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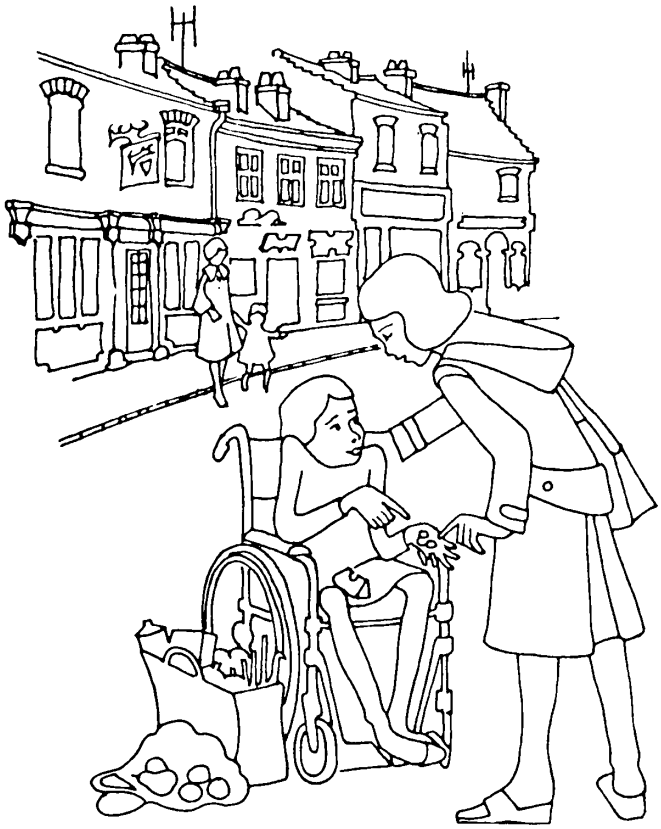

PROGRESS IN BRINGING MENTALLY HANDICAPPED CHILDREN OUT OF HOSPITAL

Price: £1.00

King's Fund Centre
126 Albert Street
London Nw1 7NF

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Peter Allen

King's Fund Centre

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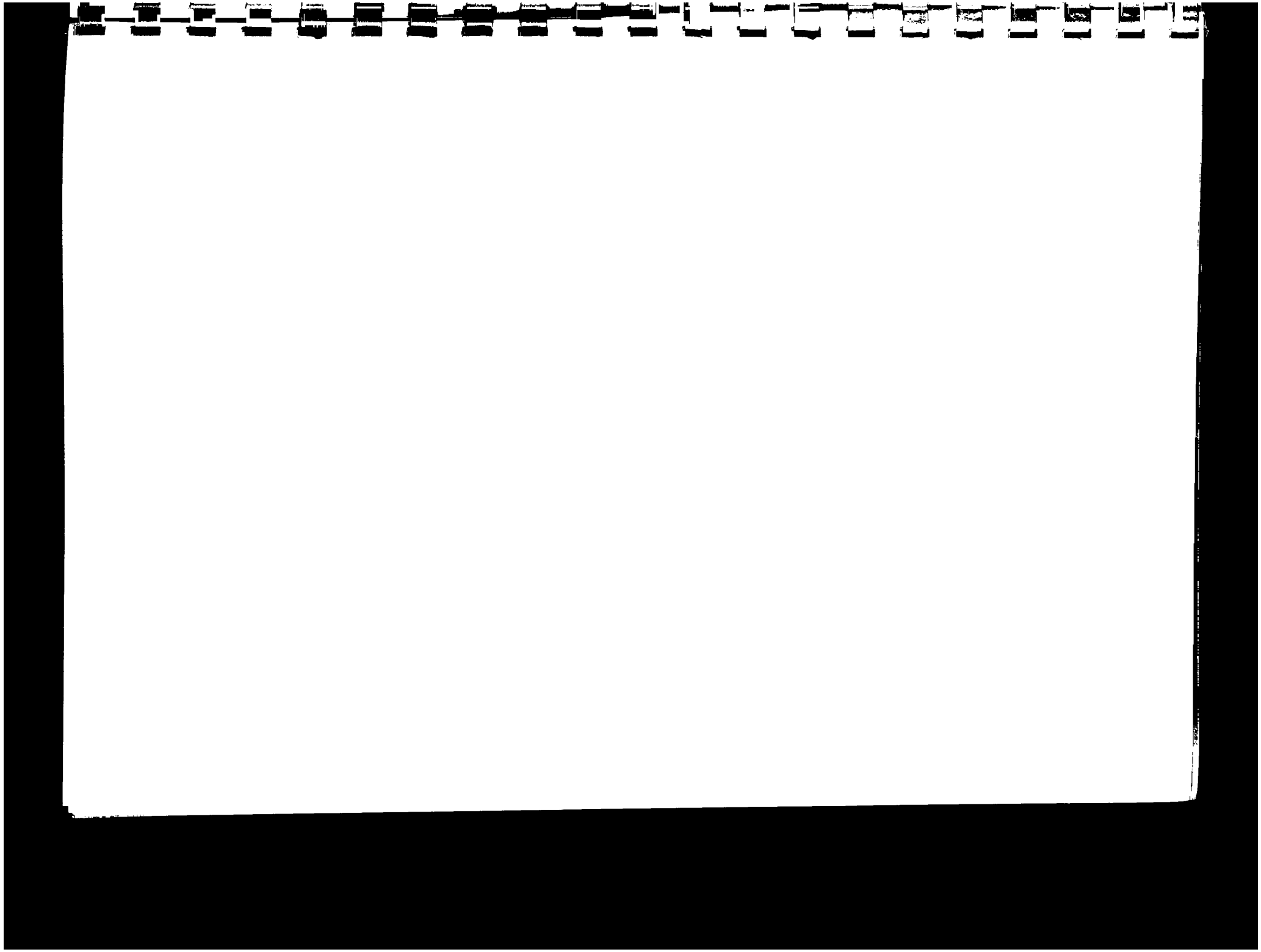

INTRODUCTION

Setting the scene

Without the pioneering work using ordinary houses for children with mental handicap the complexion of services for this age range would not have changed so much over the past seven years. The important initiatives by Barnardo's in the North West Division, and Northgate Hospital in Northumberland, forced others to re-examine their services for children and gave those with commitment the confidence to move forward.

In common with other good stories you need a receptive audience, prepared to come and listen. The King's Fund Centre is instrumental in the dissemination of good practice, putting on a number of study days and conferences looking at different aspects of the development of services for children with a mental handicap. This role has enabled others to share stories, argue issues and discuss detail which has promoted real change in services.

The 'Children's initiative' in context

There are no aspects of human service where we can afford to be complacent. We have to continually to strive to make things better and aim to deliver high quality services.

250 fewer children no longer **live** in hospital as a result of the initiative, although some would argue that the use of hospitals for short stay care is inappropriate. The Secretary of State's statement at the 1986 Conservative Party Conference asked the Health Service to:

> "..... ensure that by the end of 1988 no mentally handicapped child receiving long term care should be required to live in a large mental handicap hospital"

might not have gone far enough.

The 'Children's initiative' and this Conference

Many of the Districts represented had gathered at the King's Fund Centre on a more informal basis in April 1985, which had given them an opportunity to discuss many practical details about acquiring property and recruiting staff.

For this conference things had most definitely moved forward and new questions were being asked. A conscious decision was made on behalf of the organisers to **put the children first** and start the detailed presentations with a focus on individual need, **before** moving on to recruitment, training and neighbourhood issues.

For those of you who wish to research further, these are aspects which should be picked up in the evaluation. Schemes do vary enormously, some are more cautious than others. Some have a house in the grounds of a hospital, another no longer uses nurses to provide care.*

Now that we have changed the lives of the children it is important that through these schemes we continue to offer them a changed future.

* For those who would like further information on individual schemes, we list the names and addresses of contacts in Appendix I.

OPENING ADDRESS

"AN IDEA WHOSE TIME HAD COME"

Derek Thomas, District Psychologist
North Manchester DHA

Over the last 7 years the Kings Fund Centre has taken a leading facilitatory role in bringing people together to share ideas and experiences about services for children with mental handicap. Not only looking at how to get them out of hospital, but also informing and supporting those keen to develop and provide alternative high quality support to families.

1980 was something of a watershed in thinking, policy and services for children with a severe handicap. It was the time that politicians and policy makers spotted **an idea whose time had come.** With Patrick Jenkins' speech an uneqivocal statement was made that no child should grow up in a hospital. It captured the mood of the time and reinforced the ideas and efforts of those who had already managed to turn the idea into reality.

The conference reported here is jointly sponsored by the King's Fund Centre and the DHSS to further explore established themes around the move of children from mental handicap hospitals. Specifically the aims are:

* To share experiences across localities between those involved in moving children and young people out of hospital. Therefore ensuring these are not just locked in the minds of one or two researchers.

* To explore the issues involved in developing and maintaining high quality services for those young people leaving hospital.

* To capitalise on an opportunity to clarify our own ideas, ask questions and continue to move forward.

* Through debate and discussion begin to get a better feel of what some of the key issues are likely to be over the next 5 years. Not all children have yet moved, and we also have much to do to ensure that standards are maintained for those young people who've moved out already.

UP-TO-DATE INFORMATION ON THE SCHEMES

Les Alderman, Principal, Mental Handicap Branch
Department of Health and Social Security

In total over 250 children in 37 projects have benefitted from the scheme launched by the Secretary of State in his letter sent out in January 1983. The schemes vary in their philosophies and geographical spread. Some aim to provide children with a 'home for life'; others expect young adults to move on and be replaced by other children. There is, it is true, a concentration of schemes around the 4 Thames Regional Health Authorities, but projects have been set up in Districts as far apart as Gateshead, Norwich, Bristol and Portsmouth.

Commitment to provide alternative residential services to mental handicap hospitals can be traced through

1971 "Better Services for the Mentally Handicapped" with the intention to provide for children in "small domestic units".

1980 Patrick Jenkins speech to a Mencap conference requesting Health and Local Authorities to identify children in hospital and work in cooperation with voluntary organisations to consider how best to make alternative provision.

(At the end of 1979 in excess of 2,800 children were living in hospital, with a very real prospect that they would become adults there and be 'forgotten'.)

1981 The "£1 for £1" scheme was launched, whereby money provided by voluntary organisations would be matched from a £1 million fund. This money was for capital expenditure associated with moving children out of hospital.

This restriction makes it unlikely that potential projects would get the revenue payments they needed guaranteed. Something further obviously had to be done.

Jan 1983 A letter was sent to administrators, which stated

> "The Secretary of State has been considering what further steps he can take to help authorities speed up the move into smaller units better geared to the needs of children, and with strong neighbourhood links. Of the mentally handicapped children who now remain in our mental handicap hospitals he is particularly concerned that these children are of an age when, if they are not moved soon, they may become absorbed into the hospital's adult population, and their prospects for an early move into more appropriate forms of care in the community be reduced. As part of this drive he wishes to encourage District Health Authorities to establish residential provision in small homely units, for those children who are so severely handicapped that they need care in a health setting".

£3 million per year for three years (1983-1986) was initially made available, and later increased to a total of £10½ million which will run until the funds are exhausted. The main focus for schemes is to reprovide a local service for those children living in Hospital some distance from their home District, or develop a similar service for those Districts who had no health service provision.

April 1983 — Outline proposals for schemes, of which 80 applications were initially received, overstretching the Department's resources, about which details had to be checked.

Nov. 1983 — Initial authorisations were granted to projects. As mentioned earlier, of the 37 projects given approval many vary in aims and objectives, which the Department encourages, as it do not believe there is just 'one way' of doing things.

From the financial point of view spending on this initiative has been as follows:

1983 - 1984	£500,000	(mainly capital)	
1984 - 1985	£1½ million	(capital)	£800,000 revenue
1985 - 1986	£1.1/3 million	(capital	£2 million

THE USE OF LIFE PLANNING IN DEVELOPING A NEEDS-LED SERVICE

Paul Chamberlain, Area Manager
Ms. Beverly Cunningham, Senior Clinical Psychologist
Portsmouth District Health Authority

"We think life planning is a tool that identifies need, identifies shortfall in service provision and possibly staff training and helps us to develop our service in a responsive way".

The first house set up in Portsmouth has now been running for approximately 3 years; it and a second house have both been funded from this scheme's money.

This presentation considers the service in context, quality, life plans and the future.

The children's service in context

The Health District has a population of approximately 500,000 with approximately 1,500 people with mental handicap currently receiving services from one agency to another.

Locally Based Hospital Units were inherited several years ago and the intention is to close them and break them into smaller units. Approximately 350 people live in Coldeast Hospital. Four houses for children have been opened in the past three years.

It is a pretty average Health District, with a typical range of services but, it is felt, moving in the right direction through the use of **life plans.**

Three things have recently changed the service. **First,** general management, which identifies three distinct areas each with an area manager, who has the task of setting up services. In Portsmouth, for example, each of the areas corresponding to the 3 Social Services have a manager who relates to the Area Manager. In this way it is possible to begin to plan and deliver services in collaboration with other local professionals. **Second,** 'Care in the Community' is being taken seriously in Portsmouth, which wasn't happening 2 or 3 years ago, when it was a struggle to get the District to move into developing small houses. The money received from the children's initiative helped enormously. **Third,** the houses have proved to the District General Manager that these houses not only work but provide a higher **'quality of life'.**

Quality Issues

Over the past 3 years it has become apparent that it is essential to consider the quality of services, whilst appreciating that a number of factors contribute to the **'quality'** of the service, for example, is it about

- The amount of money the service costs?
- Which professional group runs the service?
- The type of buildings used?
- Korner and Performance Indicators?

Quality of service is about **quality of life,** what happens to the people in the service, on a day-to-day basis. With this interlinking of quality of service/quality of life and daily experiences it becomes imperative that the service responds effectively to the needs of the people.

Life Planning

In order to address quality issues Life Planning has been established, which has a procedure similar to a review system. Meetings are held approximately six monthly.

Of central importance is the need to ensure that the service is viewed from the person's point of view: "What is it like for this person to be part of/ live in this service all day?". "How relevant are these training programmes to me?". Life Planning comprises three main elements:-

- The first of these elements is for the keyworker to spend time with the client and fill in documentation, before the meeting.

- Second, when the keyworker has looked in more detail at the life of the person, he/she then starts to identify needs across the full range of his/her life. This being assisted by having categories such as 'people's rights'; 'finance'; 'health'; through to traditional skill areas. In order to identify these needs the keyworker can use whichever assessment they wish to use.

- Third, at the actual meeting it is essential to attempt to prioritise needs in terms of what it is like to be this person. What might **he/she** choose if **he/she** had the opportunity?

The processes involved in the above necessitate a commitment to staff training and support, plus the need to ensure that individual staff members and teams are correctly monitored with regard to their progress. The system **must** be very responsive to changes in people's lives, and in this way one can begin to measure just how well the service meets identified needs. If, however, needs are not being met it is essential to ask whether this is because

- staff don't have the resources?
- they haven't the skills to identify needs?
- they need to be gently encouraged?
- they need less subtle forms of persuasion?

Life Planning - An Example

Four young people, with severe learning difficulties, live together in a flat in Portsmouth given to the Health Authority on a short-term let by the Council. It is in a fairly typical neighbourhood with local shops and the town centre within 5minutes by car. The flat has 3 bedrooms, a living room, kitchen, separate bathroom and toilet.

Two of the young people have a physical handicap and one is unable to walk. The flat is staffed 24 hours per day by 8 whole-time equivalent staff, which includes the house leader and deputy. At any one time there are two staff on duty; all share sleep-in duties. All staff took part in the STEP* training package.

This is an illustration of what the move and the life planning process has meant to one young man in the flat, Graham.

"Graham is 15 years old, he has severe learning difficulties, and at an early age went to live with foster parents. This placement eventually broke down, and he went to live in a Health Authority L.B.H.U. with approximately 20 other severely disabled children.

At that time he was an isolated young man, he didn't like the company of other children or staff and spent long periods of time on his bed, chewing the front of his clothes or blankets. He had been excluded from school (because he was a hepatitis B carrier) receiving 2 hours per day home teaching. He had few skills, was doubly incontinent, fed himself messily with his fingers but wouln't hold a spoon. He became much more unsteady on his feet because of the way and amount of time he spent on his bed.

When Graham moved into the flat with the 3 other young people his keyworker spent some time getting to know him, and after a couple of months Life Plan meeting dates were set. After the keyworker had discussions with those who had known Graham in the past they began to complete the first two parts of the Life Plan documentation prior to the meeting.

Part One 'What is the service like from Graham's point of view?'

- A great deal of his day was spent lying on his bed, at his own choice, or avoiding other children.
- Very little of the day was structured to meet his needs.
- He made little use of local community facilities.
- He had no special relationships, except with his foster parents.

Part Two 'Identification of Graham's needs".

In order to do this the keyworker used a number of assessments, and the identified needs covered a whole range of areas, for example:

- He needed to learn to eat (independently) initially with a spoon.

* STEP = Skills Teaching, Education and Programme Planning - Training Package Portsmouth & S E Hants Health Authority, District Dept of Psychology

- He needed to learn to begin to tolerate the presence of other people.
- He would benefit from going back to school, to gain social contact and stimulation from other people.
- He needed further investigation into his physical conditon.

Part Three 'The Life Plan meeting'

Graham, the keyworker, house leader, peripetetic/school teacher, foster parents and psychologist met for the **life plan meeting.** They all knew Graham very well and helped to identify and prioritise his needs.

At this meeting the keyworker reviewed the complete documentation, and the action required was recorded by the house leader.

Prologue

Several months after this Life Plan meeting many of the identified needs have been met, with staff action being planned and monitored at weekly meetings, for example

- Graham now eats with a spoon
- He eats hand-held food cleanly
- He is continent by day
- He started back at school, from which he has benefitted a great deal
- He's had an operation on his legs.

Conclusion

"Graham is a young man who had lived for many years in an institution where no one appeared to have the time, or inclination, to identify or meet his needs. Having moved into this flat staff now see him as an individual and have begun to identify **and** meet needs in a systematic and supported manner".

Life Planning and quality services

In the service overall it is possible to begin to measure the impact of introducing this system, and outcomes in terms of how well each of the areas of need are being met. Although early on in this analysis it is possible to see how many structured teaching programmes, regular daily activities and intermittent activities are being provided in response to identified individual needs. Through this analysis it should be possible to further develop resources, training or support as appropriate, and identify areas which are at risk of being neglected.

It is paramount that all services realise that quality is about 'people's lives'. Unless ways can be found to look further than assessment materials per se one will never get to look at individual needs, identify them and do something about it.

Moving forward, the future

The local council have agreed to grant the Health Authority a long term let. They are impressed and have had no complaints. A second flat or house should shortly be available, because the first is too small to meet the growing needs of these children.

Finance will also be available over the next year to develop fostering services, which it is felt might provide a better option for some of the young people. Although it will most probably be necessary to continue to invest in and develop both.

DEVELOPING COMMUNITY RELATIONS
(Lessons we have learned, or are still learning)

Mr. R. Noble, Manager, Community Mental Health Team
Mrs. R. Hepplewhite, Unit General Manager
Foremost Community Programme, Brighton District Health Authority.

"You don't educate the community to accept people with a mental handicap and then set up your house. The process has to be the other way round".

"It seems to me you can either adopt a high profile or low profile approach. I'll give you my personal view of how it has/hasn't worked in Brighton. We went for a high profile approach.in 1983 with car stickers, leaflets, posters, stationery and a log of our own. If I'm honest I'd say it hardly affected the community at all, but what I think it did affect was the other agencies, the officers and the members and senior staff in those agencies. It did undoubtedly put **Foremost** on the map".

Background

The Foremost Community Programme started in 1983 as a specific response to the children's initiative and the general feelings that children should not grow up in mental handicap hospitals. Children's services at that time were largely provided from Foredown Hospital, Portslade, a 26-bedded Victorian building, formerly an isolation hospital on the edge of the downs.

Foredown predominately had long-stay residents, although some short-stay care was offered, and in addition to this the Social Services Department provided some short and long-stay care.

Uniquely an idea developed and materialised that the Foremost Community programme should be a jointly managed scheme between Health and Social services. Resources and expertise were pooled and a programme drawn up not merely to replace current services but extend the range offered, through:-

- specialist community support provided by the C.M.H.T.
- houses with a maximum of 5/6 chidren in each
- a family respite scheme
- appropriate day care in small groups of 10 to 15
- developing local training packages

Progress to date

- Foredown Hospital closed on August 29th 1986, with five of the six houses opened. These provide for children with a range of needs, some have additional physical handicaps, some a history of disturbed behaviour.

- New staff have taken part in a locally developed training.
- The family link scheme is up and running.
- The C.M.H.T. has a general manager and own premises which are a resource centre for not only specialist services but for the public at large.

The Foremost Community programme is well and truly up and running, not without challenges and difficulties, so this provides a good opportunity to share experiences with the public over the past 3 years.

The Community programme in action

The Foremost programme had the commitment and co-operation of Health and Social Services, both giving tremendous support to a comprehensive community care programme. The foundations were there for the authorities, management, parents, direct care staff, and professionals to all work together, with only the **minor** problem of convincing the local community. It was not until real conversations and consultations began with the local neighbours that it was possible to fully appreciate the task in hand.

For Roger Noble, his standing up at a local meeting to talk about the four young people from a mental handicap hospital who were going to move into the first ordinary house, resulted in him being met by a 'barrage of hostility and personal abuse'. The programme was about to intrude on the neighbours' **quiet suburban middle-class backwater**, with the result in their minds that house prices would fall and "sick perverts would accost their daughters". The meeting lasted 2½ hours and left those involved wondering whether this would, in fact, be a wise move for the four people concerned. It hardly seemed like a welcoming neighbourhood!

From a **technical** point of view, it was planning committees who had to be convinced and support the applications. In the end, the house mentioned above opened and now enjoys fairly typical support from neighbours, though nothing spectacular.

It is through developing opportunities, skills and experiences of the young people **in** the community that you begin to get the community to understand what it is about. You begin to develop community relations. You don't go around trying to convince people, you can prepare the ground in changing attitudes but it mustn't be hard hitting or too focussed.

It might be worth considering what the Foremost Community programme did: taking a slot over a week on local radio stations to talk to different people about various aspects of the project. The glossy brochure and Audio Visual presentation, again, might help provide people with information, knowledge upon which they might then begin to change their attitudes.

The Audio Visual presentation made at the conference tries, in a discursive way, to talk about people with mental handicap and show there is nothing unusual about them being around and living as members of the community.

Lessons to be learned from contacts with the neighbourhood

- Don't mount big publicity campaigns targeted at a specific neighbourhood.
- Talk to the immediate neighbours, and keep a low profile.
- Take time to match the property to the people you intend living there.
- 'Problems' will not necessarily disappear because of the move from institutional care. Some behaviour might change, new skills be learned, but **noises** remain **noises.**
- If **noise** might be a problem, ensure the party wall of the semi-detached house is adjacent to the staircase and hall (not the bedroom and lounge).

Be prepared to work with families

Although now we are more sensitised to the needs of local communities and skilled in how to approach them, both tact and diplomacy are obviously required with families. It may come as an initial shock to find that families are hostile to the concept of community care, possibly equating this move to other cuts in the Health Service. It may be devastating to find a family canvassing prospective neighbours, telling them about a local house for people with mental handicap and encouraging them to protest.

Certain families will go with you all the way, others will undoubtedly protest; it will be necessary to make decisions to press ahead.

The only way to really convince families that this approach makes sense is to show them the houses functioning with a high level of staff commitment, and with programmes meeting individual needs. It is this that persuades, rather than lengthy spiels about philosophy or normalisation.

Built-in staff training on diplomacy

This is specifically for staff interactions with other professionals, neighbours and families. There is a danger that over enthusiastic keyworkers will go out and tell people, in no uncertain terms, what they think of institutional care; or of the chances that have been missed over the past ten years. This vigorous, over-zealous approach can lead to the need to unruffle feathers, and restore good relationships with services operating under a different philosophy.

To influence committees etc.

- Take the publicity and film to all the planners, committee members etc., and use this in the support of planning applications.

- Make 'the project' (in this case, Foremost) feel 'unstoppable'.

Conclusions

Adopt a low profile approach, but ensure that other agencies, professionals etc. are with you. However, you must be prepared to accept valid criticism and complaint, especially if related to noise or when members of the public believe a client is being unnecessarily 'manhandled'.

Make sure you take your staff group with you.

Be honest with the public. (Do **we** know if we will 'continue' to succeed?!)

RECRUITMENT AND TRAINING

Anthea Sperlinger, Principal Clinical Psychologist
Greenwich District Health Authority

"....we really need to take on board the fact that new ideas require continuous support and reinforcement, and I think that we often give that much more to clients than we do to staff".

INTRODUCTION

This section looks more specifically at the training and support of staff in ordinary houses. The Greenwich project is one bungalow for six children and young people with profound handicaps. It is a purpose-built bungalow which opened in November 1985. The home leader was appointed on the 1st April 1985; other staff were gradually appointed, and all moved to a refurbished ward in Goldie Leigh Hospital, to give them some experience of doing their own cooking and cleaning before moving out.

The staff were given on week's training in the first week of October. 70% of staff were previously employed in Goldie Leigh; the others were recruited from outside.

Rather than focus on the content of training, the areas covered here consider the **issues** which should be addressed, particularly when there is only a relatively short period of time available.

Staff Training Issues

Identify the model of service to be provided

There is no point in discussing normalisation and so on unless decisions are made precisely about how that is going to work for **you** in **this house** with **these people.**

View staff-training as a process, not a one-off

There are inevitable gaps between a training week and the real work setting. It is essential to build in a supportive mechanism, with the aim of ensuring that staff were provided with ongoing support in putting new skills and ideas into practice. Weekly staff meetings to discuss clients, chaired by the psychologist were set up to coincide with the house opening.

Provide mechanisms for positive monitoring

Staff need to have clearly stated work plans, which will enable them to meet goals and objectives identified for clients.

Involve staff in preliminary discussions

For example, with regard to various key worker roles and which might be the best one to adopt in this new service.

Involve staff in deciding which areas to cover

Staff were involved in choosing the content of the training week, and filled in detailed biographical information on each of the six clients. With the goal of ensuring that discussions on future role and activity centred around knowledge of the person.

Devise a training evaluation

To consider the relevance of the training and its subsequent application in the house.

Setting clear, realistic targets

In this service Opportunity Plans were chosen, which make the most of a client's existing skills and attempts to ensure that opportunities are made available to utilise them.

A decision was made to defer 'Life Planning' until foundations had been laid, which familiarised staff with keeping records. Opportunity Plans were more achievable in the early states.

Staff Training Content

Although looking most at **issues** and **evaluation,** some information was given on training content which is reproduced below.

- Normalisation

  Skills teaching,
  with guidelines on organisation of the date, and home-making tasks.

- Understanding clients and their families.

- Initiating client-centred record keeping

- Staff group team building

- Providing supportive structure for staff to explore new roles

- Examples of good and bad practice

Staff training as a process

Staff training in Greenwich has developed a dynamic pattern which aims to be interactive, hence:-

		ACTIVITY
-	4 WEEKS	Staff Training Week
	ZERO	Weekly client-centred meeting (continue)
+	4 MONTHS	Evaluation on meeting aims
+	7 MONTHS	'Top up' study day, all staff
+	9 MONTHS	Life planning initiated.

- This process has enabled staff to feed regularly into weekly **client-centred** meetings, and an ongoing review of policy in action.

- At the 4 month **evaluation.** all stated aims and objectives were examined to see what had been achieved, and opportunity plans set for clients were measured to see how well they had been met.

- At 7 months, a **'top up'** study day was attended by all staff, the content of which had been identified **by staff** and arose from the above evaluation.

- At 9 months **Life planning** was initiated, because it was then that the necessary scaffolding had been erected upon which to build this system.

Evaluation

Initial evaluation of these areas, broken down into brief headings, suggested that the things staff found **most** useful were these:-

1. - Skills teaching
2. - Understanding clients
3. - Team building
4. - Exploring new role
5. - Normalisation

Topics staff didn't rate as unhelpful, but **didn't** rate as particularly helpful were:-

- organisation of the day
- client-centred records
- examples of good practice.

Seven months after the training, staff were asked to rate what had been most useful, and what had had most influence over the life in the bungalow.

MOST USEFUL

1. (- Normalisation
   (- Understanding clients

2. - Team building

3. - Skills teaching

MOST INFLUENCE

1. (- Normalisation
   (- Policies made for themselves

2. Understanding clients

3. Skills teaching

This continuous process where everything feeds from and into the weekly client-centred staff meetings has been one essential feature of building a system which means

- all clients have goals set and teaching plans
- all clients have opportunity plans
- client-centred business and activities are comprehensively recorded
- weekly meetings continue (being rated highly in the evaluation)
- Lifeplans are now up and running, albeit they need some fine tuning, and a distinct way of being fed into weekly meetings.

It also provides real opportunities, if management is supportive, for policies to retain a flexibility which will benefit clients.

Conclusions

When staff go to work in new settings it is essential that they and their managers are clear about exactly what is being asked of them. In some respects it is like **goal planning for staff.** It is essential that they do not feel overwhelmed with too many conflicting demands.

As a form of training, adopting this dynamic 'process' approach is **not** cheap in terms of either time, professional commitment or money. It needs total support from managment (which Greenwich undoubtedly had), plus support in terms of funding, staff cover and so on.

There are still important issues to cover, such as how to integrate new members of staff, a challenge which surely can be met.

STAFF SUPPORT AND MANAGEMENT

Mrs. C. Fincham, Clinical Nurse Manager
North West Herts. Health Authority

".... it has taken many years to work out the philosophy of **care in the community** for clients. I believe it may take even longer to work out the management and support structure for staff working in small community units".

INTRODUCTION

North West Herts opened 3 projects in late 1985, within a month of each other. There are 2 houses for 8 profoundly physically handicapped children (4 in each) and the third house has 10 profoundly mentally handicapped adolescents in 3 flats. The first 2 projects have 9 staff and the third 23. Each house has its own staff dynamics and, being relatively new projects, it is only possible to make limited predictions.

Key issues and ideas in supporting staff

1. Young Staff

The three houses have a high percentage of unqualified staff, who tend to be in the 19-25 year age range. They require more support, as often maturity tends to bring tolerance and understanding of others' needs. Because the houses are small, staff do depend much more on each other, have a broader range of responsibilities (for example housekeeping) and the support offered by being tolerant can be substantial.

More part-time staff (evenings and weekends) are to be employed, with the aim of recruiting more mature mothers, which, it is hoped, will enhance the service to the children and be a support to younger staff members.

2. Untrained Staff

Have more responsibility in their new role. It can enhance the service given to the children and increase job satisfaction. Team leaders and deputies need themselves to be supported in delegating responsibility and knowing **how** and **when** to do it.

The service will grow if it is done accurately and sensitively, but staff need to be ready to take on extra responsibility.

Staff need to understand that responsibility is not synonymous with extra authority, nor try to manage other staff.

Democracy, they have learned, cannot be achieved in small houses, and the management style needs to be clearly articulated. All staff members should feel that they can say what they think: if it is good, it will be used; if it is not, they will have to accept that it won't be used.

3. Domestic training

It can be a mistake **not** to ask about housekeeping skills at interviews. Don't make the assumption that everyone can do it - you will be proved wrong! If you do assemble a staff group who cannot manage housekeeping tasks, it will put extra pressure on the staff group and team leader. Be aware that standards vary from person to person. To change them is to change the fundamentals of a person - it might not be possible.

4. Working in a small unit

In some respects a small unit is like a family and requires the same amount of support and understanding from the staff members. However, in the houses you may not have the same motivation to understand and forgive. In a family there is love, 'give and take'; but it is not there to the same degree in the houses. One must, therefore, appreciate the relationship between staff and staff, staff and clients, and staff and families.

5. The relationship between staff and parents

This is essential. The parents **want** the home to succeed. They are the 'fortunate ones'; have a vested interest in the staff and can be a source of support.

Parents need to trust staff, and vice-versa. The relationship needs to be open and honest, but it can be hard to admit one's faults in such a relationship. Most recently parents* have become involved in staff interviews, which enables them to have some say in who is appointed and some responsibility towards that person.

6 The Risk Factor

There need to be clear guidelines from the District on **risk**, the **understanding** of parents and **support** of the manager.

The 'risk factor' can create much stress, especially on the Team Leader, who **cannot** be responsible for everything. Accidents can happen, and mistakes have to be made, if Team Leaders are to grow and develop into their new roles. The project has to be owned by the staff team, and with this comes responsibility, accountability and the need to succeed.

Risks need to be seen in a developmental context and Team Leaders encouraged, rather than just being reprimanded if things go wrong.

Ways forward in staff support

We are left with more answers than questions, but there are some suggestions:-

- Give staff **time** and **regular weekly support/supervision.** (this is shared by Team Leader and Deputy).

* One of the parents is a personnel officer who thought involving parents in this way was a good idea, and will shortly be feeding back his experiences to others.

- Meet team leaders weekly for about 2 **hours** but keep longer free in case extra time is needed.

- Use **weekly house meetings** to plan the growth of the service.

- Hold p**arent/staff** groups for each house 2 or 3 monthly to enhance working relationships and share problems.

- Set up a **support group** made up of authority members, top management in the service, members of the house team and parents to enable growth, facilitiate change and pinpoint the need for resources.

- Ensure that projects are **not seen** as failures because things are not perfect - they rarely are. They have to be seen as growing, changing, maturing, to keep up with the needs of the children.

- **Don't let services stagnate** when they have reached a comfortable point. Large institutions have caused enormous management problems by **not** tackling the real issues. We need to deal with situations as they arise, rather than cover them up and blame bad management.

Conclusions

Much has been learned over the past 12 months. The issues outlined above are real, not just speculation or ideas, and the projects have much to offer, particularly if they continue to develop and grow.

WITHIN SERVICE EVALUATION

Oliver Russell, Consultant Psychiatrist
Steve Knight, Home Leader
Paul Roberts, Community Nurse Manager
Bristol & Weston Health District

"It is all very well carrying out evaluations and doing it within the service, but what do you actually do with it? Evaluation helps you understand what's going on....whether we are involved in the service, managing it, or a family".

BACKGROUND

Five adolescent boys moved from Farliegh Hospital, Sunshine Ward, to a house in Backwell in December 1985. The evaluation spans the time immediately prior to and following this move. It was undertaken by Jo McMahon and Alison Easterbrook with a number of emerging themes presented during this presentation, it being too early to come up with definitive results.

The evaluation

Was described in terms of **Process, Outcome** and **Method.**

PROCESS or "What is going on?"

- in the service
- for the young people
- for the staff
- for the community, near neighbours and further afield
- for the families.

OUTCOME or "What has been achieved?"
in terms of....

- quality of life
- social integration
- social skills
- engagement in purposeful activity
- cost effectiveness (not done here, but an adult house is being looked at in the District).

METHOD or "How was the evaluation done?"

- Observational Studies — what people were doing how they spent time
- Structured interviews — to get a fair record of what each staff member did each day

- Questionnaires — which might be used for a larger population

- Regular staff reports — incorporating comments made in the day-to-day recordings of life in the house.

The five young men, now aged up to 20 years, had been living in hospital care for a number of years. The hospital ward, which had been built as an occupational therapy workshop was an uncomfortable environment, and one young man had lived in an institutional setting for 11 years.

Observations and interviews were carried out in November 1985 and July 1986, and although it is not possible to evaluate success in such a short time, these were matched against hypotheses, which were:-

CLIENT RELATED

i) In the house they would have their own room, own space, personal possessions, and access to play materials, and leisure equipment etc.

ii) There would be greater opportunities to spend time and do things with **each other, staff** and the **wider community.**

iii) There would be access to more rooms (as opposed to the one large room in the hospital ward).

iv) More opportunities would exist for meaningful engagement in domestic activity.

STAFF RELATED

i) The group of 12 staff (9 recruited from the ward team) would develop skills to engage effectively with clients.

ii) The amount of **joint** engagement in activities would increase. These could be linked as:-

MORE MATERIALS

GREATER ACCESS TO ROOMS

AVAILABILITY OF DOMESTIC ROUTINES

STAFF SKILLS IN ENGAGING WITH CLIENTS

LEAD TO

INCREASED RATES OF SPONTANEOUS CONSTRUCTIVE RESIDENT ACTIVITY

RATE OF STAFF-RESIDENT JOINT INTERACTION WOULD INCREASE

Initial indications from evaluation

Interviews, observations and staff reports have been utilised in an attempt to begin to test the hypotheses outlined above.

RESIDENTS

- It is too early to draw definitive conclusions from the observations on purposeful activity.

- Residents need support in structuring leisure time and using, for example, play materials.

  Structured domestic activities are important for residents; it helps them understand **when** to take part.

- Family contact **has** increased now that their sons are no longer in hospital. Having a son in **hospital** had a stigma attached.

STAFF

- Had greater freedom to go out with residents (a vehicle had been acquired for the house).

- Pressure on staff **increased,** particularly with relation to the domestic tasks, an area 9 out of 12 had **not** had to undertake before.

- There was an increased pressure to **succeed.** Here was a project which questioned the future of the hospital.

- More opportunities seemed to exist for residents to put **challenges on staff** by way of their behaviour.

The potential uses of within service evaluation

It is essential to have a clear idea of how it might be possible to utilise evaluations; for example, to realise that it can be used:-

- To help you understand what is going on, through the collection of **structured** information.

- To evaluate **change** in an individual's performance, whether this be in relation to social skills or social integration.

- To enable staff to reflect on the outcomes of their own practice, they **are** changing roles and practices and should be given the opportunity to consider the implications of these changes.

- To help managers and planners influence the ways in which services are developed and operated utilising accurate information. Whether this identifies the need for fine tuning here or a major overhaul there.

Conclusions

This evaluation made use of **available** local resources, and might have been structured differently had it been in receipt of a 3-year research grant. It has, however, identified pertinent themes which will continue to emerge as results are analysed.

ASSESSMENT OF CENTRALLY FUNDED PROJECTS

John Brown, Lecturer in Social Policy
University of York.

INTRODUCTION

This is being undertaken by John Brown, Irene Walton and Anne Leonard, and is being funded by the DHSS. It is an information gathering exercise to find out what's going on in all 29 schemes, and aims to report by March 31st 1987.

One of the team, Anne Leonard, will visit all schemes and attempt to pick up local issues to do with difficulties, successes and constraints. Each of the schemes is at a very different stage of development, which means different questions will be asked and issues arise.

Questions

These will be along the lines of:-

ESTABLISHING SCHEMES

- The **establishment** of schemes, conception, design and cost.
- **Consultation** with parents, neighbours and local area.
- Who was responsible for **planning** the project?

SELECTION OF CHILDREN

- The **selection** of the young people by age, length of stay in hospital, or local area.
- **Characteristics** of children in the projects.
- **Preparation** of children for the move out of hospital.
- Whether or not all children came from **hospital.**
- Are the projects a '**home for life**' or '**children's home**'?

SETTINGS USED

- **Settings** used for the schemes and their advantages/disadvantages.
- The **views** of carers and parents.
- Whether the projects are **homely** or not.

MODELS OF CARE

- **Model of** care in operation, and the staffing structure.
- **Training** offered to staff.
- **Reaction** of staff to working in a new environment.
- Whether or not **individual plans** are devised and implemented.

RELATIONSHIP TO OTHER PROVISIONS

- How do these '**one-off schemes** fit in to broader areas of service provision?

FUNDING AND THE FUTURE

- **Comparative** costs of schemes
- Costs at different **stages**
- Support in future years.

This seems to encompass a phenomenally large number of topics, and it was stressed during the presentation that findings would be fed back to the schemes, in a format yet to be decided, which would give participants an opportunity to learn in more detail more about the overall picture.

It is to be hoped that such information will be used in a positive, constructive way which will benefit both the children and the service provider

DISCUSSION GROUP A

PARENTAL INVOLVEMENT

In general the group felt professionals had become more flexible in their approach to parents, and relationships had improved since children moved to houses.

KEY ISSUES

* With smaller units (houses), parents seem to become more supportive to staff, the house and each other.

* When better staff-parent relationships develop the foundations are laid for more honest exchanges of views and ideas.

* Members of the group felt they had become more adaptable in response to parents who themselves felt more comfortable in the houses.

* Parents have the **right** to know what sort of contract (explicit or hidden) has been struck between them and the Health Authority. For example, is the house a 'home for life' or not?

DISCUSSION GROUP B

INDIVIDUAL DEVELOPMENT

This group looked at ways of trying to ensure that individual needs were met.

KEY ISSUES

* Devise methods for **accurately** identifying needs.

* Give the keyworker a clear role and responsibility to monitor progress and action.

* Don't overlook psychological and emotional needs by overemphasising skills teaching or physical needs.

DISCUSSION GROUP C

DEVELOPING COMMUNITY CONTACTS

KEY ISSUES

MAKE USE OF LOCAL KNOWLEDGE

* Ensure you understand local situation and culture
* If apppropriate, use local councillors and/or MPs.
* The low profile approach seems to work best

UNDERSTANDING

* Strive to impart understanding about people with handicap
* Make clear the distinction between 'mental illness' and 'mental handicap'

STAFF

* Need breadth of vision and understanding
* They have to use diplomacy and tact, and shouldn't be over zealous.

NEIGHBOURS

* Make use of them in creative ways
* Encourage them to support the houses
* Don't let the locality feel 'swamped' either in urban or rural areas.

EDUCATION AND ATTITUDES

* Some projects invite schoolchildren into houses; it can help for them to meet the children

* Encourage neighbours to visit the houses and hospitals.

DISCUSSION GROUP D

RECRUITMENT AND TRAINING STAFF

KEY ISSUES

* Be clear about the specific but varied contributions of qualified and unqualified staff.

* Face up to the issues of (low) pay staff and grading

* It is difficult to build in enough time to release staff for training.

* It can be hard to recruit staff.

* There should be a proper career structure for junior and unqualified staff.

* There is a distinct lack of training resources.

* Staff can become either over committed or disenchanted, without adequate support.

DISCUSSION GROUP E

SERVICE DEVELOPMENT

KEY ISSUES

* Out of borough placements need to be reviewed, with a view to returning, where possible, the children involved, even though this will need additional financial and staff resources.

* In order to prevent future admissions to health service care, it will be necessary to develop a range of shared-family support and increase skills in, for example, local hospitals to cater for children who become ill.

* Clarification is needed regarding whether or not it is a 'house for life' or 'support for life'. If young adults have to move, where do they go?

* Obtaining finance for the build-up of residential services only **creates problems** if there is not sufficient emphasis put on the development of a range of support services. Collaboration is very necessary, with voluntary organisations, housing and other bodies.

DISCUSSION GROUP F

FINANCE AND ADMINISTRATION

KEY ISSUES

* Central funding enables the service to be 'protected' and exempt from competing for local needs.

* Funding after 1987/88 and for individuals over 19 years old is a local issue.

* Anxieties exist over a possible backlash where services for people with mental handicap lose out ot those for other people or areas.

* Bureaucracy seems to have caught up, perhaps even overtaken the development of these innovative services.

* Quality of service does **not** necessarily relate directly to resources made available.

* Property maintenance should not, generally, be the responsibility of the conventional works department.

* Are these services likely to be Health Service responsibility in the long term? If not, then how will handovers be effected?

SUMMARY AND DISCUSSION

In the final discussion and question time, issues were raised which are reproduced here as a number of points.

* These projects are working, despite the scepticism of some a few years ago.

* We have become more sophisticated and skilled in
  - our approaches to the neighbourhood
  - staff training and support
  - evaluating the service provided.

* People with mental handicap in these services have acquired a greater status and identity.

* The majority of problems are staff or service related, rather than to do directly with the client. "Everyone has to get away from the **homes with hospital rules notion**".

* As Districts and Regions supported the initial submissions for funding **they** therefore expressed a commitment.

* Many projects now **share** much more information with parents which in the past might have been kept from them.

* A greater commitment now exists to define quality, and develop quality services.

* We must try and create a service which ensures it knows and cares what happens to people.

* The 'Children's Initiative' experiences have spilled over to a much broader client group than just those in the projects.

* 'Pump priming' and 'pots of gold' can solve short term problems but leave long term issues unresolved.

* New relationships are developing between parents and staff.

* We are becoming more skilled in identifying an individual's needs, formulating life plans and beginning to use this information in service development.

* The network of those who have learned from the good experiences of children moving out of hospital is now very extensive.

KING EDWARD'S HOSPITAL FUND FOR LONDON

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

BRINGING CHILDREN OUT OF MENTAL HANDICAP HOSPITALS

Conference - 21st October, 1986

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Appendix II KFC 86/126

King Edward's Hospital Fund for London

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

BRINGING CHILDREN OUT OF MENTAL HANDICAP HOSPITALS

Conference - 21 October 1986

PROGRAMME

	Chairman - Derek Thomas	District Psychologist North Manchester HA
9.30 am	Registration	
10.00 am	Introduction to the Day	
	Presentation of up-to-date Information on schemes	Les Alderman, Principal, Mental Handicap Branch DHSS
10.25 am	The use of life planning developing a needs-led service	Portsmouth
10.55 am	COFFEE	
11.10 am	Developing Community Relations	Brighton
11.40 am	Small Groups - key issues	
12.45 pm	LUNCH	
1.45 pm	Staffing Issues:	
	(a) Recruitment and Training	Greenwich
	(b) Support and Management	NW Herts
2.30 pm	Within service evaluation	Bristol
3.00 pm	TEA	
3.15 pm	Assessment of centrally-funded projects	John Brown University of York
3.30 pm	Question-and-answer session on key issues