieving satisfactory outcomes such as a desired lifestyle and enhanced quality of life (Felce 1996).

ACHIEVEMENTS IN SOME OF THE INDUSTRIALIZED COUNTRIES

Canada

In Canada there is a very strong movement towards community services. Dr. Andre Blanchet (1994) a council member of the IASSID was responsible for closing down institutions in the province of British Columbia from 1988-1993. This province is one of ten in Canada, about the size of France and ten times as big as Jordan. He found that getting disabled people out of institutions and back into families and original communities is not without problems, but it can be done.

In the eastern provinces of Ontario and Quebec, spearheaded by the CMCL, primarily a parent organization, more services have been provided for a greater number of mildly disabled and the severely handicapped in home units or group home units. This work has been documented by researchers of the Roeher Institute in Toronto by Marcia Rioux, Michael Bach and Cameron Crawford (Bach & Rock 1996, Rioux & Bach 1996) and in Quebec by researchers such as Wilfred Pilon, Serban Ionescu and Hubert Gascon (Gascon 1998). These changes have been documented and studied using "Quality of Life"-techniques and questionnaires, in order to assure evaluation and accreditation.

Australia and New Zealand

In Australia the provision of accommodation services for people with a disability is facing a number of challenges, wherein the Australian scene seems to mirror the international experience. Both government and non-government agencies are continuing the process of downsizing accommodation facilities including large scale institutions. To date the most common community accommodation support model has been the group home where three or four residents have their own bedroom. The agency providing the support has owned or leased the accommodation, but there is a perceptible trend towards residents either owning or leasing the accommodation themselves (Parmenter 1998).

A new law has been passed, the New South Wales Disability Services Act (1993). Research is lacking to give an adequate overview of the range of services being provided. Outside of institutions service provision is almost exclusively based on the group home model.

In order to meet the support needs, a model of practice known as the Disability Health Care Support Service has been developed in South Australia (Parmenter 1994a, 1994b). This service embraces both nursing and disability philosophies responding to the client's health care needs and adapting services to the requests and life choices of the individual requiring support in community accommodation. This model of service has challenged the assumption that people with disabilities with high medical needs require direct nursing care in an institutional environment.

A recent paper by Bennie identified the key elements of support systems for adults with high support needs to live successfully in the community in New Zealand, where the community model is also being put into practice.

England, Scotland and Wales

No model or paradigm is a panacea and the critical review in England, Scotland and Wales by Eric Emerson and Chris Hatton (1996, 1998) of the Hester Adrian Research Centre at the University of Manchester demonstrates this. In the United Kingdom recently, a census has suggested that although the majority of people with intellectual disability live in 'ordinary households'

1. there exists substantial regional and national variation in residential provision;
2. the level of provision is lower than the projected targets;
3. the majority of people with intellectual disability were in large scale congregate care settings;
4. young black men were more likely to be placed in residential provision than their peers from other ethnic groups;
5. young Asian men and women were less likely to be placed than their peers.

David Felce (1993, 1994), a senior researcher in Cardiff, notes that about 17,000 people in England and Wales still live in mental handicap hospitals despite nearly three decades of reform. Like Fryers (1984, 1997) he believes that for those countries, changes towards CBS tend to give reasonable confidence in the results in general. The authors found those that remained showed no improvements over 30 months and those that left achieved major results in the first six months. Fryers, like Felce, believes that this raises the question that it is not merely re-housing and more carers, but that there should be specific training of social and interpersonal skills to help people with limited learning capacity to benefit from the community in which they are placed but with whom they often barely react.

Eastern Europe

Europeans are working to promote CBS among some of its Eastern European members. A project has been proposed to the European commission for Bulgaria, the participating partners are Ireland, France and Holland (EU 1996). The core of the project is to establish CBS by working with a Bulgarian partner. This is a family association, quite simply because they have the most energy and motivated interest in a country that does not as of yet have a social/political/economical framework to be able to accomplish the task.

This has not yet succeeded but I mention it because the pertinent paradigm is CBS. Is this a critique? No, this is an observation for here you have a country in need, that turns to CBS for its apparent simplicity of application when there is a lack of funds and a great need. An observation that is significant when you compare it to France or Italy that are great industrialized nations that have the aforementioned parameters but equally have the weight of their history (a history of institutions) to cope with and to re-organize.

France and Italy

CBS is working in France but perhaps not with the speed or the alacrity of some of our European neighbours. The reasons I think are related to culture and language. It is noteworthy, that one of the largest psychiatric hospitals in Europe situated north of Paris had in the year 1960 over 3.000 patients, today it has 1.200. The 'institution' has not been closed for the need is still there, but many of the persons with intellectual disabilities have left and are now to be found in smaller centres. I emphasize the word centre for they are not yet, or really, in 'The Community' but they are getting there. Many of the mentally ill patients have also left for 'therapeutic apartments' where they are 'closer' to the community, and also getting there.

It could be suggested that France has taken the slow route whereas in Italy, our close neighbour, took a fast and sometimes disastrous route. The catastrophic situation of the 'institutions' in Italy in the 1970:s led Professor Basaglia (1977, 1978) to promote and spearhead a law that led to the immediate closing of all psychiatric institutions. A lot of these patients ended up in the streets, in clinics or in the outpatient departments of the local general hospitals. The move was a radical one and the response of 'The Community' was immediate: "we do not want them and we cannot cope with them". This country still has a tradition of 'institutions' for persons with intellectually disabilities but is making attempts towards CBS.

COMMUNITY BASED SERVICES - A CRITIQUE

Professor Parmenter (1998) has pointed out that the overall direction would seem to be the right one. But let us now look critically at this direction. The term 'critique' of CBS is used in the most general and French sense of the term which means more an observation than a criticism.

Fryers (1993) notes that it is very noticeable in reading the professional journals that there is still no agreement on terms classes and or taxonomy. In little more than a handful of papers he found the terms "mental retardation", "learning disability", "intellectual disability" and "mental handicap", used as though they were synonyms. In a wider literature search he suggests that we would find many others. The strong

impression given is that authors choose what term they see as politically correct within their own country although even this does not imply consistency within countries.

From a psychiatric/historical perspective the concept behind CBS has been known to us for a long time and there are many examples. In the late 1940:s and early 1950:s when the drug chlorpromazine was discovered by two Frenchmen (Professors Denicker and Lelay), we believed that containment and institutionalization was to come to an end. Under treatment, all of these patients would again return to 'The Community', where there would be no need for special centres for the mentally ill (I hasten to add that in some countries this meant both the mentally ill and the persons with intellectual disabilities). Sounds good but it did not happen quite that way for 'The Community' did not always welcome those from institutions, especially after a few unhappy 'incidents'. The move to CBS, however, was under way and has continued all the while, signalling however that, some centres, institutions, or special care services are still needed.

Recently a very interesting scientific study was reported in South Africa on the inclusion of people with intellectual disability into the community or part of the community: the world of amateur and local community sport. In this study it was found that for one special event efforts were made to include, to form groups or partnerships, amongst all. And it worked! It worked for the preparation and realization of the 'special event' but it did not work in terms of the long lasting aspect of relationship and camaraderie. What does this tell us about ourselves, what does this tell us about 'The Community'? It tells us that work has still to be done and that acceptance of difference is not easy if it is to be attained first in the short term and then in the long term. In this sense CBS touches on a fundamental aspect of our human nature. To what extent are we willing to include as friends, colleagues, working partners or fellow athletes those that are 'different'?

Is there not a place for some "institutions", or where is the middle ground? The obvious answer to that question or critique is that of course there is a middle ground, the ancient Aristotelian mean. There is a need for good centres still. Professor Mulcahy (1998) from Ireland who recently said in a presentation entitled 'Inclusion but not Always':

"I am not in favour of bad institutions, but the founders of the early institutions for the intellectually disabled were however deeply humane in their outlook. And time passes and some of the novel programs are now facing the same problems as their institutional predecessors, namely aging clients, burnt out carers and under-funding. Such is the failure of exclusively community care approach in the UK that the term has now been officially abandoned in favour of the alternative 'spectrum of care'. This semantic change reflects a change in attitude at the Department of Health and Social Security which

until recently would not sanction funding for any residential development other than CBS. There is now an acceptance that other models of care may be equally worthy of consideration. There are good institutions and they are still needed.”

Professor Parmenter writes (1998)

“Reform in residential services began by looking backward at institutions and deciding to do things differently. Three decades of development later we have a much clearer view of the design brief for the alternative service. We have learned that there are no pivotal arrangements to correctly determine all that is important, there are no levers which mechanistically produce quality when pulled. Small size does not guarantee quality and nor does community location, ordinary housing or adequate staffing.”

DISCUSSION

Do we not learn from the investigative approach that a good idea, concept, model or paradigm is temporary. It is only there as long as it is not replaced by a better idea, concept, model or paradigm. So where are the leaders and thinkers of CBS going to take us next or will their ideas be replaced by another? If so what is that other?

In my presentation I have not given any account of developments taken place in Scandinavia. It is well-known that there were early attempts to organize CBS in Sweden, Denmark and Norway. It is also in these countries that the normalization principle, a well-known idea advocating the right to live the normal life, has its roots. I therefore look forward to the presentation about Swedish experiences by Kent Ericsson to see if he will provide us with some answers.

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THE SHIFT BETWEEN TWO TRADITIONS OF SUPPORT: SWEDISH EXPERIENCES

Kent Ericsson

INTRODUCTION

The concept of the community based approach to services for persons with an intellectual disability is discussed here on the basis of experiences gained in Sweden. The reason for this is that IM/SOIR, responsible for the Sweileh Center and the Sweileh Integration Project, is a Swedish organization.

There is also another reason, maybe of a wider interest. Because of unique circumstances dramatic changes have taken place in Sweden as regards services to persons with a disability. During a 50 year period there has not only been a gradual expansion of services but also a unique change of direction regarding the support provided.

During the early years of this period it was expected that new services being established should be in the form of residential institutions. But since the 70:s a dramatic shift has taken place. A community based approach became the basis for ongoing work. At the same time residential institutions were dissolved and closed.

As a researcher interested in how the welfare of persons with an intellectual disability is influenced by his services, this ongoing shift is seen as unique. Commenting on these changes is therefore not a way of promoting national interests, but to take the opportunity to learn about the factors which contribute to a good life for these persons. Sweden can be seen as a "social laboratory" where experiences of international relevance have been formed.

COMMUNITY BASED SERVICES

Persons with a disability in the welfare society

The 30:s were years of scarcity because of economic decline. The consequences of this was felt by people as it led to unemployment and poverty. This was even more so felt by persons with a disability. Residential

institutions were built to an increasing extent and persons were admitted to be given care under poor conditions. Putting people away was possible as the attitudes towards persons with a disability were generally pessimistic, leading to restrictive measures being used. Those who were not admitted to institutions had to live without receiving the support they needed.

As a reaction to the conditions of the 30:s the idea of a welfare society was formulated together with modern forms of social support. When welfare services were to be formed for the common man, the question arose as to whether persons with a disability should also be given the possibility of using them. This was discussed at length in a public enquiry, made up not only of administrators and politicians but also of persons from organizations representing persons with a disability.

Two alternative ways as to how to meet their needs in a welfare society were discussed. One meant that residential institutions with their roots in the nineteenth century should be modernized and used by society to channel its support. The other alternative meant that persons with a disability should have the right to use the same welfare services as those being used by the general public. The discussion in this committee ended by recommending the second alternative to the Parliament (Ericsson 1993).

A new idea

A new socio-political idea was formulated by the committee when they made their suggestion about the use of public welfare services for persons with a disability. This idea was characterized by its three components. Organizationally, it meant that services provided for common man were also to be used by persons with a disability and this being achieved by giving them the right to avail of the general welfare services. In order for this to become a reality, the competence of these must be comprehensive enough to meet the needs of all persons. The intention was that when welfare services became available for all, the person with a disability could stay in the community to which he belongs and there lead the normal life, the life led by his family and others. This meant that the normal life, the second component, became a goal to strive for when delivering support and services.

The third component concerned the social role attributed to persons with a disability. The committee maintained that it was a democratic right for persons with a disability to use public welfare services like everyone else and to lead the normal life of the community. Thereby they clarified that they saw these persons, irrespective of type of disability, as citizens belonging to society. As this idea expressed the normal life of others as the life to be offered to persons with a disability, it was called the normalization principle.

The context of this idea

The committee saw the community based approach to support as desirable as this was a way of providing a guarantee for welfare to persons with a disability to the same extent as it became a reality for other users of the same services. But they also had economic reasons for their choice. The day when all persons with a disability are recognized as citizens with a right to welfare, their support cannot be met by building residential institutions, separate special services, for all. This would never be economically and practically possible for a society!

The only way to meet the needs, when all have gained a right to support, is to open up the public welfare services and to give these organizations the task of satisfying all needs, expressed by persons with a disability as well as by others. That is why local health and social services were given responsibility for all and why schools have been opened up so that even children with a disability can attend.

When leading the normal life, being part of one's local community, these persons not only become recipients of support but also active and contributing members of society. When the adult has been given the possibility to have a job, he starts earning his salary, in part or fully, thereby decreasing his demand for support from welfare services (Ericsson 1993, 1996).

INSTITUTIONALLY BASED SERVICES

Persons with a disability during industrialization

Up until the middle of the nineteenth century, support to persons with a disability was to a large extent the responsibility of the family. In the agrarian society, dominant at the time, there would most often be a family member who could give some support.

Industrialization during the nineteenth century created the new conditions leading to institutionally based services. This restructuring of society put new demands on the population as new types of jobs required competence other than that found in the agrarian society. Urbanization meant that families left the countryside and moved to town, often leaving a large part of their family behind. When support was needed by the urban family, e.g. when a child with a disability was born, expectations were that society, instead of the family, should provide the necessary assistance.

This industrialization also had consequences on the manifestation of intellectual disability. Compulsory education was introduced at the middle of the nineteenth century and was gradually extended. In school demands were made on children to learn to read, write and to do arithmetic. As intellectual disability is characterized by learning difficulties, and compulsory education make demands on learning, this led to a higher

number of children being identified. Methods, for example the intelligence test, were developed during these years to identify those children in schools who were slow learners. When identified, they were taken out of class and admitted to special education.

As the public school did not take responsibility for the education of these children, private organizations were formed to arrange this. Most often they bought a small farm or some other large facility in the countryside, away from the urban centers, where this special education could be made available. Optimism and hope for positive results characterized their work as they wanted to create a sheltered setting for the education of children with an intellectual disability. Their responsibility however was only for those children admitted, not for others.

The newly established private organizations made important contributions when they set about organizing services. In this way the first residential institutions were formed. They soon became more established and grew in size. There was also a variation of institutions, where one type had the task of providing education and the other the task of merely caring for those with more extensive needs for support. With an institutionally based system, services were located only to these institutions. Persons in need of support for their well-being were therefore taken to these places where support could be found.

The residential institution was organized as a small, specially formed, community where all facilities thought to be needed by these persons were to be found. These institutions had a patriarchal character, as in the family of the period, the father of the family having the task of fostering its members. Only for those persons with a disability who had learnt to master the demands of the institution and who had increased in competence, did it become possible to leave for a life outside.

The idea of institutionally based services

It is possible to describe institutionally based services with the same three components used to characterize community based services. On the organizational level support is channelled through institutions specially formed for persons with an intellectual disability. Outside these there is hardly any form of relevant support. The layout of the institution, its size, the type of buildings and facilities which can be found, make up the setting for the life of the person living there. On an individual level the consequences are that the person will lead the institutional life which is offered by the institution, and not that of the community at large.

The social role attributed to persons with intellectual disability, the third component, was that of the citizen in the community based approach. With an institutionally based approach other roles will be found. Those with a mild form of disability are usually seen as pupils, persons in need of education, while those with a more severe disability are seen

as patients in need of care. Although there are differences between these two roles, there is a similarity. The main one is their focus on the deficiencies of the person, his lack of knowledge or abilities, with a consequence that both emphasize his lack of competence to meet the needs of the community. His deficiencies are in focus, not the normal needs of a person (Ericsson 1993).

TWO TRADITIONS OF SUPPORT

Institutionally and community based services

The distinction between institutionally and community based services can best be described by the term two traditions of support. They have grown out of contrasting societies and there are differences as regards their structure. One creates special services for persons with intellectual disability while the other opens up the services used by the general public in a community. They also strive towards different goals, the aim for one being to offer the institutional life, while the other offers the normal life of the local community.

There are also important differences between these traditions in how they relate to persons, the institutional tradition seeing them primarily as pupils or patients in need of an increase in competence in order to be able to leave the residential institution to take part in community life. The community based tradition, on the other hand, sees them as citizens with a right to participation in community life, irrespective of the degree of disability.

As community based services are seen as desirable, as expressed in the Act of Parliament regulating the delivery of services, their realization being the basis for present transition. These are promoted and development is going on to fulfil their task of offering a good life to persons. As institutionally based services do not meet the present day demands, they are being dissolved and closed down (Ericsson 1998).

Deinstitutionalization: development and dissolution

The Sweileh Integration Project is commonly referred to as a deinstitutionalization project. Experiences show that this concept needs to be extended to describe the essence of what is really going on. The key to success lies in the services created as alternatives to those offered by the residential institution. Community based services have to be developed so that persons in the institution can have their needs satisfied when leaving. Hand in hand with this, work has to take place to dissolve and finally close the residential institution. Development and dissolution are therefore the two activities which need to take place during the process of deinstitutionalization.

It is very easy to let one's attention be caught by the energy and resources needed for development and dissolution of services. Basically however this process concerns the lives of persons. The motive for carrying out this transition is to achieve welfare for persons and their families. The core activity is therefore the development of a better life for the persons who move from the institution.

DEVELOPMENT OF COMMUNITY BASED SERVICES IN SWEDEN

Support to the child and his family

When developing support, the ambition is to offer a life to the person with a disability which is the same as others. This means that it is possible for the child to grow up in the family and to leave the family as adult. As a consequence support ought to be oriented towards giving the family support, in order to be able to live with its child at home during infancy and school years. When it becomes an adult, the family has become older and no longer able to give its support, the person needs to establish his own adult life. The task of services for the adult should therefore be to give support in his home, and in activities and work outside his home during the day.

When having the child grow up in the family, and this is often experienced as a burden on the parents, practical and psychological support is needed. Assistance can be given by a person coming into the family to deal with practical matters while the family gives its attention to the child.

The psychological needs of the family should not be neglected, as a child with a disability is seldom expected. In such a situation there could be a period of disappointment and resentment. Other families, who previously have had similar experiences can then be someone to turn to for early information as to why this has happened and what can be expected from the child and life in the future. When parents want to give attention to themselves or to other members of the family, it can be desirable to have relief from others. An extra family could for example be appointed as a form of support and of assistance in such a situation.

Early intervention means that not only the family but also the child is in need of support. As an infant it will have the same need of attention and care as other infants, but because of its disability there may be a need for extra support to cope with the various stages of normal child development. Pre-school activities outside the family can contribute to the child's play and social interaction with other children.

As all children with an intellectual disability have the right to education, schools and the education they offer must be organized for this to become a reality. For each child to have his educational needs satisfied it is understandable that there must be a variation of solutions on offer.

Special schools are no longer recognized, instead the education of children with a disability takes place within the framework of ordinary schools.

But this does not mean that all children at all times are part of the ordinary classes of that school. The task is to create a situation when the child will gain educational experiences important for him. This can be achieved through the ordinary class or in a special setting. In reality the child's week will consist of the activities which are found suitable for him, these taking place in various settings of the school. Sometimes these will take place together with children who have got a disability and sometimes the activities take place together with others. A major experience is that the smaller the group in which the child takes part, the more attention the teacher can give the child thus enabling him to experience personalized education.

Support to adults

When the person has become an adult, compulsory schooling ends. If the person has the possibility of getting a paid job like most people, he will go to work. Even if the person has a disability, if it is a minor one, he might have the possibility to get a paid job, but a job when he still receives some support from others. He can receive a full salary, but this is subsidized by some national employment body.

If he cannot get a job because of his disability, he can instead take part in day services, organized as daily activities with support. The idea with these daily activities is to give the person the opportunity to leave his home during the day and to take part in purposeful activities during the five days of the week. The type of activities will depend on his needs and requests. In this way it is possible to create a week of work for one person. For someone else needing extensive support, the week can be filled with activities which give stimulation and pleasant experiences of value for his personal development. Others may have adult education as part of the weekly programme. Earlier on these activities usually took place in special day activity centers. Today, when there is an ambition to participate in community life, the tendency is to create settings in the ordinary community, specially organized for small groups of persons.

It is common that the child lives with his family during school years. But as he grows older he leaves the family to get his own home. Because of his disability he is in need of support, this being limited if he only has a minor disability. In that case he can get an ordinary apartment of his own, like other young people, but with staff who provide support in the home when he needs it. If he is not self-sufficient and has got more extensive needs for support, a group home is an alternative. This can be a large apartment or a house where a group of persons live. In such a home there is also staff on duty around the clock, the

number of staff is less if the needs of the persons are limited. But if the needs are more extensive, for example for persons who once lived at the residential institution, the number of staff needs to be higher.

The brief presentation given here can only be a general one. For each person there must be a personal choice of services, applying the alternatives which are available at the time. The requests from the person and his family will of course influence how services will be formed. Contributions to the choice of services are also related to the degree and character of disability of the person. The cultural context will also influence services of the person, e.g. housing in the countryside being different to housing in the large city (Ericsson 1996).

DISSOLUTION OF INSTITUTIONALLY BASED SERVICES

The logic of the institution

When no support was available or when there were only services of a low quality, the establishment of the modern residential institution was a great achievement. Its services meant a better life for persons in need of support. This was the case from their introduction up until the 50:s.

The 70:s was the decade of change. New experiences were gained about community based services and these were seen and accepted as positive. By offering a more normal life, in small groups, with a higher material standard and with some participation in community life, they set new ideals which could not be found in the residential institution. As they were gradually developed and their numbers increased, they were sought after by the persons themselves and their families.

This created a challenge for the institution which started to develop its services according to the new ideals. The groups became smaller and they offered a more normal life and a better material standard. But still, this was a large place with many persons living there, most often far away from home. Therefore there was a movement away from the institution towards life in community.

As the first ones to leave the residential institution were those with a mild form of disability, only community based services offering a limited support were needed. But as persons with a more severe form of disability also left, services providing extensive support were established. When community based services had been developed to the extent that they could provide support and services to all, irrespective of degree of disability, these were seen as desirable. Consequently residential institutions were being dissolved and finally closed down. After year 2000, the residential institution is no longer recognized as a form of service in Sweden.

Closing the institution

Dissolution and closure of a residential institution is a complex process. It is therefore of importance to focus on the essence of such a process. As services are about providing support for a good life for a person with a disability, the aim of dissolution must always be to contribute to a better life for those who lived at the institution. As there are persons in need of support even after they have left the institution, there must be services in the community which guarantee a better life. The key task during dissolution is therefore the development of services outside the institution.

The dissolution and closure of an institution often gives rise to dramatic reactions and a sense of destruction. However, when one finds that a development of modern services and better lives is the task for the transition of services this becomes a process with a positive content. The most dramatic reactions can be found during the early part of the transition process. When all have left the institution and one meets people who once lived there, their families and staff, one finds that they can talk about all phases of the transition. They talk however, very little about what they have left, more about the new lives and services which have become a reality (Ericsson 1996).

Closing the institution in our minds

The work towards an increased participation in community life only becomes understandable and realistic when one sees the person as a citizen, belonging to his family and community. But as a citizen perspective is being developed, the competence perspective associated with institutionally based services, has to be left behind. This attitudinal shift is also part of the transition between the two traditions of support. Ongoing projects have shown that this is a most difficult task. It is easy to change the physical facilities of services, but it is more complicated to change attitudes. This task has therefore been expressed as one which aims at "closing the institution in our minds" (Ericsson 1998).

Persons experiencing a new life

It is only since the early 70:s that we have seen persons with intellectual disability move from an institutional life to participation in local community. Thereby a new pattern of life has evolved, with new qualities not previously experienced. The ambition has been to establish a more normal life, for these persons to live where and as others live. This has been made possible through the development of support in ordinary housing and through the provision of daily activities and work.

When people talk about their new experiences they express a sense of freedom. They also talk about having got their own home, their own furniture and belongings. "My own ..." is an expression often used by

them. But they also talk about the common issues of everyday life, that is about not having enough money, the absence of some of their friends and about not having a job that gives satisfaction. They, like we all do, talk about everyday life, with its positive and negative aspects and how this life can be improved.

Parents whose adult children have now left the residential institution recollect how they saw the period of transition with some anxiety. During the years they had become used to the idea that their child had been handed over to an institution. Today, when they talk about their sons or daughters having moved from the old institution to new services, they talk of their earlier doubts about them not being able to manage this change. Afterwards, when the persons live in their new house, parents instead talk about their happiness when they see them experiencing the new life. But they still make demands for a better life when they find out that some basic qualities are still lacking.

The change which has taken place cannot be described merely as a change in pattern of everyday life. These persons have also acquired another role in their local community and in society as a whole. There are examples of persons who previously were merely receivers of care. Today they have important tasks and functions in their community. They have taken on roles as citizens of their community and they participate in local activities. There is for example a group of persons whose task in their community is to inform the children in local schools on issues related to handicap. Because of their intellectual disability they are considered as experts. They have done this during one year, in this way meeting more than 2.000 children.

The main trend, even if there are exceptions, can be characterized as having introduced more normal patterns of everyday life and through these brought about closer contact with the ordinary man. In many situations persons are seen as citizens and met with respect. In this way new and fundamental experiences have been gained during these years. These more normal conditions of life have also important personal consequences for personal well-being and development (Ericsson 1998).

A FINAL COMMENT

In the preface of this book I pointed to some important steps towards a disability policy, particularly concerning persons with an intellectual disability, characterized by their participation in community life. In this chapter my intention has been to give an account of the consequences when this policy is put into practice.

What is to be found is a complex change of services between two traditions of support. Bringing in a new socio-political idea, emphasizing participation in community life, introduces new goals to be realized when delivering support and services. To bring this about community based

services are needed. If adequate forms of support do not already exist they have to be found. Those forms of support which do not contribute to participation of the person in community life are no longer valid and need to be dissolved. Some aspects of how this work has been carried out in Sweden have been exemplified here.

Hopefully this has not been presented as an easy task! Organizational restructuring has opened up a number of problems to be solved, often requiring social innovations. One must also recognize that there have been anxieties during a period of change when new forms of support have been vague, and irritation when mistakes have been made in delivering the new community based services.

But during this change between traditions of support there are a large number of persons with intellectual disability, mild as well as severe, who have expressed tremendous joy when experiencing a better life! When families have seen their sons and daughters, brothers and sisters living under more normal conditions and developing personally, even they show unexpected happiness! This shift of support has now been going on during a 50 year period in Sweden. This has only been able to continue as long as it has led to positive consequences for the people concerned!

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FINAL RECOMMENDATIONS

Participants of Seminar

The Swedish Organization for Individual Relief in cooperation with the Ministry of Social Development and the National Council for the Welfare of the Disabled, held a seminar entitled "Changing Disability Services in a Changing Society: 30 Years of IM/SOIR Work in Jordan", under the patronage of Their Royal Highnesses Prince Raad Bin Zeid and Princess Majda Raad, during 4-5 May 1998. His Highness Prince Firas Bin Raad and His Excellency the Minister of Social Development and a number of international experts and 185 participants from 5 Arab countries and Jordan participated in the seminar. They were from both governmental and non-governmental sectors. During the first day, the experts presented research and experiences as can be seen in the previous chapters of this book.

On the second day the participants were distributed in six groups. Each group discussed one of the following subjects:

1. The consequences of a community based approach on the child and the family.
2. The consequences of a community based approach on community participation of the person.
3. The consequences of a community based approach on the life of the adult disabled person.
4. The consequences of a community based approach on administration and economy of services.
5. The consequences of a community based approach on methods for rehabilitation.
6. The consequences of a community based approach on the role of governmental and non-governmental organizations.

Each group presented a summary of what had been discussed and of the recommendations set. After a general discussion of all the subjects, a committee for follow-up of the recommendations gathered. The committee studied the reports of the groups and took a decision to recompose the

recommendations as they had come from the groups, and include them in the final report of the seminar.

All the participants valued the Jordanian approach presented by the National Committee of CBR, The National Council for the Welfare of the Disabled in Jordan. They also agreed to have benefited from the subjects and papers presented and discussed in the seminar. The participants also saw the necessity and importance of uniting the Arab efforts in promoting CBR through establishing an Arabic Council for CBR.

The participants complimented the role of the Swedish Organization for Individual Relief in offering services for the disabled. They called for benefiting from the organization's experience, and spreading it. The participants emphasized that such scientific seminars should be held again in order to assure that the persons with disabilities are equal with other community members in rights and obligations.

RECOMMENDATIONS

Final recommendations from the group discussions after being studied by the recommendations and follow-up committee.

Recommendations of the first group

The first group discussed "The consequences of a community based approach on the child and the family", and came up with the following recommendations:

- A) Assure that moral values are present in the principles and basis of community based rehabilitation (CBR).
- B) Community participation is important in providing services in CBR.
- C) Take into consideration the needs of the individuals and their families, and help them to achieve self-confidence. Problems should be faced in a flexible way and the individuals should participate in the problem solving.

Recommendations of the second group

The second group discussed "The consequences of a community based approach on community participation of the person", and came up with the following recommendations:

- A) Use the organizations and centers of special education as resource centers for rehabilitation and training.
- B) Prepare the schools and kindergartens with qualified staff, training methods and technical aids, in order to receive children with disabilities. Also, the building code of the disabled should be applied.

Recommendations of the third group

The third group discussed "The consequences of a community based approach on the life of the adult disabled person", and came up with the following recommendations:

- A) CBR programmes should be seen as complementary to the services of the organizations, and not replacing them.
- B) Encourage the societies to expand the programmes of adult disabled persons who are over 14 years old.
- C) Emphasize the role of the media, religious organizations and different clubs in the programmes and activities dealing with changing attitudes towards the persons with disabilities and their rights.
- D) Involve the adult disabled persons in identifying their needs and planning for the services concerning them.
- E) Facilitate the procedures of receiving technical aids and medicines.
- F) Encourage the persons in the community, especially the universities, community colleges and retired persons to work voluntarily in programmes offered to persons with disabilities.

Recommendations of the fourth group

The fourth group discussed "The consequences of a community based approach on administration and economy of services", and came up with the following recommendations:

- A) Use resources built on experience and knowledge taken from the local community when planning and organizing the programmes of CBR.
- B) Adopt the procedure of central planning and non-central implementation to assure active involvement in and continuation of CBR programmes.
- C) Prepare a national document of CBR that gives clear roles on the local, regional and national levels.

Recommendations of the fifth group

The fifth group discussed "The consequences of a community based approach on methods of rehabilitation", and came up with the following recommendations:

- A) Establish a national center for information which should include full documentation for CBR programmes.
- B) Emphasize on early intervention programmes through spreading awareness, educating and training the families.

Recommendations of the sixth group

The sixth group discussed "The consequences of a community based approach on the role of governmental and non-governmental organizations", and came up with the following recommendations:

A) The concerned parties shall coordinate with the Ministry of Planning to find the necessary support for the CBR programmes and to ensure active involvement and its continuation.

B) Universities should adopt specialized courses which are congruent with the needs of CBR programmes as physiotherapy and occupational therapy, etc.

GENERAL RECOMMENDATIONS

- 1) The national committee of the CBR shall, based on the experiences and papers discussed, make a national strategy for CBR.
- 2) Arab efforts concerning CBR should be unified through establishing an Arab CBR Council.
- 3) The seminar recommends that the national council shall design a special logo for CBR.
- 4) Send a thanking telegram to His Majesty King Hussein.
- 5) Send a thanking letter to Her Excellency, Ambassador of Sweden in Jordan.

FINAL WORDS

Kent Ericsson

A GLOBAL PROBLEM AND A GLOBAL STRATEGY

All over the world intellectual disability can be found, as this is a phenomenon which is part of mankind. As long as people are born, there will be persons with a disability as the child during the period from conception to adulthood, the years during which the person is formed, is open to risks of a physical, social and a psychological character. Some, in spite of their disability, can lead a good life while others, the larger group, experience suffering. Intellectual disability can therefore be seen as a global problem.

It is only natural that UN during the last 25 years has given interest and resources to finding ways of ameliorating this problem. The international year of the disabled in 1981 saw the manifestation of the work during the 70:s in the theme for this year "equal rights and participation". The work during the 80:s resulted in the UN "Standard rules for the equalization of opportunities" in 1994, there expressing a policy for how to organize support to persons with a disability. A global problem has thereby got a global strategy for how to meet the needs of persons with an intellectual disability.

With the UN strategy a basis has been formed for international cooperation. Experiences from countries can be communicated, understood and applied within the same framework. This has also created a new basis for cooperative projects where work can be carried out in different countries, to solve common problems. This should not though be seen as opening up for possibilities of just making copies of forms of support found in other countries. International cooperation and cultural differences should instead stimulate to new solutions. A fundamental characteristic of the UN strategy arguing for equal participation in community life, is that support is specific to the culture where the person lives as it should contribute to the life the person wants to lead in his community.

Hopefully the contributions presented here are an illustration of the existence of international experiences within the frame of reference given by the UN strategy. At the same time they show that their realization is

not an easy task. The new ideas presented need to be developed further to become concrete and viable in the realities of the persons concerned. In this lies challenges ahead. At the same time as the new ideas are being formed, old ones need to be left behind. This shift demands a clear analysis of the way ahead and a determination to get there. It also needs to discard old ideas but in a way which does not demolish and discourage.

THE COMMUNITY BASED APPROACH TO SUPPORT

The question for the seminar concerned the meaning of community based rehabilitation, CBR. Based on the contributions which have been presented in this book some answers can be given. A first step towards an answer may seem too simplistic, but it is not the intention to avoid the issue. The concept of community based rehabilitation is an expression for the desirability of rehabilitation taking place in the community!

Rehabilitation is the concept used to point to those activities which lead to the development of the abilities of a person. As rehabilitation usually is used in relation to persons who once have gained their abilities in the normal way, but which they have lost, for example because of damage or ill health and therefore need to develop them again, gives the "re-" of rehabilitation its motive. This does not however feel like a correct term to use when working with persons whose disability was there when the child was born or was achieved during early years. The activities needed to support the development of abilities in the first place, ought instead to be called habilitation.

That rehabilitation takes place in the community means that activities should facilitate for the person to be able to stay on in the community to which he belongs, with his family and his relatives. The services which are offered to the public of this community are also those which he should have the right to use. If those services are not adequate and do not meet his needs, then work should go on to increase their competence. It is only when support meets the needs of the person with a disability that he will be able to participate in community life. Behind this is also the basic assumption that this person is to be seen as a member of society, like anyone else, and whose needs should be cared for, irrespective of whether they are general or very specific.

Why then is the idea of CBR being discussed when it seems so simple? The complexity lies in the history of services to persons with a disability. Since the last century the main form of support has been channelled through residential institutions. Therefore they have their roots in another period, representing other ideas. Over the years they have been adjusted and developed to form the institutions we know today. Institutionally based rehabilitation would be the term to use for the services they offer. The complex change between institutionally based and community based rehabilitation would therefore be a motive for an enquiry into

the meaning of the community based approach. In my previous chapter I talked about this as a shift between two traditions of support.

AN OPTIMISTIC VIEW OF THE PERSON

The theme of this book concerns various forms of support to persons with an intellectual disability. When dealing with this issue it is very easy to be carried away. Many persons, groups and organizations are involved. When suggesting strategies, testing solutions and when choosing priorities it is very easy to base one's judgement on the interests of some of the parties concerned in this process.

In working with these issues one must not forget that there is one party who is always concerned, but who is not always present in these discussions. The person with a disability and his family always live with the hope that they will be able to lead the life which is normal to others in their community, but which does not become a reality because of hindrances caused by the disability. The family also nourishes hopes that the son or daughter will develop personally to achieve more than has been possible up to now!

Dealing with international research and development of support we know that many of these dreams can be true. Today there is an abundance of knowledge which shows that the person with an intellectual disability has got considerable potential for personal development. We just do not know the limits for what life he can lead! We also know that social innovations during the last quarter of this century have brought forward many new solutions which brings welfare to families with a member who has got a disability. To be successful in the delivery of support, respect for the person and the family, is imperative.

SPEAKERS AND MEMBERS OF COMMITTEES

PREPARATORY COMMITTEE

- HRH Prince Firas Bin Raad, Chairman, The National Council for the Welfare of the Disabled
- Dr. Wael Masoud, Director of the Special Education Department, Ministry of Social Development
- Ms. Zeinat Abu Shanab, The Swedish Organization for Individual Relief
- Ms. Moniqa Pettersson, The Swedish Organization for Individual Relief
- Ms. Maysoun Al Bdour, Ministry of Social Development
- Ms. Silva Al Salem, Ministry of Social Development
- Ms. Siham Al Khoffash, Ministry of Social Development
- Ms. Fawzieh Al Sabbaa, The National Council for the Welfare of the Disabled

ORGANIZING AND PROGRAMME COMMITTEE

- Mrs. Zeinat Abu Shanab, The Swedish Organization for Individual Relief
- Dr. Wael Masoud, Director of the Special Education Department, Ministry of Social Development
- Ms. Patricia Ericsson, Consultant Psychologist, Skinfaxe Institute, Sweden
- Mr. Kent Ericsson, Research Psychologist, Uppsala University, Sweden

SEMINAR SECRETARIAT

- Ms. Najieh Jaouni, The Swedish Organization for Individual Relief
- Mr. Mustafa Al Jahad, The Swedish Organization for Individual Relief
- Ms. Moniqa Pettersson, The Swedish Organization for Individual Relief
- Ms. Siham Al Khoffash, Ministry of Social Development

SPEAKERS

HRH Prince Firas Bin Raad is Chairman for the Committee of CBR, the National Council for the Welfare of the Disabled.

Postal address:
Ministry of Social Development
Amman, Jordan

Mrs. Patricia Ericsson qualified as social-worker at Queen's University, Belfast, Northern Ireland, and as psychologist at Uppsala University, Sweden. Earlier on she has held posts as manager, psychologist, administrator and Director of Care in Stockholm, Sweden. Today she is a consultant psychologist working out of Skinfxax Institute, Uppsala, Sweden. As such she runs projects dealing with innovative aspects of community based forms of support in Sweden and internationally.

e-mail address: patricia.ericsson@skinfxax.se

Internet URL: www.skinfxax.se

Postal address:
Skinfxax Institute
Holmgångsvägen 3
SE-754 40 Uppsala, Sweden

Dr. Mehari Gebre-Medhin is a specialist in pediatrics. After medical studies in Lund University, Sweden, appointments at the Ethio-Swedish Pediatric Clinic and the Ethiopian Nutrition Institute, Addis Abeba, Ethiopia in the early 1970s. Studies in epidemiology and public health at Harvard University 1971-72. Degree of doctor of medical science 1977, associated professor of human nutrition 1978, consultant pediatrician and associated professor of pediatrics 1978-93, all at Uppsala University. January 1, 1994, appointed Professor of International Child Health at Uppsala University. In his research and teaching Mehari Gebre-Medhin has focused on nutrition in a range of clinical conditions among children and adolescents including eating disorders and feeding difficulties. In recent years he has worked on the prevention of mental retardation due to iodine deficiency both in high- and low-income countries.

e-mail address: mehari.gebre-medhin@ich.uu.se

Internet URL: www.kbh.uu.se

Postal address:
Department of Women's and Childrens's Health
Section for International Child Health, University Hospital
SE-751 85 Uppsala, Sweden

Dr. Roy McConkey is Professor of Learning Disability at the University of Ulster, N. Ireland. A psychologist by training he has previously worked in England, the Republic of Ireland and Scotland. He has

undertaken consultancies in Africa, Asia and South America for various international agencies including UNESCO, Leonard Cheshire Foundation, Save the Children (UK), NFPU (Norway) and the Guyana Community Based Rehabilitation Programme.

e-mail address: rmconkey@ulst.ac.uk

Internet URL: www.ulst.ac.uk

Postal address:

School of Health Sciences, University of Ulster

Newtownabbey

N. Ireland BT37 0QB, United Kingdom

Dr. Seamus Hegarty is Director of the National Foundation for Educational Research in England and Wales. A mathematician and teacher by background, he has directed and participated in more than 20 research projects covering special needs, ethnic minority issues, assessment, professional development and local authority services. He has written numerous books and papers. He has acted as expert and consultant for OECD, UNESCO, Council of Europe and the European Union as well as for ministries of education in numerous countries.

e-mail: s.hegarty@nfer.ac.uk

Internet URL: www.nfer.ac.uk

Postal address:

National Foundation for Educational Research

The Mere, Upton Park

Slough, Berks, SL1 2DQ, England

Dr. Neil Ross did his medical studies in Canada at the University of Alberta and the University of Sherbrooke, Québec. He did further training in Psychiatry and Child Psychiatry in France at the University of Paris XII. He is a consultant in general and forensic psychiatry at a General hospital in the Paris region as well as medical director for the Association de Villepinte. He is currently the President Elect of the International Association for the Scientific Study of Intellectual Disabilities (IASSID).

e-mail address: njross@compuserve.com

Postal address:

Association Villepinte - IASSID

28 rue de l'Église

93420 Villepinte, France

Mr. Kent Ericsson is a research psychologist at the Department of Education, Uppsala University, Sweden. This is also where he qualified as psychologist and researcher in intellectual disability. His primary interest concerns the delivery of support to persons with a disability and its personal consequences. As he has been active during a 30 year period of a dramatic restructuring of services in Sweden, his many

projects have covered the development of community based as well as dissolution of institutionally based forms for support. His projects have not only covered major parts of Sweden and the Nordic countries but also some European countries. At present he is involved in the introduction of community based services in China.

e-mail address: kent.ericsson@ped.uu.se

Internet URL: www.skinfaxe.se

Postal address:

Department of Education, Uppsala University

Box 2109, SE-750 02 Uppsala, Sweden