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KING EDWARD'S HOSPITAL FUND FOR LONDON

King's Fund Centre

RIGHTS OF MENTALLY HANDICAPPED PEOPLE AND THEIR FAMILIES

A report of a study day held at the King's Fund Centre
on 29 October 1979 under the auspices of
Parents for Children and The King's Fund Centre

King's Fund Centre,
126 Albert Street,
London NW1 7NF.

February 1980

KING EDWARD'S HOSPITAL FUND FOR LONDON

Rights of Mentally Handicapped People and their Families

Under the auspices of Parents for Children and the King's Fund Centre a study day was held on October 29 1979 for parents of mentally handicapped children. The aim was to help parents, whether by birth or adoption, to look ahead to the position of their handicapped children as they reached adulthood, and to become better informed about their rights and about the services available to them. It was also hoped to encourage parents to become active in working for improved services.

The day began with a plenary session chaired by Michael Meacher, MP and addressed by Sir George Young, MP and Minister of State at the Department of Health. The leaders of the day's workshops then briefly outlined the topics they would be covering, under the following titles:

i) Employment and further education
ii) Housing
iii) Health, sex and marriage
iv) Civic rights (bank accounts, voting, libraries, etc)
v) Guardianship, trusteeship and property.

After two workshop sessions, before and after lunch, the day concluded with a plenary session at which the main points made in each group were shared, and there was some general discussion, summed up by Michael Meacher.

Because of the relevance of the day's theme to a much wider audience, and because it was not possible for participants to attend more than one workshop it was felt appropriate to try to record and summarise the day's proceedings.

The following is a condensed account of the main themes. There is obviously a certain overlap in the subject-matter of each report, but it is helpful to see the overall picture by reading the accounts of all five workshops together.

INTRODUCTION

In his opening talk Michael Meacher said that mentally handicapped people were 'routinely deprived of rights' not only in terms of their mental handicap but even in the basic terms of their rights as ordinary citizens. He said that the aims of the workshop were to:

a) answer queries

b) clear up misunderstandings

c) see if there were any laws that needed revising because of the adverse way in which they affect mentally handicapped people.

He referred specifically to the Mental Health Act and asked whether it should be changed, and he also queried the rights of Guardianship.

Sir George Young MP and Parliamentary Under-Secretary of State at the Department of Health and Social Security said that he had a special interest in the care of mentally handicapped children and that he and his wife had on occasions given short-term foster care to mentally handicapped children. He mentioned his worries about the deprivations suffered by children living in long-stay hospitals and stated very firmly that these children should not be in hospital. One means of keeping children out of long-stay hospitals would be to increase help to families so that they may be helped to retain their children at home. Family help can take the form of short-term care and fostering. Adoption is another way of keeping children out of long-stay hospitals. Sir George Young praised the work of Parents for Children and said that the present Government fully recognised the value of the work done by voluntary organisations and planned to increase government aid to them.

Referring to the cuts in social services and health services Sir George Young said that his department was concerned that the cuts should be made in the least harmful way. In conclusion he said that he believed "services must be based on the needs of individuals rather than on administrative convenience".

WORKSHOP A

Further Education and Employment

Led by Peter Clyne, Assistant Education Officer, Inner London Education Authority on Further Education, and David Carter, Director of Advisory Service for Rural Training, Employment and Occupation (NSMHC) on employment.

'Is education a preparation for work or for life?' was the underlying theme of the first session. It was generally agreed that mentally handicapped young people need as great a variety of choice in further education as do their more able sisters and brothers in order to both enjoy life and manage an occupation.

Mentally handicapped children have the same rights in law to further education as all other children. That is, they have the right to free continuous education until the age of 19 if, and this is the stumbling block, the local education authority has the ability to make what is considered to be suitable provision. If the local education authority is unable to make suitable provision then it is expected to consult with other neighbouring education authorities in order to offer something suitable for each child. However, the right to further education is given by permissive legislation and the local education authority cannot be required by law to make provision where none is available. Furthermore even if parents consider that a school or college would be right for their child, the decision rests with the Local Education Authority. This decision can be challenged by parents and may be influenced by the policy of the Local Education Authority, but again the law cannot be used by parents to insist on a place for any child in any place of education. Appeals can be made to the Secretary of State for Education and Science.

The workshop discussed the different needs of mentally handicapped children of sixteen plus and it was agreed that chronological age was misleading and that on the whole mentally handicapped children need further education more and not less than other children because, for instance, sixteen plus may be the most favourable time for a very immature young person to begin to read and write.

The workshop decided unanimously that although flexibility must be a by word when providing mental handicap services, education should be available for all mentally handicapped children, as of right, until the age of 19. Local authorities should be required to make provision according to need. At the same time mentally handicapped children should retain the right to leave school at 16 if this is their choice, but they should also retain the right to return again to full time or part time education before the age of 19. The workshop acknowledged that an enforceable right to further education would make mentally handicapped children different from the rest, but felt that this difference would offer the extra help and protection these children need.

Four possible opportunities in further education were outlined by Peter Clyne:

a) Some mentally handicapped chilren are integrated in to ordinary schools and could follow non-academic courses in the sixth form. Some parents pointed out that very few schools offer such courses and that children in remedial classes are usually encouraged to leave at 16.

b) Schools for the educationally sub-normal are technically able to offer continuing education until 19, but very few do and parents are led to expect their children to leave at 16.

c) Some local authorities run link programmes between special schools and colleages from 15-18 and others offer similar programmes which link adult training centres with adult education institutes for the over 16's. At least one adult training centre in London has a special programme for school leavers who work in a separate group.

d) Further education colleges can offer special courses for mentally handicapped children aged between 16-18 but again very few actually do.

Members of the workshop felt strongly that all four choices should be available because of the wide range of needs of mentally handicapped children. Some would do best if they could stay on in the school environment, while others would benefit from a move to college after what is usually a very long career in one school. Others still might benefit most from as near a working situation as possible. Some will not fit into any system and may need an individual programme of social training and possibly vocational training. It is within the scope of Local Education Authorities to provide a home tutor to meet individual educational needs up to the age of 19, but it is most unlikely that any Local Education Authority would have sufficient resources available.

Summary

1. The workshop discussed all the options for further education which are technically available to mentally handicapped children and felt strongly that as wide a choice as possible is necessary.

2. The workshop discussed the need for mentally handicapped children to have the opportunity for further education until 19 and agreed that it should be made available as of right although it should not become compulsory.

3. The workshop considered the following questions:

   a) to what extent are people aware of their rights?

   b) how can those people who are unaware be informed so that existing provision which is satisfactory can be more widely used?

   c) how can parents, voluntary organisations, teachers and statutory bodies be involved as pressure groups to seek improvement and change legislation?

   d) how can we argue for expansion in a climate of cuts?

Employment

"Does the mentally handicapped young person have the right to work according to his ability?" was the recurring question during the session on employment. The answer was that he has the same right as any other person to seek a job and to claim social security if unemployed.

David Carter described the work possibilities for mentally handicapped people:

1. Mentally handicapped people can find work in genuine open employment. There is legislation which requires employers with large staffs to make up 3% of their labour force by employing registered disabled persons - including mentally handicapped people. This law is seldom if ever enforced and might be a two-edged sword if it were, because employers may see it as a way to limit the employment of mentally handicapped people. It might be better to leave the options open and to encourage a more compassionate attitude according to the individual needs of the mentally handicapped person.

   Although mentally handicapped people can ask to see the specialist careers officer or the Disablement Resettlement Officer to help them find a job they are inclined to be the most neglected of all people described as disabled. People who are registered disabled are given a green employment card and this may work against rather then for them. However, mentally handicapped people do not have to find a job through specialist services and do not have to be on the disabled register.

2. Sheltered employment. This work is especially created for employment of disabled people. Employees may have to acquire special operating knowledge and skill and once trained they are paid "at the normal rate for the job". Recognised sheltered employment units can receive financial support from the Manpower Service Commission in order to maintain economic viability and in some instances capital grants may be paid by the MSC - money which might be used for development of new projects, purchase of equipment and so on. There are many opportunities for physically handicapped people to be employed under sheltered conditions but mentally handicapped people seldom seem to benefit.

3. Protected Occupations. Very similar to Sheltered Employment in that these are work opportunities especially created for groups of disabled people to carry out various tasks or operations. At one time called and recognised by the MSC as 'Enclaves' the new name being brought into use for these employment opportunities is 'Sheltered Industrial Groups' (SIGS for short).

4. The Adult Training Centre is the only special provision for mentally handicapped adults who cannot find employment or are unable to work. Most adult training centres offer only an opportunity for a pastime rather than employment and pocket money rather than a wage is paid in Adult Training Centres.

   Unfortunately only 1.5 - 2.o% of mentally handicapped adults enter open employment and the figure for entry into sheltered employment is between 0.75 - 1.5%. Occupations and pastimes in Adult Training Centres are often dull and repetitive and the creative potential of Adult Training Centres is often neglected in favour of the policy of keeping mentally handicapped people busy even if bored to a high level of frustration.

   Members of the workshop agreed that mentally handicapped people should be allowed to contribute according to their ability in such a way as to help them to lead a stimulating life. It was felt that there should be more opportunities in open and sheltered employment and that all adult training centres should offer more varied programmes.

Examples were given of special schemes for mentally handicapped people:

1. Agriculture and catering offer special opportunities although workers in both fields are paid according to legislation, the rates for mentally handicapped people are reduced by local tribunals, and increments to catch up with other workers are awarded as skill increases.

2. Some Local Authorities have established recognised sheltered employment units for mentally and physically handicapped people with a guaranteed rate of pay for the work undertaken even though output per worker may be much less than average. The Government, via the MSC, makes deficiency payments to such units which are recognised by the Trade Unions - indeed, one such unit has a shop steward who is mildly mentally handicapped.

On the other hand, trade unions can effectively black employment of mentally handicapped people. Parents may have to challenge unions on grounds of discrimination.

3. The Pathway system, administered by the National Society for Mentally Handicapped Children and Adults, provides the money for what is really a specialist placement service. The scheme's specialist placement officer agrees terms with a potential employer and the NSMHC fund is used for the initial trial period of three months. The NSMHC Fund is also used to pay an established, empathetic employee an 'honorarium' for working alongside the mentally handicapped recruit, for helping with his or her training and, in general, for ensuring that the mentally handicapped employee has a good chance as possible of succeeding in the new job. The system is very successful and is currently being extended. It is accepted by the trade Unions.

4. The Manpower Services Commission can recognise non-profit making companies set up by voluntary bodies to employ mentally handicapped people. One such company was set up by parents as a cooperative to repair school furniture.

5. Village communities can offer a comprehensive way of life to some mentally handicapped people but these are often financed by voluntary organisations and trust funds, and places are only available if parents can afford to pay or the local authority will support the placement.

Social Security. It was pointed out in the workshop that mentally handicapped people who are only able to earn a very low wage may be financially better off on social security benefits.

If the non-contributory invalidity pension is awarded, the disabled person loses the right to earn more than £11.00 a week.

SUMMARY

The workshop felt that although work and pastime opportunities existed for mentally handicapped adults, there should be much improvement both in the quality and in the quantity of what is offered, and that action as follows is needed:

a) A review of the legislation concerning the employment and registration of disabled persons with positive action to ensure that mentally handicapped people are not excluded on grounds based on the nature of their disability.

b) A determined and adventurous attempt to establish genuine sheltered employment for mentally handicapped people with central government, the local authorities and voluntary agencies all becoming involved with such schemes.

c) That 'placement services' and 'work-seeking systems' be improved and coordinated.

d) That the Trade Union movement at all levels be asked to cooperate in ensuring that mentally handicapped people can make a contribution to their own livelihood - in whatever sphere this may be.

e) That adult training centres be required to provide a full programme of social and vocational training so that all mentally handicapped trainees may acquire experience, skill and knowledge commensurate with their intellectual ability. Participants in the workshop recognised that not all of the trainees at an ATC could enter gainful employment. Indeed they demanded that the ATC programme should be so designed as to provide the best opportunity for all trainees to enjoy a fulfilled and enriched life whether or not they could attain the level of ability needed to hold down a job.

WORKSHOP B

Housing

Led by Christopher Heginbotham, Area Manager, Circle 33 Housing Trust, London and Rosemary Wurtzburg, Housing Corporation.

This group looked at housing needs, various forms of housing and the laws relating to housing. It recommended much greater freedom to be given to mentally handicapped people regarding their own choice of housing. It would seem that mentally handicapped people are too often excluded from opportunities of choice simply on the grounds of their being mentally handicapped - this may lead to their having to put up with multi-occupied housing (hostels) when they might be in flats of their own.

Local authorities have a responsibility under the 1977 Housing Act for people who are handicapped. Funds are available from local authorities and the Department of the Environment for the purchase of houses or flats for handicapped people. The NSMHC can help to establish and manage housing trusts for mentally handicapped people.

Voluntary agencies may obtain housing by raising enough money to pay a deposit on a house and then take out a mortgage which might be paid off by the rents paid by the mentally handicapped residents.

Alternatively a Housing Association may be approached for help. Some local authorities encourage housing associations because of their flexibility in providing for individual needs which may not be so easily met through traditional local authority provision. Housing associations also offer greater flexibility than does a traditional mortgage with a building society; they can offer a range of provision, from ordinary housing to minimum-care hostels; they can experiment with converted old property and with various types of tenancy, e.g. groups of students and mentally handicapped people, clusters of bedsitters for single people, flatlets, accommodation for couples, mixtures of able and handicapped tenants.

It was suggested that group homes could be supported in a number of ways: by a home help, occupational therapist, good neighbour, or an able tenant. It was recognised that where possible the residents of a group home should be chosen for their complementary social and domestic skills, and that they should be encouraged to give each other mutual support.

The group recognised the need for a variety of housing provision and also the need for parents of mentally handicapped children and adults to encourage them to achieve as great a degree of independence as possible, and to concentrate on social training and skills for living in the community.

(Chris Heginbotham's article 'Housing for Mentally Handicapped People', published in Parents Voice Vol 29 March 1979 is appended to this report).

WORKSHOP C

Health, Sex and Marriage

Led by Ann Shearer (Campaign for the Mentally Handicapped) and Michael Libby (Social Worker).

The discussions in this workshop centered on personal and human rights, and some moral issues affecting mentally handicapped persons and their families. The following questions arose:

1. Health. Why do so many mentally handicapped people have difficulty in obtaining medical treatment which is their right; should surgeons be allowed to refuse treatment to a person simply on the grounds of his being mentally handicapped?

   There was general agreement that mentally handicapped people had -

   a) a right to treatment
   b) a right to information

   It was suggested that parents should link up to give each other advice and support, and press for the best service for their children.

2. Sex, Marriage and Relationships. Discussion centred on the provision of sex education for mentally handicapped children and the difficult issues of care, responsibility and control.

   Members of the workshop felt that the need for sex education would vary according to the degree of handicap. But all adolescents, they agreed, experienced some sexual feelings, regardless of the degree of their handicap - this should be more widely recognised.

   There was considerable discussion about how far, if at all, parents should continue to exercise responsibility for their adult child. At what point does a necessary concern, and perhaps even degree of control, become a denial of someone's rights to learn and grow? It is certainly not right that mentally handicapped people are moved by professionals - to another house, school or training centre - without being consulted. But how prepared are parents to allow that mentally handicapped young people have as much right to an adolescence as any other people of their own age? The right to be different, to experiement with dress, friendhships, recreation and relationships may sound incontrovertible; but what if it leads to quite disasterous mistakes and exploitation? Should parents, for instance, feel responsible for the contraception used by their adult daughters? These questions are easier to ask than answer, and the answer will probably be for each family to work out. But what help can be offered to, for instance, able bodied tenants in shared housing, who may have to face similar questions without the authority of parents, and without wanting it?

3. Brothers and sisters. The final theme concerned the brothers and sisters of mentally handicapped children and the pressures they may feel. Opinion differed on how far the more able brothers and sisters should be expected to take responsibility for a handicapped person. It also differed on the usefulness of group support for brothers and sisters, some people feeling it very desirable, others having experienced young people rejecting the offer of it.

WORKSHOP D

Civic Rights

Led by Alan Tyne (Campaign for the Mentally Handicapped) and Katherine Dunne (Legal and Welfare - MIND).

The workshop looked at common civic rights of mentally handicapped people and how these might be affected by laws or ignorance or misunderstandings. The discussion covered the following topics:

1. Voting rights - no citizen of the United Kingdom should be deprived of the right to vote. Voting rights are very important because they enhance the importance of mentally handicapped people and alert MP's to their existence and to their rights as citizens. The only questions polling officers are allowed to ask are "What is your name?" and "have you voted today?" No other questions aimed at denying the right to vote are permitted.

2. Financial matters - parents may apply for the financial affairs of the mentally handicapped to be managed by the Court of Protection if they wish. This involves an annual fee, worked out on the percentage of the money involved. (See report of Workshop E).

3. Legal matters - any queries and difficulties can be dealt with by legal advice services and Citizen's Advice Bureaux or by MIND's legal and welfare rights department, or by 'Network' at Bedford House, 35 Emerald Street, London WC1 This is a legal advice service for the parents of handicapped children. The National Society for Mentally Handicapped Children and Adults also has considerable experience of guiding parents.

4. Health and Safety at Work Act. On the whole mentally handicapped people are classified as employees, and they gain from this status, with rights to Trade Union representation, etc. So it is helpful to get this status established. Employing bodies (e.g. a local authority) have no parental rights or obligations, (even if they sometimes act as though they had) and also no duty to supervise.

5. The Right to Work. Mentally handicapped people who attend adult training centres, if not classified as employees, have only the right to a reward for their work, not a wage. In fact, as local authorities provide adult training centres as a service there may be a charge for attendance. In a hospital setting rewards are seen as therapeutic wages.

The Disability Employment Act of 1944 has not been totally successful; individual employers have made assumptions which have led to a policy in their own firms which have resulted in turning away disabled and mentally handicapped people. Prejudice about mental handicap, as about epilepsy, is only slowly dying out and fears are usually exaggerated and based on ignorance.

6. Trade Unions. Mentally handicapped people can join recognised trade unions and some are members of T&GWW and COHSE.

7. Use of Public Facilities.

Libraries: Mentally handicapped people are sometimes denied the right to borrow library books; if this happens, the local authority should be asked the grounds for this ruling.

Pubs: A publican need only serve the customers of his choice.

Landladies: are free to make a contract or not, but not to break one on the grounds that the person is mentally handicapped.

Swimming Pools: Bye-laws can be discriminatory. They should be contested by using existing common-law rights.

Physical Access: can still be a difficulty but people can insist on their right of entry to public places and for facilities to be made available.

8. Visas. Some countries do not admit mentally handicapped people - e.g. Australia. It is advisable to write to the embassy of the country concerned well before the date of the planned visit and ask how they apply the law. Applications often take twice as long as for non-handicapped persons.

9. Overseas Health Insurance. Cover is sometimes refused when the insurance company knows that the applicant is mentally handicapped.

10. Personal Freedom: People living in hostels are often restricted with regard to where they go in the evenings, their recreations, theur right to change jobs, their right to make friends of their own, their freedom to have sex if they wish. Hostel staff often believe (incorrectly) that hostel residents are 'in care' of the social services department and have no rights to decide personal issues. Staff need more information about the rights of residents and there is a great need for an advocacy system to be set up.

    A social worker in the group commented on the need for up-to-date information to be made regularly available to social workers (through courses booklets) in order to equip them to advise parents helpfully.

WORKSHOP E

Guardianship and Property

Led by James Ross (Director of Welfare and Rights Services, NSMHC) and Rolf Hermelin (Legal Adviser, NSMHC).

This group discussed guardianship, property and this existing legislation and how it might be improved.

One little used form of guardianship can be given by the Director of Social Services under the Mental Health Act of 1959. The steps involved :-

i) Two psychiatrists must certify that the person is severely mentally handicapped and that a guardianship order would be appropriate.

ii) Application must be made to the Director of Social Services for a guardian to be appointed.

iii) The Director will probably interview the applicant to discuss the matter.

iv) The order may be made or refused.

The effect of such an order is to give the handicapped person the status of a child of 14. It gives the guardian the right to custody, the right to the ward's earnings but not to other property and the right to intercept correspondence. Orders are renewable biennially and a tribunal can discharge them. An order cannot be made if the handicapped person is in hospital.

Only 134 such orders were in existence in 1974, in most cases making the local authority the guardian.

The NSMHC has declared its oposition to guardians being attached to the local authority and has proposed the setting up of regional guardianship support committees under the Home Office. It believes that guardians should have duties as well as powers, particularly to help provide services needed.

There was seen to be a dilemma between retaining the rights for independence gained for mentally handicapped people over the last 20 years and maintaining appropriate protection for them. The law does not protect people who are 'boarderline' handicapped and parents have no rights or powers when such children become adults. The group felt there was a need to legislate for parents to have the right to be consulted about matters concerning their severely handicapped children.

Court of Protection.

The role and functions of the court were explained. It can be used where a person:-

a) is mentally handicapped

b) has property amounting to at least £1,000.

The Court can pay debts, buy or dispose of property, run business affairs, and give help with wills - either made by or in favour of the mentally handicapped person.

The Court is administered by the Lord Chancellor's office and on the application of an individual or through a solicitor a Judge will be allocated or a Receiver appointed who can be e.g. a relative, a friend or solicitor. A fee for the service is charged to the estate of the handicapped person.

Wills.

Parents can make a will in favour of a mentally handicapped person and if doing so should state in it that a copy should be sent to the Court of Protection with an application from a named person. However, the NSMHC advises against leaving money or life insurance in the name of the mentally handicapped person, since the state usually rules that he or she is unable to handle his own affairs and may take over the administration and take the person into care.

Alternatives -

a) A bank's Trustee department will set up a plan as desired - and will operate it

b) A solicitor will draw up a Trust deed as desired and will operate it

c) A Private Trust of family or friends can be created, drawn up by a solicitor.

Disadvantages of these schemes -

a) A bank provides a commercial administration of funds and no personal contact with the beneficiary.

b) Solicitors also provide an impersonal service and may well ask the social services department or hospital's advice on the administration of the money.

c) Family members or friends may move away, or not wish a continuing involvement.

National Trustees for the Mentally Handicapped

A fourth alternative set up in 1976. This is separate from the Trusteeship scheme (see below), but the participants must be members of the latter. The scheme provides a tailor-made Trust deed for each person concerned, provided that a minimum of £3,000 is available. It also guarantees a monthly visit to each beneficiary and is the only scheme which offers this.

The NSMHC Trusteeship Scheme

Leaflets were available describing this scheme, which can set parent's minds at rest about the care of their mentally handicapped children after their death.

£750.00 is paid either from the parents' estate according to their will, or directly into a lump sum during their lifetime, or by insurance. The National Society for Mentally Handicapped Children and Adults then appoints a visitor to befriend and visit the handicapped person monthly. There are about 150 visitors throughout the country, who report monthly to the society's headquarters. The society can act very quickly in cases of emergency, and take steps to ensure the well-being of the individual.

SUMMARY

The final session showed how wide-ranging the topics discussed had been, from precise points of law and people's rights to more nebulous attitudes and individual human problems. In summing up Michael Meacher suggested there was a great need for information to be more widely disseminated, and for the identification of ways in which legislation needed to be changed and services improved. Several particular recommendations had been made:

a. for an advocacy system for mentally handicapped people to be set up;

b. for improved guardianship provision, and the right of parents to be consulted;

c. for further education to be made available as a right for mentally handicapped children until the age of 19;

d. for an improvement in both the quality and quantity of work opportunities;

e. for mentally handicapped people to have a greater say in their choice of housing;

f. for the right to the same medical treatment and information about medical conditions as anyone else.

It was also necessary for better use to be made of existing legislation and common law rights and for prejudice and ignorance to be confronted and overcome, so that mentally handicapped people could enjoy as full and free a life as possible within the limits of appropriate protection according to their individual needs. In the final analysis, human resources (ie other parents, sympathetic professionals and other children) are the most important, and laws will only be changed and attitudes improved because human beings are ready to support each other.

It was agreed a report of the day should be produced, and there were requests for further such days to be repeated. One possible format would be a 'consultancy day' at which a panel of experts would be available for questioning by parents, social workers and any other interested people. These suggestions are being explored.

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Legal Tr[illegible] for the Mentally Handicapped

a. for an advocacy system for mentally handicapped people to be set up [illegible] (see below), but [illegible] participants [illegible] of the latter [illegible] for each person concerned, provided [illegible] parents to be consulted [illegible] gives a monthly visit to each home [illegible]

b. for improved and [illegible] provision [illegible] the rights of parents in the consultation [illegible] which offers this

c. for further education to be made available as a right for mentally handicapped children until the age of 19;

The NSMHI Information Scheme

d. for an improvement in both the quality and [illegible] of work opportunities;

Le[illegible] describing this scheme, which [illegible] parents [illegible] of the mentally handicapped children [illegible]

e. for mentally handicapped people to have a greater [illegible] say in their choice of housing;

f. for the right to the same medical treatment and [illegible] according to their will [illegible] as anyone else;

[illegible] National Society for Mentally Handicapped Children [illegible] to befriend a [illegible] mentally handicapped person [illegible]

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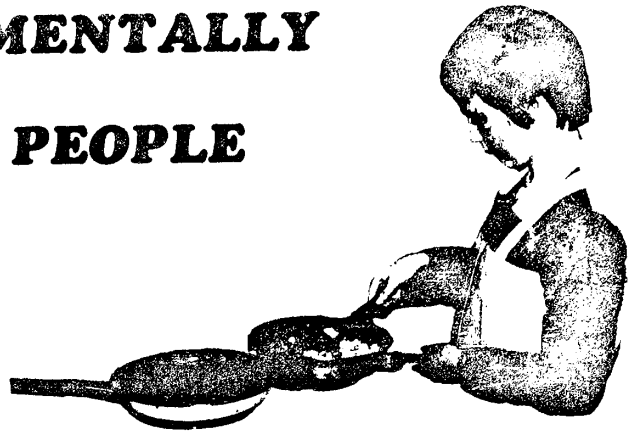
HOUSING FOR MENTALLY HANDICAPPED PEOPLE



Housing grants

Chris Heginbotham

Decent housing is a basic right for *everyone*. In this, the first of a series of three articles on housing for mentally handicapped people, Chris Heginbotham discusses possible sources of capital for housing projects, and looks at the organisations which can help a Local Society provide suitable accommodation for retarded people. Chris is Area Manager of the Haringey Team of Circle 33 Housing Trust Ltd, one of the larger rehabilitation housing associations working in north and east London, and Chairman of Camden Society for the Mentally Handicapped.

What do we mean by 'housing'? In this article housing covers quite a wide spectrum from individual houses or flats with no residential support, through group homes and all the variants on that theme, to semi-supportive hostels. The term 'semi-supportive' is used deliberately. Although it is theoretically possible to obtain some of the grants discussed below for fully staffed hostels in practice it is not easy; and this type of provision is best left to the local authority if willing.

Ways of providing housing

Local Societies can go about obtaining housing for mentally handicapped people in a number of ways. The first possibility is by raising all the capital themselves either directly or through grants from various charities. The house or rooms can then be let at whatever rent the Society chooses, as long as it is acceptable to the Rent Officer. This approach imposes *all* management and maintenance costs on the Society unless other grants can be obtained. A variant is to raise sufficient capital for a deposit and to take out a mortgage which will be covered by the rent(s) paid by the residents.

The disadvantage is that the Society is responsible for what may be quite a large debt—and someone has to be prepared to take that responsibility. Some Societies have regretted taking this option, especially for hostels, as they then spend all their time raising revenue monies.

The second option is to go to the local authority (LA) and obtain a house or houses from the housing department. Until recently councils were reluctant to enter into agreements with local organisations to manage group homes and the like. This is now changing and a number of Societies have projects using council houses. The maintenance remains the province of the LA, and the Society takes on certain management responsibilities by mutual agreement with the housing department.

Thirdly it is possible to use housing associations (HAs). Out of six projects being undertaken by Camden Society, four are with housing associations, one with the housing department and one owned outright (thanks to an Urban Aid Grant). There are some 2,500 associations registered with the Housing Corporation and therefore eligible to obtain government grants under the terms of the 1974 Housing Act. This Act did two particular things: it set up the Housing Corporation as a quasi-nationalised body to act as grant-giver to associations; and it brought in the Housing Association Grant (HAG) of which more later. Associations also obtain funds from local authorities, but the majority of their money—£350m last year—comes from the Corporation.

The particular advantage of housing associations, less so than in the past but still important, is their flexibility. LAs are now attempting projects where they have been 'shown the way' by HA projects and this is to be welcomed. However HAs have over recent years been in a position to try new models of housing especially where a caring element is required. Indeed it is Housing Corporation policy, and that of many LAs, to encourage HAs to provide more 'special' projects—group homes, clusters of bedsits or flatlets and hostels—and funds are fairly easily available for these schemes.

Housing Associations normally obtain funds for rehabilitating older properties, or for new buildings, and only very rarely to buy smarter houses with full existing facilities. HAs obtain HAG (see above). This covers the majority, often around 90 per cent of the capital cost of purchasing, renovating and converting a property, leaving only a very small mortgage to be paid out of rents. The mortgage is calculated on what the rents can pay, after deduction of standard management and maintenance allowances kept by the housing association. The rents are 'fair rents' set by the Rent

Officer. One advantage of using housing associations is that HAs will often pay over to the Society, which undertakes all or part of the management of the house, a proportion of the management allowances, to assist the Society in its work. The proportion is often between 50 and 75 per cent of the available money—meaning anything from £25 to £150, per annum, depending on the size of the project and the part of the country.

Local authority or housing association?
The advantage of using either LA or HA houses is that financial responsibility is largely taken away from the Society. The Society will probably enter into a management agreement, or, more rarely, a lease, with the LA or HA. This will stipulate what are the responsibilities of the Society and what of the LA or HA. Normally the Society will be expected to provide volunteer welfare visitors or befrienders, collect the rents and keep the books for this activity, deal with minor repairs internally, and be involved in tenant selection. The HA or LA will retain responsibility for structural or major repairs, and for dealing with the detailed financial aspects such as paying the mortgage and collecting any allowances due. There is really no particular advantage to be gained from using one source of housing in preference to another. The possible exceptions are the management allowances passed on by housing associations, and the greater flexibility of HAs. But if the Council are keen, use them!

Other grants
Other grants are often available from a variety of sources. Social Service Committees of LAs will often give grant aid for staff or furnishings for houses or hostels. Housing Committees may similarly grant aid housing costs. For example there is often no money available directly either on LA or HA schemes for furnishings of communal areas of houses. LAs will sometimes help to provide carpets, curtains and furniture for common areas, but for bedrooms it is best to obtain statutory grants from the DHSS (Social Security) in the first instance. These grants are not large and are only available to claimants. A mentally handicapped person who is working, but not receiving a large wage, often finds difficulty in getting together enough money to furnish a room. Social Services will sometimes help, as will certain national or local charities. It is well worth getting hold of the *Directory of Charities and Grant Making Organisations*, and applying for money for specific things.

In urban areas, the Urban Aid Grant scheme will provide money for housing where a particular need can be shown. It is probably best not to try to obtain money in this way however where other channels exist for providing funds for housing and are working fairly smoothly. For example, HA finance comes from the Department of Environment, as does Urban Aid. So it might be best to apply for Urban Aid to cover the salary for five years for, say, a peripatetic care assistant to work with a number of group homes.

Area Health Authorities or Social Service Departments are also able to aid voluntary organisations from 'joint funding'. This is a pool of money given to AHAs for projects agreed jointly with Social Service Departments. Social Services gradually take over paying the whole cost, and are fully funding the project after five years. Initially the AHA will pay up to 60 per cent of the cost, though this can be as high as 100 per cent in special circumstances. These monies are particularly geared towards providing for those areas which 'ought' to be dealt with by Social Services, but traditionally may have been a Health Department responsibility, for example, residential care. Hence joint funding could certainly be applied for to build a hostel, especially if a LA is unwilling to tackle a project, and the Local Society has enough committed people prepared to put in the work (some have and have worked wonders!).

Conclusions
It is impossible in a short article to list all the possible types of grants; and there are bound to be some Societies who have managed to obtain funds for a project, where this article has suggested it might be difficult. In the main, though, these are the normal channels for obtaining grants.

Hopefully Society members will feel confident in attempting to provide decent housing for mentally handicapped people. Good housing is a basic need and right for us all—let us make sure mentally handicapped people obtain *their* rights.

The other articles in this series (to be published in the June and September issues of *Parents Voice*) will look specifically at management issues of running housing projects; and describe the projects currently undertaken by Camden Society, showing the lessons that have been learned. But at this stage, two tips:

* Don't be afraid to have a go. Approach the officers of LAs or HAs. Face to face contact works wonders. There is a lot more money around than you might think—he or she who shouts loudest, gets it!
* However, don't apply to two bodies at the same time for the same thing. Often councillors are on LA committees and Area Health Authorities etc. They will just get confused. Talk to them first and ask them which is the best body to approach—and then get them on your side.