

THE AMMAN PROJECTS

Experiences from the community based approach
to disability services

Kent Ericsson

Uppsala University

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FOREWORD

As the Swedish Organisation for Individual Relief, SOIR (Individuell Människohjälpp, IM), carried out extensive changes to its disability services in Amman, Jordan, it was thought desirable to study this change. I was given the task of documenting and analysing The Amman Projects. This book is the result.

It is based on information from several sources. During the project period the SOIR director in Amman, Mrs. Zeinat Abu Shanab, has been a constant source of information. Her staff have also told me about their views of the project. I have also had conversations with members of families. Not all persons with disability communicate with language, but some do and I have had exchanges with them about their experiences.

A valuable source of information is contributed by Dr. Majed Abu Jaber, then Dean of Princess Rahma University College at Al Balqa Applied University. Together with a group of teachers and students he has carried out a study of views and attitudes towards The Amman Projects. Families, staff and members of the public were in this way given the opportunity to express their ideas of the projects.

Psychologist Patricia Ericsson, the SOIR consultant to The Amman Projects, has provided information to this documentation. Her reports from the early analysis of the Sweileh centre have been a rich source, as has her report from the process of establishing the community based services in Amman. My ongoing discussions with her concerning the transition of services in Amman have also given valuable information to this documentation and analysis. She has also reviewed the language of this book.

A grant for this documentation has been received from SMC, the Swedish Mission Council to cover costs for my work. Contributions have also been received from SOIR, Lund, and Skinfaxe Institute, Uppsala. Through the posts of Dr. Majed Abu Jaber and the teachers in his group, Al Balqa Applied University has contributed to the analysis of The Amman Projects. Skinfaxe Institute, Uppsala, has contributed to psychologist Patricia Ericsson in her work on documentation for this book.

I would like to thank all who have contributed to this book! As the task I was given by SOIR has been a most rewarding one I would like to thank SOIR for the opportunity to contribute to The Amman Projects in this way.

Uppsala, June 2006

Kent Ericsson

PREFACE

JORDAN

In the foreword I mentioned that work on this project has been most enriching. This is not only because of the character of the project, but also the “meeting” with the country of Jordan which has contributed to making this project a valuable personal experience. I have had the opportunity of getting to know the country and its people, big words maybe as I have only made a limited number of visits, but still enough to gain more than a superficial knowledge of the country. Some reading about the culture and history of Jordan, and the Middle East, has also contributed.

When this is written celebrations of the 60 years of independence of Jordan has taken place. The explanation is of course that what is Jordan today was once part of the old Ottoman empire. After the First World War, England became its new ruler. Following the Second World War the country, the Hashemite Kingdom of Jordan, gained its independence. During a large number of years King Hussein’s reign made Jordan well known internationally.

Much can be said about modern Jordan. Some striking characteristics should however be mentioned. The first thing ones notices on arrival is the architecture of Amman. The city is built on hills and consequently the buildings are seen as climbing the hillsides! One is amazed by the ability to build, and live, like this! Much of the landscape of Jordan is characterised by sand and desert, and the consequences of the lack of water. There are, however, two places dominated by water which are of special interest, the Dead Sea and the port of Aqaba, at the Red Sea.

Jordan is a Muslim society, Islam being its religion, with the prayers from the Holy Koran being sung from the mosques several times per day characterizing the atmosphere. In spite of being a visitor who does not understand Arabic this provides a pleasant background to everyday life, a part of the culture which is missed when leaving the country. Contact with this society has increased one’s understanding of Islam and deepened one’s cultural knowledge of the country at a time when this religion is being given increasing attention internationally. The warm hospitality of the people of Jordan has had an enduring impact which has contributed to both a greater knowledge of the culture but also a depth of friendship which long extends the project and my task in documenting it.

The King’s Highway from Aqaba to Palmyra in Syria was in early times the connection for trade from as far away as present day Ethiopia to the Silk Road, then the trade route from the Mediterranean which ends in Xian in China. This was the route along which merchants transported their wares to be sold internationally.

Along this highway there have been tribes who have gained economically from the merchants passing through their areas. The most well-known are the Nabateans who lived in the south, and close to the highway. They have left their mark by penetrating into the mountains where they created their extensive settlement, the place which today is Petra, an impressive and most sought after attraction for tourists.

In Petra there are also remnants from Roman times. These are not the only ones to be found in Jordan. They also exist in many places in the country as Jordan was once part of the Roman empire, many of their buildings still remaining. The very well kept Roman theatre in the old town of Amman, the city called Philadelphia by the Romans, is a good example. Another is the impressive site and ruins of Jerash, a city not far from Amman.

Jordan is also part of the area where much of the Christian heritage has its roots. The most impressive is Mount Nebo, the mountain from which Moses viewed the valley of Jordan and showed his people the promised land, the land of milk and honey. The stories of the bible acquire a very concrete significance when reflected on from Mount Nebo, looking over the River Jordan into Israel.

Experiencing Amman and Jordan makes one also very aware of present day politics. This is a country very close to a number of wars which have been fought since the end of the Second World War. Arab - Israeli conflicts have led to a loss of substantial areas of the country and an influx of Palestinian citizens who have left their country and now make up a large part of the population of Jordan. The wars in Iraq have also had deep influence culturally and economically on this young nation.

SOIR, THE SWEDISH ORGANISATION FOR INDIVIDUAL RELIEF

During the political unrest in Europe during the 1930:s a number of concerned persons, mainly from Lund in the south of Sweden, joined to form an organisation in order to help people in need. They had a Christian and humanitarian ethos as basis for their work. Inomeuropeisk Mission (Mission Inside Europe) was the name they choose (shortened IM). After the Second World War their help was extended and projects were set up in various places of Europe.

Their work in Amman represents a widening of their assistance. After they extended beyond Europe services were set up in Jerusalem. It was there they were approached by representatives from Jordan, East Jerusalem then being under control of Jordan, requesting help with the care of children with mental retardation. The positive response to this request led to the project which is reported here.

The widening of their ambition also led to a change of name. IM became Individuell Människohjälp, I standing for Individual, and M for Assistance to People. The name was translated into English as the Swedish Organisation for Individual Relief, SOIR for short. Their work has escalated and projects of assistance today take place in Europe, Asia, Africa and Latin America. Many of them are concerned with support to persons with a disability.

This book naturally focusses on the work of SOIR in Amman as it is the process there which is to be described. All the activities taking place in Amman do so under the auspices of SOIR in Lund where board and administration, is located.

Current information about SOIR and its work is therefore presented on their website: www.manniskohjalp.se

THE AMMAN PROJECTS

The task

Since the end of the 1960:s SOIR has been delivering services to persons with an intellectual disability in the city of Amman, Jordan. Since the middle of the 1970:s this has taken place at the Sweileh centre, a residential home for children and adults. But a special service like this has a limited period during which to be of value. Physical renovation becomes necessary when a large group has used facilities like these over many years. New ideas concerning the meaning of good disability support also emerges over time, and requires re-assessment and development.

In the middle of the 1990:s the SOIR services were given a new direction. It was recognised that to develop better lives for persons new disability services had to be established within the framework of a community based approach. Over a 10 year period new services were set up in the communities of Amman and the Sweileh care-home was dissolved.

The work which has taken place can be seen as a welfare project. The main task for SOIR was to achieve better lives through the means of new disability services, for persons then utilizing the ones at Sweileh. The new services were not specified at the outset of the project. The framework for them was however given and thereby the goals could be formulated for the new services and better lives. The task of SOIR in Amman therefore consisted of realising services which could fulfil these goals.

Contributions

The work by SOIR in Amman has consisted of a series of projects. These are presented in chapter 3. The person behind these is naturally the SOIR director in Jordan, Mrs. Zeinat Abu Shanab. She, together with her staff, are the ones whose daily work during the project period have realised the transition of services which has taken place. A number of formal bodies in Jordan, the relevant ministries and the SOIR board in Sweden, have provided the conditions required to carry out the task. She has also been supported by a number of significant people in Jordan.

SOIR in Sweden appointed a consultant, psychologist Patricia Ericsson, to assist the SOIR organisation in Amman. As she had considerable experience from the work which was to take place, the development of community based, and the dissolution of institutionally based services, the task was no experiment. Instead it was an application of the knowledge gained during a similar change of disability services in Sweden.

Dr. Majed Abu Jaber, then Dean of Princess Rahma University College of Al Balqa Applied University, together with teachers and students carried out a study describing views and attitudes towards the Amman Projects. Family members, staff and the public were thereby given an opportunity to express their views, the SOIR work being reflected upon by people who were concerned.

The task of documenting and analysing the Amman Projects was given to Dr. Kent Ericsson of Uppsala University as he had previous experiences of evaluating the transition of disability services in Sweden (www.skinfaxe.se/sdr.htm).

Documentation and analysis

The documentation of the Amman Projects started with a limited task. The intention was to describe the first of the new services and the funding by the Swedish Mission Council was limited to this task. As the work progressed it was realised that this was a very interesting and important project, seen from a wider perspective than that of Jordan. New knowledge was formed about how to organise modern disability services in countries like Jordan and it was seen as a responsibility to make this experience available to others.

Resources were therefore added in order to cover the full length of the project period. The work of Dr. Majed Abu Jaber through his study was a contribution to the project. As psychologist Patricia Ericsson had experiences from the full project period, she contributed to the documentation by summing up her experiences. The present author also prolonged his contribution in order to cover the full project period.

But all aspects of the transition could not be covered as this has been a most complex process. Many people were concerned. Persons' lives are changed when they move to new services. The lives of their families also change as they no longer visit a residential centre, but services in other places of Amman. Staff acquire new jobs, in new areas. Such a change takes place over a period of several years, the task requiring a gradual change in order to establish the new lives of persons many of whom had previously lived at the centre.

There were also a number of organisational issues which had to be tackled. As staff change jobs their working methods must also change, for example tasks which require close cooperation with the local community. Economic matters are also part of this process as a restructuring of disability services is necessary if the transition is to be carried out. Several organisations are involved, like the concerned ministries and the organisations who are to run the new services. To carry out their tasks requires an understanding of the idea behind this change. Educational establishments who train people for work in the disability field will require opportunities for training for the community based services. Attitudes toward disability in the Jordanian society are also issues being touched on by this transition.

It is necessary to understand that a full documentation of a process like this cannot be carried out. The issues to be analysed have to be chosen. This choice is influenced by factors like economy, interests and practical issues.

It would have been most desirable to describe the consequences of transition for the persons themselves, but no funds were available for this task. Another issue which has created considerable interest is the management side of this task. Matters concerning staff and economy has for now been left aside, the intention being that this aspect of the task will be analysed by someone with a closer knowledge of this part of the process. The choice which has been made here has focussed on describ-

ing the transition of services, the dissolution of the residential centre and the establishment of the new services.

The chapters of the book

The documentation and analysis of the Amman Projects has been summed up in the 12 chapters of this book. It begins (chapter 1) by describing the Sweileh centre, its development and dissolution. An ongoing disability reform in Jordan, Sweden and globally (chapter 2) gives an understanding of the ongoing shift from institutionally to community based disability services.

The organisation of SOIR in Amman, with the task of establishing new services is presented in chapter 3. This is followed by a description of the new classes for children (chapter 4) and the new day services for adults (chapter 5). A minor group of adults have received new homes (chapter 6). A team of experts (chapter 7) provide support to persons with disability, to staff and to the public.

A number of variables are chosen to sum up development during the project period (chapter 8). The attitudes of families, staff and the public have been described and major results are given in chapter 9. Views of family members are also presented in chapter 10. In chapter 11 the Amman Projects are reflected upon and discussed. In chapter 12, based on the experiences from the Amman Projects, the community based approach to disability services, the frame of reference for this transition of services, is analysed and presented.

1

SWEILEH CENTRE: DEVELOPMENT AND DISSOLUTION

FROM JERUSALEM TO AMMAN

In 1965 SOIR decided to get involved in humanitarian work in east Jerusalem, then a part of Jordan, to assist in the current extensive refugee problem. Jordan was at that time also in need of development of social services, particularly for persons with an intellectual disability. This led to a request to SOIR from the Ministry of Social Affairs to establish modern disability services. The answer was positive. In a rented house in Jerusalem services were established in 1967. Only a short time later the six days war broke out (Sehlin, 1968).

After the war work continued in Jerusalem, but conditions were no longer the same. To fulfil the promise of establishing disability services, work began in Amman in 1968. In a rented villa in the Shmeisany area, a home for the care of children with a disability was started. The first child was received in November 1968. In 1969 a school for special education was set up for 40 pupils, children with a mild or a moderate disability. As the needs of families were identified a programme was also started consisting of counselling and material support to the parents of the children (Jaber, 1994).

As information regarding the SOIR services spread the limited provisions met with an increasing number of requests from families who asked for support for their children. To meet these requests SOIR made the decision to establish a special home in order to provide for a larger group. For this purpose a piece of land in Sweileh, a village north west of Amman, was bought in 1972 and planning started for new services. The land was part of a hilltop with local housing at a distance (Olausson, 1996). In the early 70:s this location was the commonly accepted way of responding to the need for support to persons with disability.

The care-home was established by SOIR, based on drawings made by a Jordanian architect. Plans were also discussed together with those authorities in Sweden which dealt with the building of residential homes in this country. Consequently there were many similarities between this Jordanian home and the residential institutions being built in Sweden at the time. In 1975 the Sweileh care-home was established.

SERVICES OF THE CARE-HOME

The same services as had been provided previously, were also offered here. Care was organised through a system of wards, the intention being that the children would stay there for a period, from 6 months to 2 years. During this time they would receive the training they were considered to be in need of, after which they should return to their families. A school was also set up for those with a mild or a moderate disability. A new service was also offered to those children who had become too old for the school. This enabled them to continue in a vocational training centre, the VTC, where education was directed towards preparing for working life outside the centre.

The original intention was that after attending the special school and the VTC the children would gain some form of employment. But this only became a reality for a few. In 1979 a sheltered work-shop was therefore opened for those who had left the VTC, but who could not find employment in the local labour market.

During the 70:s a gradual development had taken place in Amman, as new special schools were opened for children with a mild or a moderate disability. As this development took place the need for the special school at SOIR decreased. This led to a change at the Sweileh centre, the special school being converted into a training school. With the curriculum of this form of schooling children with a severe disability could be admitted. The special school which originally had been established in Shmeisani, when SOIR had begun its work in Amman, was closed in 1983.

This meant that a change took place not only regarding the character of the education provided by SOIR. It was also a sign that the Sweileh centre was transformed. Previously it had concentrated on the needs of children with a mild or a moderate disability, but now a shift had occurred towards persons with a more pronounced severe disability. This had consequences for the Sweileh centre: this development required that new objectives and methods of working were necessary in order to meet the needs of the children.

In 1982 an agreement was made with the Ministry of Social Development concerning an extension. In the following year three new wards were established for the care and training of 30 children. The same year a system of day-care was also started for 24 children.

The services provided through the wards, day-services, education and sheltered work covered the everyday life experienced by those attending the centre. In addition to these the services included a group of specialists. A nurse, a physiotherapist, a sports teacher and a social-worker contributed to the services directed to children. Staff and families could also receive advice and counselling from this group. In addition there was also a dentist and a medical doctor who made regular visits to take care of the needs of the children.

During the initial years in Amman SOIR had set up a programme for support to families. This had continued and was extended at the Sweileh centre. This enabled families, not only those who had children attending the centre but also those

who had needs recognised by SOIR, to visit the Sweileh centre regularly to meet with the social-worker or the nurse.

In 1990 a new development took place whereby cooperation was established with other organisations in Amman, who were involved in the delivery of disability services. SOIR participated in an out-reach programme set up by The Jordanian Hashemite Fund for Human Development (formerly the Queen Alia Fund), aiming to support families in the upbringing of their disabled child at home. In 1992 cooperation started with UNRWA, United Nations Relief and Works Agency for Palestine Refugees in the Near East, in a programme in Palestinian refugee camps aimed at the education of children with a disability. SOIR contributed with a special education teacher whose task was to implement an educational programme. In 1993 the Othman Bin Affan Society Centre for Special Education began to provide services for children with intellectual disability in Zarqa. The approach of this development was to provide special education close to the homes of the children, instead of transporting them to centralised schools. At its outset SOIR cooperated with this organisation in the development of their special education programme.

SOIR, throughout its work in Amman, has had an ambition to provide support to its staff. For example, the specialists at the Sweileh centre have had a role in the training of local staff. Courses have also been arranged with contributions from Jordanian and international experts. Scholarships have been given to staff to enable international exchange, primarily with disability services in Sweden.

The residential services

The services which were provided required staff with varying qualifications. Staff were needed for the provision of care on the wards, and to provide the education and training offered in the schools and the sheltered work-shop. Apart from these, there were also the experts. The services provided by SOIR was a response to a request to introduce disability services in Jordan. A way of meeting this need was to provide Swedish personnel. During the time in Shmeisani and during the early period at Sweileh, several of the staff came from Sweden. Gradually, however, Jordanian staff took over the functions which had been provided by the Swedish staff.

Residential services however, requires more differentiated staff. This was a large organisation which took care of a greater part of the lives of those who lived there. An administrative and financial group dealt with matters concerning the economy of the centre and the formalities concerning both the persons living there and the staff. The kitchen required a cook and kitchen staff to provide for both residents and staff. A house-mother with staff, including a dressmaker, ran a laundry and took care of the residents' clothes. These services, including a staff dining room and conference facilities, were provided in the main building.

A technical and maintenance group managed the buildings, the extensive grounds and the transport system. As the centre was located far from the homes of the residents and the staff, small buses were the main means of transport. These were managed by a group of drivers.

A director had the overall responsibility for running the centre, including all its functions. The holder of this appointment had responsibility to see that the centre was run according to the rules and regulations of formal bodies of Jordan. The director was also responsible to SOIR, and together with the staff in Sweden was responsible to the elected board of SOIR which had the full responsibility for the Swedish residential home in Amman.

These different services were located to a number of buildings located to the grounds in Sweileh. Originally three wards were built for the resident children. An additional three wards were added later, in a separate building. Each ward had a common room, sleeping accommodation and hygiene facilities. A group of staff was attached to each. School buildings provided premises for both special and vocational education. The sheltered workshop was also located to a separate building.

In addition to the facilities for residential care, for schooling and for sheltered work and daily activities, there was a series of buildings forming the administrative centre including the director's offices, a conference room, premises for the varying specialist staff and some maintenance staff. The central kitchen and staff dining facilities were in close proximity to these administrative offices.

In the grounds there was also a series of buildings with housing for staff. The director and the Swedish staff lived in these apartments. There was also a house with apartments at the entrance to the grounds, intended as a gate lodge and location for the night guard or watchman.

There was also a small building set aside from the other buildings, overlooking the city of Amman. This was known as "The Quiet Hall", offering a place for contemplation and reflection without being disturbed.

These buildings covered only a minor part of the institutional grounds. There was therefore an area of planted fir trees providing a shaded place close to the residential facilities. Olive trees were also planted in the grounds, providing a seasonal crop which were used by the centre or sold. Likewise a large garden provided fresh vegetables for use at the centre and as a basis for daily activities for some of the residents. During a period a donkey was kept in the grounds which provided recreational activities. There were also areas reserved for ball sports.

Persons receiving support

Over the years the number of persons receiving support at Sweileh have varied. It was originally a policy that they should be admitted for maximum two years during which they would receive the training found suitable for them. Following that they would be discharged to their homes. Later, when children with a more severe disability were received, they stayed on for a longer period.

The number of residents in 1994 illustrates the situation when changes were introduced at the Sweileh centre. 10 children lived on each of the five original wards, in all 50 children. Their ages varied between 5-11 years with the majority, 27 children, in the age group 5-7 years. The services they received, mainly care and training, was provided on the wards. The Sweileh centre was characterized primarily as a residential home for small children.

6 adults, 2 women and 4 men, were resident on the ward which had been most recently built. In addition to residential care they had day activities at the vocational school or the sheltered work-shop. These 6 were spoken of as the abandoned children, their family background being unknown.

The school also provided education for children living at their family homes in Amman, travelling to Sweileh on a daily basis. The training school provided education for 24 day pupils and the vocational school for 30 day pupils. Day care was provided for 3 groups, each with 8 children, 2 days per week. The sheltered workshop provided daily activities for 30 adults.

A study carried out at Sweileh (Jansson et al, 1990) gives some information about the children. 203 were admitted to the centre during the four years of 1984-1987. They came from 7 districts of Jordan. All of them, except one, were born during the years 1975-1985. At the time of the study they were therefore a young group, in the age-group 2-12 years. The study describes their disabilities as mild mental retardation (11 %), severe mental retardation (74 %) and probable severe mental retardation (15 %). When looking at their social background the study shows that 8 % of the fathers were unemployed, 43 % were unskilled workers, 34 % were skilled workers and 15 % were semi-professionals. The study illustrates well the ambition of the Sweileh centre to be a place for the needy in society, those who were not taken care of by others, namely children with severe disability, from families with limited means of caring for them within the home.

Another study from 1992 (Jansson, Pettersson & Jaber, 1992) illustrates the consequences of the ambition that the centre be a place where children were admitted only for a limited time, to receive the training they needed. This is based on a group of 245 children admitted to the Sweileh centre during the period 1988-1991, the training being provided for an average of 12 months. Each of the 5 variables, A - E, show the achievement of training during this period.

The results given here illustrate the group with full achievement after 12 months. Two numbers are shown here for each variable. The first one give the number of persons in the group at admission, the second the number at discharge. A) Keep dry: 32 - 169, B) Eat with spoon: 40 - 150, C) Eat with hand: 148 - 207, D) Eat family softened food: 206 - 226, E) Walking: 123 - 157. As there are clear differences between the situation at admission and at discharge, the Sweileh centre can be said to fulfil its ambition to be a place for the training of the child's functions, during a limited period of time.

A NEW DIRECTION FOR SERVICES

The introduction of the training school, and the enlargement of the Sweileh centre in 1984, meant that children with a more extensive need for support could be admitted. This new group of children gradually became the challenge for the centre. It was no longer possible to give them training during two years, and then to send them home to their families. The disabilities of the new group demanded instead extensive support and a long-term stay, in addition to new methods of habilitation and care. There was a need for a new direction for the services. This presented a

challenge for the care-home. The basic objective and the working methods which had been developed during its early phase, which were still in practice, no longer met the needs of this new situation.

Contributing to this gradual shift in the needs of the children was the ongoing development in Jordan and in Amman. The training of teachers to work with children with a mild disability had increased in the country during the 70:s and the 80:s. This led to a wider knowledge and awareness concerning these matters, both generally in the country, and specifically in the area of special education and disability services. The disability law of 1993 in Jordan, and the preparations for this, also indicated a new direction for disability services. These emerging reforms led to the provision of new community based disability services and to the establishment of schools for special education. As these catered primarily for children with a mild disability, those with more extensive needs were seen as children in need of placement at places like the Sweileh care-home.

During the early years of the 90:s several expressions for irritation and unrest were found at the centre. The extent of the discontent was such that it was regarded as a potential crisis situation. In the Spring of 1993 a member of the SOIR board, also an expert on disability issues, visited Amman. Not only the Sweileh care-home was visited but also the community based projects in which SOIR was involved. The report to the SOIR office in Sweden was critical of the situation at the residential home. In the Autumn of 1993 Swedish staff also expressed criticism of the conditions in a letter addressed to the SOIR office in Sweden. This information became the basis for the secretary general to decide that a study of conditions at the care-home in Sweileh be made.

To analyse the situation SOIR invited a consultant to carry out the task. Psychologist Patricia Ericsson, with extensive experiences from disability services in Sweden and of an earlier involvement in another SOIR project, was appointed in 1994 to look into the situation, and the services being offered. This resulted in a series of reports (Ericsson, P., 1994a, 1994b, 1994c) where she presented her analysis. Two alternative futures were identified. Either it could be maintained as a residential home, this requiring renovation of the buildings and the development of services in a new direction. The other alternative would be to offer relevant services in the community, located to various places in Amman. This latter alternative implied the closure of the institution. The consultant recommended SOIR to choose the alternative leading to the development of community based services and the closure of the care-home.

The importance of working towards an integration of disability services was recognised by SOIR. However, no formal decision regarding the future of the Sweileh care-home was made at this stage. With the implications of an alternative direction for services still unclear, the consultant was asked to clarify the meaning of a community based approach and its consequences for the care-home. This task was carried out through a series of studies (Ericsson, P., 1995, 1996).

The analysis showed that there was a lack of clarity of direction for the services during this period which had led to unrest in the leadership. The proposal of the

Swedish teacher to set up a day-school was therefore seen as a step in the right direction. The change was prepared during 1995 and in January 1996 all children living at the care-home were discharged to live at home with their families. The provision of bus transport on a daily basis enabled them to continue to receive their schooling on a daily basis at Sweileh. A fleet of small buses enabled the children to be picked up at various places in Amman in the morning and returned to home in the afternoon. An additional group of drivers were employed to provide the service.

A small group of adults, who originally had been admitted as children, had no families to return to. Their needs had been met by their being located to one of the previous wards which was renamed as the "Home of Love". These were persons with extensive needs for support.

In 1996 the board of SOIR decided on the closure of the Sweileh centre, the remaining services then provided there to be replaced by alternatives located to suitable areas of Amman. To realise this, the "Sweileh Integration Project" was to begin as of Autumn 1996. It was intended as a three year project, the task being to establish alternative services, to be provided by SOIR, but located in the local communities of Amman. It took one year to resolve how the project should be organised and to find a director to carry out the task. As there was still considerable hesitation concerning the intentions for the future a number of meetings were held during this period both with families and staff to inform and discuss the new direction for the services. As the decision made by SOIR was interpreted by many as withdrawal from work in Amman, the board of SOIR declared their intentions to remain and continue to provide services in Amman.

In 1997 a new director was appointed to carry out the task of establishing a community based service as an alternative to the previous services at Sweileh. The person appointed had previously held the post of accountant and had participated in the task of reviewing the situation and developing the idea of the alternatives to be developed. The tasks being carried out at Sweileh could continue parallel to the starting of the integration project.

The task for the project was therefore to develop new disability services in Amman. Hand in hand with this, the residential services were closed. The consultant from Sweden, who previously had been involved in the analysis of the centre, continued to work on a consultative basis from Sweden, with regular visits to Amman.

2

DISABILITY REFORM

The years from the opening of the residential home in Amman in the 1970:s to its closure in the middle of the 1990:s, was a period of intense reform with regard to services to persons with intellectual disability. A transition was taking place from institutionally to community based services. On a national level this change can be seen in both Jordan and Sweden. On a global level, the work of United Nations illustrates this transition.

JORDAN

Jordan is a young nation which has striven towards modernisation since the 1950:s. An analysis of conditions for the development of the country (bint Talal, 2004) regards its geographical location as a factor which has become a hinder for change. Jordan is situated among a number of Arab states and has therefore been involved in, and closely related with, some of the conflicts in this area of the world. Jordan was for example involved in the 1967 Arab-Israeli conflict when it lost part of its territory. As a neighbouring country it was affected by the Iraq-Iran war during the 1980:s and in the Gulf war of 1991. At present the war in Iraq also has consequences for the life in Jordan.

There are also a number of internal factors, for example limited natural resources, which have made Jordan reliant on economic support from outside. At one time the Arab countries contributed, while latterly economic support has tended to come from the Western world. These are some conditions which have contributed to the difficulties of establishing modern social services.

During the 1950:s early steps were taken to organise a social sector. A Ministry of Social Affairs was established and a number of NGO:s, local and international, were formed to deliver services. During the 1960:s the first NGO:s for services to the disabled were set up, SOIR being one of the early contributors in 1967. These NGO:s provided services by building institutions (Turmusani 2003). This was natural as it was the common way of delivering disability services at that time.

The United Nations Year of the Disabled in 1981 furthered the development of disability services. Concerned people started discussions aiming at achieving legislation to protect the rights of persons with a disability. These efforts soon led to a bill being put forward by the Ministry of Social Development which became the 1989 Provisional Law for the Welfare of Disabled People. Further amendments were made and in 1993 the Law for the Welfare of Disabled Persons (1993) was passed.

A number of organisations make up the social sector involved with the delivery of disability services in the spirit of the law. One of these is the General Union of Voluntary Societies (GUVS), a body which coordinates the work of a substantial number of NGO:s in Jordan. The Jordanian Hashemite Fund for Human Development is an organisation at the forefront of disability work in Jordan. A number of Ministries, the emphasis being on the Ministry of Social Development, have a responsibility for realising the aspirations set out in the law. These organisations, together with representatives of disabled persons, are headed by the National Council for the Welfare of Disabled People, a body with the task of implementing the law. Its content has been characterised by Turmusani (2003, p.79):

“This law is based on the philosophy of the Hashemite Kingdom of Jordan with regard to its disabled citizens and springs forth from Arab-Islamic values, the Jordanian Constitution, the National Charter, the Laws governing education and higher education, the World Declaration of Human Rights, and the International Declaration on Disabled Persons”

At the same time his view is that large parts of the law is unenforced (Turmusani, 2003, p.83):

“Although disability legislation in Jordan emphasises many rights for disabled people in line with western legislation, it clearly lacks specific mechanisms for implementation as well as necessary political will.”

He also points to the lack of economic resources to implement the rights of the law.

Community based rehabilitation (CBR) is an expression for an approach towards disability, based on the acceptance of the idea brought forward by United Nations. Persons with a disability are in this perspective seen as members of society and should thereby be able to receive their support in the community to which they belong, just like other members of society. The task is to set up non-institutional and local services which meet the needs of persons of that community. CBR can therefore be seen as a means of furthering disability services which express development in a new and desirable direction.

There are several expressions for the development of CBR in Jordan. A seminar in Amman (JSMA 1991) argued at an early stage for the introduction of CBR. Apart from presenting the concept examples were given of disability services having used this approach in Jordan. Turmusani (2003) in his overview of services available in Jordan refers to several examples of projects working within the framework of CBR.

The National Council for the Welfare of the Disabled has a CBR Committee. When presenting its view on disability services the committee summed it up by saying that

“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” (bin Raad, 1999, p.16).

Apart from introducing the concept, the committee in this article provides nine examples of CBR programmes in Jordan, run during the years 1982-1996.

UNITED NATIONS

The basis for a new perspective on disability can be found in the United Nations Declaration of Human Rights. This argues for the right for all people to experience "... equal and inalienable rights of human dignity and freedom" (United Nations, 1948). Another aspect of the perspective found in the United Nations Declaration of the Rights of the Child "... proclaims the rights of the physically, mentally or socially handicapped child to special treatment, education and care required by his particular condition" (United Nations, 1959).

These declarations have become the basis for positions by international bodies on the issue of disability. Inclusion International, a worldwide association representing national organizations promoting the interests of persons with intellectual disability, published its "Declaration of general and special rights of the mentally retarded" in the 1960:s (ILSMH, 1968). In seven Articles attention is given to the consequences of these UN positions for the person with intellectual disability. Of particular interest is the thought expressed in Article V, which states "the right to live with his own family ... to participate in all aspects of community life". It is concluded by focussing on the right of the person with an intellectual disability to be met with respect. Thereby the declaration expresses in 1968 a new vision for the coming years.

The first step of UN to clarify its view on persons with intellectual disability came with the "Declaration on the Rights of Mentally Retarded Persons" (United Nations, 1971). This is followed in 1975 by the "Declaration on the rights of disabled persons" (United Nations, 1975). In thirteen points this clarifies the position of UN on the rights which are the consequences of the Declaration of Human Rights and of the work of other UN bodies.

The 1981 United Nations "Year of the disabled" stands out as the point in time when this global body gave full recognition to the issue of disability, based on these declarations. The motto of this year, full rights and participation, provided the perspective out of which one was to view the disability issue.

This year also accelerated the work of UN aimed at promoting the welfare of persons with a disability. This led to the United Nations Standard Rules on the Equalization of Opportunities for People with Disabilities (United Nations, 1993). The Standard Rules can be seen as a major step forward in forming a strategy to promote the lives of people with a disability in a country. The Standard Rules set out 22 points intended to cover undertakings which should lead to better lives for persons with a disability.

Equality is the concept which forms the value basis for these Standard Rules. Equal participation, a life lived like others, together with others, is the goal to be striven for in everyday life. This can be achieved if society is organized in such a way that an equalization of opportunities can become a reality. A community has the task of extending its functions and services, to members of that community, irrespective of disability. Equal rights and obligations of persons with disability is the value basis which provides the logic of an equality approach to disability.

The UN task regarding disability has been intensified further and given an even clearer direction, through the frame of reference based on the concept of human rights. Consequently the UN Commissioner for Human Rights and its office are responsible for the coordination of this work. An analysis of the meaning of the human rights approach was carried out at an early stage and resulted in the report "Human Rights and Disability: The current use and future potential of United Nations human rights instruments in the context of disability" (Quinn and Deener, 2002).

Currently it is not only the Declaration of Human Rights, but a number of other declarations concerning the human rights of people, which have become the platform for disability activities. Some of these are the "1965 International Convention on the Elimination of All Forms of Racial Discrimination", the "1979 Convention on the Elimination of All Forms of Discrimination against Women" and the "1984 Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment". The present situation and activities have had more than a 50 year period to mature. The tasks have been of varying character but with the common intent to develop a view on the disability issue as a question of human rights.

SWEDEN

The introduction of the welfare society during the 1940:s created conditions for a new idea on disability. The national ambition to guarantee the welfare of the public led to the development of new modern social services. These should provide people with the prerequisites for a good life, even if problems do constitute a hinder. The disability movement of the time raised the issue as to whether persons with a disability were to be part of this welfare society or not. Were they to receive its benefits, or were they to be referred to the care of the traditional residential institutions of the time? The debate concluded, in 1946, with an agreement that persons with a disability also had the right to use public welfare services. At the same time the old residential institutions were criticized and seen as unsuitable in a modern society. This became the starting point for the development towards community based services and the dissolution of institutions (Ericsson, K., 2002).

In this debate a new socio-political idea was formulated. The right of persons with a disability to use the public welfare services was seen as an organizational choice. The hope was that by using these services persons should gain the opportunity to live the normal life lived by others in the community to which they belonged. Behind this view concerning the type of service, and the everyday life offered to these persons, was a recognition of them as members of society. Their use of public welfare services was seen as a democratic right. In this way persons with a disability were recognized as citizens. This new idea was called the normalization principle and became a tool in the Swedish disability reform which was to follow (Ericsson, K., 2002).

During more than 50 years a dramatic change has occurred. Through a series of social innovations it has become possible to channel disability services to persons so that they will be able to live in the community to which they belong, and to be

included there. Community based services have been developed, and residential institutions have been closed (Ericsson, K., 2005b).

Through these new services family support has made it possible for children with a disability to grow up together with their family. Educational support has given children the opportunity to go to school while living at home and their schools are the same as those used by other children. When a person starts life as an adult he moves out of his family home. For a life on one's own a home with support is required. Could he not acquire employment day services are necessary.

Any house in a community can be used as a home, but any person with a disability can not live in any house! A choice has to be made to find a suitable house. A factor influencing this is the number of persons who will live together. Someone may want to live on his own or he may live in a small group. But a physical building is not a home for persons with a disability. They need support from others to live there and therefore a staff-group needs to be available. The number of staff, and their profession and training must be related to the needs of persons. However, for a house to become a home requires the experience of privacy, being able to live a life of one's own liking (Ericsson, K., 2005a).

Some, but not all, will gain employment. Those who are in need of support during daytime will receive day-services outside their home. During the five working days of the week they participate in activities which provide them with an active life. An organisation for day-services has responsibility for organising and offering relevant activities. For these to function as a service they need to be purposeful, that is, they must assure the persons a good life. Purposefulness is a relation between a person and his need for support, and the chosen activity, not something intrinsic in the activity itself. As there are persons with a wide variety of needs this will result in a wide variety of activities (Ericsson, K. et al, 2004).

The home and the location for daily activities become the platform for participation in community life. For everyday life a person also needs to shop, and to take part in leisure and cultural activities. He will also have social contacts with family and friends, either by visiting them or them visiting him. For his well-being he needs to have access to the public welfare services of the local community. For this participation to become a reality requires that the person has the assistance of others, be it staff, family or friends.

These community based services became recognised during the early 1970:s. In the beginning they primarily met the needs of persons with a mild disability. Gradually they have extended their capability of meeting the needs of those with a more severe disability and become a qualified service for everyone.

Hand in hand with the development of community based services with more extensive support, institutionally based services were being questioned. The institution, with many wards, each with large groups of persons, were found to offer a standard of living which was no longer seen as acceptable. The institution was also a service which did not contribute to the new ideals for disability services expressed as the right to live a normal life under more democratic conditions. This started a

process of closure of residential institutions in Sweden which ended in year 2000, when they were dissolved by law (Ericsson, K., 2002).

During institutional closure it is easy to let organisational matters dominate the task. Disability services exist, however, in order to provide support to persons. The consequence is that the core issue during institutional closure consists of assisting persons to leave the institution and through the creation of community based services provide a better life outside the institution. The key to institutional closure lies therefore in the establishment of community based services, that is, the provision of new homes and the setting up of daily activities for these persons. Only when these are available can the persons move. Depending on the size of the institution it will take some years to establish these alternatives.

With this task expressed as that of setting up new and better lives outside the institution, an important part of this process starts first after persons have left the institution. A new life, in a new place, requires the provision of support to the person in order for them to become accustomed to their new home, activities and the neighbourhood. Staff, family and others need to be involved in the development of the quality of life the person is to experience.

One of the motives for the new socio-political idea of the 1940:s had been the right of persons with a disability to use public welfare services. When this had become a reality special disability services at national level were no longer necessary. The development of community based services and the dissolution of institutions which has followed was carried out by a special organisation for persons with intellectual disability. This special regional organisation had existed since the establishment of institutions during the 19th century. It was not until the stipulations of the social legislation during the 1980:s and the 1990:s that general public welfare services were also made responsible for persons with intellectual disability and that the special services for this group could be dissolved. For the first time the social services of the local municipality were designated as responsible for providing support during the everyday life of these persons.

COMMENTS

The work of UN illustrates the development of a new perspective on the lives of persons with intellectual disability. This has covered the period since the second half of the 1940:s up until today. This has resulted in a new perspective on the quality of the lives of this group of persons, and has led to a number of UN declarations of human rights, equality becoming the value-basis for their position. For those responsible for disability legislation and for the running of services, the work of UN can be characterized as a frame-work which sums up the global experiences of persons and organisations, regarding what is seen as a desirable life.

Development in Sweden towards a citizenship perspective also began during the second half of the 1940:s. Human rights and democracy were the expressions used to clarify the value basis for the new socio-political idea suggested at the time. The development since then can be seen as an attempt in the realization of this frame of reference. Disability services seen as necessary to effectuate this new idea have

been developed, this leading to services in the community where others live. Consequently the residential institutions, seen as not fulfilling these values of human rights, have been closed. The special services still existing illustrate, however, the complexity of the process of finding services which ensure the vision of human rights.

In Jordan, in spite of the difficulties of establishing a social sector, the work of UN, especially during the year of the disabled in 1981, has stimulated legislation which expresses the global frame of reference, as well as the values of Islam. This has also led to substantial steps been taken to realise this legislation. A series of disability projects have been launched implementing the method of CBR, community based rehabilitation.

The theme of this chapter has been termed disability reform. The intention has not been to maintain that reform has taken place, but to point to tendencies of ongoing reform in services for persons with intellectual disability. At a global level this is a major human problem as many persons live under unacceptable conditions. However, during this 50 year period, change has taken place globally and in several nations and a new direction has been given to activities in this field. New services have also been developed but not however to the extent that one can argue that needs are being met.

These international developments had consequences for the future of the centre in Sweileh. The institution had come to a point when a choice had to be made about its future. Was it to be adjusted to meet the new demands, those of persons with a severe disability, or were new disability services to be located to the community, thereby giving persons the opportunity to leave the institution? Awareness of the ongoing disability reforms and their further development made the choice of community based services seem natural.

This situation can be said to have similarities with the one of 1967 when SOIR was invited by the Ministry of Social Affairs to set up disability services in Jordan. They did so and they brought new ideas to Jordan. This time, 30 years later, they also implemented new ideas when they organised new services in Amman. These projects were based on an acceptance of and the realisation of the ideas of the inclusion of persons with intellectual disability into everyday life, as presented in national legislation and in the accepted global frame-work.

3

ESTABLISHING NEW SERVICES

To dissolve the Sweileh centre, new services had to be developed to replace the disability services previously provided there. Initially established as a care-home the centre had become mainly a place for education and sheltered work. It was also a home for a small group of adults. The persons then at the centre would gradually be able to leave concurrently with the establishment of alternative external services being provided. Establishing these new services therefore became the key task for SOIR.

TRANSITION OF SERVICES

After the decision by the SOIR board to close its centre in Sweileh a project group was established to carry out the task. Locally the project was headed by the existing director of the centre, a person with both administrative and financial experience. The SOIR consultant from Sweden who previously had carried out the studies of the institution, was appointed in a consultative role as project co-ordinator and advisor to the director. Her task was carried out on a visiting basis with three visits per year, initially appointed on a three year agreement, commencing in 1997. Regular contact was also held by e-mail and telephone. Physically the project was located at the Sweileh centre, existing office premises being made available. When appropriate, existing staff members for example teaching staff and the specialist staff, participated in the project.

As the closure of a residential institution had not previously taken place in Jordan, one started anew. With only limited experiences of community based disability services in Jordan, new models had to be formed. This complex task was therefore a challenge for the organisation and came to be known as the Amman Projects.

Several categories of people are affected by a change of this kind. Persons with disability have to leave the institution where they have received their services and instead avail of alternatives provided in new locations. They will therefore have to adapt to new conditions in the community. Families need to be informed and become involved during such a transition. Staff at the centre will have to leave their jobs as the institution will no longer exist. Some may find comparable jobs in the new services, while others may have to seek new employment. Many may have reached the age which will entitle them to their pension. Delivering community based services demands new methods compared to those at the institution. Schools

and universities providing programmes for staff need therefore to be informed and prepared to provide alternative training suitable for these new tasks.

As the new services will be located to places where other activities take place, for example shopping areas, mosques and community services, the general public will come into contact with persons with a disability and their staff. Preparation needs to be made to facilitate constructive contacts. Representatives of public welfare services, such as chemists, dentists and health centres, will also meet the needs of persons whom they previously have not known as their customers and patients. Some of these may have previous experiences of running disability services while others are meeting the needs of these persons for the first time. A task for the Amman Projects was therefore to establish a relationship with them and to introduce them to the needs of these persons.

Disability services are controlled by disability legislation and by formal regulations administered by state ministries who may also have a financial responsibility for some of the disability services. A task during this process of change must therefore include close contacts and new relationships with such bodies.

The transition from a residential institution to community based services was not a known phenomena in Jordan. One needed to be prepared that the public would therefore ask questions and expect to be informed. Radio, TV and press have a role in raising the awareness of the needs of persons with intellectual disability and to inform about the progress of new services. The Amman Projects had a responsibility to provide answers to such questions.

Towards a community based approach

During the onset of a project like this there is a need for a direction of development, a "roadmap". To produce this the goals to be achieved, both long-term and short-term, need to be formulated in order to facilitate the process of how to get there. Information for creating such a roadmap should be collected from sources relevant for the delivery of such services. From the beginning there were a number of documents which provided this direction. These were summarized and formulated as a community based approach and became the frame of reference for the task ahead.

On the wall of the entrance hall of Sweileh centre there was a document, in English and Arabic, indicating the values held by SOIR. This was the "Declaration of general and special rights of the mentally retarded" expressed by the international organisation representing groups of people concerned with the well-being of persons with an intellectual disability. The character of this declaration is best understood by its first article: "The mentally retarded person has the same basic right as other citizens of the same country and same age". Stressing the rights of persons has become a part of the frame of reference for the Amman Projects.

In the disability law of a country rules are given regarding the delivery of services. Goals are formulated and services which will be offered to persons are identified. The rules regulating the provision of services are usually expressed in a law or in regulations stating how to implement the law. At the time when a law is formulated it is not possible that it be realised immediately. The bodies which have

been given the responsibility of providing services must set them up in adequate numbers and offer them to those who have a right to avail of them. The disability law of Jordan was a given prerequisite which in this situation could now be adhered to. The values and goals of the "Law for the welfare of the disabled persons" (1993) are expressed in Article 3. The primary right is expressed as "The right of disabled persons to be integrated into the general life of the society". The community based approach of the Amman Projects therefore rests on the disability law of Jordan.

During the early stage of the Amman Projects the SOIR consultant (Ericsson, P., 1994a, 1994b) presented a frame of reference for a direction for the development of services. This had a background in the Swedish disability reform. At the time there were current Swedish experiences of setting up community based services and of the dissolving of residential institutions. SOIR, as a Swedish NGO, could not refrain from relying on experiences gained during this transition of services. These experiences were the basis for the decision by the board of SOIR to move towards integrated services in the communities of Amman. More detailed steps towards realising these services were then taken in a series of memos (Ericsson, P. 1994a, 1994b, 1994c, 1995, 1996). These had been formulated together with people at the Sweileh centre and discussed with staff and families during a series of meetings arranged to prepare for future developments. An aspect which came to be of particular importance was the recognition of the family and the home community of persons, when localising future services and finding suitable service partners.

In 1997 SOIR arranged a workshop to further develop its disability policy for work in Amman. Representatives for a broad range of organisations with which SOIR was to cooperate were present. Introductions were given by MOSD (Ministry of Social Development), UNRWA and SOIR. The representative of MOSD presented a paper (Massoud, 1997) with a broad and ambitious programme as to how to meet the needs of persons with disability. In a number of areas strategies were proposed e.g. regarding prevention, early intervention, assessment and diagnosis, integration, family counselling and professional training.

In this presentation (Massoud, 1997) community based rehabilitation was seen as the way to contribute to growth and integration of persons:

"We have to look at CBR as a main element of social policy for any community to enhance the rights of the disabled to live in their local communities and to have the same opportunities available to any member in the community and to participate in social, educational, religious, economical and political activities."

Three objectives were formulated to realise this ambition. This form of rehabilitation should aim for development of persons, should utilise the community resources and should strive for integration into community. A set of procedures were also presented to facilitate working in this way.

The representative of UNRWA (Ramadan, 1997) took the equalisation of opportunities, "the way of putting the general rule for making society available for all", a concept from the UN Standard Rules (United Nations, 1993) as a starting point. The four principles seen as necessary to achieve this were a) "handicapped shall stay in their local community and participate in general life", b) "handicapped

shall participate in making decisions especially in their concerned matters”, c) “they shall get the help they need in education, medical care and social services” and d) “take their needs into consideration in planning, to be able to have an active role in developing local communities.” The consequences of these principles were also discussed by the workshop.

The recommendations of the workshop recognised the contributions of SOIR and encouraged the organisation to continue its work as “a pioneer”. Stress was put on the need for activities which led to documentation of experiences and to them being spread to other bodies in Jordan, private organisations, universities and ministries, in order to make them public.

Plan of Action

Information from these sources contributed to a Plan of Action (Individuell Människohjälp 1997) in which SOIR in Sweden decided on the direction for the Amman Projects. In this document they recognised the goals set by the disability law of Jordan and those expressed by the 1997 workshop. CBR, as expressed by the three UN organisations ILO, UNESCO and WHO (1994) were seen as the model for organising new disability services which were to be alternatives to the institution. The Plan of Action gave six objectives for the SOIR work, each with a number of activities by which they would be realised.

Objective 1, “secure leadership for the project and secure relations with the Government and NGOs in the integration process”, pointed to the necessity to work on a broad front relating to those in Amman with contributions to a successful project.

Objective 2, “integration and dissemination of the pre-school and training school to locations and facilities in the communities from which the children with intellectual handicap come”, recognised the importance of the fact that a child belongs to his own family and that he needs his support in his own home community.

Objective 3, “to find suitable opportunities for employment for the youth and adult persons [at] present attending vocational school and workshop in Sweileh, or seek possibilities for starting a sheltered workshop in the community”, gave attention to the needs of adults who would need some form of daily activity or employment after leaving the services of Sweileh. As persons already lived in their family homes, the issue of homes with support were not a task of SOIR.

Objective 4, which concerned 6 adult men and women who lived at the Sweileh centre, stressed the task “to find a suitable residence out in the society for those at the group home at Sweileh”.

Objective 5, recognising the administrative tasks of the Amman Projects, pointed to the responsibility of local bodies for the provision of services to persons: “by the year 2000 reduce SOIR’s involvement in the rehabilitation of the persons at the pre-school, training-school, vocational training and sheltered workshop and find alternative financial support for services and education to the present group attending services at Sweileh”.

Objective 6 of this plan of action recognised SOIR's responsibility for staff in this process of transition: "to work for different solutions for the staff now employed at SOIR/Sweileh, and to try to arrange work opportunities with other organizations".

These objectives and the activities identified for each of them, defined the working programme for the Amman Project.

Home communities of persons

By the time of commencing the Amman Projects the persons no longer lived at Sweileh centre, but received day services either in one of three forms of education or in the sheltered workshop. There was one exception however, this being the 6 young adults who still lived at the centre, this group having no family as they had been abandoned in early childhood. Apart from this group all previous residents now lived in their family homes.

One aspect of the community based approach was the recognition of the importance of the families of persons. This meant that the home community had to be taken into account when planning for new services. Localisation of services closer to the homes of persons reduced distances between the home and the service. In addition to facilitating communication between the home and services was the positive aspect that the person and the family had previous knowledge of the area.

In order to plan where to localise services it became necessary to identify the home communities of the persons still receiving their services at the Sweileh centre. In January of 1997 a study was carried out to describe the home communities of all the persons receiving services (abu Jabes, 1997a).

As seen from table 3:1, 8 areas were identified as home communities of persons. The distribution of persons over these areas are similar, with the largest group coming from Sweileh.

Table 3:1. Home communities in Amman of persons receiving services at Sweileh centre in 1997.

Areas	Preschool	Training school	Vocational school	Workshop	Sum/R
Wehdat / Musdar	6	1	5	4	16
Ashrafieh Jofeh / Taj	6	-	2	4	12
Nazal / Akhdar	9	3	3	1	16
Naser / Hashimi	6	2	4	2	14
Nuza / Hussein	10	1	3	4	18
Sweileh	6	7	5	3	21
Baqaa	5	5	1	-	11
Jabal Amman / Wadiseer	4	-	2	3	9
Other	4	1	1	3	9
SUM/C	56	20	26	24	126

Local disability services

In line with the ambition of applying a community based approach in the development of alternative services it was of interest to identify existing local disability organisations. The intention was to find those who had existing experiences of working with persons in the community and to exchange experiences and knowledge with them. To find out more about existing services a study was carried out (Jaber 1994). All organisations concerned for persons with intellectual disability in Jordan were identified and described in relevant aspects. The results for the governate of Amman is presented here, these being the potential partners for coming cooperation.

The study showed that in Amman in 1994, there were 22 organisations which offered their services to persons with intellectual disability. Of these 2 were run by a government body while 9 were private societies. Other associations, for example NGOs and charitable organisations, were responsible for 11 services. On this occasion those run by UNRWA were not taken into account. The services available were primarily on a daily basis, providing support to 1.015 persons, while 160 persons were receiving boarding facilities.

These 22 organisations provided services for persons with varying degrees of disability, the categories mild, moderate and severe being used in this study. Multi-handicapped was also a category used by one organisation without specification as to the degree of disability. Some services gave support to several of these categories. Persons with a mild disability were catered for by 20 organisations, while 16 service providers took responsibility for those with a moderate disability. Only 3 organisations provided care for persons with a severe disability and 1 for those with multiple disabilities.

These organisations offered their services to different age-groups. In the survey pre-school was defined as ages 1-3 years, school-age 4-20 years, while adults were those over 20 years of age. Of these organisations 1 offered services to pre-school children and 19 to children of school-age. Services to adults were provided by 3 organisations.

The financing of these organisations was arranged in several ways. Government bodies were responsible for 7 organisations and charitable associations contributed to 3 of the services. Fees were the source of income for 10 organisations and 4 received donations to run their services. There were therefore several sources from which an organisation could receive funding.

After having identified these disability services the person responsible for carrying out the study took contact with a number of organisations to discuss possible interest for cooperation with SOIR. This gave rise not only to a general discussion regarding possible future activities, but also the special issue of providing for the needs of those at the centre who were mainly persons with a severe disability.

In the report from the study the major conclusion was that "many associations and organisations have the will to work with persons with severe mental retardation, and have the will to cooperate with SOIR in this field." This could be

achieved, they said, by extending existing buildings. But it was pointed out that there was a need for qualified and trained staff if this was to become a reality. These organisations also explained that they were in need of financial support to take on such a responsibility. But there were also organisations which made clear that their policy was not to work with persons with a severe disability.

Raising awareness

A community based approach requires awareness and is therefore an important issue if such a project is to be understood and to be given a positive reception in the community. A basic concept is the development of good relations to persons and organisations in the neighbourhood where a project is being introduced. Positive attitudes from local individuals are necessary in order to be welcomed into an area. An openness from the public, from businesses and organisations in the locality is something to strive for, as local resources are essential for such a project. Welfare services, such as those providing for social and health issues need to be informed about a new disability service and the persons who will avail of it. Other relevant organisations which need to understand and support such a project include both ministries and other disability organisations. As the community based approach is often regarded by those involved in disability issues as something new it is important that they understand this way of working.

In the monthly reports from SOIR Amman to SOIR Sweden, one can find a catalogue of activities which have taken place during this period of the project. Some of these naturally refer to contacts within the SOIR organisation. There is however a category of activities which reflect the relationship between the Amman Projects and various aspects of Jordanian society. From these monthly reports it is clear that during this period there has been a very active participation in community life. One category are visits made by SOIR as part of the programme to establish contacts with other services in Jordan and to become informed about other ongoing developments. SOIR also received a large number of visits, not only from Amman but also from other parts of Jordan and from countries in the Middle East. Naturally several visits were made from Sweden. It can be seen that visitors have shown great interest in the new services and experiences made there.

Another category of activities concerned with the development of a greater awareness are the number of lectures made by visitors to SOIR as part of an ongoing capacity building programme. Likewise SOIR staff have visited other services, schools and universities in Amman and other parts of Jordan. Lectures concerning experiences made in the new services have been held and SOIR staff have regularly participated in conferences and meetings on these subjects. The aim and intention has been to describe and share experiences from delivering disability services emanating from the community based approach.

During these years SOIR has also had intensive contacts with organisations and formal bodies in Jordan as it has been necessary to find and establish links with potential partners with whom to run new services. As such partnerships require government approval parallel relationships have been established with appropriate ministries, with whom close cooperation has been maintained. As many disability

services in Jordan are run by private NGO:s they have also been an important source for an exchange of experiences in the disability field.

A most important source of support has also come from representatives of the Royal House.

In addition to the formal relationships necessary for carrying out the task there are also important informal connections and activities in relation to a local community. Good relationships with neighbours need to be established and maintained. Experience has shown the importance and value of support from the local community. Examples of such support is the local sale of products from a day activity centre for adults, likewise the participation of the persons from the centre in locally arranged public bazaars. It has also been experienced that a local business has contributed to the work on an informal basis, for example, a bakery which contributed bread to a project in the neighbourhood.

A number of work-shops have been held to inform and to keep contact with persons and organisations with whom the work of SOIR is related. Such workshops provide a forum where presentations can be made not only from SOIR but also from other organisations. The discussions at these workshops are occasions when ideas and strategies are presented and developed further. A workshop which played an important role in the Amman Projects was held on the initiative of the Ministry of Social Development when they presented their views on a desirable direction for development and when the course of work for SOIR was discussed.

Princess Rahma University College of Al Balqa Applied University has contributed through a study regarding the views of families, staff and public (abu Jaber, et al, 2002) . This project began with a workshop at which the Amman Projects were presented. Another example of a workshop was one at which experiences gained from the integration of school-children into the Khansa school in Sweileh were presented. The Ministry of Education later held a workshop with representatives from the schools of Amman to present new and current experiences and knowledge. A number of work-shops have also been held when the staff of SOIR communicate their experiences and develop the methods being used in the projects.

Major conferences have also been held to give wider attention, in Jordan and internationally, to the Amman Projects. In 1998 SOIR celebrated its 30 year presence in Jordan with a conference. The work had just started so there was limited information available. The goals of the project were however presented. The main contribution came from a number of international experts who shared present knowledge on a number of issues relevant for SOIR (Ericsson, K., 1998). A second conference was held in 2000 when initial experiences from the Amman Projects were presented. Many of these attending came from neighbouring Arab countries.

After having summarized experiences from the activities presented in the monthly reports and from workshops and conferences, the conclusion is clear. To run community based services it is necessary to organize a social network and to maintain an active contact between all its members. This structure and these relationships should be seen as a necessity, not an inconvenience.

“Knocking doors”

Based on the ambition of finding and establishing relationships in a local community, with local resources, it is necessary to take an active role in the pursuit of finding persons, activities and organisations which are willing to contribute to the setting up and the delivery of services. Persons or companies in a neighbourhood may be able to assist personally, or through their business connections. Cultural, religious or commercial activities which take place in the area can also provide an opportunity to create an awareness in the neighbourhood of the fact that disability services are being provided locally. In this manner new partners may be found which can contribute to the development of these disability services.

During the Amman Projects “knocking doors” became an expression which illustrated the approach taken to identify possible local resources. Essentially this required an active approach to the task. One had to look for doors, physical as well as mental, which could lead to a possibility for cooperation. Having found a door one had to knock!

Not always the door was opened. If it was opened one could find persons, attitudes or activities which did not accept the idea of being involved in matters such as disability services. In such a case it was just to move on!

It was also possible to knock the door and find someone willing to co-operate, but what was offered did not meet the needs or expectations of the project. For example expectations on a profit-making scheme were not compatible with the project. In such a case it was also a matter of trying another door.

But occasions did also occur when after knocking the door one met persons, activities and attitudes which were welcoming and desirable. Such contacts could lead to a positive relationship and further cooperation. Several of the partners in the new services set up by SOIR had come about in this way. Therefore one came to regard this “knocking of doors” process as an important part of the community based approach.

Partners and agreements

Initially the Sweileh care-home implied a total Swedish commitment. Swedish funds were behind its establishment and the key staff were originally from Sweden. Gradually a Jordanisation had taken place and financial support from Jordanian sources contributed to an increasing extent. Gradually the majority of the staff could be recruited locally. Setting up community based services was yet another step in the direction of Jordanisation. This required the recruitment of Jordanian partners willing to take responsibility for the new services. SOIR still had the main financial responsibility for the new services but the Jordanian share of funding was also to increase. The basis for these new services was an agreement between SOIR and the Jordanian partners with the intent of a gradual transfer of total responsibility.

An agreement regulated the role of SOIR and the local partner for an agreed number of years. The relevant government department was also participant in this three party agreement. The key issue was of course the service to be delivered and

the number of persons who should receive support. SOIR retained responsibility for the manager of the new service but other staff members became the responsibility of the partner. An agreement was made between the parties which could vary in duration, with the possibility of extension if necessary. The general length was however a three year period. A gradual shift of economic responsibility was to occur during this period, SOIR reducing its commitment as the counterpart increased its financial responsibility. The agreement could be prolonged if the partners found this desirable. The agreement was to be renewed on an annual basis and in collaboration with the responsible ministry.

The process of “knocking doors” led to SOIR, through its director in Amman, finding a number of partners willing to take on the responsibility for the new services. This was a long and demanding task but for SOIR it led to many constructive and successful relationships. The particular partners and the agreements will be described in chapters to come.

Private organisations were among those who became partners willing to take on a responsibility for support to these persons. The centre in Quosoor is an example of such a Charitable Society which was initially founded to provide support to girls with disabilities. They extended their work to include girls and women who had previously attended the Sweileh centre.

As many of the persons attending the Sweileh centre lived in refugee camps this became an important factor when planning the new services. As UNRWA was responsible for these camps and they were also familiar with running social services they became a natural partner for some of the new services. UNRWA was the formal body with whom an agreement was made, together with the local committee in the camp which was responsible for the day to day running of the centre at a local level.

As a Muslim one is committed to donating alms for distribution to the needy. In addition to special donations made during Ramadan, a certain percentage is also paid on a regular basis. The terms of these commitments are regulated by the Department of Islamic Affairs. These payments can be made to the local Zakat Committee associated with the local mosque. These in turn are distributed by the Committee to needy causes and for the welfare of people attending the mosque. The beneficiary of this support is defined in the Holy Koran. Traditionally persons with intellectual disability have not been seen as recipients of these donations. As a consequence of the co-operation which had been established between SOIR and one local Zakat committee, which was providing a centre for children, the issue of Zakat funding became relevant. In partnership between the SOIR director and the Zakat committee the Department of Islamic Affairs was approached and discussions led to an agreement that persons with a disability be regarded as natural receivers of financial support from the Zakat fund. Following this several other Zakat committees in Amman have become partners in establishing new services for persons with intellectual disability and the organisation continues to show interest in providing such services.

Children with a disability in Jordan have by law (1993) the right to education but this has not been generally adhered to in real life. As children in one of the

school classes of SOIR lived in Sweileh village, attempts were made to acquire facilities for them to attend the local school. This approach was welcomed by the school, the head-mistress, teachers and pupils expressing an optimistic view as to the possibility of establishing classes for these children. The SOIR maintenance team assisted in making some necessary alterations to facilitate for the children with wheel chairs, providing entrance ramps and adjustments to the toilet facilities. This example has proved to be successful and as the Ministry of Education is responsible, they are now one of the partners in the provision of services for children. The experience gained from the project at the Sweileh local school has led to further agreements with other schools in Amman city.

The Amman Projects

When looking at the task carried out by SOIR in Amman one must recognise that it is complex. One way of providing structure to the work carried out is to see it as consisting of a series of projects, each having a goal which was to be fulfilled. Those presented here are the ones which can be identified from the beginning of the period, with the analysis of the care-home, to the present final report.

Apart from the 11 projects mentioned below the task of establishing the new services is also seen as a number of projects. For SOIR each was a project as long as one was involved in the task of establishing the new service. After the agreement set up between SOIR and the partner, it became a new centre which was run by the partner. A number of projects were therefore carried out to establish the centres for education of children, for daily activities of adults and for homes for some persons.

The tasks naturally do not end here but continue and most probably there will be more projects to come.

The Amman Projects, from the analysis of the care-home to this final report, are presented here with regard to the task to be carried out and the person responsible for the project. The person concerned with the dissolving of the Sweileh centre and the establishing of new services has been the SOIR representative in Amman, director Zeinat Abu Shanab. Psychologist Patricia Ericsson has been the SOIR consultant in this task. Director Abed Jaber was head of the Sweileh centre prior to the period of transition. Dr Majed Abu Jaber was at the time Dean of Princess Rahma University College, a part of Al Balqa Applied University. Dr Kent Ericsson is a researcher into issues of disability and support currently at Uppsala University, Sweden.

Analysis of the Sweileh Centre (Patricia Ericsson): When SOIR in Sweden decided to investigate staff dissatisfaction with the running of the Sweileh centre, psychologist Patricia Ericsson was appointed as a consultant to look into conditions at the centre. This task resulted in a series of memos. The early ones became the basis for a decision by the board of SOIR on the future of the Sweileh centre, while some later memos clarified the policy needed to establish new services.

Local Disability Services (Abed Jaber): A consequence of a community based approach is that welfare services used by the public and others with disability should, as far as possible, also be available to those then attending Sweileh. A study

therefore looked into which disability services were available to persons with an intellectual disability in the communities of Amman.

Home Communities of Persons (Issa Abu Jabes): With this new policy it became apparent that families should have a role in the lives of their children, young and old, not being cut off from the life of their family member. A consequence of this was that disability services should be localised in or as close as possible to the home community of a person. This led to a study to describe the home communities of persons currently receiving support from SOIR.

Disability and Need for Support of Persons (Issa Abu Jabes 1997): A survey was carried out to describe the current needs of those then attending Sweileh Centre, the intention being to have a baseline for future possible follow up study.

Closing Sweileh Centre (Zeinat Abu Shanab): Based on the ambition to develop disability services outside the institution, Sweileh centre had to be closed. This not only concerned persons with disability but also staff. They had to find new jobs or be retired. An issue in this project was also the future use of the institution and grounds.

Awareness (Zeinat Abu Shanab): To succeed with community based services people and organisations in Amman needed to be informed about the intention with the new way of delivering support. A number of activities, from informal contacts with relevant people to large conferences with concerned organisations, were therefore needed to inform and involve others. Contact with the media was also an important factor throughout the project years.

Education for Children (Zeinat Abu Shanab): As special education was the basic disability service provided by SOIR from the very beginning, new forms of non-institutional education had to be developed.

Daily Activities for Adults (Zeinat Abu Shanab): As a group participated in daily activities at the Sweileh centre, alternative opportunities had to be provided in other areas of Amman.

Follow up of Persons who moved to Employment in Open Market (Issa Abu Jabes): Over the years one had been successful in finding employment in the open market for persons who moved from Sweileh centre. As part of the transition of services a follow up of persons was carried out to identify the success of this form of daily activity.

Homes for Adults (Zeinat Abu Shanab): As the centre at the time for its dissolution offered daytime services, persons lived at home with their families. There were however some few adult persons who had no family. New homes therefore had to be found for them.

The Community Support Team (Zeinat Abu Shanab and Patricia Ericsson): One aspect of disability services is the support offered to the persons themselves, their families and staff, by specialists of various kinds. This group existed at the Sweileh Centre and they had to become part of the new community based services. This was provided through the services of the Community Support Team.

The SOIR Programme for Quality Assurance (Patricia Ericsson): After having established new services a method was sought to guarantee the quality of the services being provided. This was achieved by formulating a programme for quality assurance.

Documentation and Analysis of the Amman Projects (Kent Ericsson): There are several reasons to document and to analyse such an extensive change of disability services as the one carried out by SOIR in Amman. People who have been involved need to be given feed-back as to what has taken place. As this has occurred in a country where dissolution of an institution and the development of alternatives on this scale has not taken place before, there is a general need to be informed.

Views and Reactions of Families, Staff and Public (Majed Abu Jaber): At an early stage a link had been established between SOIR and Princess Rahma University College, a part of Al Balqa Applied University. This led to a project which contributed to the analysis of the Amman Projects. This was headed by the dean who, together with lecturers and students, carried out a follow-up study of views of families, staff and public who had experiences from the transition of services.

Documentation of New Services (Patricia Ericsson): A contribution to the analysis of the new services was carried out by the SOIR consultant who had been part of their development.

Interviews with Families (Kent Ericsson): A series of interviews were carried out with families of persons, who received education and daily activities for adults. The intention with these interviews was to hear their comments on the consequences for their family members.

4

EDUCATION FOR CHILDREN

SOIR's primary task in Jordan was to provide education for children with intellectual disability. This had been the original task from the time when SOIR had initially begun to provide services in Jordan and had remained so after the establishment of the Sweileh centre. Following the closure of the residential services at the centre and the return of the children to their family homes, they continued to receive education at Sweileh but on a daily basis, being transported from their homes by a bus service provided by SOIR. In order to close the centre entirely the primary task was therefore to provide alternative education for the children. The undertaking to which SOIR was committed, was to provide educational support to children with a severe disability. As none of the regular schools at the time of closure were willing to provide education for these children, it was seen as the responsibility of SOIR to find alternative solutions. This commitment to organising new projects implied taking responsibility for finding suitable facilities in which to locate classes for these children.

CLASSES IN BAAQA

The first new service was established in September 1997 for a group of 15 children. Facilities were located to a newly opened community centre in Baaqa, an area north west of Amman. This is a community on the outskirts of Amman with the status of a refugee camp under the auspices of UNRWA.

Based on the early study of home communities of persons attending Sweileh centre it was clear that the Baaqa area had priority because of the high number of children then attending at Sweileh. Those who therefore were considered as eligible for the new classes were those between 4-14 years, with a severe intellectual disability and who had attended either the pre- or primary school at Sweileh centre. They could also be on the waiting list for admittance.

Another motive for the establishment of classes in Baaqa was the fact that it was a community in which a large number of the staff working at Sweileh centre were resident. This together with the willingness of UNRWA to participate contributed to making Baaqa an obvious choice in which to establish the first classes outside Sweileh centre.

A few years previously a community centre had been opened on a main street, adjacent to a health clinic also run by UNRWA and in the same vicinity as a regular local school. The centre was built to facilitate persons with disability to enter all floors by a system of ramps. It provided advisory as well as rehabilitation ser-

VICES for persons with various disabilities including those with physical, visual and hearing disabilities as well as children with a mild intellectual disability. A consequence of these provisions being available was that close relations had already been established between UNRWA and various disability services. It was therefore seen as natural that even children with a multiple or a severe intellectual disability, should be provided for.

Children at the Sweileh centre and those on the waiting list who came from the Baaqa area, had already been identified and the intentions of the project had already been discussed with the families concerned. They were therefore well prepared and viewed this change positively. The provision of classes in Baaqa was seen as an improvement as many of the children could be brought to the centre by their parents. It also enabled the family to develop a closer relationship to the class of their child. There was also the advantage that teacher and assistants could be recruited from within the community.

The premises provided at the community centre initially included 2 classrooms, each adequate for 7-8 children, the number registered at the start being 15. During the period of the agreement the number first expanded to 3 classes to be later reduced to 2. This variation was related to the complexity of acquiring the necessary number of assistants to pupils. Each group had access to hygiene and kitchen facilities.

Expert staff were seconded by various organisations, independent of the community centre, the intention being that together they would form a team which could meet the needs of persons with different disabilities. The teacher, as the educational specialist, was thereby the team member specifically seconded by SOIR. Other experts were social worker, physio therapist, speech therapist and advisor for the deaf. The assistants to pupils, whose appointment was as a volunteer, were chosen by the local committee and received a nominal financial remuneration.

Responsibility for the daily programme lay with the teacher provided by SOIR. She was responsible for planning and implementing the educational programmes in the classes and any additional programme provided through expert staff. She also acted as manager for the assistants.

Responsibility for the coordination of the various services provided at the centre lay with the local committee in association with UNRWA together with the Ministry of Social Development and SOIR, as they were the parties in the agreement concerning this project. This agreement was signed in 1998 for an initial period of 3 years and could then be extended annually. This agreement continued until 2003, the 2 classes then providing education to 14 children. Then the cooperation ended as the local committee could no longer guarantee that services be provided for children with a severe intellectual or a multiple disability. In accordance with the initial agreement financial support to the classes from SOIR was withdrawn. However, the classes have continued to provide services for children with a mild disability.

CLASSES IN WEHDAT

The school, run by a women's organisation within the Wehdat camp, is located off a

small road adjacent to a busy main thoroughfare in the centre of Wehdat area of Amman. This proximity to the local neighbourhood has facilitated attendance at the school. Most of the children are accompanied to school by family members and as they do not require special transport this has contributed to their participation.

SOIR opened its classes for admission of children in March 1998. When it started the intention was to admit 15 children. But because of the provisional nature of the premises, a prefab building of limited size, the number was reduced to 12. They were divided into 2 groups of 6 attending on a half-time basis, 3 days a week for each group. This was seen as acceptable for the moment, the alternative being to postpone the transfer of children from Sweileh centre to their home community. In order to be compatible with the children attending the primary school the age range was limited to 6-11 years.

The choice of location was based on the early study of home communities of children attending the Sweileh centre. Wehdat was then found to be an area of Amman which should be given priority. 7 children had been attending Sweileh centre on a daily basis and 2 of the teachers were resident in the area. This group was therefore seen as a suitable basis for this location of classes. During the period of preparation other children with intellectual disability suitable for these classes were sought for.

A new school building came into use during year 2000 in which 2 classrooms were reserved for children with intellectual disability. The number decided on was 14 children, divided into 2 classes of 7. Efforts were also made to create natural social contacts with other children in the school by the use of the common playground.

An additional motive for the choice of Wehdat was the fact that this, like Baaqa, was a community with the status of refugee camp under the auspices of UNRWA. During the months since the start of the classes in Baaqa the local committee in Wehdat had been in touch with their counterpart in Baaqa and developed an interest to participate in a similar project. This together with the willingness of the national office of UNRWA to cooperate further, led to an agreement. This was signed by SOIR, the local UNRWA committee and the Amman office of UNRWA together with the Ministry of Social Development. The agreement was signed 1998 for a period of 3 years with a possibility to be extended annually.

The main responsibility for SOIR was the provision of a teacher for the children and the services available from the members of the SOIR Community Support Team. The assistants to pupils were chosen and appointed by the local committee and were to receive a nominal financial remuneration.

Coordination of these provisions lay with the local committee in association with the Amman office of UNRWA. The teacher provided by SOIR was responsible for planning and the implementation of the educational programmes in the 2 classes and any additional programme provided through the staff from the Community Support Team. She was also manager for the 4 assistants to the pupils. The recruitment and payment of these was the responsibility of the local UNRWA Committee.

Work in these classes still continues. The practical terms of the agreement are still applicable while the financial support from SOIR is gradually being reduced according to the agreement. Continuity of staff has been difficult to maintain partly due to social and financial aspects of their appointment, but also because of shortage of persons with relevant qualifications.

CLASSES IN HAI NAZAL

The third educational project to replace schooling at Sweileh centre was arranged for the children who came from the Hai Nazal area of Amman. The study of home communities had shown that Hai Nazal was an area from which over 10 children and several staff travelled to Sweileh centre on a daily basis. The area is at a considerable distance from Sweileh and involved a long cross town journey arranged by special transport. It was therefore seen as desirable that the area be given priority.

Apart from contacts with the families little was known about the possible services for children with disability in the area. It was therefore necessary to become acquainted with the community and to initiate contacts in order to identify possible partnerships. The obvious starting point were existing organisations and schools in the area. Initially two existing services were visited and possible co-operation discussed. However, neither were seen as reasonable alternatives.

The process of making enquires led to contacts with both private organizations and other service providers who sought contact with SOIR. One of them was the local Zakat committee. It was found that within the Hai Nazal area the Zakat committee was responsible for running social as well as health projects and were interested in the idea of taking responsibility for providing a service for children with disability. This contact led to cooperation where the suggestion of running classes for children with intellectual disability, under the auspices of and in the premises of a local mosque, was an innovative idea which the local Zakat Committee was interested in exploring further.

The premises suggested were part of a building in which the prayer hall of the mosque, some administrative offices and a social centre also were located. The premises offered consisted of three rooms suitable as classrooms, a small assembly room, an office, a kitchen and hygiene facilities. The size of the classrooms was adequate for classes of 7 children, a number considered as optimal. The premises were on the ground floor and could easily be reached from the street. The mosque is located on a main street, mostly residential in character but in close proximity to an area with shops, a local school and public transport.

Realization of this project, which was the first of its kind then known in Amman, required extensive negotiations with the Ministry of Social Development and the Ministry of Religious Affairs. Both were found to be helpful and eager to find ways of realizing such cooperation and regarded the task as a challenge which could prove constructive for services for persons with disability.

The negotiations therefore took some time before the official agreement could be ratified, this being followed by a period in which the premises were prepared, equipped and furnished. During this period of approximately 1 year the children

identified as the Hai Nazal group formed an entity of their own, while still attending the Sweileh centre on a daily basis. When the premises were complete and the formal agreements negotiated it was possible to move into the new centre prior to the summer vacation and the start of the new school year. The premises made available provided for 21 children from the local neighbourhood, 15 of whom had previously attended Sweileh centre.

One consequence of the somewhat long process of planning and preparation was that the neighbourhood was well prepared and saw with enthusiasm the establishment of the classes in the area. Through the work of the local Zakat Committee the project had become well known and well supported by the community. Local involvement was enthusiastic and encouraging, with commitments of support, both material and social, from groups and individuals.

Material help was promised, for example a baker's provision of bread, petrol for the bus from a local station and a mechanical workshop which would service the wheelchairs. The authorities involved with regard to the future running of the classes, e.g. the relevant Ministries, the Zakat Committee and SOIR, were able to feel a confidence in the future through these promises and commitments.

In 1999 the agreement between the parties was signed for an initial 4 year period. It has been revised and extended as the work continues. The original teacher is still financed by SOIR and there are contributions from the SOIR Community Support Team. The assistants to pupils are the responsibility of the local Zakat Committee. The salary level for these has varied during the years depending on the financial status of the Zakat Committee.

The classes in Hai Nazal has, due to the innovative character of the work, attracted some considerable attention. The partnership with the Zakat Committee has also attracted interest and led to further partnerships in other areas of Amman.

The initial period of the agreement has now expired but the project continues under the leadership of the Zakat Committee, with support from the SOIR Community Support Team and where required from the SOIR administration. Plans for the further development of the work is ongoing in close co-operation with SOIR.

CLASSES IN AL HUSSEIN

The fourth project to replace education at Sweileh centre was aimed at children who came from the Hussein area of Amman, this also an area which originally was established as a refugee camp. The reason for locating a project to this area was also found in the study of home communities of children attending the Sweileh centre. Jabel Hussein was an area from which over 10 children and some staff, travelled by special bus to Sweileh. In addition many requests for services had been recorded from the area. Jabel Hussein is at a considerable distance from Sweileh and the journey cross town was not satisfactory for those attending Sweileh centre.

At an early stage priority was therefore given to finding a partner interested in establishing educational services in this area. Although a number of possible counterparts were visited and investigated, including existing schools and private organisations, none of these resulted in a proposal which met the needs of those

children who remained at the Sweileh centre. The experience gained from cooperation with the Zakat Committee in Hai Nazal earlier that year had been both positive and constructive, therefore it was seen as natural to approach the Zakat Committee in the Hussein area.

Within a short period an offer of premises was made and cooperation begun. The facilities were located on a side street near to the main shopping thoroughfare. As the task of co-operation and consent with the respective Ministries had been established when starting the Hai Nazal project, the process of negotiation in the Hussein area was facilitated. An agreement could be signed in 1999 and activities started at the beginning of year 2000. Initially 2 classes were started which was extended to a third class. Thereby 22 children, aged 6-12 years, received their education there.

The premises provided had previously been used by the Zakat Committee as a health clinic and was comprised of one large open room, a number of smaller rooms as well as kitchen and hygiene facilities. After some conversion and decoration it provided adequate space for a general meeting room and 3 class rooms. The entrance is located to a side street providing a sheltered area from the otherwise busy thoroughfare. A school in the vicinity provides an atmosphere where other children could be seen and heard even if no specific playground or park facilities could be found in the immediate neighbourhood.

The agreement between the parties was signed for a preliminary period of 4 years. It has since been revised and extended. Work continues and the original teacher is still supported financially by SOIR and professionally through the SOIR Community Support Team. Other staff in the form of assistants are the responsibility of the local Zakat Committee.

THE KHANSA SCHOOL, SWEILEH

Negotiations with the Ministry of Education began in the spring of year 2000. This followed a period of meetings and discussions when the wishes of SOIR to establish a class within the framework of a government school had been presented and discussed.

The question of school integration had also been a subject of discussion at an earlier conference initiated by SOIR and the Ministry of Education had been approached on several occasions to discuss the matter. Due to the changes in serving Ministers and their staff, the process of discussion on the issue extended over a period of time. During this time the successes and positive experiences from earlier projects could be presented and provided assurance for the feasibility of the present wish to establish a project within a regular school. Representatives from the Ministry of Education had also been consulted and involved in some follow-up studies of the earlier projects and thereby were informed as to the aims and progress of the Amman Projects.

Meanwhile the headmistress and other members of Al Khansa, a local school in Sweileh district, had also been approached and their willingness to co-operate was clarified. The families of the pupils who still were attending school at the

Sweileh centre had also been informed regarding the wishes from SOIR to move to the local government school. This suggestion had been accepted and supported.

The facilities which could be made available for 2 classrooms were agreed upon. At an early stage the school had taken the initiative to build a ramp at the entrance as a token of its willingness to welcome children with a disability. Some adjustment and renovation of the premises were necessary, in particular to provide adequate hygiene facilities. The furnishings required for the classrooms were provided, as in previous projects, by SOIR. Much of the equipment had been made in the SOIR workshop by the adults there.

Parallel with the preparation of the classrooms the teachers and the assistants to the pupils who were to work in the Al Khansa school were introduced. Children were gradually prepared for a transfer to their new school. The transition from Sweileh centre took place at the start of the new school term, Autumn 2001, when 14 children aged 6-12 years started their school year in these classes.

Experiences from this project have shown that integration into a setting in an ordinary school did not give rise to any form of resistance or protest. The children and their families have been well accepted and quite a high degree of social interaction takes place. The children with disability have not experienced any form of discrimination, instead there has been an eager interest in who they are and how their needs are to be met.

As this was the first project where physical integration was introduced the school had been well informed by both the educational staff and by members of the SOIR Community Support Team, its social worker having responsibility for this task. Compared to other projects where integration implied a closeness to other social environments, for example a housing or a shopping area, this project required greater emphasis on social relations and interaction within the school and less on relations to the external environment.

A consequence of this experience was that SOIR and the Ministry of Education reached an agreement on further development regarding responsibility for the project. It is now considered both natural and desirable that the Ministry of Education takes responsibility for the education of the children with disability and thereby also take a full financial responsibility for the provision of teaching staff. These are issues which are currently, together with a proposal of an expansion to other schools, under discussion with the Ministry of Education. An agreement has been signed regarding the establishment of further co-operation in schools, including areas outside of Amman City.

CLASSES IN MANARA

The need for classes in the Naser/Manara area of eastern Amman had been identified in the 1997 study but in spite of intensive enquiries it had been difficult to find suitable premises in which to start the work. Apart from contacts with the families little was known about the existence or character of services for children with a disability in the area. It was therefore necessary to become acquainted with the community and to find out which contacts could be made in order to identify pro-

spective partnerships.

The obvious starting point were the existing schools in the area. Two were visited and possible co-operation discussed. However, neither were seen as reasonable alternatives. It was proposed for example that land should be purchased for building a unit together with adults with disabilities. But this was not seen as a suitable or desirable proposal. Several other alternatives were investigated but for various reasons were not found to be feasible.

Support was however expressed by the local Zakat Committee of Manara, which had become acquainted with the Amman Projects of SOIR through the Zakat Fund and the work taking place in Nazal and Al Hussein. The Zakat representatives were therefore already familiar with the needs and nature of the proposed project in Manara. With their assistance available premises were finally found and their role as counterparts in such a project established. The premises for the classes in Manara were not optimal as the rooms had previously been used as offices with little space and with a lack of good facilities for outdoor activities.

However, the involvement of the local Zakat Committee in the negotiations between the parties eventually led to an agreement regarding permission to use the premises for the classes. Once permission was acquired the necessary alterations were speedily carried out and the children could be received from May 2002.

In the initial study in 1997 it was found that 12 children from the area were attending Sweileh centre on a daily basis. Other children in the area with a need for education had also become well known. Families of these were well informed and prepared to have their children admitted as soon as possible. Preparations for the start of the new school year and the transfer from Sweileh centre, could therefore take place prior to the summer vacation of 2002. For some of the children identified in 1997 the placement was no longer relevant but the needs of children within the area were such that the classes could be easily filled and the Autumn term could begin as planned. In spite of the crowded conditions the classes continue to provide for 21 children, aged 6-12 years, in 3 classes of 7 children each.

Characteristic for this project is a strong sense of loyalty between the families, the Zakat Committee and SOIR. Consequently there is a high level of involvement on the part of the families. This is reflected in the attendance levels at parents' meetings, in the practical and material support provided by families and in the continuity of the teacher and the assistants. The initial agreement was signed for a 4 year period. The work continues and the original teacher is still supported financially by SOIR and professionally through the SOIR Community Support Team, while the assistants to pupils are the responsibility of the local Zakat Committee.

COMMENTS

The task of finding new classes for the education of children from the Sweileh centre was a challenge for the Amman Projects. At the beginning the regular schools of Amman did not accept these pupils therefore relations were developed with other organisations. During the period from 1998 to 2002 six projects have been started by SOIR providing educational facilities for a total of 107 children, in centres/schools

which provide for between 14 to 22 children, divided either in 2 or 3 classes. Motivated by the ambition of providing education for these children closer to their homes a study had been carried out to identify the areas where their families lived. This information was used when the search for locations and counterparts began.

The challenge of finding partners willing to take on an initial responsibility for contributing to these disability services and in the end a commitment to a long-term responsibility, led to the process of searching for partners. Experience has shown that they could be found. As some projects were localised to refugee camps administered by UNRWA, this organisation and their local committees became the natural partners. In other cases the involvement of the Zakat committees led to other partnerships and areas of interest. In both cases the contacts have led to new relationships with responsible partners who have provided constructive solutions for the work of SOIR. The relevant ministries, Ministry of Education, Ministry of Social Development and Ministry of Islamic Affairs, have also been partners in these agreements.

Each of the projects is regulated by an agreement between SOIR and the parties who took on the responsibility for the services being delivered. 5 projects have an on-going agreement with SOIR, the original agreement having been extended. One agreement has expired as the partner chose to continue without the support of SOIR in order to keep its freedom to select pupils.

In this way a number of classes were set up, originally 3 classes with 15 children in Baaqa, 2 classes with 14 children in Wehdat, 3 classes with 21 children in Hai Nazal, 3 classes with 22 children in Al Hussein, 2 classes with 14 children in Al Khansa and 3 classes with 21 children in Manara. This makes a total of 107 children who receive their education in various places of Amman.

Through these classes a considerable step was taken towards establishing community based services outside the institution represented by the Sweileh centre. An even bigger step was taken when one of the projects, the Al Khansa school, welcomed 14 children, divided in 2 classes, into the local school in Sweileh village. When this is written another 2 regular schools have started classes and several more are being planned in regular schools in Amman.

The new classes have enabled some children to transfer to a school closer to home while new children, previously known to Sweileh but not receiving any education have now been given this opportunity. The classes are located to a regular school in the Shafra Badran and the Ashrafiah areas of Amman, each class providing for 7 children. The teachers have been seconded by the Ministry of Education and the assistants appointed by SOIR, whose community team also provides support.

5

DAILY ACTIVITIES FOR ADULTS

After having completed the basic education provided at the Sweileh centre children could continue at a school for vocational training. This was a way of preparing them for activities and employment in adult life. The original intention was that children would leave the centre when they became adults, return to living at home and take part in some activity outside their home. But this could not be realised for all. When employment could not be found outside the Sweileh centre activities were arranged in the form of a sheltered workshop in the grounds and those participating attended on a daily basis. The vocational school continued for those between the age of 16 to 22, while the sheltered workshop was for those over 22.

In the study of those attending the Sweileh centre in January 1997, before the start of the Amman Projects, it was found that 50 teenagers and adults were then attending either the vocational school or the sheltered workshop. Apart from 6 young adults resident at the Home of Love, all were attending on a daily basis and were living together with their family. Of this group the majority had been at the centre since early childhood and on the whole were not among those with a severe intellectual disability. A substitute for the vocational school and the sheltered workshop had to be found when persons were to leave Sweileh centre.

THE AL SALAM CLUB

The incentive to this project emerged at a conference held in collaboration between SOIR and the Ministry of Social Development in the Autumn of 1997. A person who attended the conference was at the time running a social club for men with a disability. He proposed that this Al Salam club could be used as a facility for the persons then attending the Sweileh centre.

At this time 26 persons were attending the vocational training school and 24 adults the sheltered workshop. These included both men and women. The fact that it was mixed, men and women together, was acceptable as these services were provided in an environment not accessible to the public. In order to provide an alternative service outside the Sweileh centre it was considered necessary that men and women would have separate facilities.

As the Al Salam club was intended only for men with a disability it was seen as an opportunity for those men who came from that district, the Mahatta area of Amman. The activity which was available was primarily of a recreational character. The proposal of SOIR to provide a daily activity in the form of handicrafts such as weaving and carpentry, was seen as an additional asset attractive not only for those

who had previously attended Sweileh centre, but also for others who attended the club.

During the first months of 1998 the premises were slightly extended and renovated in order to provide a room for handicrafts and another for adult education. This was provided through the building of an extension, while facilities for recreational and social activities were available in the original building. By March of 1998, 7 young men were attending on a regular basis following an introduction which included preparation for independent travel between their homes and the club. The staff support provided by SOIR included one person from the Sweileh Centre while the club provided an assistant.

The extended facilities of the Al Salam club were formally declared open in May 1998. The number of men had then increased to 12. Relationships had been established with family members who participated actively in meetings to discuss the development of persons. In the Autumn of 1998 a workshop was held together with the persons concerned with the project to discuss its further development. In spite of limited space the activities continued to develop. Participants had become more independent when travelling to the club and in availing of services in the neighbourhood, for example visiting shops. The number of participants reached a maximum in Spring of 1999 with 13 attending on a daily basis.

However the numbers attending began to fall and on returning in August 1999 only 5 persons were registered for the coming term. As the numbers did not increase during the Autumn a meeting took place to discuss the situation. It was interpreted as being caused by the uncertainty brought about by the notification that the existing building would be demolished in connection with a future road widening scheme. The club had been requested to find alternative premises. The location of the Al Salam club had been one of the most important aspects in the initial choice of the project, its proximity to the homes of the men and its accessibility to adequate public transport being an important incentive. This motivation to participate had now been taken away.

In order to establish a new centre for the Al Salam club its board canvassed for supporters prepared to sponsor a new building, localized to the Marka area of Amman where land had been acquired. Sponsorship of the new building, which was to provide facilities and activities for different groups of persons with a disability, proved to be a demanding and time consuming task, which contributed to an increasing uncertainty about the future. In addition, the location of the new facilities were not easily accessible for the persons who had initially transferred from the Sweileh centre so the problem of transport became a further hinder for their participation and attendance figures continued to fall.

The initial agreement covering 3 years, had been extended on 2 occasions in order to provide time to establish the new centre. However, after a 6 year period the agreement was finally terminated. It was found that 7 persons then continued to attend on a regular basis. As a consequence of the termination of the agreement the committee of the club no longer employed the vocational assistant and those who continued to attend did so on the same basis as other participants of the club.

THE QOSOUR CENTRE FOR LADIES

The background to this project is related to the decision to develop the Al Salam club to include activities for men with an intellectual disability. One of the members of the committee supporting that club was also a member of "The Training and Rehabilitation Charity Society for Girls with Disability", an organisation which also ran a social centre for women with a physical disability. The centre also provided facilities for the sale of products made by other persons with a disability who were members of the society. Based on the early experience of the Al Salam club it was suggested that the same approach could be applicable also for women. After a relatively short period of planning in October 1998 it was decided that a group of 10 women, then attending the Sweileh centre, would be offered the opportunity to participate in the activities at the centre for women, which was located in the Qosour district of Amman. As a consequence of the tradition that women preferably refrain from using public transport unaccompanied, it was natural that they should continue to avail of the transport provided by the society, as had been the case at the Sweileh centre. Because of this special transport, attendance was not so dependent on the proximity of the centre to the persons' homes. It was therefore possible to offer this service to all persons for whom it was a relevant activity, irrespective of the travelling distance to the Qosour district. Closeness to daily activities in their own community, was however still a matter that had been emphasized as desirable.

The premises rented to be used as the Qosour centre were located to a large house on a main thoroughfare, close to a school but some distance from the main shopping area of the community. The main activities carried out by the women were the production of handicrafts with an emphasis on textile work, including both handwork and the use of sewing machines and a loom for weaving rag floor-mats. Programmes for personal and social development were also carried out on a personal basis, for example domestic activities, cooking and personal care. These activities were familiar to the women who had attended the Sweileh centre, a factor which facilitated the transfer to the new premises.

The ambition from the beginning, which had come to be realized to a high degree, was that all the women who attend the centre would benefit. Each person's choice of activity was to be the decisive factor for the daily programme, not a standardized production work for all. Marketing of the products was also an important factor, therefore the centre was open to the public for purchase of products and attendance at charity bazaars and such events, was a significant aspect of the activity. In addition to local marketing in Amman a considerable number of the products have been found to be attractive objects for sale through the SOIR shops in Sweden.

The staff support provided for the new participants in 1999 included a supervisor from the Sweileh centre, initially remunerated by SOIR and a volunteer assistant provided by the Qosour centre. Participants with a physical disability can in many cases provide support for those with an intellectual disability, while they are of assistance in meeting the practical needs of those with a physical disability. The management continued to be provided by the original members appointed by the Charity Society, with the addition to the board by a person with SOIR experience.

From the time of the agreement between the two parties, the location and character of the building was seen as problematic. As the premises were located to a main thoroughfare with dense traffic, providing difficult conditions for any pedestrian, it was not easy for these persons to take part in outside activities without support and transport. From the start of negotiations with SOIR the director of the centre had declared his ambition to acquire land on which to establish a purpose-built facility, in which it would be possible to expand the activities of the centre. He was well acquainted with the disability movement in Amman and familiar with the needs and wishes of persons with a disability.

His ambition to acquire support for larger facilities was realized with the opening of a new centre 5 years later. This was localised to Nuzha, on land provided by Amman Municipality and financed by donations collected during the years of planning, one of the contributors being SOIR.

Parallel with the search for an alternative location efforts were made to develop relationships within their existing neighbourhood in Qosour. One example is the establishment of contact with the nearby girls' school, the pupils being informed as to the nature and purpose of the centre and being welcomed to visit on an informal basis. The commercial area of the neighbourhood was also seen as a natural environment for social activities. For a period the centre had an agreement in which their products were being sold in a small local shop and a member of the group at the centre was welcomed to assist in the shop on a part-time basis. Contact with the shopping area was maintained through daily visits to the local shops for necessary purchases for meals etc.

Because of the demands and requests for the services of the Society, the numbers attending the Qosour centre had increased. In spite of the crowded conditions the number of persons with an intellectual disability attending had been increased to 10 according to the original agreement. The number stayed at this level during the remainder of the time in the original premises, increasing to 15 when the new centre was opened in September 2004. Currently, in the spring of 2006, 16 persons are attending on a daily basis.

The new premises have also facilitated the realisation of the ambitions to provide a service to which people from outside are welcomed. This includes the families of the persons attending the centre, where, for example, the mothers have been encouraged to participate in the activities. They are also welcomed on an informal visiting basis and since the transfer to the new building meetings with invited speakers have been held. A series of lectures were for example held with the theme "Educational and family counselling for families, volunteers and neighbours of Qosour". The intention is that this centre can also be used for events by other organisations and that daily activities can be extended to the provision of services for visitors, for example a cafeteria.

Throughout the period since the start of the Qosour centre great emphasis has been put on the value of publicity and creating an awareness as to how the centre is meeting the needs of those attending. This is achieved through the encouragement of activities such as visits to public places and events, media participation and an

openness towards the public. This has led, among other activities, to a programme about the society and its work which has been shown on national TV.

THE WEHDAT CENTRE FOR MEN AND WOMEN

In the initial study of home communities of those attending the Sweileh centre it was shown that a considerable number of adults, those then attending the vocational school and the sheltered workshop, came from the vicinity of the Wehdat refugee camp and other districts close to that area. It was from this area that experience had been gained of co-operation with the Zakat Committees of Hai Nazal and Al Hussein. The idea therefore emerged that the Zakat Fund could be approached as a possible counterpart for the development of a project for daily activities for adults. As experiences and knowledge as to what was required to work with adults had been gained from two other projects run by private societies it was thought that a Zakat Committee could carry out the same task.

These enquiries resulted in what came to be an enthusiastic and supportive relationship with the local Zakat Committee in the Wehdat area. The immediate response was to seek premises in which daily activities could take place, if only on a short-term basis. The chairman of the Zakat Committee, himself an educationalist, took a personal and involved interest in the project and soon a suggestion was made regarding premises which could be used on a temporary basis.

The premises were located to a narrow and busy thoroughfare in a central area of Wehdat, the entrance of which opened onto the pavement. The facilities consisted of one relatively large room, off which a small kitchen, toilets and an additional room were accessible. These rooms on the ground floor were made available for use by the Wehdat Zakat Committee, under the management of its chairman. The rooms required redecoration and preparation for use as a centre for daily activities, a task which was financed by SOIR and carried out by maintenance staff from the Sweileh centre.

Preparations were made during the spring and in April 2002, 14 persons, men and women, were registered as attending the Wehdat centre. 8 persons had previously attended the centre at Sweileh, the additional 6 were persons from the area who were known to be in need of such an activity centre. One supervisor who had been responsible for the group while at Sweileh centre was transferred and an additional assistant was recruited locally. The assistant was a lady and was appointed to take responsibility for the ladies programme. In this respect the Wehdat project was a new initiative in that it provided for both men and women within the same premises, however in separate rooms and with different activities.

Both groups continued to work with the same tasks as at Sweileh centre namely carpentry and wood-work for the men while the ladies continued with handicrafts like sewing and needlework. Some activities took place together, for example educational programmes and meals. In order to organise a centre with men and women together it was necessary to acquire the approval of the families, an issue which proved to be without problem and much less controversial than was expected.

Based on the experiences from the Wehdat children's project SOIR had acquired good knowledge of the area and the work carried out by the Swedish organisation had also become well-known and respected in the community. This knowledge and these contacts facilitated the establishment of the adult project.

The early premises were regarded as provisional because of their simplicity and the crowded conditions under which persons had to work. It was realised that a new location was desirable and should be sought by the Zakat Committee. A consequence of the location of the centre was also that its work had become known and respected in the local community. An example of the local reaction has been the comment that the entrance and area around it had been so well kept that others had to follow the example. The standard of the street had improved and the whole area had become cleaner!

This recognition of the task carried out and contribution made by the centre had, as a consequence, the effect that the Zakat Committee was offered the opportunity to avail of premises in a new Mosque under construction in the Wehdat district. The Mosque was being built to the memory of the mother of a well known local businessman. It was located to a hilly area of Wehdat with the consequence that it was a very tall but small building constructed so that it can be entered from two street levels. The building is five stories high, topped by a minaret. The first two floors provide the quarters for prayers, for men and women, while the next two floors are the premises made available for daily activities, also with a floor each for the work of men and women.

These new premises, taken into use at the beginning of 2005, are open to 30 persons, each floor providing for 15. The facilities are modern and spacious allowing for various activities. The basic character of the work remains the same, namely different types of handicraft for men and women, but it is also now possible to extend the variety of activities to include both social and educational aspects of daily life. The increase in the numbers has also put demands on a wider variety of activities to meet personal needs and wishes. The facilities now available make this a realistic possibility. It has also offered the possibility of providing more social activities which persons from outside can avail of, like a cafeteria and a sales area where the products of the centre can be marketed. Various aspects of development are still under discussion. At the end of the spring of 2006 the numbers attending the centre had increased to 25.

EMPLOYMENT ON THE OPEN MARKET

It has become a reality for some persons to find employment on the open market after having finished their schooling. Finding this employment was the task of one of the supervisors at the sheltered workshop. During the period from December 1984 to October 1999, 21 men had acquired some form of employment. This was work for example with social and charitable organisations, in shops, in businesses and in factories. Several of these placements were in a business belonging to the person's family. All these men were included in the follow-up study presented in January 2002 (abu Jabes, 2002).

The first 2 were men who in 1984 had received employment close to the Sweileh centre, in a factory which produced paper products. One of the men had continued in the job for 15 years, the other remained there at the time of the follow-up 17 years later. This employment was seen as a good example and was often used as a recommendation to other employers. A total of 5 men acquired and remained in similar form of employment throughout the period.

Another common form of employment was as an assistant in a shop, 9 persons having had this form of work, 7 of them in a shop owned or run by a family member. 4 of these men remained with these jobs throughout the follow-up period. Another category of employment included different community or social centres run by charitable organisations either with educational or productive activities or both. 6 persons had participated in such activities, either prior to or after another work experience. At the time of the follow-up 6 persons were reported as just being at home with the family. For 3 persons a decision to leave employment had been taken at the request of the family. Of the original group of 21 persons one had died and one had left employment following involvement in a car accident. None of those who then lacked employment were reported as currently seeking another form of occupation.

One conclusion is that if the person and the family genuinely wish to find an employment for a person with intellectual disability, this task is not impossible. There has been a generous response and a willingness from people in the community to make a contribution by giving support to a person with a disability. Not so seldom there has been a greater resistance on the part of the family, who feel a strong protective responsibility and a fear of their family member being mistreated or abused. This has also led to the reluctance to allow persons with a disability to travel unaccompanied. The experience from the SOIR organisation has not confirmed these fears. Instead support and help has come from others.

Regarding women fear has however been the natural attitude with the consequence that few attempts have been made to find an employment outside the work of an organised society and then only if protected transport is made available. Employment would have been possible for some who originally attended Swelieh centre, but this was not seen as appropriate.

Summarizing the experiences from the follow-up study one finds that it is possible to find employment and concerned people prepared to give support. Those who have received this form of placement have given satisfaction to the employers. Two categories of employment have been found as suitable and appreciated namely production work in a factory and assisting in a small local shop. Termination of an employment has in all cases been self-determined.

THE SWEILEH CENTRE

Those who participated in the sheltered workshop were non-resident and in spite of a considerable travelling distance attended the centre on a daily basis. Priority was therefore given during the early years to finding and creating alternative daily activities for those from other areas of Amman. It was this choice of strategy which

resulted in the gradual development of the Al Salam club, the Qosour centre and the Wehdat centre. Those who remained at Sweileh were those who lived locally and had their home in the Sweileh district.

In the autumn of 2002 a private organisation, "Jordanian Society for Rehabilitation", made a proposal to co-operate in the running of a centre providing daily occupation for adults. The group with whom they were mainly concerned were persons with a physical disability. It was proposed that the activities take place in premises the society had acquired on a main street in central Sweileh, on the ground floor and easily accessible for persons using a wheel-chair. The premises were regarded as also being most suitable for the 15 persons then still attending the Sweileh centre, so negotiations regarding co-operation began.

The location of the premises was also appropriate, situated slightly off the main street, on the ground floor easily accessible to public transport and to a commercial area of Sweileh. The condition of the premises was however such that it required extensive repairs and decoration. This task was undertaken by the maintenance staff from Sweileh centre and an agreement was made to start from the beginning of year 2003.

During spring of 2003 it was found that renovations and redecoration of the premises was not entirely satisfactory. Further investigation revealed that the problem was not only one of decoration but rather of construction, the damage to the ceiling and walls seemingly being caused by damp, thus the formation of fungus and the difficulty in heating the premises. After further investigation it became clear that more extensive repairs were required to make the premises acceptable and to be approved by the authorities as a centre in which people were to spend their working day. The alternatives that emerged were either to withdraw from the agreement or that SOIR undertook responsibility for the necessary and extensive repairs.

Faced with the issue of further investment it was decided that SOIR withdraw from the contract. It was not seen as feasible that SOIR should undertake such a project, not being the primary tenant and not seeing the long-term consequences of such an investment. The agreement with the Society was therefore cancelled after half a year, participants and equipment being transferred back to the premises at the Sweileh centre. The buildings previously used for daily activities at the centre were again put to use and currently share the grounds with the administrative offices and the premises for the Community Support Team.

The group is therefore comprised of both men and women, including persons with a severe as well as a mild disability. Persons are able to participate in daily activities such as carpentry and textile work, also some outdoor jobs in the grounds of the Sweileh centre. Some also participate in the tasks carried out by maintenance staff who assist in the SOIR projects throughout the city. The variation in activities is therefore considerable. The intention is still to transfer this group at Sweileh centre to a setting somewhere in Amman. This question is however closely related to the ongoing discussions as to the future use of the grounds of the centre.

COMMENTS

There are some important experiences gained from the setting up of daily activities for adults. These new services show the need for day services for adults, men and women. In this way persons get an opportunity to take part in activities outside their home. They also meet friends at the centre and members of the public on the way. During the day it is also common that they have contact with neighbours.

Establishing these day services has involved considerable work including finding localities , premises and potential partners with whom an agreement could be made. This specification indicates the quality of the new service. After the agreement has been signed the service is run by the partner according to the content of the settlement.

The importance of such an agreement is illustrated by experiences from these new services. Circumstances changed for some which prevented them from providing the daily activities which were agreed upon. Consequently the agreement was suspended by SOIR.

6

PERSONS IN NEED OF A HOME

At the time when the persons at Sweileh centre returned to their family homes in 1995, it was confirmed that 6 of the residents did not have a family home to which they could return. These were a group of young adults who had been living at the Sweileh centre between 7 and 25 years, 2 having been cared for by SOIR from the time of its transferral from Shmeisani to Sweileh in 1975.

This group consisted of persons for whom no stable family connection had been established, they often being referred to as the "abandoned children". All had initially been found and admitted to the Swedish home as babies or young children, either literally from the street or from an orphanage or a reception centre for abandoned babies. One of the men with a very severe disability had been admitted by elderly adoptive parents who had taken him as a child. After his admittance to the Sweileh centre they had maintained contact as long as they themselves were able.

In addition to the absence of biological parents all they had in common was an extensive disability, either intellectual or physical or both. Of the group 3 relied on wheel-chairs and were totally dependent on help for all their needs. During their years at Sweileh centre extensive enquiries were made without success to identify the children or to find a family connection. For 2 of them a guardian relationship had been established. With time they became a group for whom SOIR guaranteed financial sponsorship, in some cases with identified donors.

A GROUP HOME AT SWEILEH CENTRE

In 1995 the group included 4 men and 2 women, then between 17 and 31 years. It was then decided that they, some of whom had previously lived at different wards of the residential home, should live together in one of the wards, the one which had been built in 1984. At the time of their transfer this was named The Home of Love and the running of the ward changed its character. It had been one of several units run on an institutional basis with collective sleeping accommodation, food being delivered from a central kitchen, clothing being cared for by a central laundry and staffing being provided on a rota system.

The initial idea was to find a group home for them outside the Sweileh centre. The Home of Love therefore introduced working methods based on the model of a group home as practised in Swedish disability services during the 1980:s. In this way all would be prepared for moving, without too much interruption of relations and routines.

The staff were chosen to provide only for this group, one of them having the role of house mother. The entire running of the unit was seen as an entity and the house staff were given responsibility for food, including shopping, care of clothing and the domestic running of the group home. The size of the staff group was calculated according to round the clock needs of persons, one staff member having woken night duty. From the support team, the nurse was given special responsibility for the supervision of the group home.

Each of the 6 residents had access to the daily activities being provided at the Sweileh centre, each attending an activity which had been chosen as appropriate. In this respect they could maintain contact with the persons with whom they had previously shared a daily activity, namely other participants still attending the centre on a daily basis. The Home of Love remained the home for these persons from the spring of 1996 until alternative homes were found. One of the men died however before a new home could be established. This group had a common life style, sharing sleeping accommodation, bathroom facilities, kitchen and eating facilities and a common room.

A GROUP HOME IN THE COMMUNITY

Experiences from the Home of Love was that a collective life style was not necessarily desirable if personal characteristics and needs were to be recognised. Each had not only a personal history and life experiences, but their personal and social needs also varied greatly. During the spring of 1999 an open approach was formed as to whether individual or group alternatives were to be sought. The model of a group home was to be investigated but the personal needs of each one was to be regarded when finding a new home (Ericsson, K., 2005a). In the search for new homes both options were therefore considered.

Housing suitable for a group home was sought and several alternatives investigated. Their feasibility from a social (the size and location of a dwelling) and a financial perspective (investment in property), was discussed. Recruitment of staff was also seen as problematic as they required either access to transport or private housing in proximity to the group home. Some possible housing alternatives were found and investigated but these were associated with difficulties.

Another aspect which influenced the development of this idea were the experiences of the period at the Home of Love. Many who previously had known these persons or who now worked with them, told of the incompatibility of the group. It was not self evident for them that they themselves gained from or enjoyed the collective life which the group home implied. Not only did the group vary in age but also in degree of disability, intellectual or physical and in personality. 4 of them had conditions requiring regular attention from medical services.

A NEW HOME IN A FAMILY

Based on the knowledge gained from having looked into the group home alternative it was decided to give further attention to providing a future home in a private family. During the transition of the Sweileh centre the question had been put to staff whether they were interested in future employment in the new projects either as

teachers, assistants to pupils or caring staff. After the discussions about new homes, a new possibility was to take on the task of a foster parent. A proposal was therefore put to staff whether they would be interested in such a task.

The response to this proposal was encouraging. Many previous staff and even others who had heard of the proposal and knew of the work of SOIR, took contact. The search for alternative homes gained a new momentum. It was decided that the co-ordinator of the Community Support Team should be responsible for the project and that a proposal should be presented. A reference group composed of staff members with varying experiences was appointed, along with the Swedish consultant. The task of the group was two-fold, to identify and specify the personal needs of each of the persons and to assess the proposals as to how to care for them made by interested persons.

The work-group studied the many proposals for new homes. The offers were judged based on issues such as necessary additions to or material adjustments of existing housing, suitability of and accessibility to outdoor environment, relationships to other family members and the neighbourhood. Availability to other services, for example health services and transport were also considered. A final task for the working group was to carry out an evaluation and make recommendations as to which of the homes they saw as suitable. Following the recommendations of the working group the legal and financial relationships between a family and SOIR had to be investigated and regulated, this also requiring the involvement and approval of the Ministry of Social Development.

Parallel with this planning discussions took place in SOIR in Sweden as to the feasibility of providing family homes, financially as well as in terms of its sustainability. An important factor influencing the decision was an earlier commitment made by the founder of the Sweileh centre to this group of so called abandoned children. Responsibility for their continued well-being was strongly felt by SOIR in both Jordan and Sweden.

Following a decision regarding a suitable family it was necessary to adjust the new home to the needs and requirements for the person. In some cases this required physical adjustments to the home, in others an agreement with other service providers, for example the local health services. The choice of a home for a person was simplified as the staff who had offered to provide a home did so on a personal basis. Based on their relationship with the persons they expressed their preferences as to which of the 5 persons they wished to consider having as a foster "child". During this process the administrative and legal aspects of such a relationship had been negotiated with the responsible Ministry.

After the choice of a home for a person practical and social preparations for a move to a new home could begin. Experiences from this period confirmed the belief in the appropriateness of the project. The persons concerned began to show a previously unseen interest in their everyday life showing expressions of pleasure on a visit to the suggested home and disappointment at having to return to the Sweileh centre from such a day visit. Their reactions acted as a confirmation and added

further impetus to this project. The process of setting up these homes, which had begun in the spring of 1999, was first realized in the autumn of 2001.

The first person

In one family the woman had been a member of the staff at the Sweileh centre and had left to care for her own young children. Hearing of the possibility of providing a family home she offered to do this for the blind girl whom she knew well. Today she lives in a small village on the outskirts of Amman. She is treated as one of the family. They together with their extended family and neighbours express support for this way of arranging a home for the girl. Apart from her being able to use the whole house, she has her own bedroom which was furnished and decorated by SOIR according to her wishes together with the family. During the past 5 years she has become a welcome member of the family and the entire community.

The second person

The other lady, in her early thirties and with a severe physical and intellectual disability, has been provided with a new home in a traditional Jordanian extended family, also in a small village outside Amman. The lady who offered her a home had worked for many years at the Sweileh centre. She is the second wife of the senior man in the household. The other members of the family are the first wife, a son and his family, including young school-aged children.

In order for the lady to have a room of her own a small extension was made to the house, adjusted to her needs including space for the use of a wheel-chair. She has been provided with a bedroom and separate bathroom suitable for a person with a physical disability. The entire ground floor of the house and the yard and garden, is thereby accessible for her and her wheel-chair. By the family and the local community she is now regarded as another one of the family members.

Prior to her moving to the new home the local health clinic were in contact with the family to hear about her needs and independently took the initiative to prepare a ramp at the entrance in order to make the clinic easily accessible. Her everyday medical needs are met by the clinic who have access to guidance from a doctor who had previously provided support at the Sweileh centre.

Both of these women maintain contact with the activities of the Sweileh centre which they attend on a part-time basis, availing of bus transport provided by the centre. According to their personal needs they also have access to the services provided by the Community Support Team, whose social worker is responsible for follow-up and support to the families.

The third person

Following the decision to dissolve the Sweileh centre the post of sports teacher was withdrawn. The man having had this post therefore returned to his home town some distance away and begun to work as a business man and trader. The sports teacher had also been employed as additional staff at the Home of Love taking responsibility for recreational activities and when extra male support was desirable

for the male residents. He was a married man with several children and a wife who was familiar with the work at Sweileh.

The third person to be offered a home by a previous member of staff was a man in his twenties. His main disability was autism. The former sports teacher at Sweileh centre had a long-term and close relationship with the man. He was also greatly liked and respected by the young man. This young man, who previously had attended a day activity centre was now offered the opportunity of taking part in the tasks of the father of the house, for example participating in the delivery rounds made daily in a small lorry. The relationship between the men was in many ways one of friend and brother rather than as a father.

In the follow-up visits it has been found that the relationship has become one of a family member where participation in the family business is as important as the housing provided. In all respects the young man has genuinely become a member of the community. His autistic characteristics remain but it is seen as part of his personality and his role as a family member is fully respected.

The fourth and the fifth person

The other two men who were part of the group were relatively young, both with severe physical disabilities, primarily being regarded as persons with cerebral palsy. Neither had however learnt to speak in such a manner that an outsider understood. Those who knew them well maintain that they could communicate with each other and that others, for example members of staff, had learnt to interpret their views. One of the men availed of a signboard, Bliss, to communicate with others who were familiar with the method. This relationship was therefore seen as a factor which should influence the choice of a new home for them. Several members of staff had indicated their interest in caring for them but the suggestion that they should remain together and their need for an environment which was suitable for two persons using wheel-chairs, was not seen as easy to achieve in an ordinary family home.

The solution was therefore that a home for the two men could be provided by using one of the buildings previously used as housing for Swedish staff at the Sweileh centre. These houses were concentrated to an area of the grounds comprised of housing and office facilities and close to the main entrance and an ordinary housing area outside the centre.

A review was made among previous staff to find a possible house mother to support the young men in one of the vacant houses. One of the staff who had expressed an interest in this task had for a period worked at the Home of Love. She was interviewed regarding her interest and welcomed to take on this task. Following renovation of the house, especially with regard to the bathroom facilities and other matters enabling the use of a wheel-chair, it was possible in November 2001 for the 2 men to move from their old unit, which could then be closed.

COMMENTS

Following the decision in the summer of 1999 to investigate possible alternatives to life at the Sweileh centre it took over 2 years before persons could leave the Home of

Love. Approval had then been gained from the Ministry, agreements were made with respective families, practical issues of preparing the houses had been carried out and the persons could move to their new home.

The new homes which were realized to meet the needs of these 5 persons have one factor in common namely that each gained a home where support was provided by a person with whom they already had an established relationship. In the process of seeking a home for those who no longer had a family of their own, it was seen as both natural and desirable to avail of a previous staff member who already had a relationship with the person. During this development it has also become evident that many others in the community have shown an interest in and willingness to support these persons in their quest for a good life.

THE COMMUNITY SUPPORT TEAM

From the start of the SOIR work in Amman in 1967, six categories of staff, here referred to as experts, were of tradition recruited from Sweden as they were then not easily available in Jordan. An exception was the medical doctor who was seconded to the centre by the Jordanian authority. The other categories of staff were a special teacher, nurse, residential manager, occupational therapist and house mother. For most of the period from 1967 to 1990 these posts were therefore filled by persons from Sweden, most of whom served in Jordan for shorter periods of time, usually 1 or 2 years. During the 20 years of SOIR services over 40 Swedish staff had worked there in one or other of these professions.

From the mid 1980:s some of these posts, the nurse, the social worker, the head of education and the manager of the day activity programmes, had been filled by local staff. In time the tasks of house mother and residential manager were also filled by local staff. A Jordanian sports teacher was employed to organize recreational activities and a physio therapist was appointed. The first Jordanian director was appointed in 1989, more than 20 years after the establishment of SOIR in Jordan. These appointments were on a permanent basis. A medical doctor had for some years been assigned by the Ministry and served the centre on a part-time basis, as consultant, holding a surgery at regular intervals together with the nurse.

CHANGING ROLES FOR THE EXPERTS

With the establishment of new community based projects it was agreed that services being provided by the experts should take place at the new centres. This required a change of approach. Instead of the person with a disability attending the clinic of the expert, be it nurse, physio therapist or social worker, this staff would instead be required to visit the centre attended by the person. This shift from a stationary to an ambulatory service required new practices and relationships.

The role of expert therefore became a subject in need of clarification. As each of the new projects was led by a locally placed manager it was soon seen as self evident that the role of the experts became that of a consultant to staff, rather than a supervisor of them. They should not exert the role of an overseer, this being the task of the manager. In this way the experts assumed a peer relationship with the local managers of the centres.

Physically and administratively the support team was located at the SOIR head office, while professionally their duties were carried out within the local projects, or in the homes of persons concerned. In the case of the nurse and social

worker some tasks in relation to persons not attending a local centre continued to take place at the head office, at Sweileh.

THE COMMUNITY SUPPORT TEAM

In order to clarify the character of the new role for this category of staff, it was decided to use the term Community Support Team (CST). This illustrated that this was a group of experts who would provide support, within the community setting. In the organisation, the team members were therefore auxiliaries to the SOIR director in the same way as the managers of the local projects. In order to clarify the new characteristics and the tasks of the experts, now referred to as members of the Community Support Team, new job descriptions were drawn up and negotiated.

Following the increase in the number of local projects a review was carried out regarding which professional categories were desirable and to what extent. In the report an expansion of the team was suggested to include an additional physio therapist and a special teacher to provide educational support to teachers and assistants. Both these suggestions were realized. It was also proposed that the qualifications of a psychologist as well as a speech therapist would be desirable on the team. The unavailability of these professional groups has meant that this suggestion has not yet been realized. At the initial stage a Swedish employee was appointed as coordinator but this post is no longer considered necessary. The team is therefore currently composed of a teacher, a nurse, an occupational therapist, two physio therapists and a social worker (Ericsson, P., 2001).

SUPPORT BY ADDITIONAL EXPERTS

In addition to the support provided by the Community Support Team, medical and dental care is also available. The tradition established early in the work of SOIR, that a medical doctor be assigned by the Ministry as part-time consultant, has continued. For those centres run under the auspices of a Zakat Committee additional services such as medical and dental care can be made available from the same source. Jordan University Hospital also provides easy access to this support. Currently the doctor involved makes visits to the Sweileh centre on a regular basis and acts as a consultant to the nurse and to the families concerned. The role of the doctor has often been to assist in the referral of a person to a relevant specialist or to the local doctor, as well as access to free hospital care in the case of financial need.

A dentist who is closely familiar with the work of SOIR has for many years made his services available to families who need assistance to provide for their children. This dentist has on a regular basis attended the Sweileh centre and held a surgery there. Following the establishment of centres in other parts of Amman he has found and encouraged colleagues to provide similar voluntary services in the local communities to which the children belong. A consequence of the fact that the number of persons attending the new centres has not been so excessive, the doctor or the dentist have not been discouraged from following this voluntary tradition.

8

DEVELOPMENT DURING THE TRANSITION PERIOD

The intention with this chapter is to provide an overview of the Amman Projects. Previous presentations of the new services were focussed on their establishment. This describes changes during the project period in some chosen variables.

It is a problem to create a model which provides a set of variables at an early stage when the project is characterized as being a process as in this case. The goals in the beginning were quite clear. The intention was to close the institution and to create community based alternatives. However, at the early stage it was unclear as to how well it would succeed. The specific character of the new services were unclear as was the duration of the project period. This created problems to decide in advance on which individual variables were to be described during the transition period to follow.

Later, when the project was being summed up a set of variables were available which made it possible to present development during the full period. They are collected from the monthly reports which the SOIR Director sends to the SOIR office in Sweden. The first report was written in 1997, for the month of April. The years 1997-2004 is the period which is being described here. The entire year is not presented. Instead the situation in Amman during the month of April has been chosen to represent each of the years.

Table 8:1 illustrates development in 9 variables. In variable 1 the number of newly established projects are presented. These are the ones which have been presented in previous chapters. Variable 2 shows the number of persons at the Sweileh centre at the same time and variable 3 the number of persons in the new projects. These three variables can be said to illustrate the change in the character of the SOIR services in Amman. Variables 4 - 8 describe the content of the new services, that is excluding those of the Sweileh centre.

Variable 4 describes the organised habilitation work being carried out. Staff in the new services carry out the habilitation of the persons on a daily basis. This variable is however related to the planning which is made by the expert in the Community Support Team. Training advice is one aspect which is noted in the monthly report, that is the advice which an expert gives to staff of a person. Habilitation meeting, also noted in the monthly report, is also an occasion where the habilitation of a person is planned together with an expert. The number given for this variable indicates the number of persons having received this contribution to his habilitation.

Three variables, 5 - 7, express the relationship between the SOIR service and the families of persons. As was noted in a previous chapter on the community based approach, the relationship with families was seen as important. Persons with a disability do not belong to the service but to his own family. Therefore it becomes important to have a close relationship with families when delivering services. Variable 5 describes the number of home visits made by the service while number 6 shows the visits of parents to the centre. Both these describe individual visits. Variable 7 is based on parents' meetings.

Activities outside the centre, using local resources, is a sign of a service with a good relationship to the local community. Variable 8 illustrates this by showing the number of times picnics and horse riding has taken place.

Variable 9 shows the number of staff employed by SOIR during the month of April. These figures are collected from the register showing the number of persons receiving salaries from SOIR. There may be other staff in the new centres, such as volunteers and trainees, who are not employed by SOIR. Variable 10 shows the total cost for SOIR in Amman. This covers the Sweileh centre as well as the new projects. The cost shown is the total for each year expressed in SEK 1.000.

Table 8:1. The SOIR Project described in 10 variables over the period 1997-2004.

Year	1997	1998	1999	2000	2001	2002	2003	2004
1. New projects	0	3	4	7	7	8	11	9
2. Persons in Sweileh centre	145	112	93	49	39	29	2	2
3. Persons in new projects	0	25	53	97	116	109	154	137
4. Habilitation	0	0	0	5	10	15	43	34
5. Home visits	0	0	0	11	12	26	17	15
6. Parents visit	0	0	5	21	24	41	57	45
7. Parents meeting	0	0	8	0	0	0	61	17
8. Picnic / horse riding	0	0	2	2	2	4	6	9
9. Staff	75	74	68	57	49	30	24	25
10. Economy (SEK 1.000)	3.262	3.983	4.050	4.193	4.408	4.112	2.280	2.178

Table 8:1 shows how the number of SOIR projects have increased over the years (1). There has been a gradual development as all cannot be started at once. The task has been to concentrate on one project, getting it established before starting on others. The consequence of this procedure is that it takes several years, in this case 8 years, to set up new services for a group of this size. This is characteristic for a process which is working towards achieving set goals. From this table it can also be seen, years 2003 and 2004, that there is a reduction in the number of projects. This is based on their no longer being partners of SOIR. Agreements with these have ended and new ones have not been agreed upon. These projects may still be going on but they are no longer receive funds from SOIR.

The core issue of a transition project, when institutionally based services are dissolved and community based ones are developed, is the change of lives for the

persons. Variables 2 and 3 illustrate how 145 persons at the outset have left the Sweileh Centre for the new services which have been set up. The 2 persons recorded for years 2003 and 2004 are men whose housing is provided in an apartment located to the Swileh centre.

Variables 4-8 show some aspects of the new services. The general picture is that it took at least three years before the process of change could be started. During 1997 the work started on the transition to community based services, but no new projects were established that year. It was in year 2000 when there were 7 new projects that activities termed as habilitation and family work had begun to be systematic and to be recorded. From that level there was an acceleration until year 2004. That year 25% of persons are recorded as receiving the attention of the habilitation services. Whether this is adequate or not is hard to say as this work is often carried out by the physio therapist and the receiving persons are only those who need this form of support. Not all have a disability concerning their mobility.

In the original approach to services the importance of the families of the persons was recognised. This table shows how this was handled. There is a gradual development of the relationship between the families and the new centres. Staff and representatives of the Community Support Team make visits to the families and families visit the centres. Formal meetings are also held. It is satisfying to see that this aspect of the work has been established and takes place to a high level. As all of the persons now live with families it could be expected that there is a relationship between the services and the family for as many as possible. At the same time this is an activity which requires resources and which takes place in addition to the activities with the person. It also requires an acceptance by the families to receive home visits or that they themselves visit the centre.

Picnics and horse riding are two activities which can be part of the service provided. They are good examples of a community approach as one uses local resources outside the centre. There is an increase over time in this respect, but it is still carried out at a low level.

The staff referred to by variable 9 in table 8:1, are those who are employed by SOIR. They were 75 at the beginning of the process and 25 during the last year. This means that 50 staff have left the organisation. One explanation to the change, which is a common phenomena when an institution is closed, is that many were employed at the institution to deal with issues no longer needed, for example the provision of food, laundry work and the care of clothes, as well as the maintenance of buildings and the grounds. Such staff were not involved in the direct services to the persons. These tasks are no longer required or are carried out by others in the new services. The staff still employed in 2004 are some administrative staff responsible for running the SOIR projects and those who are members of the Community Support Team. There is also the group of senior staff who are the managers of the new services. But more staff are involved in the provision of these services than is shown here. The reason for these not being recorded here is that the counterpart organisations which are running the new services have become financially responsible for the local staff. They may be professional staff like a teacher assistants or volunteers, sometimes also trainees.

The economy of the projects presented here, variable 10 in table 8:1, is the total cost for SOIR during this period. As is seen there is a decrease during this period. From SEK 3.200.000 during the first year it reduced to SEK 2.200.000 eight years later, that is a reduction of SEK 1.000.000 during these years. One main reason for this is that a number of the functions which took place at the institution no longer need to be carried out in the new services. Maintenance of the physical institution and of the gardens, buses for transport, kitchen and dining facilities and accommodation for staff are examples of costs which no longer exist. The increase in costs during years 1998-2002 are also shown. These show the effect and price of the transition, a "hump" in costs, common during the period while the closure is ongoing. The reason for this is that during a period the institution has unavoidable costs for maintaining the old at the same time as the new services are being established. When this period is over, costs will decrease. It should also be noted that these are costs for SOIR. The organisations which have taken over the running of the new services also have costs during the same period.

During this period responsibility for staffing and economy has decreased for SOIR, the Swedish organisation, whereas there has been an increase in the responsibility taken over by the Jordanian organisations. This is an indicator of the "jordanisation" which has taken place during this period of transition. There are now Jordanian organisations who take responsibility for the persons with disability. This has also meant that the staff are locally employed and that Jordan takes a greater financial responsibility for the costs for the disability services provided.

This review over time illustrates the implications of the fact that it has taken 8 years to set up new community based services and to provide a relevant alternative content for this group of persons.

In the monthly report there is also a presentation and catalogue of various activities which have taken place. Some of the activities refer to contacts between the services within the SOIR organisation. There is also a category of activities which show the relationship between the new projects and various aspects of Jordanian society. From these monthly reports it is clear that the Amman Projects take a very active role in participation in community life. One category concerns professional visits. This can be SOIR visiting other services to become informed about ongoing developments in the country. SOIR also receives a large number of visits, not only from Amman but also from other parts of Jordan and from countries in the Middle East. Naturally several visits come from Sweden.

Another category of activities concerns the holding of lectures, either by people coming to SOIR to give lectures as part of an ongoing capacity building, but also a considerable task for staff from SOIR to lecture for others. This can be to other service providers, to the ordinary schools and not least to universities where the experiences gained from the new projects is being sought after. The focus is primarily put on describing the experiences and implications of delivering disability services emanating from the community based approach.

During these years SOIR has had intensive contacts with organisations and formal bodies in Jordan. As this has been a period of establishment it has been

necessary to find and to link up existing and potential partners in the running of the new services. Naturally, the provision of services requires the acceptance and approval by government departments. SOIR's legal and financial relations with several public bodies requires attention in order to keep them informed regarding ongoing services and activities. As many disability services in Jordan are run by private NGO:s it is also important to maintain relations and to exchange experiences in the disability field. A most important support has come from representatives of the Royal House which has shown continual interest and encouragement for the ongoing changes.

After having studied the monthly reports for these years the conclusion is clear that the running of community based services requires an organised social network and active support to all its members. For the successful running of such services this must be seen as a necessity, not an inconvenience.

9

THE VIEWS OF FAMILIES, STAFF AND THE PUBLIC

QUESTIONNAIRE TO FAMILIES, STAFF AND PUBLIC

During the early phase of the development of the SOIR Project cooperation was established with Princess Rahma University College of Al-Balqa Applied University. After a series of meetings and workshops together a study was carried out by the college. This was headed by Dr. Majed Abu Jaber, then Dean of the college and a group of teachers, Mr. H. Katanani, Mr. M. Al-Kumash, Mr. R. Al-Zghoul and Mr. M. Ateyat (abu Jaber, et.al., 2002).

The aim of the study was to clarify the views of families, staff and the public towards the ongoing development of community based projects. The background to the research questions asked in the study was an attitude generally held that the delivery of disability services in the community was not possible in Amman. In various ways the feeling was expressed that this approach could possibly apply in Sweden but not in Jordan.

Three questionnaires were formulated to be answered by families, staff and members of the public. The items varied between these questionnaires. As the questionnaire was in Arabic, it is the English translation of the items which is quoted in the report and in this presentation. In each questionnaire there was also an open question which gave the respondent an opportunity to express his personal views.

The questionnaires were administered by students from the college. Each item was responded to by marking one, the one you agreed with, of the four answer categories. An accompanying text also defined their meaning: 4 - "applicable to a high extent", 3 - "applicable to a moderate extent", 2 - "applicable to a low extent" and 1 - "not applicable". At that time 53 persons, children and adults, had left the Sweileh centre for six new community based centres. Experiences relating to these persons were the basis for the answers to the questionnaires.

The views of families

There were 3 areas, together described by 21 items, in the questionnaire directed to families. Area 1 covered the attitudes of families towards CBR in general. Area 2 described the attitudes of families to services provided by the new centres while area 3 described the participation of families in these services.

Representatives of 49 families in 5 of the 6 centres responded to the questionnaire. The mean of their answers to all 21 items was 3,35. The mean was 3,35 for area 1 (family attitudes to CBR in general). It was 3,46 for area 2 (family attitudes to services offered by the centres) and for area 3 (participation of families in the services of the centres) the mean was 3,16. In this way families expressed that they were satisfied to a rather high degree regarding the centres (areas 1 and 2). However they themselves participated in the provided services only to a lesser degree (area 3).

Of the 21 items of the questionnaire, 16 showed results with a mean between 3,16 and 3,90. The other 5 items had means below 3,00.

Table 10:1. The views of families - the 5 items with highest scores.

	Mean
A) "I feel more comfortable because my son is near my residence"	3,90
B) "I do not feel ashamed when visiting my child in the centre"	3,88
C) "I endorse establishing more centres for the children in the local community"	3,69
D) "Understanding the needs of our child has increased"	3,61
E) "We feel satisfied about moving our child from the main centre to the local community"	3,55

These items represent a positive view of families towards their family member receiving support in the communities of Amman and in close proximity to their family homes.

The answers in the open questions reflect some personal and concrete views of families. Some mentioned that neighbours to one centre were annoyed when it was established. They did not understand the disability of the children and some therefore made jokes about them. Some families, regarding another centre, said that there were parents who did not accept the idea of change because they were afraid that necessary services might not be offered. The comments regarding yet another centre pointed out that they thought there was a lack of volunteers and that salaries for staff were too small.

The views of staff

The questionnaire to staff contained 4 areas, based on 27 items. Area 1 described attitudes of staff towards CBR in general. Area 2 covered the issue of career satisfaction of staff. Area 3 was related to the attitudes of families towards the project, as seen by staff, while area 4 described the satisfaction of staff concerning the quality of services offered by the centres.

This questionnaire was answered by 43 staff from 5 of the 6 centres. The means of their answers for the 4 areas varied between 3,11 to 3,60. For area 1 (attitude of staff towards CBR in general) the mean was 3,44. The mean for area 2 (career satisfaction of staff) was 3,45 while it was 3,11 for area 3 (attitudes of families towards the project as seen by staff). For area 4 (satisfaction over the quality of ser-

vices offered by the centres) the mean was 3,60. Staff rated the project as very positive, between 3,44 to 3,60. But they consider the families as not being so satisfied when their mean for area 3 was 3,11.

Of the 27 items only 3 had a result below 3,00. The highest scores were between 3,74 and 3,86. As there were 3 items with 3,74, these high scores are represented by 7 items (table 10:2).

Table 10:2. The views of staff - the 7 items with highest scores.

	Mean
A) "The Swedish Organisation makes a continuous follow up of the centres and shows attention for the children with disabilities"	3,86
B) "The centre practises activities in both the centre and the local community"	3,77
C) "I feel contented and satisfied working in the integration project"	3,77
D) "People around the centre do not feel ashamed because of the children with disabilities in the area"	3,77
E) "The number of children registered on the waiting list decreased after implementation of the integration project"	3,74
F) "The Swedish Organisation provides qualified staff to deal with the children"	3,74
G) "I think the adaptation in society is better after the implementation of the integration project"	3,74

These 7 items express, in the eyes of staff, a contentment with SOIR and to be employed by this organisation. there are also expressions of satisfaction with the community based services being offered.

When responding to the open questions these are some views which were expressed. Staff in one centre argued that daily meals should be served. Persons were also seen as being in need of training and recreational aids. Regarding another centre they pointed out that there was a need for financial support and means for transport. Children also ought to have a larger building. At one centre staff thought that there was a need for a courtyard or a garden outside and playing instruments indoors. One centre was seen as in need of technical instruments and a bus. At yet one centre staff meant that children were in need of medical insurance.

The views of public

The questionnaire to be answered by the general public consisted of 16 items. Together they described the attitudes of members of the local community towards the project in general. It was answered by 29 persons in the communities of the 6 centres. The mean was 3,54 for this group of respondents regarding these items.

Table 10:3. The views of the public - the 5 items with highest scores.

	Mean
A) "I prefer that they participate in the activities both in the centre and in the local community"	3,86
B) "I prefer the children to be in the centre within the local community"	3,79
C) "I welcome the idea of moving the children from the Swedish Organisation (Sweileh) into centres near their homes"	3,69
D) "I do not feel ashamed because the centre is in our area"	3,48
E) "I do not avoid children with disabilities when I see them"	3,41

Together the items represent a positive view of the public towards disability services being localised in the communities of Amman. These items therefore do not support the initial worries about negative reactions of people in the communities where the new centres are localised.

When answering the open questions people had some comments. One theme stressed the need for more centres and for developing their level of quality. To realise this they meant that there was a need for financial support. Another theme pointed out the need for families to participate in the work of the centres in order to make them understand that persons with a disability are part of the community. People also suggested that more work-places should be arranged, preferably with the assistance of families.

COMMENTS

It is a somewhat unexpected result shown in this study. The hesitant attitude to community based disability services which was expressed during the development of these projects, could not be illustrated. Instead there was a very positive reaction. All three groups, families, staff and the public showed a strong and positive support for the ongoing services.

It is interesting to note the positive answers by families, expressing delight over the fact that services were now established in the local community. This gives support to the fundamental aspect of the community based approach that family members with a disability really belong to their family. It is apparently the views of families that they want localisation of services to the home community and that local resources are used for this purpose.

Also staff show a positive attitude to these new services. They express satisfaction over the way that the services have been handled by the SOIR organisation when leaving the institution and setting up the new services. They also see that there has been a value for themselves as the jobs they were offered are positive. This also indicates that they see the opportunities providing for a good career.

It was a common view that families and staff saw members of the public as potentially resentful towards living in a community where there also were services

for persons with a disability. When they were asked, as in this questionnaire, the public instead express positive views about these persons. They welcomed them and they thought it should be the natural thing that they receive their services locally.

In addition to these responses there are also a number of experiences from delivering these new services which illustrate the often positive attitudes of the public. There are examples of women in the neighbourhood who offer to assist, for example in a class when there is lack of staff. Bakers have also offered bread to a centre, a petrol station has filled the bus and the bicycle shop has helped when the wheel chair has been in need of repair. The health clinic was quick to build a ramp when a person in need of a wheel chair moved to the community. Examples of a good community relationship do not need to be dramatic. Instead they are small expressions of a welcoming attitude.

Naturally the question arises as to why the hesitant, sometimes negative, view towards community based services does not show up in the answers of this questionnaire. One reason could be that negative attitudes only exist as long as one does not have information about the character and functioning of these services. When they are unknown, a service can be seen as an alien phenomena which arouses hesitation. This study, however, was carried out in connection with the establishment of 6 new centres. People had had time to see them and to have had an opportunity to understand their way of functioning. They may also have had the opportunity to see positive consequences for the persons. In this situation when one's attitudes are based on a concrete reality, it is natural to find these positive responses as shown in this study.

10 VIEWS OF FAMILIES

With the introduction of the community based approach to disability services the importance of families was emphasized. One consequence was apparent in the planning of the new services for both children and adults, the ambition being that they were located close to the family of the person. This was the motive for the localisation of services to a number of places in Amman.

This had also consequences for the everyday work of the services. There was an openness to the views of families. The monthly reports from SOIR in Amman show the number of home visits which were made during a month, primarily by the social worker but also by others. This documentation also recorded the visits made by families to the services during a month. These monthly reports have shown that visits did take place every month and this to an increasing extent over the project period.

As part of the evaluation project it was therefore considered natural that the views of families should be heard in order to get a broader view as to what was taking place in the SOIR community support projects. In each of the ongoing projects families were invited to attend a meeting where their views would be heard. There was an active response to this invitation, many attending the meetings which took place in the new centres. Apart from family members the local manager participated as did the SOIR director and the Swedish consultant. Communication between the evaluator and the families was translated by the SOIR director.

FOUR CLASSES FOR CHILDREN

At the time of the interviews four classes for children had been established, Baaqa, Hai Nazal, al Hussein and Wehedat. At each project families were invited. In all, 61 families were represented. Apart from one father, mostly mothers but also brothers and sisters, attended.

Major tendencies in the views of families are presented here. They are categorized into groups and each group is illustrated by comments from families. Even if there are only some few comments given here, there could be several families who expressed a similar view.

“What about the future?” was the most frequent reaction which the families brought up in the interviews, an expression for their worry about the coming years for their children. The tradition is that this basic period of education ends at age 14. During these early years it is accepted that boys and girls attend the same class.

After that age it is not acceptable that they are educated together. For non-disabled children they would then transfer to new forms of schooling. For these children with a disability there is no new school, which means that their period of education ends at age 14. If a child is lucky there may be an opportunity to attend another disability service for adults. If there is no such place, he or she will have to remain at home without support.

The other major reaction from families were the various expressions of happiness over the development of their children. As these were school classes one could expect comments on the academic achievements of children. But this was not the case. Only one mother mentioned something of this kind as she was now *"glad that he could use the pencil"*.

Instead the families described their happiness over issues which belonged in the area of personal and social development. *"Now he can eat, dress and visit the toilet himself"* and *"Before he depended on others, now he feeds and dresses himself"* are two expressions which illustrate a familiar story told by the families. Mothers especially expressed satisfaction over toilet-habits having been changed: *"She is clean when she comes home so she is well taken care of"*. This development is not necessarily the effect of a training programme but a consequence of the fact that the child leaves the home in the morning and is met with new expectations from teachers and classmates who make up the social group in the everyday life.

Having the opportunity of getting involved with these educational activities has also had stimulating consequences, compared with the alternative consequences when lacking social and educational activities. *"Before he was very active, now he is much calmer"* was the comment of a mother when asked about what it meant for her child being at school.

It was a common experience when talking to families that they expressed sadness over their child's lack of spoken language. This is of course a natural reaction! *"He has started to talk"* was the immediate comment of one mother when asked about the meaning of going to school for her child. Often the families ask for help from the teacher to develop the speech of their child. There are also requests for a speech therapist to be part of the service.

But the discussion did not centre only on aspects of development of their children. In several ways they also mentioned about the happiness of their children when going to school. A mother told about her waking her daughter in the morning by telling her that it was time to go to school because this made her happy! When another child comes home from school *"She talks about everything exciting which has happened in school during the day and she talks about how she likes her teacher"*.

Another expression of this happiness over school is the irritation of children during Fridays and Saturdays, the days when there is no school. Some are also annoyed when they cannot go to school during the summer holidays! The families also talked about visits to the school and that they feel welcome when they are there. They generally find it easy to talk to the teacher about their worries, be they big or small. There were also comments about having had visits from the teacher in their home to talk about their child.

The child being able to attend the school during the day has also benefits for the family as they see this as being a relief for themselves. While the child is away during the day the family can get some rest and get a chance to recover and to meet the child with new strength after school.

Some families took the opportunity during this discussion to express their worries about the general lack of disability services for children. Some families have another son or daughter who would need the same type of education but does not receive it. They argued that more services of the sort being provided in these classes should be available to others.

They did not wish, and this was explicitly expressed by some, that their child should return to the Sweileh centre.

CENTRES FOR ADULTS

Families at two day centres were interviewed about the meaning of these services for their adult sons and daughters. In one, Quosoor, there were only girls and young ladies. The other was only attended by men. As the experiences differ between men and women, the findings and impressions from these two centres will be presented separately. 13 mothers participated in the discussion at Quosoor, while 5 mothers, 1 father and 1 brother participated in the discussion at Al Salam Club.

Quosoor

"I swear to God about the Swedes! We were frightened at Sweileh (when we heard about its closure). SOIR had done a lot of good - we thought it would disappear. Now you have shown us again that it is possible (to give our daughters a good life)." Families had once been very worried when they heard about the dissolution of the Sweileh centre, especially if they had a daughter there. They feared they would be exposed to ill-treatment from the public when they heard that new services would be set up in the community. This created a considerable degree of anxiety among the families.

During these interviews, after their family member had left the Sweileh centre, they expressed much satisfaction about the new service. They found it especially important that a bus collected the young ladies in the morning and left them off at their home in the afternoon. This arrangement made them feel secure. There was a broad agreement among families about the bus and the security it gave them. It was this feeling which was expressed by the mother in the previous quotation.

The same feelings were expressed by the mother who meant that *"The family was lost when the project started - today we are happy"*. Another said that *"SOIR pioneered again to move to new areas (of Amman) - SOIR does things that others don't"*.

Families are very glad about Quosoor. It is a private welfare organisation and several families donate to them and encourage others also to support them. They like the leadership and the staff: *"All people are good - like a family"*. *"They celebrate when there are birthdays - they are happy"*. The concern for the girls shown by Quosoor is very high, as one expressed it: *"They come home to the family if they miss the girl"*.

In the discussion about the meaning of Quosoor, its importance for the families is often mentioned. When the daughters have the opportunity to spend the days there they are also happy persons at home: *"She was very nervous, throwing things around. She has changed a lot. Comes home, happy, tells the family about what has happened during the day"*. *"The atmosphere in the home has changed. The girl is happy, the home is happy"*. *"When she is at Quosoor she is happy, when she is at home she is unhappy"*.

A day activity centre is a place where several types of activities can take place. Persons are usually occupied with some productive activities but there should also be room for various forms of adult education if it is found desirable. But this is not mentioned very much by the families. However, one mother says that *"She has learnt a lot, she is happy"*, while another says that *"She is very happy. Loves Quosoor more than the family. She has learnt the routines of home"*. Yet another mother says: *"Now we want some adult education!"*.

Al Salam Club

One aspect of the discussion at this social club centred on participation in community life. There were arguments as to whether these men be part of the community: *"We want our sons to be in the community. When he is at home he is isolated. Here he has contacts"*. *"He is secure here. He is grateful"*.

But there was also some hesitation about the wisdom of participation in the community and this was based on negative experiences: *"He will be teased in the community"*, *"In our community they laugh at them"* and *"Our communities are not civilized. Only families with a disabled member will understand"*.

However, not all experiences after having been part of this social club were negative: *"When at home he now goes to shop. He has become responsible at home"*.

The lives of these men have changed a lot after having joined this club: *"My son has started to look after his looks and his dress"*, *"He wakes up, does his toilet, dresses and leaves happily for his job"*, *"He is happy to be here, better now than before. He is happy with new friends"* and *"My son has changed a lot. Before he hit his sister and was very nervous"*.

There were expectations from the families about a more clear focus on jobs, in the club and in the community. They wanted this social club to prepare them for employment: *"Looming? Any other kind of activity?"*, *"We want vocational training for him"* and *"This is only a place to spend some time. We want a profession for him"*.

The brother in the group started a discussion about individual programmes for the men: *"Would it not be desirable with personal planning while at the club, and with activities to satisfy their needs?"*. At this stage there were no immediate plans for this.

COMMENTS

The main picture of these community based services which emerges in these interviews is an expression of great satisfaction. At the same time as this is said one must be aware that there may be a group who were not fully satisfied. Whether it is small or large cannot be confirmed from this study as those who may not have been fully

satisfied did not voice their opinion. This is not unusual in the case of a service being delivered to a group, as someone might have needs differing from what is common in the group.

It should also be remembered that these were interviews with the families of persons which reflect how they view the support provided for their children. Other categories of people would most likely see other aspects of these services.

The presentation which has been given here may not seem extensive. But behind these quotations from the interviews there are many families who expressed the same views. This indicates that it is a considerable opinion which is represented here.

Persons who have received these services, be they classes for children or day centres for adults, are happy over what they get. This is referred to in several ways. Maybe this is not something to be surprised about as the alternative for them would be to stay in their home without access to activities. The alternative would most probably be a passive life which would lead to the person being "nervous", the expression used by many of the families.

Being in a group away from home, with friends and staff, creates a stimulating environment different from that offered at home. Being part of these services offers new activities and social relations. The personal and social development of children which was reported by families becomes a natural consequence of such a situation. For natural reasons attention is given to dressing and toilet. Relations to staff and friends provides incentives and expectations for communication and talking. It is therefore not surprising if their speech develops as a natural consequence.

The widening of experiences and the access to new relations which occurs in classes and centres, becomes a natural basis for personal and social development. This growth of the person is naturally seen and recognised at home, resulting in the new atmosphere which families talked about. A good disability service therefore is not only something which benefits the individual person but also various aspects of family life.

As it was families who took part in the discussion it was the factors which they saw, their family perspective, which came to the fore. One must therefore accept that they did not express concern about with the content of the education provided in the classes. These are issues which are the concern of the professional groups and which leave little room for comments from others. It can be seen as natural if they did not comment on these matters as the teachers and assistants are seen as very competent.

In the centres for adult men and women, families were content with the activities which took place and the consequences for both personal and social development. There was no real criticism of this service as it was seen to fulfil their expectations on occupation during the day and away from home. It has also been too early to develop the principle behind the function of the day activity centre. When this takes place one will find that the intention with this service is a broad programme of activities which lead to greater participation of persons in their community. There

were however some few comments which point in this direction. One is the comment from the brother who suggested individual programmes as a basis for choice of activities. Even if this centre is not a place which can solve unemployment for these persons, more could be done to relate to productive work which takes place in local community.

Another reason for the satisfaction of families, and this was expressed specially by those whose children were adults, is that they at last have got a service for their sons and daughters. Because of lack of disability services in Jordan, they have for a long time sought assistance but not received any. Instead they have had to cope with their child in their own way. Now when they have gained access to a service they want more families to get the same chance as they have been given.

11 REFLECTIONS

The purpose of this chapter is to reflect and comment on the Amman Projects. At the outset the objectives of work were formulated as an ambition to provide better lives for persons with disability through a reorganisation of the disability services provided at the Sweileh centre. A community based approach was the term used to indicate the central idea, namely participation in community life of persons through the provision of community based services. The goals were not specified in detail, only the frame of reference was expressed and thereby the direction for the development of new alternative services. Work would have the character of a process during which the goals gradually would materialise and finally be decided on, when one had found a satisfactory solution to the person's need for support.

In the first part of the chapter the main achievements are summed up. In the second part some reflections are made on the experiences of the new disability services. Finally a comment is made on some main achievements of the Amman Projects.

A NEW STRUCTURE OF DISABILITY SERVICES

Supported education

The first step that led to the provision of supported education was the result of cooperation with responsible bodies involved in educational work for persons with disability in some of the refugee camps in Amman. As teachers with relevant competence could be transferred from the school at Sweileh they, together with local assistants were able to provide the children with adequate education.

Further opportunities were provided when cooperation was established with some local Zakat committees. Through the extension of their existing involvement in the provision of welfare services premises in mosques were made available and offered for the education of children. This became a very important step towards finding new forms for the education of children with a disability.

The reason for having to use the camps and the mosques for education was the fact that the ordinary government schools were not, at an early stage, sympathetic to the idea of admitting children with an intellectual disability into the ordinary school system. A consequence of this reluctance gave SOIR an increased incentive to find a way of establishing some classes in an ordinary school.

Eventually a school made premises available and a positive relationship was established. It was the local school in the Sweileh district which was familiar with

the work previously carried out at the Sweileh centre and who agreed to take on the challenge. This enabled those children from the Sweileh area to transfer from the classes of SOIR to the local school in their home district, together with other children from the area. The experience from this was seen as positive and has led to several other schools opening up for children with intellectual disability.

Daily activities for adults

A short period before the establishing of the Amman Projects, the Sweileh centre had ceased to be a residential home. All, with the exception of a small number of adults, returned to their family homes. But a person with a disability still requires support for his everyday life. If he gains access to activities with support during the day and outside the home, he can experience an active and fulfilling life, in a new setting, together with others. Education fills this function for children. Adults have two possibilities either employment with or without support or through day services. For a group with a more extensive need for support employment is less likely. Instead day services are more favourable.

A number of persons, even if they are few, have acquired employment after having left the Sweileh centre. They are mainly persons with a limited need for support, but their situation has become an important example for others for whom it has not yet become a reality. It has also been possible to establish several new centres for groups of persons with a severe disability who now receive services and activities on a daily basis. Some groups are only for men, some only for women and some are mixed. The development of these centres has been innovative and greatly appreciated, especially by women who otherwise are confined to spending their day with their family.

Homes for persons

There were a few persons at the Sweileh centre who had never known a family of their own, these persons having been abandoned in early childhood. When the residential services were to be closed they had no family to return to. Much consideration was given to finding an alternative solution to this situation. The idea of a group home, familiar in the Swedish context, was investigated but no suitable answer was found. The idea of a foster home was seen as an alternative, it not being uncommon in Jordan that single adults remain in the parental home. Staff previously employed by SOIR agreed to welcome a person into their own home, in return for financial remuneration covering additional costs for the person incurred by the family. As each of the persons in this way acquired a home, it became a very personal alternative for each one.

A community support team

Persons with a disability are in need of expert support for their disability, irrespective of whether they live in a residential home or in the community. The expert group which had served at the Sweileh centre retained their functions after its closure, the character of their work being redefined and organised as a community support team.

The Sweileh centre had also had access to other experts on a consultative basis, for example the medical doctor and a dentist. These resources have been retained and even extended, following the closure of the centre.

New partners and local resources

There are some specific consequences of having chosen a community based approach when establishing new disability services. The importance of the family and the local community is given greater emphasis in this approach and presupposes the ambition to localise the new services to places close to the homes of the persons. Consequently the new settings are now spread to various places in Amman, depending on where the persons live. Another consequence of this ambition is the localisation of services to already existing buildings in an area. It then becomes possible to provide services close to home. If special buildings are required one can be referred to areas where there is space, but not necessarily close to the home communities.

Educational and day services have become a reality to a large extent because of SOIR:s success in finding partners with whom to set up the projects. A lot of energy and ingenuity went into the search for new partners. As several projects were localised to the refugee camps, UNRWA became a natural partner. But also private organisations, those already existing or those formed for this purpose, took on a responsibility to provide support for these persons. After having approached some Zakat committees and having had this cooperation formally approved, these have had an extensive influence in the establishing of new forms for education and daily activities. A positive and constructive contribution to education naturally came when the Ministry of Education accepted that a class for children with special needs could be located to a local school.

A transition of services of this nature requires a number of formal decisions. To achieve this one has to have a very clear idea of what is to be accomplished and how the necessary changes be achieved. The director of SOIR has had a decisive role in the central task of establishing and maintaining these important contacts with responsible ministries and authorities. Finding such public acceptance for the projects has led to the developments which have taken place during this period.

The experiences of the Amman Projects soon became well known in Jordan. Representatives for SOIR therefore became very much involved in presenting their services for visitors and other interested groups, for example in training programmes for professional staff. Locally, in the neighbourhood of the new services, interest was aroused. This required that staff responded to this interest and established relationships with local people and businesses. On many occasions the new services received contributions and support from local people. The creation of an increased awareness of the rights and possibilities for persons with a disability to live better lives also became a task during the transition period.

This new structure of disability services can now be said to be well recognized. Established by SOIR in Amman and stimulated by the community based approach which had been chosen as its frame of reference, SOIR has widened its

community network. An open attitude towards neighbours, local resources, interested persons and organisations and national ministries was essential. This task and the achievements made by SOIR in Amman, has to be seen as an important landmark in Jordan and internationally, in the establishing of services for persons with disability.

New lives of persons

The aspiration of the Amman Projects was to achieve better lives for persons through the establishment of new disability services. When summing up these community based services they can be seen as an important achievement in themselves. But these are only means to achieve better lives for persons! Had additional resources been made available a study of individual consequences could have been carried out. However, there is now only indirect information about their lives as views concerning these issues having been made by family members in discussions with them. Information has also been gained from the questionnaire to family members, staff and the public.

The main view which emerges is a positive one. These are persons, children and adults, who in various ways have benefited from their education and daily activities. The common reaction has been an expression of unhappiness when or if they cannot leave home for their daily activities. This illustrates that they see the life being offered through these services as something valuable and desirable.

At the same time as this is said one must be aware that this is information gained when describing a group. Had there been a study where the life of each person had been analysed one would most likely have found a variation within this group. A major group would be satisfied, a few would be found who would have benefited to a very large extent and most likely one would also have found a few persons who are not satisfied with the life offered. A consequence is of course that more can always be done to achieve better lives for persons.

There is one further aspect of the lives of these persons which should be commented on, namely the views of families and their relationships to SOIR. Based on the ambition to localise services close to the homes of persons, new relationships to families have been established and these are viewed positively. Contact is frequent, the families visit and participate in the services, often being supportive in contributing to the work. Likewise staff visit the homes and are familiar with the home life of those attending the centres.

A platform for further development

The work by SOIR in Amman has been successful. By offering persons new services new lifestyles have developed. One can say that a new platform in society has been formed for this group and this is very different to the one once offered at the Sweileh centre. But this is not the end of development. The new platform is merely a stepping stone from which to continue.

Services can be developed and extended further. A challenge has been accepted by the Ministry of Education with a positive attitude towards welcoming child-

ren with an intellectual disability into the ordinary schools of Amman. This provides new opportunities for children and for teachers. SOIR has also been seen as an organisation which has taken responsibility for providing education for children with a more severe disability. More still needs to be done for these children, for example the need for further development of curriculum and working methods. To achieve this also requires attitudes which recognise these children's right to education.

Experience so far has also shown that there are opportunities for the development of daily activities. It has been seen that it is possible to arrange employment even for adults with disability. This is a route which should be pursued further to avoid all adults being limited to receiving daily activities instead of employment. It is necessary to prepare a way out of day services.

As the essential idea regarding day services is to offer a good life to persons, the aim must be that persons are able to experience a working week which is purposeful for the individual. The means by which this will be achieved are the activities available during the week. As the needs and requests for a good life varies between persons, there is a need for a variation in the activities which are made available. This in turn requires a mechanism which guarantees that the week will be experienced as purposeful by the individual. A programme for quality control has been developed in the hope that its use will contribute to such a development (Ericsson, P., 2005).

With this choice of a community based approach to disability services which has been realised in so many ways, SOIR has also a responsibility to share its experiences with others. Spreading an awareness of the potentials for persons with a disability to lead better lives is natural when viewed from this new platform.

New services as alternatives to the institution

During any process of transition from institutionally to community based services, one has found that the key to institutional closure lies in the development of the alternative, the community based services. This has been the case even here. The extensive development of community based alternatives for all persons who previously attended the Sweileh centre, opened up possibilities for their participation in community life. In this case it not only became a reality for those with a mild but also for those with a severe disability.

To close a residential institution the persons living there must move. However, they need support because of their disability, inside as well as outside the institution. The alternative community based disability services are therefore the key to institutional closure. This has been illustrated here.

SOME SURPRISES AND DISAPPOINTMENTS

Without previous experiences from Jordan the development of the Amman Projects was of course not easy, considering the many aspects of the task. Adding some dynamics to the process were the unexpected factors which facilitated and those which hindered the process. To understand the character of the process some of

these factors need to be described. The heading, surprises and disappointments, is chosen as a way of illustrating the process. How a transition like this is seen depends of course on who is looking at the process. In this case it is the SOIR consultant to the Amman Projects who reflects over some of the factors (Ericsson, P., 2005b). The reflections are therefore those seen by one who was involved, who had visions and expectations concerning the outcome of the project.

Continuity of the new services

Of the 6 new centres which have been established for children 5 are still being run according to the original agreement. Of these 4 are still located to the original premises in which they began. This reflects both success and continuity and a desire to extend the work to new services.

The present target is to find means of providing education for children over 14 years. The schooling which is now provided ceases when the children reach that age as boys and girls can, for reasons of tradition, no longer attend the same school. This challenge presently faces 5 of the present centres. The centre with which the agreement no longer applies found the cost of providing staff for children with a severe disability too costly and have therefore reverted to providing schooling for children with less need for support.

The centre which has changed premises reflects a positive development. Two groups of children have been provided with new purpose built classrooms in a building in the same grounds, the original classes having started in small temporary prefab premises. The initiative to replace the old premises was taken and supported by the Jordanian counterpart with assistance from SOIR and other contributors.

The assessment to-day is that the present 5 centres for children have reached a state of stability which guarantees continuity for the future.

Of the initial 4 centres for adults all are currently in existence, 3 of which are well established and have every prospect for continuity. One project however, the first one to be started for men, has ceased to provide a service which meets the needs as drawn up in the initial agreement. Because of a change in location the original group is unable to attend and contacts have not been established with a new group of men requiring such a service. The contract with SOIR has therefore expired.

Of the remaining 3 projects for adults, 2 have changed premises. In both cases the counterparts having acquired funding and support, in one case to build and in the other to avail of premises in a newly built mosque. Both have remained in the same area and thereby been able to maintain social contacts and established local support. The development has also enabled the centres to increase the numbers attending and to extend the choice of activities being provided. In both centres there has been a continuity in management and staffing, a factor which is seen as very positive.

Support from public authorities and organisations

Looking back one of the first events which caused a certain amount of surprise and

satisfaction at the time was the open and willing attitude expressed by the Ministry of Social Development towards the idea of developing an alternative to the existing centre in Sweileh. The workshop held in October 1997 was based on an initiative by the Ministry and followed up by the participation of a representative from the Ministry in a study visit to Sweden. In retrospect one must recognise that this relationship was significant, the Ministry having been one of the partners in the negotiations with presumptive counterparts. Opinions have varied but their long-standing commitment has been to the common goals formulated in 1997 regarding community based services.

The response shown by local communities during the so called "knocking doors" phase of the Amman Projects can also be seen as one of the positive surprises experienced. Admittedly one was at times met by indifference or a refusal to further discussion but never by open hostility. The overall response by possible partners has been one of sympathy and interest to discuss the issues. Even if lack of interest was expressed at times, the reasons most often were understandable and realistic. The conclusion from the Amman Projects is that the idea of inclusion of persons with disability in the Jordanian society is accepted and achievable.

Specific and individual positive experiences are many, as for example the development of foster homes for adults lacking a family connection. Also the positive response of the communities in which they came to live and the supportive reactions in neighbourhoods where the different centres came to be established. In no case was there any expression of negative reactions or protest towards the introduction of these activities in a neighbourhood.

Another aspect of these relationships with and acceptance by society has been the experience of co-operation with the Zakat Committees. During the initial phase of the Amman Projects this possible relationship was unknown to the Swedish representatives of SOIR. An awareness and understanding of the function of Zakat in a Muslim society gave rise to new opportunities for the development of community based services. It also led to a new understanding and interpretation of the meaning of the term community based services for persons with disability in the Islamic tradition.

Local acceptance and enthusiasm

Following the establishment of a centre in an area of Amman, further surprises and positive experiences were made. In retrospective one can see that the characteristics of the area has been decisive for how well a project has become a part of the community. Responses have varied depending on the character of the neighbourhood. In one case a local petrol station offered to assist with transport costs by contributing petrol, likewise a bakery offered to provide bread. In an area lacking such services, these offers would not have been possible. In a residential area a neighbouring housewife offered her voluntary services as an assistant and on occasions near-by families to persons have volunteered to help if required.

On no occasion has there been any expression of opposition or protest shown towards the establishing of a centre or of the presence of persons with disability in

the neighbourhood. Often they have been welcomed and at a personal level it has been realistic to find work opportunities for the adult persons with a mild disability.

When discussions took place regarding the desirability of locating special education to an ordinary school, opposition was the expected reaction. In reality the immediate response was that the school took the initiative to build a ramp as a demonstration of their willingness to accept children with a disability! A similar example concerned a foster-home for a person with a physical disability. Before the agreement had been finalized the local health clinic had already prepared a ramp to facilitate the person's attendance at the clinic.

Unexpected sources of support

Co-operation with the Ministry of Islamic Affairs and Zakat Committees as it is experienced to-day is a source of support and development which was not identified or expected at the start of the process. During the period of "knocking doors" and the search for possible partners and suitable facilities for a centre for children in the Hai Nazal area, the suggestion was made that premises located in a mosque could be made available. Further contacts showed that these would be suitable for the needs expressed by SOIR and they led to the local Zakat committee.

As an organisation already involved in the provision of local welfare services, co-operation with them was seen as a new and interesting alternative. At the time experience had been limited to co-operation with the UNRWA committees and a private charitable society, therefore this suggestion was seen as a way to widen the group of partners. New experiences were gained through this relationship with an organisation characterized by its community based approach and its central role in a local community.

Following this initial agreement with the Zakat committee in Hai Nazal co-operation has been established concerning two other projects for children in Hussein and Manara and a project for adults in Wehdat. The enthusiastic involvement shown by these committees was a new and unproven perspective for SOIR and one which led to an extensive and encouraging co-operation.

Representatives for the Zakat committees have also shown interest in developing their knowledge and experience from this field, two of the representatives having visited Sweden to gain impulses for the further development of their projects. This experience has shown that a community based approach needs sensitivity for and understanding of the community in which one is involved. New ideas and opportunities can be found when a receptive approach like this is applied.

Expressions of pride and satisfaction

The general reaction of the Jordanian counterparts, those responsible for running the new projects, is one of pride and satisfaction. There were some initial expressions of hesitancy and lack of confidence but most centres are to-day stable and secure in their task and expressing satisfaction over their achievements. Of the original group of projects only two have chosen not to extend the agreements and ceased to provide the services as intended. One of the reasons have been unexpected

changes in environment for example redirection of traffic and roads leading to the dismantling of buildings. Another project was short-lived primarily because of an incorrect assessment of the financial stability of the counterpart. In both cases it has been a disappointment as the original potential was positive.

The overall picture from these experiences of locating disability services to the various communities in Jordan, is that SOIR has been met by positive reactions to the Amman Projects. For many this has been seen as a surprise, for others merely a confirmation of what had been expected based on experiences gained from other countries. Now it has been shown that community based services for persons with intellectual disability are realised and accepted in Jordan.

Good relationships with families

One of the reactions to the closure of the Sweileh centre which was feared was a negative response from parents. At an early stage the parents had sometimes rejected their child when it was time to return home and this was now seen as a possible reaction. Their fear was that their child would be discharged and left without services. The fact that the first step in the closure of the Sweileh centre was its conversion into a day-school, the children continuing to attend on a daily basis, was therefore seen positively as a step towards "normality", their child attending school like other children.

This reaction was a surprise for many and one which positively facilitated the transfer to new services closer to home. One of the consequences of the change into a day-school was the shift in the view families had towards their children. By attending school on a daily basis their child acquired the role of being a pupil with a disability, rather than a patient in a disability institution. This was reflected positively both in how the family interacted with their child, its dress, its participation in family life and the parent's chance for involvement in the daily life of their son or daughter.

When the early new centres closer to home had been established it was therefore seen by most families as an advantage, that the child now was closer to home and to the life of its siblings. This closeness to the life of the child also led to new and more frequent relations between the families and the teachers. They also gained contact with the members of the Community Support Team, with whom the family had had limited contact while at Sweileh centre.

This was for many an unexpected development which provided a basis for new relationships between the children and their families and between the families and the centres. The reaction was therefore a switch from a negative expectation of a service being "closed down", to a positive experience of new relationships and more valuable support. At some of the centres this has developed into a feeling of "ownership" on the part of the parents, expressed in their support and involvement in the running and maintenance of "their" centre.

Commitment of staff

The development of the relationship between SOIR as an employer and its staff, has

also been affected by the transition. At the time of the initial enquiry into Sweileh centre in 1994 there was considerable staff discontent regarding working conditions and the lack of clarity as to the goals. Staff were often seeking new employment in other services. During the period of change, from the initial proposal to embark on a community based project in 1995 until the start of the first new service in 1998 staff had time to consider the alternatives and decide whether they would participate in the process or not. The decision regarding the future direction of work provided a new and clearer future and an opportunity for staff to make a choice. Of those who chose to remain and participate many are still involved in the work of the Amman Projects. Several are now holding senior and responsible positions either within the SOIR organisation or having been employed by the counterparts with whom SOIR has established agreements.

Of the 27 persons responsible to SOIR, the administrative staff of the head office, the Community Support Team, the managers of the new centres, the foster parents and the maintenance staff, all but 6 have been involved throughout the period of transition from an institutional setting to the community based projects of to-day. This means that 21 of those responsible for the Amman Projects to-day have participated in and influenced the process which has taken place.

This indicates that those to-day responsible for the management of the new projects have themselves had influence over their formation. In addition to this group many of those now employed by the counterparts have also previously been employed at the Sweileh centre. A consequence of this continuity has been the commitment of staff to the idea of a community based service and their potential to be ambassadors for the entire project. This staff commitment has been one of the most important factors for the success of the new projects.

For those who have chosen not to participate it has not been necessary to remain. Many have found new employment either in other services in Jordan or in neighbouring countries where their experience has been valued.

Expected and unexpected disappointments

Persons experienced in the area of development, irrespective of the field, often have a sensitivity to the strengths and weaknesses of the project. Therefore they acquire a sensitivity regarding the hopes and hazards of the task. So called "surprises" can be experienced by the uninitiated while the one familiar with the field is unimpressed. Disappointments on the other hand, often reflect "negative surprises", or unexpected developments, for which one is not prepared.

Looking back at the transition which has taken place in Amman it is the unexpected which has caused disappointment rather than surprise. Difficulties which have occurred and for which one was prepared, have not necessarily caused disappointment as they have been understandable. Lack of finances to achieve all that is desired is such an example.

Lack of enthusiasm and satisfaction over what has been achieved is on the other hand a disappointment. In Jordan interest and involvement from some disability organisations has been limited and much effort has been needed to explain and

defend the process in spite of its compatibility with Jordanian disability law and current international knowledge and disability policy. The positive surprises regarding support and encouragement came instead from representatives from the ordinary society, the so called uninvolved citizens.

Enticements of seeking employment outside Jordan

A disappointment which cannot be seen as unexpected are the attractive offers made to qualified Jordanians to leave their own country. Highly competent persons who could be seen as potential staff within the Amman Projects have instead chosen to work in other countries in the region. This applies to many categories of professionals in the SOIR services. The terms of employment available generally in Jordan and specifically within SOIR, has not stood the competition of offers made from abroad. Some exceptions should however be noted where former SOIR employees returned to Jordan to take up a management post within the project.

Dependence on volunteers

Another aspect concerning terms of financial remuneration has been the tradition of dependence on volunteers. From one point of view one can express respect and admiration for those who are prepared to work as a volunteer. Many who accept this condition of employment are however educated but unemployed and see this as a temporary appointment to gain experience while waiting for full normal employment. They can also be untrained but with their life experience they can make a good contribution to the work.

For this category the level of remuneration, which is merely the equivalent to pocket money, prevents them from remaining when offers of real employment becomes available. The consequence of this reliance on volunteers is however a lack of continuity and high turnover. This is naturally detrimental for the work and has shown how the organisation loses those with good qualifications for the task of assistants to pupils. Could they be remunerated with a reasonable salary the chance of continuity would rise greatly and the standard of the programmes improve.

In concluding this reflection one can see that the positive surprises have outweighed the disappointments and as expressed already not all of the disappointments have been a surprise! Instead they have been an endorsement of some of the concerns held and which have now been confirmed. These reflect conditions over which SOIR has little control but which must be seen as part of the circumstances in which one has to work. An awareness of these factors is however a step towards finding means of countering them.

CONCLUDING COMMENTS

The disability reform in Jordan

A long period in the work of the United Nations based on the concept of human rights has in turn led to the standard rules on equalisation of opportunities for persons with a disability. In an introductory chapter the dissolution of the Sweileh centre was seen as part of the ongoing disability reform, based on the new ideas

represented primarily by UN. During the early phase of the Amman Projects the intentions of SOIR were met with some doubt and hesitation. One often heard the expression “this is only something for your western countries”.

From the experiences gained from the work by SOIR it must be recognised that the ideas represented by UN are valid also in Jordan. When attention has been given to showing respect for the culture of the country the global ideas of UN are seen as equally relevant and possible to implement. Naturally there were occasions when there was uncertainty as to how they should be implemented. But there have also been many surprises regarding new possibilities which were revealed when people and organisations were receptive of the work being carried out by SOIR.

Commitment

The achievement of the Amman Projects is rooted in the understanding and commitment of the SOIR director in Amman. Her understanding of the community based approach and the new goals of SOIR has developed over the years together with the SOIR consultant. Together they have provided a roadmap to be followed. In this way the ambitions set by SOIR in Sweden have been realised in the setting and conditions offered in Amman and by the culture of Jordan.

The SOIR director chose the staff to develop the new services. A majority of the core staff had previous experiences from having worked at the Sweileh centre. But these experiences are not enough during a transition from institutional to community based services. Working in a community, close to persons and their families, requires a different approach to that used in the residential institution. A number of activities therefore took place during the project period in order to develop the competence necessary to provide the new type of support required. The SOIR organisation held responsibility during the period of preparation for this task in relation to the other organisations, neighbours, families and not least the persons themselves. In this way a high degree of commitment became a characteristic of the entire organisation.

Local resources are available

At the onset of the work by SOIR in Amman it was not in any way decided how the transition of disability services should be managed. The closer relationship to the ordinary community indicated by this approach pointed to the use of local resources, one of the characteristics of this method. But at the early stage it was unclear which resources were to be involved.

It has several times been mentioned that “process” also is a characteristics of the community based approach. The direction is clearly given by the frame of reference, the goals are set, but the actual solutions are not given. These are the result of the factors which contribute to the outcome of the process. Under these circumstances a most important experience was made by the Amman Projects. “Knocking doors” has been mentioned as the method used to maximise the outcome of work in this process. By knocking doors contacts were made with persons and organisations and those willing to contribute to a better life of persons were identified. Cooperation was established and in the end agreements were made with Jordanian partners

about their responsibility for the welfare of these persons. In retrospect one sees that several private organisations, religious bodies and public organisations have taken responsibility for the persons with a disability.

These experiences can be seen as a validation of local resources as one of the characteristics of the community based approach and the fact that local resources can be found in a community.

Residential institutions can be closed

During the early phase of the project a dissolution of the Sweileh centre was not seen as necessary. People were instead familiar with this form of disability service and regarded it as still being a possible alternative if certain changes took place. This opinion was based on the view that it was unrealistic that persons with a disability could live a life outside the institution.

The most significant outcome of the work carried out by SOIR in Amman has actually been the closure of the Sweileh centre as a residential institution and its replacement by community based services. When this is written no-one is any longer resident at the institution. One person lives in his new home, in a previous staff house, together with a former member of staff in an apartment at the entrance to the grounds. The administrative office of SOIR in Amman and the Community Support Team continue to have their offices there. What was previously the sheltered workshop is now a centre for daily activities for a group of adults resident in the Sweileh area of Amman. Its location there is regarded as temporary while waiting for more suitable premises.

Another reason for the continued use of the premises for these purposes has been the issue of a future function for the centre as until recently there has been a lack of clarity concerning the issue of ownership, now and in the future.

A better life is possible

The issue of intellectual disability is often associated with a feeling of pessimism. The general picture presented here is instead positive showing that it is possible for persons with a disability to experience better lives. This gives cause for a more optimistic view concerning the possibilities open for these persons.

The key lies in the shift from an institutional to a community tradition of disability. With the dissolution of a residential institution a new structure of community based services has been developed. Thereby a new pattern of life has been offered. This gives persons experiences which are more stimulating than those provided at the institution. This in turn has also opened up new resources. A closeness to the families has led to an awareness and a recognition of their contributions to a better life. In the neighbourhoods one has found persons who are generous with their support. New organisations are discovered which have made contributions towards a better life for the persons themselves.

Jordanisation

SOIR was initially invited at the end of the 60:s to Jordan to assist in the solution of a

social problem, the care of persons with an intellectual disability. They did so through the provision of residential services, to begin with in local houses, later on in a purpose built residential home. This was regarded as the appropriate form of disability service at that time. In line with development in Jordan this centre changed character from being a place for short term training to long term care of persons with a severe disability. Had this tendency continued a consequence for SOIR would have been a life long responsibility for caring for these persons. But it is hardly relevant that an organisation in one country should take on responsibility for a group of citizens in another throughout the life time of persons.

The Amman Projects which came to be developed can therefore be seen as a “jordanisation” of disability services. Persons now receive their support in the local communities in Amman and they live with their families under the cultural conditions of Jordan. Local organisations have taken responsibility for providing services or education for these persons as for other citizens. All posts which had previously been provided from Sweden, now have staff locally employed in Jordan.

When representatives from different cultures meet to co-operate on disability issues it can be difficult to find a common platform from which to carry out the task. This however has not been the case here. The SOIR director and the SOIR consultant have cooperated in such a way that there has been full agreement as to how the delivery of disability services can take place. At present the Amman Projects have acquired a high degree of sustainability and compatibility with Jordanian society.

In 1967 SOIR responded positively to the Jordanian request to start something new. They did so by applying the working methods seen desirable at the time. During the years since then SOIR has contributed to disability work in Jordan. But conditions in the country have changed during this period. To meet the demands for development SOIR has again applied methods which currently are seen as desirable. Their work may once again widen the scope of disability services in Jordan.

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THE COMMUNITY BASED APPROACH TO DISABILITY SERVICES

At the time of the decision about future services for persons at the Sweileh centre, the ongoing global disability reform indicated a direction for development towards community based services. The group with the task of setting up the new services chose a community based approach as an indication of the way forward. Several expressions were chosen as a basis for this approach as seen in chapter 3. This approach has been implemented during the course of the Amman Projects. As a consequence substantial experience has been gained. When summing up the Amman Projects it is also desirable to formulate the model which can now be more coherently expressed as the community based approach to disability services.

A SHIFT BETWEEN TWO TRADITIONS OF SUPPORT

The community tradition

After the second world war new ideas concerning the organisation and running of society emerged. Democracy, as a reaction to previous totalitarian regimes, represented the values which were furthered globally. An early consequence was the idea of human rights formulated by UN in its declaration of 1948. These ideas also inspired the introduction of the welfare society, an ambition that members of a society would receive support for a good life during periods when incomes were inadequate or deficient, for example because of sickness or unemployment.

Experiences from Sweden illustrate the importance of the introduction of the welfare society for the new disability services. The reaction to this political project was a request from disability organisations that they be included in this welfare system. They wanted the right to avail of the modern social services which were necessary for the realisation of their welfare.

Faced with a choice between a separate system of welfare for persons with disability, based in the old institutions, and guaranties of welfare through the public welfare system, society choose the latter alternative. Welfare for persons with a disability was to be achieved by them being given the democratic right, as citizens, to avail of public welfare services. This was the essence of a new socio-political idea which provided the first step towards participation in community life for this group. The development of community based disability services and the dissolution of institutionally based ones had begun. This new community tradition was a reaction against a long institutional tradition (Ericsson, K., 2002).

The institutional tradition

It was during the second half of 19th century that residential institutions were established. Industrialisation during these years made new demands. People were expected to adjust to the new life brought about by an industrial society. Those with a disability were one group which did not meet the expectations put on them and were consequently excluded. As families could not always care for their members society was faced with expectations to provide them with support. The natural way at that time was through institutional services.

Development in the field of intellectual disability is an illustration. During the mid 19th century compulsory education was introduced. It was expected that people would learn to read, write and do arithmetic. In the new schools it was found that there were children who did not meet the new demands. As a consequence they were usually excluded. In response to their need for education, residential schools were created which were extended into residential institutions for all persons with intellectual disability. The early ones were often established by charitable institutions but as financial demands increased responsibility was taken over by public authorities.

These institutions were organised for various groups depending on the type of disability. Based on ability, persons were sorted and sent to the institution to which they were seen to belong. Those with intellectual disability, blindness, deafness, epilepsy or physical disability were therefore placed in different institutions.

The initial but vague optimism concerning the possibilities of personal development during this early period gradually changed into pessimism during the first half of 20th century. The eugenics movement saw this group of people as a liability and argued for a restrictive attitude towards them. It was during these years that institutions increased in size and were surrounded by walls. Contacts with the outside world became limited and lack of funds led to poor living conditions.

Following the Second World War, especially during the 50:s and 60:s, institutions were still being built but the parallel ongoing disability reform led to them gradually being dissolved.

Comparison between traditions

The key to the community tradition is the idea that a person with a disability is a citizen and member of society and as such has the rights which belong to this citizenship. One immediate consequence, the second aspect of the new socio-political idea, is the right to full participation in community life, that which is lived by others. This has often been described as the right to live the normal life. A third aspect of this tradition concerns the character of disability services. The services being used by the public for their welfare are the services to be used by persons with a disability. The task of services is therefore to contribute to the realisation of the same community life as for other persons.

When the institutional tradition is described in these three aspects one will find that there are two roles which characterize persons. Those with a mild intellectual disability, who received their education through the residential school, the

“educable”, were seen as pupils. They are there to be taught by the special teachers. Persons with a more severe disability, the “uneducable”, were mainly provided with passive care. Their role as patients was underlined when the institutions later acquired a medical character. The roles of pupil and patient are similar in that in both cases persons are seen as recipients of care or of education and that they are expected to increase their competence by being taught or being cared for.

In the institutional tradition it is of course the residential institution which has responsibility to deliver disability services. Consequently society puts its disability resources into the institution, not into the community. It is therefore an institutional life which is provided by the disability organisation.

One way of comparing these two traditions is to look at how they view participation in community life. The institutional tradition accepts participation in community life first when the person has gained competence to meet the demands made in everyday life, outside the institution. The person has to master the expectations of life in the community. In the community tradition it is seen as a right for persons to participate in community life and this can be realised to the degree that there are adequate services to support the person in the activities of everyday life.

The shift between these two traditions became a reality when an awareness of the community tradition gradually developed into a new perspective. One saw that a new life could be possible when community based services were available. Persons could live in ordinary housing and could contribute to the everyday life of a community. It also became clear that they enjoyed this life. From viewing the institutional tradition with a knowledge of community living, critique was formulated and demands were made on the dissolution of institutions. The disability reform illustrates how this awareness, and the following shift in perspective, has become a reality in disability services.

THE UN STANDARD RULES

A new socio-political idea

Over the years there have been several expressions and models used to characterise the socio-political idea of the community tradition. This should be seen as welcome as it illustrates attempts to conceptualise this new idea. But it also becomes a matter of choice when one for example wants to describe the true meaning of community based services.

One of the early and most common models is represented by the expression “normalisation principle”, a concept which has gained global recognition. The original formulation dates from the beginning of the Swedish disability reform (Ericsson, K. 2002). The basic perception of this principle is that the patterns of everyday life in a community should be available also for persons with a disability. This emphasis on the normal life was a conceptualization of the alternative to institutional life.

There is also a group of expressions characterising whether persons are being brought into, or out of, a society or a community. When integration points to actions leading to persons becoming a part of society, segregation is its opposite, pointing to processes leading out of society. Another set of expressions with the same implica-

tion is inclusion and exclusion. Participation and separation also indicate possible alternatives lives for persons.

The standard rules as expressed by UN (1993) used equality as the basis for its model. Here this is chosen to sum up the community based approach to disability services. This points to three aspects to strive for when arranging a society which enables persons with a disability will be able to lead good lives. The basic goal is seen as an *equal participation* of persons, that is a life which is equal to that of other people in the community to which the person belongs. *Equalisation of opportunities* means that a society is given a composition and structure, for example through its activities, rules and welfare services, that enable the person to experience the same opportunities in life as those offered by society to other persons. *Equal rights and obligations* is the value-basis for this socio-political idea which indicates that the person with a disability is a full citizen of society.

Equal rights and obligations

One way of expressing how persons with a disability are seen in a society at different periods is to study the social roles given to them. When the church and religious orders took a responsibility to protect them persons with a disability were seen as "the Child of the good God". On the other hand societies who saw them as inhuman admitted them to very large residential institutions, lacking in normal standard, committing persons to a life under inhuman conditions. Seeing disability as a sickness led to a medicalisation of disability services. When these persons were seen as individuals under development, disability services became dominated by training philosophies.

The Swedish socio-political idea of the 1940:s, the normalisation principle, underlined that the use of public welfare services for persons with a disability was a matter of democracy and human rights. The view of UN has all along, since 1948 until today, been one of human rights. The social role expressed by these is therefore that of a citizen.

A consequence of this role is belongingness. The person with a disability belongs to a family. He has parents, grandparents and relatives and they have the same responsibility for this person as for other members of the family. He thereby also belongs to his home community, the place where the family in this generation and in earlier ones, have had their roots. He is one of the citizens in this community, which in turn has the same responsibility for him as for others. The person also belongs to society, a disability being a normal phenomena. In every society there is a group of persons who can be considered as disabled. Of all persons born there will always be some few individuals who will be the bearers of an impairment which will contribute to difficulties in meeting demands of everyday life.

Control over one's life is another consequence of citizenship. As long as the person is a child this is the responsibility of the family, as an adult it is the person himself who has the right to control his own life. There are of course possibilities for a society to restrict the freedom of a person, but this must be regulated by law.

The issue of control becomes important for persons with a disability. Services have the basic task of supporting and facilitating the everyday life of persons. Too often they are formed to meet the needs of groups, thereby having difficulties in meeting personal needs. The right to control one's own life implies giving the person the opportunity to influence the nature of his disability services.

No argument exists which limits citizenship to only some of all with a disability. Instead the role of a citizen applies to all, irrespective of type and degree of disability. For those with intellectual disability the degree becomes an issue as persons with a moderate or a severe disability usually have difficulty in expressing their views well enough to convey their requests for the life they want to live. In spite of this they still have the right to control their own lives. Consequently there is a need for someone to assist them in expressing their views. For the child it is the family who has this right. For the adult there is a need for someone to represent him in personal matters.

Equal participation

The main goal of a disability service is to contribute to a good life for persons with a disability. It is therefore necessary to have an idea as to what one means with the "everyday life" one wants to be realised. Here some general characteristics are given based on the life led by others.

A home

The two basic functions of everyday life are the home and the daily activities away from home. The child has a home with his family while the adult has his own home after having left the family home. In the family home it is clear with whom he will be living and the family may need support from others to give the child a good home. In the case of the adult the question arises whether he will live on his own or if he is going to live with others, for example a group of friends.

For persons with disability to be able to avail of a home there is a need for support. This is not part of the physical house but is provided by other persons who are there to assist. It is therefore necessary to arrange a staff group who provide this support. Their number and competence must be related to the needs and requests of the persons. If they have a limited need for support, few staff are needed. If persons on the other hand have got extensive needs, staff support must be extensive. Special needs in the group, for example deafness, may put special demands on the abilities of staff, like an ability to communicate with sign language.

The house becomes a home for a person when his views have been expressed regarding how he wants to live his life there. Wall-paper, furniture, carpets and curtains are some aspects of a home which are to be decided upon when moving. This is the occasion when the person has an opportunity to express his views, either by himself or through a representative. Photos of family and of his own background, attributes of a leisure interest, are some examples of what contributes to the making of a home.

The home is also the platform for participation in a local community during leisure. It is during evenings and weekends that a person does his shopping or takes part in entertainment and cultural activities. This is also the time when he has contact with family and friends.

Daily activities outside home

Leaving one's home during the day can mean attending a pre-school for the small child or the ordinary school for an older child. The adult usually has employment but if not he may participate in a job-creation programme. Others may participate in adult education. Some with a disability may have employment with the assistance of support. It is however a common experience that the more support a person requires the more often he tends to be without employment. If this is the case the possibility of being involved in day services outside the home can be the alternative.

Through employment a person participates in a productive process and thereby has an income which can be spent to realise the life he finds desirable. With the provision of day services this is not the case. Such services are part of disability services the objective being to contribute to a good life for a person. The means by which this is realised are the daily activities taking place outside the home during the five days of the week. A person, single or in a group, may participate in a series of activities during a week, while receiving support from staff or someone else in the community.

What characterizes activities that can take place? There is a wide variation so it is not possible to point to some as being more important than others. As such activities are part of a disability service it becomes a personal issue whether a certain activity is of value or not. The task of day services is to offer purposeful activities which respond to the needs and requests of those participating. These may vary within a group as what is seen as purposeful will be a personal matter. The main task of the organisation running such a day service is to find the activities which lead to a purposeful week for each one of those attending the service.

Qualities in everyday life

The basic pattern of everyday life consists of time spent in the home, in daily activity services and in activities in the local community. If one is to define equal participation it is not enough to describe how a person moves between available environments in a community. It is also necessary to be able to discern the various qualities of everyday life.

There are several qualities which may contribute to a description of equal participation. As regards persons with a disability material standard is one factor of interest. As these are persons who seldom have remunerative employment they must rely on economic support from other sources. They are still in need of financial resources to cover basic necessities such as housing costs, food, clothing, transport and leisure.

Persons with a disability are often attributed degrading roles. As equal participation is based on the concept of citizenship, a quality of everyday life could be

assessed through an analysis of the extent to which persons are recognised by others as citizens.

Personal well-being

The general public, including persons with a disability, occasionally require help from various experts for their well-being. Such examples are access to dentistry, services for well-being and the medical expertise provided by health-centres and hospitals.

When looking at the meaning of equal participation one must recognize that a substantial part of everyday life consists of activities with the intent to enhance the abilities of a person. The child goes to school for his education. There are social programmes to train a person to cope with local traffic. Therapy is necessary for some to develop speech, or physical movement. Some require surgery to improve vision or hearing. These are just some examples of activities to increase the well-being of persons.

Some may assume that persons, in spite of their intellectual disability, are very similar as regards their needs, but this is not the case. The differences between them can depend on the many types of origins for their disability. Some may also have an additional disability, for example concerning vision, hearing or mobility. Persons with an intellectual disability vary greatly with regard to their need for expert support. There is no single method which can alleviate this form of disability. It must be recognised that contributing to the well-being of a person is essentially an individual issue.

Equalisation of opportunities

This section refers to the actions of arranging disability services to achieve equal participation and the value basis for this approach, equal rights and obligations.

Everyday life in one's home community

This model puts emphasis on the importance of the person belonging to his family. It is also therefore most likely that his answer to the question as to what sort of life he wants to live will lead to a request to live in the community to which he and his family belong.

The consequence is that the disability organisation must be able to localise services to the home community. The characteristics of the community, be it a big city or a country village, will determine the character of the services to be offered.

Local resources

The natural way of achieving disability services with characteristics of the community is to use local resources. When providing housing for persons it is the local housing in that community which can be used. The housing market available to the public is the one also to be used by persons with a disability. The same principle applies to daily activities. The building of a special day centre is not necessary if one makes use of facilities, activities and support which can be found locally.

Public welfare services

In the earlier discussion concerning the origin of the community tradition it was shown that a crucial factor for its choice was the discussion about the welfare services for the public. Were they to be used by persons with a disability or should there be special welfare for them? The choice made was that there should not be special welfare services. Those used by other citizens should be open to all.

This approach is a fundamental characteristic of community based services. Social services, health centres and hospitals, pharmacies and dentists, are all examples of welfare services which should be open to all. In addition other welfare programmes such as housing benefits, support for employment and pension schemes could be open to persons with a disability. The basic logic of this approach is the recognition of this group of persons as eligible citizens.

A process towards goals

In this model one cannot work with centralised services, specially designed and created for a certain disability group. In the institutional tradition this was the case and persons were placed where the organisation found it suitable. When recognising that the person and his family have an influence over everyday life, when services are localised to the home community and local resources are being used, one understands the importance of being involved in realising the life requested by the person.

There are, however, several factors which influence how this goal will be realized. A number of partners are involved in influencing the end result of the process. Not only the person concerned and his requests for a good life will influence the outcome, but also the views of the family, of staff, and of representatives of the community. Factors like economy, personal and public, and the rules and regulations of society will also decide the outcome. This process requires that goals are clear and that the skills to achieve them are available.

Awareness

In the process towards participation in community life members of the public may perhaps for the first time, encounter persons with intellectual disability. Questions will be asked, informally and publicly, about these persons and their disability. For many the reason for such a disability may be unknown. When persons wish to participate in the same way as others there are often questions about what sort of life is appropriate for them. When they wish to be part of life in a local community people may be surprised a common belief being that these persons should be referred to institutional life. By tradition these persons have been "put away" in institutions so knowledge about them is limited among the public.

Questions like these should be welcomed and be replied to with adequate answers. When they are seen in the community questions may be raised. A result of this exchange can be an increased awareness by the public concerning the needs and rights of these persons.

Personal support

The essence of disability services is the ability to deliver personal support to each and one of those for whom the organisation is responsible. This requires a process in which goals are set for the support to be offered and for their realisation.

Receiving support from others creates a dependency on those who provide the services. From a citizen perspective the issue of control over one's own life is important for the person with a disability. There is therefore the need for occasions when the person is given the opportunity to express his requests, and to reach an agreement about the life he wishes to live.

What sort of life does the person want to live?

The task of disability services is to contribute to making a good life attainable for the person with disability. But what is a good life? As persons are different there will be a variation of opinions as to what constitutes such a life. A good life is nothing which a central administrative body can decide about. The one who has knowledge about its meaning is the person himself! He has his interpretation of what it means and in this situation the key question when delivering disability support will be "What sort of life do you want to live?". If he has difficulty in expressing himself he will require a representative who promotes his interests.

Agreements

The answer to this question becomes the starting point for the delivery of support to this person. If the answer is not considered realistic and attainable a discussion may be needed between the person, if necessary with his representative, and the organisation providing the service. The discussion may even have the character of a prolonged negotiation. The aim of the discussion however is to come to an agreement between the two parties, the person and the organisation. The content of this agreement will be the goals for the delivery of the disability services to be provided.

Activities to realise the agreement

Activities of a disability organisation are not carried out at random. There are, or should be, relevant goals for each and one of the persons for whom one is responsible. These goals make up the basis for the activities of the organisation. For a person the result of the activities he will experience should reflect the everyday life he asked for.

Does he experience the life he requested?

Delivering support to a person begins with the question as to what sort of life he wants to live. Thereby the goals for services to be delivered were formulated. In a professional organisation it is necessary to control whether one is working towards the goals agreed upon. The answer is found when a follow up of the activities has been carried out. One can also talk about quality assurance in the delivery of services. Quality has been defined as the extent to which these contribute to a good life for a person. This will be clear when one finds an answer to the question "does the person experience the life he requested?"

COMMENTS

The ongoing change of disability services is here seen as a shift between two traditions of support, from an institutional to a community tradition. This shift is complex, taking place on several levels as it concerns the persons with a disability and people around them. It also concerns the organisations and the type of services they are expected to deliver. There is also a cultural level of this change which concerns the social roles attributed to this group of persons.

This change between traditions is not a matter of technical differences between disability services. As they have emanated out of different periods, the middle of 1800 and the middle of 1900, the roots of change lie in the conditions of different societies.

This change between traditions may seem easy as one is familiar with the characteristics of the institutional tradition. It has prevailed since the middle of the 19th century and residential institutions still exist! But this change can only be realised to the extent that one understands the community tradition. This makes the shift more difficult as there is generally less knowledge about this tradition. One does not necessarily know what to strive for.

The purpose of this chapter has been to take some steps towards clarifying the meaning of the community tradition. By elaborating on the community based approach, and the experiences gained from the work in Amman, some light can be shed on the issue.

Identifying the two traditions of support has also led to an understanding of the disability reform. The character of disability reform may seem vague but the expression "two traditions of support" gives a more theoretical meaning and greater clarity to the ongoing process of change.

The Amman Projects started with the closure of a residential institution, the Sweileh centre. With a background in the ongoing disability reform and the shift between two traditions of support this must not be seen as a transient idea but as a logical process of change.

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