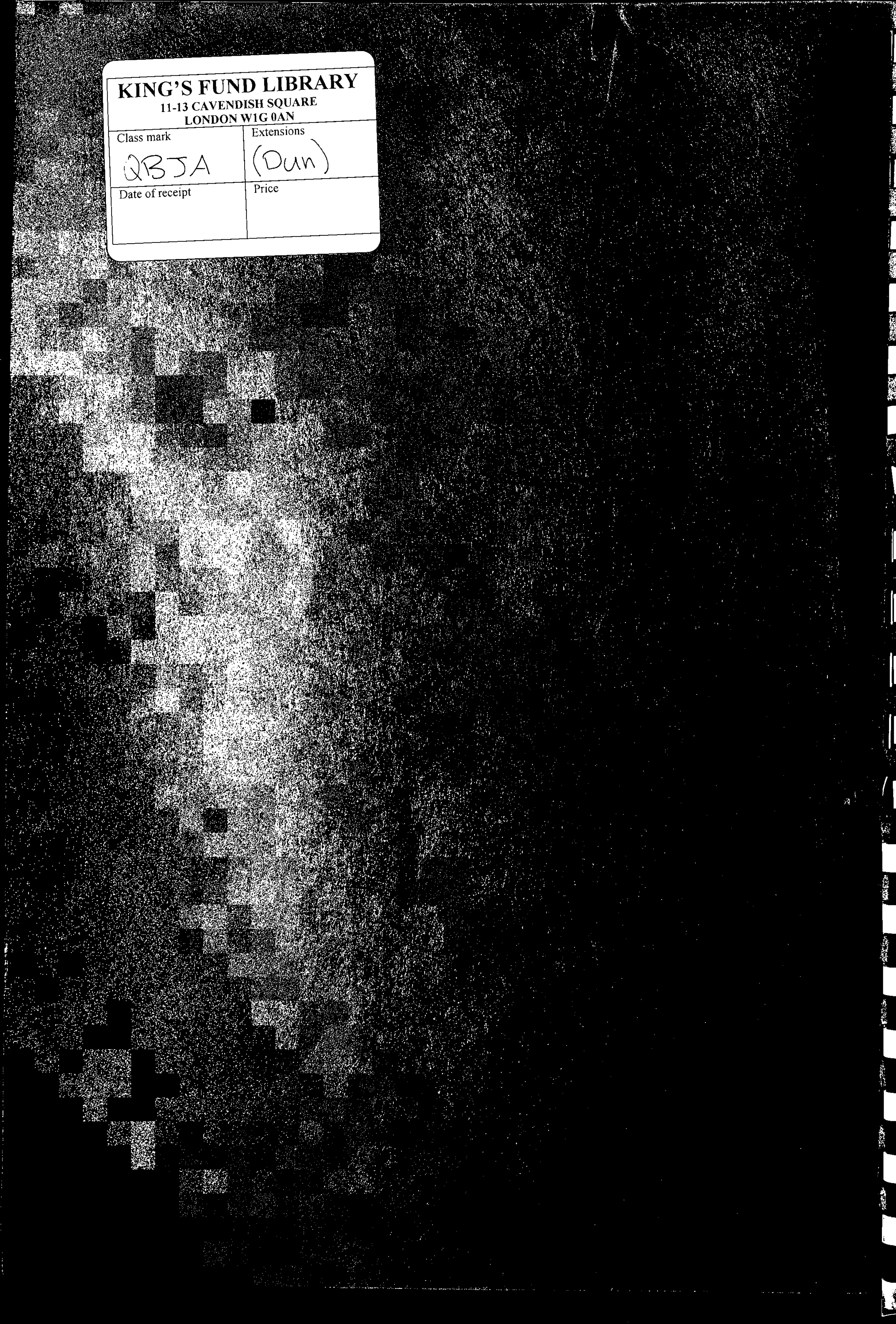

KING'S FUND TRAVEL FELLOWSHIP

REPORT OF A STUDY TOUR TO SWEDEN
TO EXAMINE THE DEVELOPMENT OF SERVICES
FOR PEOPLE WITH A MENTAL HANDICAP

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1. WHY SWEDEN?

1.1 Before embarking on a detailed record of my Study Tour it might be helpful to detail the reasons why I chose Sweden as the country that I wanted to visit:-

- the country had an extremely progressive reputation for developing services to people with a mental handicap, especially day services
- important to see option for service development
- identical philosophy for Community homes to my own Health Authority ie 3 to 5 place homes in normal community settings
- interested to discuss the factors that had led to the shaping of the attitudes of staff, public and the relatives

2. FACTORS THAT HAVE ALLOWED DEVELOPMENT OF SERVICES

2.1 In order to give some sense to these developments it would seem useful to identify the factors that have led to the establishment of the progressive services within Sweden over recent timesand to this end I have attempted to highlight the following factors:-

- within the population in general there is a high level of consciousness in relation to the handicapped and, indeed, there is a long tradition of public care which dates back to the 16th Centuary
- an acceptance of a higher level of tax which has financed a more developed Welfare State
- the country is rich and highly industrialised
- there are not the range of social problems as compared to the United Kingdom with a small population of 8 million people
- the nation has not been involved in war for 170 years which has allowed the country to develop at a faster rate
- the Swedish movement of disabled people and their relatives have been instrumental in developing services. In the consultative process they are automatically involved in the decision-making arrangements
- the Swedish Authorities have chosen to underpin their mental handicap services with legal rights for the individual person

- the personal committment of Government officials, particularly Mr Carl Grunewald, to the development of services. Mr Grunewald is not only revered in his own country but has an international reputation for his knowledge and insight into the needs of the Mentally Handicapped and the ways in which these needs can be met within the philosophy of normalisation and integration.

2.2 Profile of Present Services

Over recent years the general direction of the Mental Handicap service has been to create normal homes in ordinary communities in which the Mentally Handicapped people can live with appropriate support relative to their handicap and this type of care can either be with their own parents or in Community homes. The aim is to have no more than four or five residents in a Community home but there are as many as eight in some homes. It is also part of their policy to encourage parents of adults with a mental handicap to let their relative move into a Community home but still retaining close contact with their parents, as of course would happen normally with adults who are not mentally handicapped.

The policy also encourages people with a mental handicap to achieve a level of independence to enable them to live independently either alone or with another person with a mental handicap but with appropriate support nearby in case of need.

The effect of these policies is that there is some movement continually of people with a mental handicap going from Institutions into Community homes, going from their parents into Community homes or into independent flats and going from Community homes into independent flats.

Because of the experience gained over many years in rehabilitating people with a mental handicap, it seems that the failure rate on the need for people with a mental handicap to move back into sheltered accommodation is minimal.

Whilst there are still a number of Institutions remaining in Sweden, these have been reduced to very small numbers with the residents remaining being the more elderly handicapped.

Within the Community there is a continued development of day activity centres although there is no standard model adopted throughout the country. At present there is a range of activities which include some commercial outlets and over recent years the dependancy levels of residents attending these centres has changed significantly as the Institutions have run down.

3. DIARY OF VISITS AND CONVERSATIONS

My first day began at the Swedish Institute, Stockholm on the morning of Monday 9 February 1987. The Swedish Institute is a Government body that assists with cultural exchanges and, indeed, in my case a detailed programme had been drawn up which included visits to Community homes and day care centres in both Stockholm and Gothenburg and arrangements had been made to hold discussions with relatives' organisations.

Later that day my Study Tour began when I visited Omsorgsnämnden in the Liljeholmen district in Stockholm. The Omsorgsnämnden was a centre for the local Community Mental Handicap Team and I was shown round the premises by Ms Karin Kallin, Psychologist, and one of her colleagues. The premises, itself, was clearly of an exceptionally high standard and not only acted as an assessment centre but also as a base for the teams providing support in the Community. On going round the building, I was introduced to the person responsible for developing leisure activities. Although significant progress had been made in establishing good links with outside leisure organisations progress had been slow. She stressed that it was essential to ensure good follow up in order to guarantee that the leisure activities continued. Regarding annual holidays, ordinary hotels were used and included visits abroad to such places as Greece and the Canary Islands. When I asked her about public acceptance on holidays and leisure activities she replied that it very much depended on the type of group and their degree of dependancy. As an aside, I was subsequently told that all the members of the Team were involved in some form of public relations activity. Local activity was assisted by national initiatives where a lot of work had been done to give a higher profile to the plight of people with a mental handicap through TV programmes and information in schools. The schools themselves were integrated which did much to raise consciousness although some observers felt that more could still be achieved. At present separate classes existed within normal schools and it was thought that such initiatives as communal music and physical education classes could assist in the integration process.

Members of the Team explained to me in some detail the financial allowances payable to the person with a mental handicap ie based on levels of

dependendancy (four dependancy levels). Each person would receive 500SK (£50) to 2,000SK (£200) approximately each month and indeed once a person was over 16 years of age they received a "pension" which could range up to 3,8000SK (£380) a month. On top of this a disability pension could be payable. All people with a mental handicap had, however, to apply for this pension and would only be entitled to this allowance if they could not hold down a substantive job. Of their 300 clients 10 were holding down full-time jobs, 39 were working in sheltered workshops, 96 attended day centres and two lots of 60 places were living in residential homes. Within these residential homes they had their own day activities although it was now law that these 60 place homes be phased out and be split into 6 houses with 10 places each. Local councils now had a statutory obligation to plan architecturally for a set number of houses or flats for people with a mental handicap.

The Team also mentioned that they had regular contact with the FUB (relatives' organisation) and it was felt that when the Teams, as the service providers, and the FUB joined forces they became a very effective pressure group against the politicians in getting resources and, as I heard on several occasions later, the FUB had been instrumental in introducing the new law in 1986.

The Team also explained to me the role of the "Contact Person". Such a person was paid something like 200SK (£20) per month and would act as a friend/advocate for the person with a mental handicap and would do such things as sending birthday cards, take him home, take him to a movie, introduce him to leisure facilities and generally befriend him. Twice a year the Community Teams would have a meeting of the contact persons and give them any support that they require and such sessions would include talks on what it means to be mentally handicapped.

The following day, I was collected by Mrs Ingrid Jönsson who was responsible for the day care activities in the North West area of Stockholm. Initially I was taken to one of the most modern centres in the area which offered a wide range of day activities and was an attempt to move day centres closer to the residents.

Links had already been established with local employers although full pay-

ments had not been requested for the mentally handicapped workers as they believed that the initial way to win over employees was not to demand wages. In the long term the day centre managers hoped that eventually this would change when the employers recognised their worth. While saying that the day centre had already established a textile/weaving workshop and a drapery/curtain shop which was selling direct to the public. In addition residents were undertaking the following work with local employers:- churchyard gardening, library filing and laundry work in a nearby swimming baths. Within the centre itself a number of activities were being undertaken such as traditional industrial therapy, art, pottery, workshop activities and a fixer group (which did things like simple repairs and plant growing). I subsequently visited the drapery shop that afternoon which was situated opposite the day centre where the residents with a mental handicap were making up curtains and selling them direct to the public which also gave them experience of managing money. In addition there had already been occasions when the residents with a mental handicap went to homes and took measurements in order for them to make up curtains, although to date this had been confined to staff homes. Similarly they had also established a coffee shop for the public in a premises adjacent to the day centre which appeared to be doing well. The Managers of the centre remarked that they had noticed an increase in the dependancy level of the residents as the Institutions ran down and this put increasing demands on the centres themselves.

This particular centre, like the other centres, was based on the philosophy that small centres in terms of numbers (no more than 50) were best and allowed more opportunities to concentrate on the needs of the individual rather than the group. For the more disturbed residents a day centre had recently been established in a more rural area which was in essence a small-holding and included activities in gardening, tree cutting and the rearing of hens and chickens.

That afternoon I visited another day centre which was in all reality a Coffee Shop and included an Exhibition Centre downstairs. When I arrived they were preparing food for a visit from parents although it did offer a commercial service to the general public. The aim of the shop was to

provide a catering training to the residents with the long term aim of them going on to full-time catering employment. The residents were divided into two groups, one group doing the catering and waitering and the second group responsible for the cleaning and the managing of the exhibition centre which was rented out to public groups. I spoke to some of the residents who were obviously of a low dependancy (one of them spoke English!) and they seemed to be delighted to be working in such an area.

As I visited the premises when it was closed it was difficult to judge the trade that the shop was doing but I was told by the manager that recently the residents had been going round local shops and had been selling their bread and cakes very successfully. In the summer time they intended to buy tables, chairs and parasols and would provide a street cafe service.

With regard to their exhibition centre they had recently advertised for members of the public to exhibit some of their artistic displays with a view to the centre taking 10% of the rent.

The next day I visited Carlslunds Vardhem which was one of the few remaining Institutions in Sweden and clearly turned out to be one of the most valuable visits of my Study Tour.

Carlslund was situated near Uppsala which was a suburb of Stockholm. At the time of visiting only 70 residents remained in the Institution having reduced from 530 in 1980. I was met by Mr Bengt Marcusson, the Manager, and one of the Psychologists and a day of intense discussions began. Many subjects were covered during the course of the day but our initial talks concentrated on staff related matters. Like all Institutions in a run-down situation, they had experienced a loss of staff and a fall in morale. Staff had been replaced by temporary employees and they felt that in some ways this had actually worked well as it had brought new blood and ideas to the organisation. They stressed strongly the need to have regular discussions with staff and involve them in the process of change. The staff were the most knowledgeable about the residents and it was essential therefore that their wealth of experience was recognised in the run-down process.

With regard to training, this included visits to flats with groups and they believed that as far as staff were concerned, it was best to mix different disciplines, attitudes and age groups. The Managers believed that the professional staff within the Institution had a role to train others for community care eg Occupational Therapists and Dentists. When discussing my own situation they expressed the view that the British system of a "medical type" Institution was more difficult to change with the consultant and nurse working at a higher plain to the resident rather than being on the same level. They believed that such a regime provoked a hierarchial relationship between practitioner and resident. As an aside to this it was interesting to note that the Institution was staffed by care assistants rather than our system of mental handicap nurses. If a nursing input was required this was provided from an outside source in the form of the District Nurse.

When I asked them about how they had monitored the standard of service during the run-down they stated that they had made the conscious decision not to reduce staff in proportion to the reduction in residents and thus created a higher staffing ratio. As Managers they had instituted a philosophy of establishing within Villas, groups of staff with groups of residents with a view to them being discharged together. They believed that this had helped the transition process as both the staff and residents became more aware of what the future held and had already built up a group cohesiveness before discharge. This system was also supported by the philosophy of converting wards/villas to a more homelike environment where nearly all residents had their own room and were involved on the ward in such activities as cooking, shopping and laundry work. By adopting such a system the Managers had created a "halfway house" before moving to full Community care which, in the long run, made the process much easier. The creation of this "halfway house" had been accompanied with the full delegation of budgets. This had allowed local ward based Managers to make decisions about whether to buy curtains, carpets, paintings or furniture and as a result staff felt much more involved. Bengt Marcusson realised that it had taken a long time to gain acceptance by the Managers to let go and devolve financial responsibilities as in many instances it had been contrary to their previous way of working. What I personally found astonishing was the fact that these groups had been established in small numbers throughout the site rather than concentrating the residents in a smaller number of wards. This meant that you often

found only 4 or 5 residents living with staff in a large ward. When I challenged Bengt Marcusson about the financial implications of distributing the residents in this way his reply was "Yes, we recognise the additional cost but any cheaper arrangement should not be to the detriment of the quality of life of the residents".

Other areas that they identified as crucial in the run-down process was the involvement of the FUB. In fact within the institution there was a part-time FUB worker who would not only advise the Managers on the quality of the service that the residents were receiving, but would also act as a focal point for relatives who had queries or concerns about Community care. The Managers were adamant that although on some occasions they had been a thorn in their side they had also been extremely useful in carrying the other relatives with them in implementing the transition. In order to involve the relatives more in the process the Managers had organised twice a year weekend courses and talks and these sessions had proved useful in provoking discussions and interest in Community care. In the early stages it had been difficult to convince the relatives about the merit of Community care as they did not have any units to show them.

It was also clear that the Managers had gone out of their way to retain staff to "close the doors" and they had done this by guaranteeing employment to the people who were last to leave. In addition they had consciously tried to raise their status and ensured that they felt very positive about the fact that they were the last to leave. In 1979 they had issued a questionnaire to all staff asking about preferences in terms of place of employment, nature of work and training requirements. Although a large number of staff had left since that date through natural wastage, they still felt that it had been a very useful exercise. On a personal note, I was disappointed to learn that Bengt Marcusson and his psychology colleague had not been given any personal commitments in term of job employment which I would have thought could only have an adverse affect on the more junior staff. They accepted that along the way they had crossed swords with many groups in order to facilitate the change and in English quoted a Swedish phrase which translated roughly meant "You don't close an Institution and go unpunished".

Other useful suggestions they made included the necessity of planning a use for the site. In the case of Carlslunds plans had already been made to change the Institution into a camp for refugees when the place was emptied. They believed that this at least allowed the Managers to offer some form of employment to the non-caring staff eg catering and works, in the long term.

Just before I left Bengt Marcusson and his Psychologist spoke together for the first time in Swedish. I subsequently was told that they had been remarking that the type of questions I had been asking and the problems I had within a major institution were the same as other visitors had mentioned who had come to Carlslund from all over the world to learn from their experience. Such a remark leaves you clearly with the impression that many of the hurdles a Manager faces in running-down an Institution are universal throughout the world.

At the end of the day they summarised their advice in three key words which had helped them through the transition period ie information, support and participation and the principal of ensuring that the residents should be guaranteed a better quality of life outside the Institution before they are allowed to leave, must always be adhered to.

On Thursday 12 February I visited my first Community homes in the Kallhälls area, which was again in the north of Stockholm. During the day I was accompanied by a Mr Anders Wahlström who was the Group Home Manager.

The first home that I visited was like all other homes of a very high standard, situated in a normal suburban area. This particular house was located on a housing estate of around approximately 600 houses with 2 or 3 houses being specifically allocated by the Council for use by people with a mental handicap. The house was a conventional dwelling providing a home to 4 residents.

At the time of visiting, all the residents were out at different forms of day activity which included sewing, weaving and furniture polishing. Interior furnishings were clearly of a high standard and it was apparent that they had no institutional connotations. On visiting this house Mr Wahlström immediately brought to my attention the problem they were having with transport for the residents. Presently they were obliged to use the Council transport for the 5 residents which I was astonished to find was costing around £300 a day. They were having great difficulty convincing the Authorities that it was sensible financially to purchase their own transport. At weekends they tended to use taxis which seemed to be the regular practice throughout Sweden. I was subsequently told, as an example, that if a resident wanted to travel a distance such as Stockholm to Gothenburg (250 miles) he could travel by either taxi or plane at the equivalent cost of the rail fare. This would include the cost of a member of staff if this was required.

At the first house I spoke to the staff about their jobs, training and previous experience. I was particularly interested to find that the staff came from varied backgrounds and I subsequently found that this was the case in the other group homes that I visited. One female member of staff had previously worked as a hairdresser and another girl as a waitress. The Authorities had adopted the view that if you had the right caring approach then at the end of a probationary year you would be sent on a formal 10 week training course and at the end of this would be slotted into the first permanent job that came up. The female staff that I spoke to, although relatively happy with their present jobs, were a bit disillusioned as work within the homes offered them only a limited career progression.

The relatives themselves paid approximately 1,300SK (£130) of the total economic rent which was around £240 per month. The 1,300SK was paid from the residents' pension and the Council made up the difference.

The staff at this particular home, like the other homes, all indicated that they had seen a marked improvement in the behaviour and attitudes of the residents following the transition from an Institutional to a Community setting.

Mr Wahlström,as the Manager, was given complete financial autonomy within his budget to run the home although he had to be careful to plan for the replacement of any major item of equipment. Within his budget he was given flexability to pay overtime to staff to make sure that if residents' outings went over the prescribed period, that they were properly covered. With regard to sickness and absence cover, a call out list existed of staff who were prepared to come in at short notice and provide cover rather than the possible alternative of using staff from other homes. Maintenance of the property was carried out by a handyman who would work for the Council and covered several homes but in an emergency situation it was not unknown for a regular tradesman to be called direct.

The second home that I visited was geared for the more dependant or disturbed resident and when I visited, one member of staff had just spent a very difficult morning with one of the residents who had been attending the dentist. They felt fortunate that the dentist was able and willing to deal with the residents but they identified this as a future problem as more demands would be put on conventional dentistry services. Another problem area I detected was potential friction between the Community Home and the Day Centre. This was not helped by the transfer of a day record book between the two services. Unfortunately this book often provided the opportunity to pass cryptic comments between the two groups.

Another practical problem they identified within this house which was also a difficulty in other homes, was creating an opportunity for the staff to have breaks. Because of the fairly constant demands of the residents and the fact that the Community homes naturally did not have a staff rest room, this had developed into a problem particularly if the residents were not out at some form of day activity.

The third premises that I visited that day was a flat which had not yet been occupied but presently staff were preparing for the residents to take up permanent occupation. Again it was clear that no special precautions had been taken for the occupation of the residents, such as guards over radiators and protection from the hot oven but this was in line with their philosophy that the home should be as normal as possible. Over lunch I discovered again that staff came from a variety of backgrounds ie two had been care assistants at Carlslunds and one of them was completely new to the care of the mentally handicapped.

Later that afternoon I visited another flat in the nearby locality and found myself present at the birthday party for one of the residents. Relatives were also in attendance and it was clearly a very happy occasion with staff generally very caring in their approach. This increased interest and involvement of relatives was undoubtedly the result of the development of Community care.

The following day I visited the premises of the Riksförbundet för Utvecklingsstörda Barn, Ungdomar Och Vuxna, National Association for Mentally Retarded Children, Youths and Adults (FUB). I was met by Mrs Lisen Sylwan who was the Public Relations Manager and Editor for the varous FUB magazines. She told me that the FUB was an organisation set up in 1956 and had been formed by relatives and parents. Presently they had 30,000 members with 132 local societies, some with branches of 15 to 20 members and some branches of up to 1,000 members. Headquarters had a full-time staff of 15 with some local groups having their own full-time workers. The fee for joining the organisation was 100SK (£10) per annum.

In the public relations field FUB had produced several publications, some of which I brought back with me. An example of these are as follows:-

- magazines for both residents and relatives
- brochure for relatives of the severely handicapped
- an information booklet for outside organisations such as shops, taxis, police, companies and other agencies explaining how best to relate to people with a mental handicap
- similarly an information booklet for acute hospital staff who may encounter people with a mental handicap
- a cartoon booklet ridiculing many of the misconceptions of Downs Syndrome written in a humorous format
- a newspaper produced for people with reading difficulties.

Other functions of the FUB were to:-

- represent the interests of the mentally handicapped and the relatives to the Government (many people that I spoke to thought that the FUB had been particularly successful and to this end, in fact, had been instrumental in pushing the Government into the new Law of 1986)
- ran courses for relatives on the care of people with a mental handicap
- establishing and developing research work
- updating other material (one project they were presently engaged in was ensuring that literature in libraries about people with a mental handicap was accurate and in tune with current thinking and advising them of books that they could purchase)
- act as a focal point for parents who wished to ask questions and raise queries regarding the development of Community care.

Although not a political organisation they did urge their members to join parties and attempt to influence them from the inside. They had, however, as an organisation managed to establish links with such sponsors as SAAB.

Over the weekend I moved 250 miles across country to Gothenburg and on the Monday morning I was met at my hotel by Mr Yngve Andersson from the Gothenburg Board who took me to one of the nearby Institutions that remained and there I was introduced to the Assistant Manager, Mr Jüri Sonne. Mr Sonne gave the historical background to the development of services within his Region. In telling me this he was adamant that it was, in fact, the relatives and the FUB in the 60s and 70s who had been instrumental in stimulating the debate about Community care and who had been responsible for pushing the principles of normalisation. He believed that the principles of normalisation were merely the stating on paper of the thoughts of many relatives and parents. As a result he believed that parents were taking more upon themselves by adopting this philosophy because it meant that they had to provide more support.

Again I raised the question of how he had managed to maintain standards and morale during a period of transition. He responded that along the way they had been careful not to interpret the change of policy as a criticism of the Institution. Once again the view was emphasised that it was vital to break the residents down into small groups and establish small family groups within the Institution prior to discharge. Similar to Carlslunds, wards/villas had been run self-sufficiently with their own kitchens and household budgets. By getting the staff to work in small groups it had increased their loyalty and motivation as they became very loyal to the Group.

Later that morning I met the Medical Superintendent for the Institution and I raised the general question of awareness amongst health care professions, particularly General Practitioners. He agreed that even in Sweden, there was still a need for a greater input on the needs of people with a mental handicap within medical school training, but also clearly from the GP's point of view care in the Community meant an increase to patient numbers, not only as a result of the rundown of mental handicap institutions but also the rundown of some psychiatric institutions was happening in parellel. We also spent some time discussing drug management arrangements within the Community homes which is an area of some discussion in this country. He informed me that they presently worked on a box system for drugs which clearly indicated which pills should be taken each day. Although a simple method, it avoided any chance of misunderstanding regarding type and dosage. If a particular medical problem developed or advice was required about drug doseage then the local General Practitioner or on call nurse would be contacted. If there was a resident with a particular medical problem then there was a distinct advantage in having a nurse as a regular member of staff although it was clear that this did not happen as a natural course.

That afternoon I visited another local Community home at Lindome which was again of the same high standard as the ones I had seen in Stockholm. On this visit I concentrated on issues which had not been raised when visiting homes in Stockholm. I got the impression that because the staff were of an older age group than in Stockholm there was less of a staff turnover and generally I felt that staff morale within the homes was higher.

It was apparent that staff had gone out of their way to involve parents and relatives in the running of the homes. All staff who had previously worked in an Institution were adamant that with the development of Community homes they had seen an increase in the interest of relatives as they were now more prepared to get involved as they now felt proud of the home as opposed to being ashamed of the Institution.

During discussions with staff in this particular home, we got onto the subject of managing the residents monies. At the moment the Manager kept charge of approximately 900SK a month (£90) and it was apparent that the whole system was based on trust. They believed that this was the only way to run such a home if it was to be seen as a normal home.

Later on that afternoon, I visited a respite home in Balltorps Korttidshem run by an English woman who had lived in Sweden for 25 years. Rather surprisingly this home was run on the system of parents booking respite care direct with the home and bookings could be for up to three weeks but generally would be for a week or a weekend. Amongst the staff they had regular weekly meetings and the home had a fully delegated budget based on a projected attendance figure. For four children they had an establishment of four full-time staff and two part-timers but at night they had a separate night staff of one member of staff awake all night with one member of staff sleeping in. If, during the stay, one of the children fell ill local GP's or Accident and Emergency Departments would be used. Each child did not have their own medical record but a medical history was taken from the parents before the child was brought to the home. Speaking to the staff it was interesting to note that over the years they had detected a significant difference in the skills and behaviour of children from a home compared to an Institution.

The following day I met Mrs Elaine Johanssonwho was not only an Investigating Officer for the Gothenburg Board but also Chairman of the Gothenburg FUB and mother of a severely multiply handicapped child.

As Investigating Officer she had recently been engaged in a study into the physical needs of people with a mental handicap and initially looking at potential eyesight problems. The project was undertaken with the help of two Orthoptists who undertook to carry out an examination of the mentally handicapped people living in the Region. With the assistance of retinascopes, which basically shines a light through a tube to the patient's eye, this allows the Orthoptist to make a subjective judgement on eyesight without having verbal feedback from the patient. 70% of the residents seen were able to give some form of response but subjective judgements had to be made on the remaining 30% of the residents that were examined. It was discovered that 1 in 4 required glasses and that there was a higher incidence of eyesight problems amongst people with a mental handicap. These residents were then prescribed glasses and with training for them and the care staff, 75% of the group began to wear spectacles regularly.

During the study Mrs Johansson cited the case of a female resident who had lived within an Institution for many years and avidly watched the ward television. Suddenly the staff noticed that this particular resident was no longer interested in watching the TV and after much thought it became clear that this had been the result of the TV being moved to the other side of the room and the staff had been unaware that she was blind in the other eye.

As a follow up to the study, it became obvious that with the issue of spectacles to the residents there had been a marked improvement in their quality of life and they became much more involved in what was going on around them. This study begged the question of what other physical needs were not being met eg hearing.

Mrs Johansson wrote this study into a very interesting report which she subsequently delivered at the International Conference on Mental Handicap in Brazil, entitled "The Right to See".

That afternoon I was taken by Mrs Johansson to the Regional Headquarters of FUB where she performed her second part-time occupation as Chairman of the Regional Branch. I was also introduced to the full-time Social Worker who was attached to FUB. The development of this post was a result of the need that FUB had recognised in providing an independent advice and support service, particularly to parents who had been informed that their new born child had been born mentally handicapped. As an organisation they had found that parents in such circumstances often wanted to talk to someone outside the direct professional groups and FUB offered this service. The FUB provided a useful information resource and plugged a gap which the acute hospitals were not able to fill. The FUB Social Workers also got involved in problems between staff and parents and again the FUB acted as an independent third party. Although involved in fund raising this formed only a small part of the activity that the FUB undertook. As an aside, I was told on more than one occasion that the Swedes as a nation were not as supportive as other nations to charitable activities. I was told that the reason for this was because the Swedes believed that charity work should be unnecessary because their high tax system should supply everything through the welfare state.

That afternoon I was also introduced to the two Leisure Activity Officers who worked for FUB. I was disappointed to hear that they were beginning to conclude that leisure had to be organised separately from general society. They felt that because people with a mental handicap often lacked self-confidence, they preferred to arrange their leisure time separately rather than in conjunction with normal activities. They did, however, accept that contact and befriending schemes were the best way to proceed if normal services were to be more utilized.

As an organisation they felt particularly proud of their efforts in getting the new Law of 1986 introduced although they recognised that in terms of numbers, mental handicap was small in relation to the size of the overall numbers who required state support. Another result of their pressure was the fact that County Councils as the governing body had, under the law, to co-operate with the FUB which indicated the Government's wish to see relatives' organisations involved in the decision making process.

The following day I was met by Mrs Eva Wahlstrom who was the Senior Physiotherapist for one of the Community Mental Handicap Teams in Gothenburg and taken to the Team's base. Over coffee, I met all members of the Team and discussed many issues relating to their daily work.

Residents at present were referred by GPs or Social Workers and the overall caseload was split between the two teams, one for children and one for adults.

Within the children's team there was a pre-school teacher who, although not directly employed by the County Council, liaised closely with parents and made sure they got some priority in arranging for them to get an advanced place in kindergarten. They also arranged for weekend parents to be made available and, if required, the provision of a foster family. Parents, as a whole, receive around 2,000SK (£200) a month depending on the degree of handicap.

At the time of visiting, the children's team was having some difficulty liaising with such a large number of doctors from the Community and on balance they would have liked to have seen a formal paediatric medical input for the team, who would also have acted as the medical liaison point.

It was interesting to note that they, as specialist teams, were concerned about their own futures and believed that if the philosophy of using conventional services was followed then their services would not be required (eg use of local hospital based physio service, rather than the specialist physiotherapist on the Community Mental Handicap Team).

The team had their own delegated budget and as a group they were all involved in how these resources should be used. I was impressed to see that this financial delegation had even lead to the allocation of a small sum of money for them to socialise together outside work. The belief was that this sort of activity should help to build up some form of team spirit which the Authorities regarded as essential. In addition to this there were occasions throughout the year when they attended training courses together and had sought the assistance of an outside psychologist to lead their discussions.

Later that day I was taken to another day centre in Gothenburg and I spent most of the day with the Head Occupational Therapist who managed the centre. Again I was told of the change and increase of dependancy levels of the residents within the day centres as the Institutions continued to be run-down. As a centre they tried to ensure that residents who lived together in a Community home went to different centres so that they could take up new relationships. Attached to the centre and other centres was a County Council worker who provided a liaison function with local employers. When I visited, a number of their residents were out working with local organisations eg library, swimming pool, office work, laundry work and cleaning jobs. Again residents travelled back and forward to the centre by public transport and if this was not possible, by taxis. It was encouraging to note that special arrangements were made for those residents who were not able or did not wish to attend for the full day and transport was willingly laid on to take them back and forward.

On this visit, although always inferred, I heard for the first time the view that the development of Community care was not the end of the road and, if at all possible, independent living was the final objective. Within this particular day centre there were staff based who were specifically appointed to give support to the resident who, for the first time, found himself living independently.

That afternoon I was taken by the day centre Manager to a local warehouse run by RKAPP/AHL who were a clothing manufacturer. Within the complex eight mentally handicapped residents were working, arranging garments under the supervision of one member of staff from the day centre.

Similarly to this country, the residents were not paid the full wage and acceptance of this arrangement had only been obtained because the local trade unions had accepted that the jobs the residents were doing would not be done by anyone else.

Although the group were working in an area slightly apart from the main workforce they were using communal changing and canteen areas. Naturally the Manager of the day centre wanted to see the development of this type of arrangement.

In the afternoon I visited a further Community home in Gothenburg and again heard similar points to those that had been made earlier eg staff career development, improvement in skills and behaviour of residents, problems with using local services particularly hairdressers. One feature worthy of note was the use of a word game as a means of communicating with the resident with the aim often being of trying to find out the resident's views or wishes.

This visit concluded my study tour, other than an informal trip on my last evening to a dance for mentally handicapped people, attended by approximately 600 residents. On certain evenings they had a rock band performing composed of people with a mental handicap and this group had clearly become a semi-legend amongst mental handicap circles and indeed shortly before my visit there had been an extremely well written article about the group in a major national newspaper.

The evening was obviously a very happy occasion for those residents who attended but again it reinforced the view that I had heard earlier, that leisure activities had to be organised separately , which I had found disappointing.

4. In summary rather than make general points at this stage, I have tried to highlight the key learning points/issues that I have taken from the visit based chronologically on the diary as detailed above. They are as follows:-

   1. Interesting to note the factors that have lead to Sweden's development of a very progressive service.
   2. The view of the government that the rights of the individual person with a mental handicap should be underpinned with legal enactments.
   3. Problems in ensuring that leisure time is fully integrated.
   4. Advantages of integrated schools.
   5. Local councils having a statutory responsibility to provide housing for people with a mental handicap.
   6. Role of the "contact" person.
   7. The development of semi-commercial outlets providing skill training and day activity for residents.
   8. Change in the dependancy level attending day centres as the Institutions run-down.
   9. Day centres - emphasis on small numbers and the needs of the individual.
   10. Need to involve staff totally during a period of transition from Institutional to Community care.
   11. Importance of relating groups of staff to groups of residents prior to discharge.
   12. Need to train professions and occupations outside the Institution to prepare them for the new service eg dentists, chiropodists and possible guidance to private services such as hairdressers.

13. The view held by the Swedes that the traditional UK "medical" type institution created a hierarchial relationship with the residents.

14. Staff trained differently to UK working inside and outside the Institutions.

15. The need to create a "halfway" house ie convert the villas/wards into a home-like environment prior to discharge. This should be accompanied by staff beginning to work with small groups of residents.

16. The importance of involving fully the relatives' organisations in the run-down process and the considerable help that they could potentially offer in that situation.

17. Need to raise the status of the staff remaining to the end "to close the doors".

18. Community homes with no form of Institutional connotations, with staff coming from a variety of backgrounds.

19. Complete financial autonomy for the homes with money management by staff based on trust.

20. Possible areas of friction between Community homes and the day centres.

21. Potential career development difficulties for staff working within the Community homes.

22. Relation organisations (FUB) heavily involved as a political pressure group and as a group trying to improve general public relations.

23. Day to day drug management within the homes can be successful without the direct involvement of professional staff.

24. In all homes staff had remarked at the improved development and behaviour of the residents following their discharge from the Institutions. In addition they had also seen an increased interest from the relatives.

25. The need to ensure that the physical problems of a person with a mental handicap are given due attention.

26. Specialist Community Mental Handicap Teams concerned about their future.

27. Need for more professional paediatric input into the teams.

28. Importance of building up a team cohesiveness.

29. Community living was not regarded as the end of the road.

30. As a side issue it would appear that the development of services to people with a Mental Handicap has been made easier by having one management and co-ordinating body ie the County Councils.

5. CONCLUSIONS

At the end of my visit, I must conclude that the Swedish system of caring for people with a mental handicap is extremely well developed and is clearly geared to coping with the needs of the individual. Mental Handicap is not regarded as a problem of the individual resident but is instead a problem for society in making sure that the person with a mental handicap has the opportunity to experience all the varied aspects of life that are often taken for granted by the general public. This view shaped their thinking in the way they had developed their services so comprehensively over the years.

6. ACKNOWLEDGEMENTS

I would like to take this opportunity to thank first of all, the Kings Fund College for giving me the opportunity to undertake this very worthwhile study tour and to assure the Fund that I will use the knowledge I have gained to every effect both within my own Health Authority and, as far as possible, nationally, to promote what I believe to be an acceptable and proven strategy in Sweden for people with a Mental Handicap.

I would also like to thank the very many people in Sweden who gave of their time and knowledge and enabled me to get the most out of my time in their country. These people are too numerous to mention but I must single out Ms Catharina Mannheimer at the Swedish Institute who went to great trouble in organising my excellent programme.

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