KF REPORTS

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PROGRESS IN BRINGING MENTALLY HANDICAPPED CHILDREN OUT OF HOSPITAL

King's Fund Centre
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On Wednesday, March 21st, 1984 a conference was held at the King's Fund Centre to describe new initiatives and progress in bringing mentally handicapped children out of hospital. This paper is an account of that conference, with a description of innovatory schemes and a discussion of the issues described. A conference programme and list of participants are attached.

PROGRESS IN BRINGING MENTALLY HANDICAPPED CHILDREN OUT OF HOSPITAL

ANN SHEARER

The importance of this issue cannot be stressed too highly. We've known about the effects of institutional life on children with mental handicap since the Brooklands experiment of the 1960s conducted by the late Jack Tizard. We have also had the evidence from Maureen Oswin's work on children in long stay hospitals. Both these pieces of research show conclusively the active damage we are doing to children who live in institutional settings. So, what can we do to enable these children to grow and develop, because we know they can do these things.

This is an urgent matter. Time is running out for many children. At the end of 1979 there were 2,840 children under 16 living in long-stay hospitals. Now there are only about 1,600. But where have the 1,240 gone? We know that the 31 projects with special government funding to bring children out of hospital will only provide homes in the community for 250 children. Most of the rest have simply 'disappeared'; they have passed their sixteenth birthday and moved into adult wards. We have found an 'administrative solution' to human lives.

What sort of alternatives are being developed for these children leaving hospital? Government funding seems to support the provision of 'small homes', but is this the most appropriate solution for all children? How do we stop this automatic planning for groups rather than for individual children?

Making alternative provision in the community must mean a consideration of more than just housing and residential care. Sometimes no planning is being undertaken for education so that children are being bussed back to hospital schools because local schools can't make provision. And for the older children, what provision in terms of vocational services and/or further education are we making? How far are we involving families?

BARNARDO'S NORTH WEST DIVISION

PROFESSIONAL FOSTERING SCHEME

CHRIS SPENCER AND ROSEMARY HINDLE

The scheme works more or less to an annual cycle beginning with the advertising campaign in the autumn and culminating in the placement of children with foster families in the following July or August.

Advertising is undertaken using a 'saturation approach'. There is heavy advertising in all the local Liverpool papers (including the numerous free papers). Advertisements are placed in the 'Jobs' section on the papers' classified advertising. Newspapers are also persuaded to carry feature articles about the scheme wherever possible. Barnardo's use local radio and television too, although this doesn't appear to be as successful as the press. Advertisements are also placed in local Job Centres.

During the advertising campaign, offices 'phones are specially manned to deal with enquiries, which are usually in the region of 300-500 calls. Written information is then sent out to enquirers who wish to find out more. This information will include articles written by foster parents and some brief information on the children seeking homes. After two weeks Barnardo's telephone prospective foster families who are then invited to attend an open meeting. This meeting, attended by prospective foster parents, the children's care staff, Barnardo's workers, and existing foster parents provides further information and interested families are given an application form to complete.

By early December families will have been expected to return the completed application forms. By the end of March each family will have spent time in discussion with a social worker from the project and will have visited an existing foster family. Applications are then presented to the Fostering Panel who will decide which families are to be accepted.

Families which have been accepted will then undertake the initial training programme which lasts for five sessions. At the same time families and social workers will be discussing the needs of each of the children and the possibility of the family meeting those needs. Introductions to the children begin in about May and final placement is likely to occure during July or August.

The fostering team was set up in 1979 and so far 29 children have been placed with families. It is hoped to place a further 14 children this summer. So far there have been no breakdowns in placements.

Foster parents receive a professional fostering fee (presently £57.50 per week) in addition to the normal boarding-out allowance (currently about £25 per week). Some families are also able to claim attendance and/or mobility allowance on the child's behalf.

Families are offered 21 days a year respite care although they are not obliged to take up this offer.

The fostering team offer continuing support in the form of monthly visits by a social worker to the foster parents and regular group meetings of staff and foster parents.

Families participating in the scheme are expected to:

- attend the statutory six-month reviews of their foster child and make either a written or verbal contribution to it;
- keep a diary about the child;
- attend monthly ongoing training and support sessions;
- maintain contact with foster parents where this is appropriate:
- participate in promoting the project.

Granada television featured the project last year in their 'This is your Right' programme and Barnardo's have a video of the programme (not available for hire; all enquiries directly to Granada). The video, which describes the operation of the scheme, includes interviews with foster parents who talk about their own experiences of being foster parents - the rewards, the initial fears, dealing with community attitudes - and shows some of the children being fostered including very young children and adolescents.

DISCUSSION

Q. What about the more severely handicapped children?

A. The majority of the children being fostered have no expressive language; some have problems with behaviour and some are doubly incontinent. Only five children have Down's syndrome. One little girl being fostered had a long history of institutional care; she was doubly incontinent, and unable to talk or walk. Through fostering with good support and coordination of specialist services she is now making some progress - she is beginning to learn to stand.

Q. Where do the children come from?

A. Mostly from Barnardo's homes although we will place children directly from hospital. Sometimes children will come out of hospital and spend a period in a Barnardo's home before being fostered.

Q. What happens after the child is 16?

A. Where older children are being fostered at present, payment is continued up to the age of 21. We would then go to the DHSS and discuss payment of benefits. Foster parents are asked to make a commitment until the child is 18 but no parents have so far suggested that the young person should move out at the age of 18. Training sessions are used to help parents plan for the future of the young adults.

Q. What education arrangements are made?

A. When the placement is being set up the education authority is approached to arrange a place at the nearest special school.

Q. Are your foster parents 'special' in some way?

A. No, not really. But we believe that good support is absolutely essential from social workers, psychologists and other resources in the community.

Q. Why aren't more local authorities operating schemes?

A. It may be because their resources are stretched with statutory work. It is certainly true that the voluntary child care organisations are often leading the way in this field.

Q. Do you ever recruit single people?

A. Yes. We have two single parents who are fostering for us.

Q. How do you 'cope' with the natural parents?

A. This can be difficult. Where natural parents are still in contact with their child they may see fostering as threatening. It needs lots of work! No natural parent has yet refused to allow a fostering placement but if they did we would refer the matter to the local authority. It would be their responsibility to deal with that situation.

Q. What happens when you reject people as foster parents?

A. Most people drop out before this happens if they are not suitable. Where families have their application refused, we go and visit them and explain our reasons why. If they are suitable for fostering non-handicaped children we may suggest referring them on to a local authority.

Q. How do you go about matching families and children?

A. We have a book which has a photo and details of each child. We use this as the starting point when we talk to families. We ask them which child do they think would fit into their family. We discuss the families with the child's care staff. This information is pooled at a meeting and we work out recommendations.

Q. To what do you attribute the success of the scheme?

A. Several factors:

* success breeds success and when you can quote actual examples of successful fostering it helps;

* we have a very clear timescale for recruiting and we make sure that we stick to it so that parents do not feel let down. For example, if we say we'll phone in a fortnight, then we do.

* we provide good continuing support for the foster parents.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

John Wallis
Paul Chamberlain
Moira Angel

The health authority has one large hospital with 461 beds and a 55-bed hospital.

The authority is planning alternative services for 43 children who are, at present, in the large hospital (17 children), in the smaller hospital (12 children) and in a locally-based 'Wessex unit' (15 children). In both hospitals some of the children are sharing accommodation with adults. Most of the children are over 12 but there is one 3-year-old.

The authority drew on the King's Fund 'Ordinary Life' work when planning alternative services and were strongly influenced by the principle of normalisation. The service has been designed on the following principles:

* The service should be comprehensive (no child should be excluded).

* Services should support established social networks.

* Staffing should be flexible in order to meet the users' needs.

* Services should be provided in the least restrictive settings.

* The service should be flexible - the needs of the individual are paramount.

* Investment should be in 'human resources' (i.e. staffing) rather than in bricks and mortar.

* Generic services should be used wherever possible.

Planning for change

It was necessary to identify the key people who would need to be involved in any changes. They were brought together in a working party. The working party not only discussed future services but did site visits to other services in the community and prepared papers for consultation. Submissions were made to the DHSS (for earmarked funding) and to the district health authority. It was essential to 'sell' the proposed services because not all the key people were convinced that all the children could live in the community.

The first group of five children has moved out of the large hospital and they are currently in a flat attached to an adult hostel until the house which will be their ultimate home is ready.

The five children are:

Mark who is sixteen and has spent a long time in hospital. He is partially sighted. Since moving out Mark has learnt some self-care skills and will remain at school until he is 19.

Terri is 15. She has spent 9 years in hospital, has scoliosis and uses a wheelchair. She is also very 'chesty'. In hospital she spent most of the time screaming. Since leaving the hospital she has learnt to feed herself and there has been greatly increased parental interest and contact. She met her sister for the first time recently.

Danny was someone who many of the hospital staff thought would have a lot of 'problems' if he left hospital. In fact this has not been the case; his eating skills have improved and he is almost toilet-trained although in hospital he was completely incontinent.

Jason is partially-sighted and non-ambulant. In hospital he screamed a great deal. Now he giggles a lot and loves a good cuddle. His contact with the other children has increased a great deal (from virtually nil in hospital). He almost feeds himself now and is learning to sit. It is hoped that he may perhaps learn to walk in the future.

Nicola is fifteen and has spent most of her life in hospital - staff are busy trying to stop her calling everyone 'nurse'. Her speech is developing and she is learning Makaton.

As is self-evident from these brief descriptions, all the children have made considerable progress since leaving hospital. Each child's learning is carefully structured through the use of individual programme plans.

When the children left hospital there was considerable anxiety on the part of staff about what would happen if 'accidents' occurred, but this has not in fact been an issue.

Staff do all the cleaning and cooking; there are no domestic staff. Rotas are arranged so that there is maximum staffing during evenings, weekends and school holidays.

In the new house the children will have local doctors and dentists, selected according to the child's individual needs.

Unfortunately the children will have to continue returning to the school on the hospital site.

The house will have an ordinary car for use by the staff and children.

Staff training

This has been an important feature of the new service. It is likely that staff will be non-qualified in most cases or will lack the appropriate skills. So, you need to give staff skills and set up a system that maintains them and provides external support.

The STEP (Skills Teaching Educational Package) method is used which enables the team leader (of a house) to teach their own staff. It is based on four steps:

Read -----> See -----> Practice -----> Do

The basic training for staff is in six units:

1. Introduction to the principle of normalisation.
2. Practical applications of the principle of normalisation.
3. Behaviour .and skills
4. Assessment - community living skills.
5. Assessment - baselines.
6. Individual Programme Plans.

It is planned to hold weekly staff meetings with the psychologist. These will provide opportunities for work on IPPs and for positive monitoring of staff activities.

In setting up a service like this, a number of issues (or problems) can be identified under a series of headings:

1. Grouping of the children

(a) Parental contact/homes
(b) Age and sex of children
(c) Special needs
(d) Educational placement
(e) Children's friends
(f) Availability of houses

2. Staffing

(a) Selection criteria
(b) Career structure
(c) Hours worked
(d) Redeployment of existing staff
(e) Stress involved in making changes

3. Finance

How much control do we have over money and how do we manage the 'transitional' funding for new services?

4. Planning

How do our plans for these children fit into the general planning picture for the district?
How do we deal with the local authority?

5. Parents

(a) Do parents want the new service we are offering?

(b) At what stage do you involve parents in the planning?

(c) What if parents demand continuing hospital care for their child?

What are the key factors for success? In the experience of the authority they are:

- Having a good team leader for the home.
- Having staff with the right attitudes.
- Having a method of teaching staff real skills.
- Having a proper system of supporting and maintaining each individual house.
- Having a team of like-mind managers.

and above all HAVING THE RIGHT PHILOSOPHY OF CARE.

Discussion

Q. What staffing levels and shifts do you have?

A. There are 7 full time and 2 part time staff. The main shifts are 7 a.m. - 2.30 p.m. and 1 p.m. - 9.30 p.m. The person on sleeping-in duty will work till 10.30 and then be 'sleeping in'.

Q. Have you had any problems over fire regulations?

A. We are lucky to have a very enlightened fire officer so we have, for example, been able to provide the children with duvets.

Q. What are your criteria for staff selection?

A. We are not looking for any particular professional background. Our main criterion has been to look for people with the right sort of attitudes towards handicapped people; we have also looked for a willingness to learn appropriate skills.

BARNARDO'S DEHOSPITALISATION SCHEME

Peter Allen

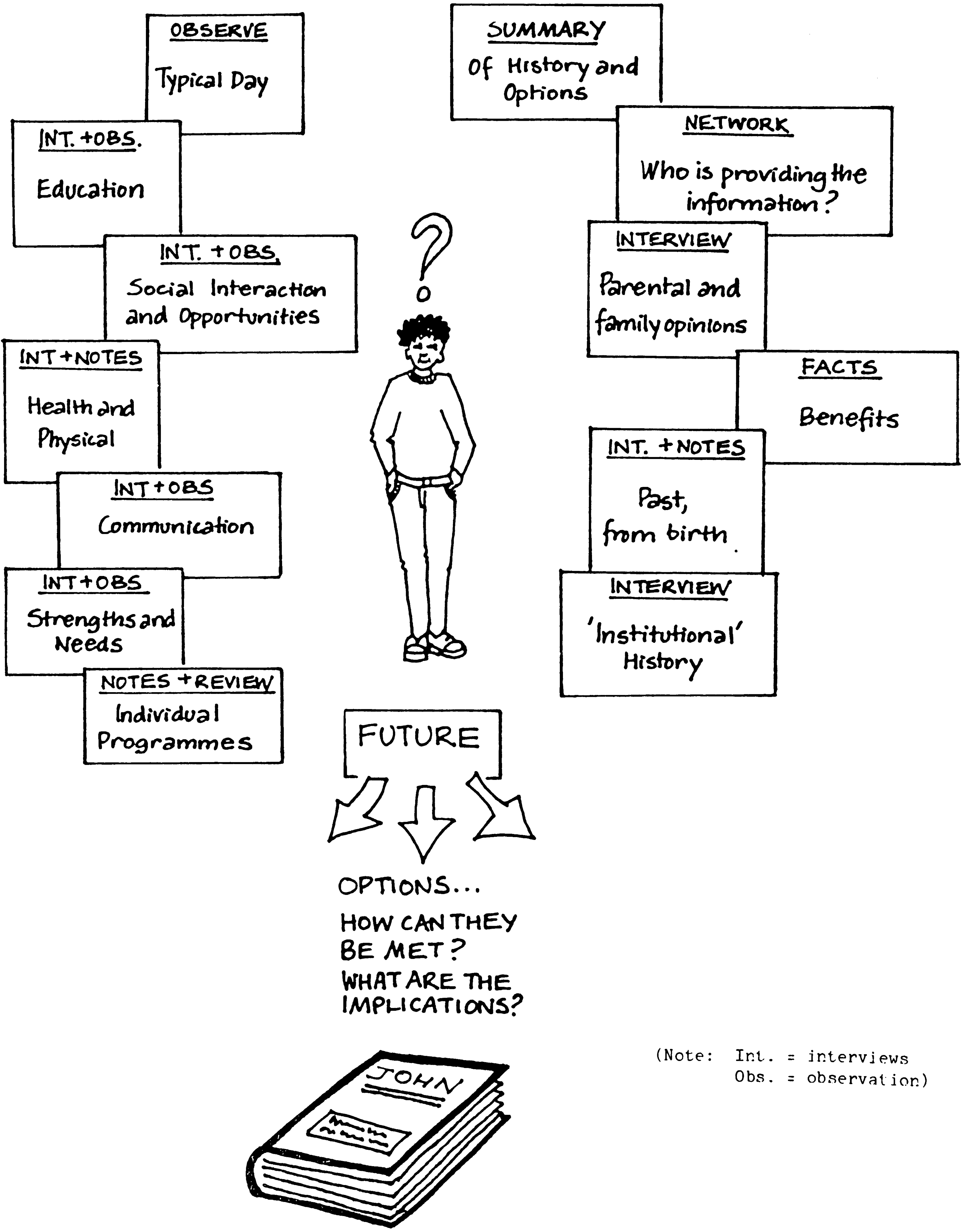
This scheme, which operates within the London Division of Barnardo's, was set up with the broad aim of "making recommendations on the services mentally handicapped people under 18 currently living in mental handicap hospitals in the South East Thames Region would require, should they leave hospital to live as part of the community".

The work has been focussing more specifically on the areas of Lewisham and North Southwark and the children who originate from these areas.

The way this has been approached has been to develop a "schedule" which starts by identifying the network of contacts which a young person has and uses the experiences of those people to see what shape a service might take if it were community-based.

Interviews with parents, social workers and care staff revealed a range of information and some key features which were common to many of the interviews and which contribute quite strongly to the overall picture.

WHO ARE THE YOUNG PEOPLE?



(Note: Int. = interviews
Obs. = observation)

SOCIAL WORKERS

1. The differing style of intervention with families, part due to being fraction of a total social service. i.e. therapy, counselling, rights, crisis work.

2. Social worker only potential contact with a community based service.

3. Role of transmitting and interpretation of messages

4. Compromise of trying to be an advocate

5. Punctuating lives of family and/or child

6. "Key position" when new decisions made

THEREFORE, it is important to consider:-

FAMILY CONTACT

ADVOCACY

THERAPEUTIC WORK

COMMUNITY (SERVICE) CONTACT

PARENTS

1. Unsympathetic/unrealistic "telling" even in late '60's early '70's.

2. Little early counselling or support /often by accident

3. Polarisation between "self sufficiency" and "someone help!"

4. STILL not fully understanding why child is handicapped, BUT realistic about implications.

5. Unique set of events leading to requests for residential care, emotive to recount; still feelings of attributed blame.
6. Positive toward current carers.

7. Vigorous campaigns to get services, therefore exhausted.
8. "Lack of ownership" of decisions and future plans, FEAR of the future.
9. Lack of knowledge of possible future options.

10. Lack of REAL contact with present carers.

11. Desire to talk about experiences, particularly if it will help others, or in the future.

IMPORTANT FEATURES:—

PRESENT, TEMPORARY REPRISE

PAST, MADE ITS MARK

FUTURE? UNKNOWN

SOMETHING VALID TO OFFER!

CARE STAFF

1. Constraints on working with young people individually (Environment, skills, staffing levels).
2. "Obvious" improvements in smaller settings!
3. Difficulties in developing relationships with parents (unless take own initiatives).
4. Lack of feeling "part of" new plans.
5. Some know young persons past by records, only.
6. Few photographic records personal to the young person. (many "owned" by staff).
7. Intruiging comparisons when contrasted with own childhood or adolesence.
8. Pressure in groups where communication most significant problem.
9. Feelings that biggest stumbling blocks (to community care) will be the "public" and poor recreational facilities.

IMPORTANT FEATURES:-

NEED MORE INPUT TO FUTURE PLANS

DESIRE TO INCREASE SKILLS

LIMITATIONS CAUSED BY CURRENT REGIMES

SMALLER SETTINGS SEEN AS GOOD

The next task is to 'translate' this information into options for the future. This is being done, taking the following underlying philosophical base:

> All mentally handicapped people should be afforded the right to live as full members of local communities. This necessitates planning and developing services which best respect their needs as individuals and ensures that they do not live in segregated settings. Services should be organised in a way which maintains that person's claim to a family life and should residential care be used, it should be situated as part of a local neighbourhood.

The implications of this are:

* an end to living in segregated settings;
* the assumption that a 'valued setting' is family life;
* thought must be given to the site; where would you and I choose to live and why?
* consider the size;
* remain flexible over time.

To explain the process, here is an example of one young man.

John is 16. He moved into residential care 6 years ago and his parents say he was described as 'autistic' prior to this. Family circumstances and difficulties coping with their own problems led to his admission into residential care.

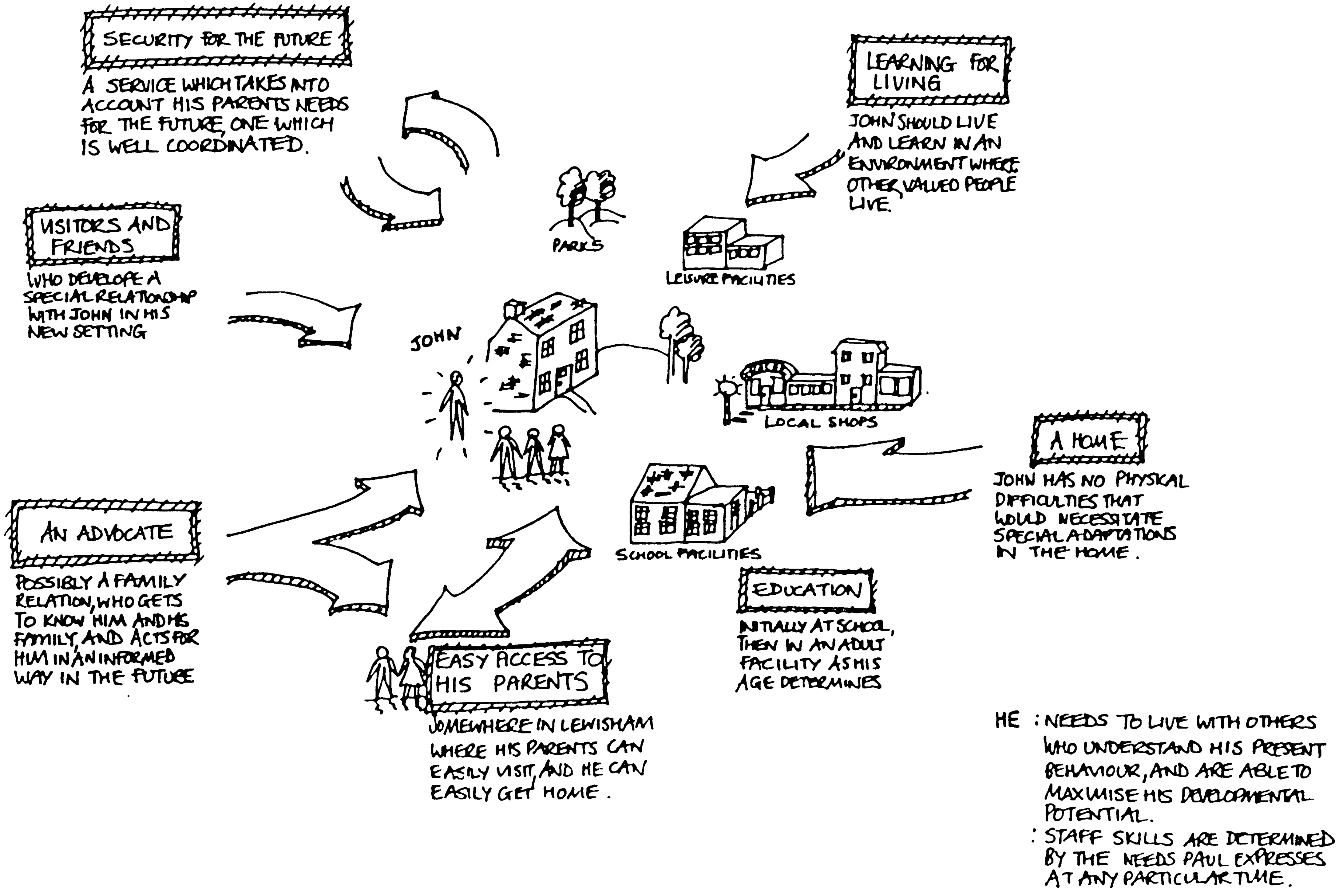
His parents still regard him very much as part of the family; his photographs are in their sitting-room and they are most keen to see his future settled. A visit to John, however, means two hours of bus journeys and not surprisingly it is difficult for them just to call in. John has no physical problems but has several 'difficult' behaviours which means he requires close supervision. He interacts minimally with other people and has no visitors apart from his parents' infrequent visits. He has few opportunities to go out except on organised outings.

These are some (obvious) characteristics of his present situation:

* He lives with a number of mentally handicapped people in a group;
* His 'care' is given by paid people;
* He uses few signs with which to communicate;
* He does not play constructively;
* He is described as 'disruptive';
* There is no photographic record of his past in the establishment.

The following is one 'picture' of what John's future might look like, taking account of his needs:

A SERVICE FOR JOHN : SUMMARY



SECURITY FOR THE FUTURE

A SERVICE WHICH TAKES INTO ACCOUNT HIS PARENTS NEEDS FOR THE FUTURE, ONE WHICH IS WELL COORDINATED.

VISITORS AND FRIENDS

WHO DEVELOPE A SPECIAL RELATIONSHIP WITH JOHN IN HIS NEW SETTING

AN ADVOCATE

POSSIBLY A FAMILY RELATION, WHO GETS TO KNOW HIM AND HIS FAMILY, AND ACTS FOR HIM IN AN INFORMED WAY IN THE FUTURE

EASY ACCESS TO HIS PARENTS

SOMEWHERE IN LEWISHAM WHERE HIS PARENTS CAN EASILY VISIT, AND HE CAN EASILY GET HOME.

LEARNING FOR LIVING

JOHN SHOULD LIVE AND LEARN IN AN ENVIRONMENT WHERE OTHER VALUED PEOPLE LIVE.

A HOME

JOHN HAS NO PHYSICAL DIFFICULTIES THAT WOULD NECESSITATE SPECIAL ADAPTATIONS IN THE HOME.

EDUCATION

INITIALLY AT SCHOOL, THEN IN AN ADULT FACILITY AS HIS AGE DETERMINES

HE : NEEDS TO LIVE WITH OTHERS WHO UNDERSTAND HIS PRESENT BEHAVIOUR, AND ARE ABLE TO MAXIMISE HIS DEVELOPMENTAL POTENTIAL.

: STAFF SKILLS ARE DETERMINED BY THE NEEDS PAUL EXPRESSES AT ANY PARTICULAR TIME.

The service could also be described as follows:

1. <u>Physical siting and type of accommodation</u>

   Ordinary domestic (no physical problems)

   More opportunities for peer/adult contact

   More opportunities to use community resources

2. <u>Other people with whom to live and interact</u>

   Skills teaching in an appropriate environment

   Developing close and consistent relationships

3. <u>A service respecting his age</u>

   More privacy than a dormitory can afford

   Less routinised bathing

   Not being put into bed clothes at about 4.30 p.m.

   More appropriate possessions

4. <u>Security for the future and a life plan.</u>

   A secure service (shared by different agencies)

   A service which is well co-ordinated between residential and fieldwork services.

   Explicit plans.

5. <u>Education and occupation</u>

   Changeover time after school.

6. <u>An 'advocate' for the future</u>

   Especially if parents are unable to continue with this role.

THE NORTHUMBERLAND HOUSES

Frances Brown

The health authority has now opened three houses for children from hospital, the first being 224 Alexandra Road in Ashington.

"Alexandra Road" house provides a 'home for life' for five young people, which represents the authority's commitment to these young people - not a prison sentence! (Some of the young people may choose to move on somewhere else.)

The house is rented from the local council. This is more flexible than buying property as it can be handed back if no longer required at some future date. The house was funded by pump-priming finance (although the second and third houses have been funded from savings incurred by closing the children's ward at the hospital).

The health authority decided that home leaders should have an RMNS qualification - although most leaders wouldn't say that that training was particularly relevant. The current staff in houses come from a variety of backgrounds including teaching, nursery nursing and fine arts. They are local people, which is important as they have local networks and are in fact sometimes already acquainted with some of the families who use the service.

The young people were selected by geographical ties. Friendship was on the whole not considered an important factor since observations of the children in hospital revealed that most of them were extremely socially isolated. By using geographical links the aim was to return the young people to their former networks.

Staffing is geared to the children having daytime activities although this is causing some problems at the moment as there is a shortage of appropriate daytime activities to meet individual needs.

Those involved in developing the houses for children and young people are committed to the importance of providing an ordinary life and meeting the needs of the young people on an individual basis.

There are five young people living in the Ashington house:

Jane who is now nineteen and who had spent fourteen years in hospital before moving out. She had many speech difficulties and displayed a lot of inappropriate social behaviour. The change in her life is perhaps best typified by her 18th birthday celebration which was a disco held in a local hotel and attended by her family and friends. She has re-established family links and has 'found' her Granny. Jane attends a further education college and travels to it independently. She has a boyfriend, belongs to various social clubs, and enjoys housework.

Keith is seventeen years old and has spent all his life in hospital. He is multiply-handicapped and uses a wheelchair. Keith is frail and in hospital was very prone to chest infections; he is also partially sighted. Since leaving hospital Keith has been making small but perceptible steps in growth. He is beginning to vocalise more and has had far fewer chest infections. He has developed a taste for Indian food and loves going out to Indian restaurants!

Melanie is 14. She has a curved spine (due to scoliosis), is doubly incontinent and has no speech. Since leaving hospital she has learnt to stand with the aid of a brace and support. Her mother says she seems happier and less anxious and Melanie goes home every weekend.

James was described as someone who was always 'nipping, kicking, biting, spitting and eye-poking' when he lived in hospital. These behaviours now only occur if he bumps into someone who he remembers from his days at the hospital. Instead he has learnt to play Space Invaders and enjoys cooking, shopping and other household tasks. His contact with his family has increased enormously and he has been able to re-establish some former community contacts.

Medina has cerebral palsy and was described as 'very destructive' when she was living in hospital. She used to spend a lot of time just rocking. She now goes trampolining every week at a centre where she meets her sister who goes trampolining on the same night. (She had not seen her sister for five years prior to this.) She has also established contact with her grandmother. In hospital she always enjoyed the 'special' riding sessions so she now goes riding once a week in an ordinary beginners' class at a local riding school.

Katie, Michael and Steven are three young people who have moved into one of the other houses in Northumberland:

Katie lived in Northgate hospital for nine years. She left when she was 12. Her close relationship with her grandparents continued after she left hospital but as she settles into her new home and her need for them to be 'substitute parents' lessens, they have taken on the more typical grandparental role of being spoiling grandparents who give her treats.

Michael is a very physically handicapped young man who uses a wheelchair. His regular activities include going to pop concerts, going out for meals and visiting the local pub.

Steven came out of hospital 'with a lot of behaviour problems'. Not all these problems disappeared when he moved into his new home and other families using the scheme became quite concerned about their own children's safety although they did not wish to see Steven returned to hospital. A very strict programme to alter his behaviour has been put into operation - and it seems to be working. He has had a home tutor for 2 hours each day; this tutor reckons Steven is 'the most interesting person she's ever met' and she is now introducing him to the local high school - which appears to be working.

From the experience of setting up the houses many lessons have been learnt; some things have been done well and other things have been done less well.

What things were not done well?

As far as the young people are concerned:

* they weren't sufficiently involved in the planning;

* we did not and still have not ensured a guarantee of employment or occupation which is gainful, creative, and stimulating;

* we haven't yet given people in 'the hierarchy' (e.g. DHA members) the opportunity to know and care for the young people;

* the young people haven't been sufficiently involved in staff selection;

* we haven't given them enough space and privacy (e.g. there are still shared bedrooms for four out of the five "Ashington" residents).

As far as the families are concerned:

* they were not involved sufficiently early on in the planning of the service;

* they are not yet involved in staff selection;

* we haven't always treated them with enough respect by involving them in our troubles and asking them for their help.

As far as the staff/carers are concerned:

* we didn't anticipate sufficiently, the hospital staff's feelings of grief and loss;

* we haven't been clear enough what skills, abilities and temperament we are looking for in our staff;

* we haven't worked out who supports the support team;

* we've offered low remuneration, no career structure and no future training possibilities;

* we haven't offered staff enough in-service training and opportunities for development;

* we haven't allowed for the sort of flexibility in staffing which could meet the changing needs of the young people.

As far as the community is concerned:

* we worried about them not caring enough when we should have remembered that they are, in fact, us - and that the community does care.

As far as the people who were left behind in hospital are concerned:

* we have left them with an increasing gap between their quality of life and that of the people living in the community.

What have we done well?

As far as the young people are concerned:

* we have tried to plan for them as individuals;

* they have a home for life;

* the planning team knew the young people they were planning for;

* we have encouraged opportunities for them to share their lives with non-handicapped people;

* we have high expectations of them:

* they weren't asked to pass any tests to live in the houses;

- we didn't try and make them fit the service;
- they are getting better medical and paramedical services than when they were living in hospital.

As far as the families are concerned:

- we tried to consult with them as early as possible;
- we tried to work through our anxieties about the scheme together;
- we involved them in the selection and purchasing of furniture and other items for the houses;
- we have involved not only immediate but extended families as well (e.g. grandparents and siblings);
- we keep checking with them that they are happy;
- we haven't put pressure on those families who have found it difficult to re-establish contact with their handicapped relative.

As far as the carers/staff are concerned:

- we have offered them initial training and preparation;
- we have tried to provide support and positive monitoring;
- we have offered them new and different ways of working which can provide opportunities for autonomy, creativity and life-sharing;
- we have reduced staff sickness levels.

As far as the community is concerned:

- we have proved that they do care and that they will share their lives with people with mental handicap;
- we have involved a very wide range of people, including GPs, dentists, shopkeepers, leisure amenities staff, neighbours, restaurant staff and the manager of the local bus garage.

As far as the people left behind in hospital are concerned:

- we have proved for them that ultimately no one needs to be left behind.

BUT...... we haven't always managed to get it right yet. Clive came out of hospital to live in one of the houses. After he had been out for eight weeks he attacked a young girl in the neighbourhood and was returned to hospital. Clive is now living on a locked adult ward and is heavily medicated.

His family are very unhappy about his present situation, and many members of the local community have said they would like to see him back in the neighbourhood. The grandmother of the young girl who Clive attacked has also been to visit him in hospital. The problem was WE GOT IT WRONG. We tried to make Clive fit into a service which did not meet his needs. We think now that we know what sort of service Clive would need to live outside the hospital; it still remains for us to find the funding to make that possible. Clive had only been out of hospital for eight weeks before he went back .... but he had made some progress, even in that short time.

SUMMING UP AT END OF CONFERENCE

Ann Shearer

Three main themes seem to me to have emerged during the course of today. These are:

The firmness of philosophy. This is paramount in the services we have heard about today. Those involved are totally commited to building services which are true to their stated philosophy.

The 'carefulness' of the approach. I have been struck by the enormous carefulness with which people are developing these services.

Striving for the perfect. I am struck by the persistent striving for the ideal, for the perfect. No one has talked about being content with what they are already doing.

Everyone has said how they realise that they are still striving to provide a better service.

In all this we are beginning to see moves beyond 'services' to 'living'; that is what providing services should be about - providing stepping-stones for life. We are striving to make the leap beyond providing 'services' to showing that people can live as part of the community and that the 'single community' can care.

Appendix A

PROGRESS IN BRINGING MENTALLY HANDICAPPED CHILDREN OUT OF HOSPITAL

Conference on Wednesday, March 21st, 1984

9.45 a.m.	Coffee and Registration	
10.15 a.m.	Introduction	Ann Shearer
10.30 a.m.	Barnardo's N.W. Division Families caring for children who are mentally handicapped	Chris Spencer Rosemary Hindle
	Video and presentation and discussion	
11.30 a.m.	Developments in Portsmouth	John Wallis
	Moves from an institutional base	Paul Chamberlain
12.30 p.m.	Lunch	
1.45 p.m.	Barnardo's London Division Dehospitalisation scheme Planning for individual needs	Peter Allen
2.15 p.m.	Three houses in Northumberland How the young people, their families and the staff are getting on	Frances Brown
3.15 p.m.	Summing Up	Ann Shearer
3.30 p.m.	Tea	
3.35 p.m.	Group work	
4.30 p.m.	Disperse	

Appendix B

King Edward's Hospital Fund for London

KFC 84/49

King's Fund Centre

PROGRESS IN BRINGING MENTALLY HANDICAPPED CHILDREN OUT OF HOSPITAL

Conference on Wednesday, 21st March, 1984

LIST OF PARTICIPANTS

Valerie ANTELL	Family Support Nurse	Winsley Centre, Bath
Gina ARMSTRONG	Senior Social Worker	Family & Community Services, Sheffield
Marion B BALLINGER	Senior Clinical Medical Officer	Folkestone
Mrs Janet BATH	Senior Nurse	Lanthorne House, Broadstairs
Mrs K R BLAKEBROUGH	Director of Nursing Services	High Wood Hospital
Mr Raymond H BUTTON	District Administrator	Basildon & Thurrock HA
G M CARRUTHERS	Community Unit Administrator	S E Kent DHA
Mr J CHESTER	Vice Chairman	Mid Downs CHC
Mrs J DROWER	Member	Ealing CHC
Miss Christine ELWELL	Basic Grade Clinical Psychologist	E Cumbria Community Mental Handicap Service
Mrs F D GRAY	Education Officer	ENB for Nursing, Midwifery & Health Visiting
Mrs GREENWOOD	Chairman of Sub Group	Worthing CHC
Mary HARDY	Senior Nurse Manager	Osbert Street, SW1
Kay HOBBS	Team Leader	LB Lewisham Social Services
Mrs F A HOLMES	Post Basic Nurse Tutor	Frimley Park Hospital
Mrs M E HOWARTH	Member	CHC, Macclesfield
Peter HUTCHINSON	Chief Assistant (NHS Liaison)	Sheffield Social Services
Mrs B JARRETT	Unit Administrator	Bexley HA
Clare JONES	Principal Psychologist	St Cadoc's Hospital
Eileen JONES	Senior Social Worker	Hammersmith & Fulham Social Services
Mrs P F KAPSALIS	Committee Member	Friends of Winifred House
Mr G A KEIR	Director of Nursing Services	Goldie Leigh Hospital
Dr Leila B KETTLE	Senior Registrar in Psychiatry	Stoke Park Hospital
Mr Michael G KEY	Senior Social Worker	Lincs. Social Services
Mr H KILVINGTON	Senior Nurse	Friarage Hospital
Sara KORLEY-QUAYE	Officer In Charge	LB Lewisham Social Services
Mrs Daphne LINDSAY	Member	Bromley CHC
Jake LYNE	Senior Clinical Psychologist	Royal United Hospital
Gina McDONALD	Assistant Unit Administrator	Wellhouse Lane Community Unit
Mr R MILLS	Service Planning & Management Information Officer	Bexley HA
Mrs P J O'CONNOR	Director of Nursing Services	Bexley HA
Mrs C PETERSON	Deputy Unit Administrator	Wellhouse Lane Community Unit
Neville PETTITT	Houseparent	Bath
Mr PICKARD	Senior Nurse	Wellhouse Lane Community Unit
Mrs Marion PRICE	Director of Nursing Services	Herefordshire HA
Lionel M PROVIS	Volunteer	Burnley, Pendle & Rossendale CHC
Trevor RICHARDS	Secretary	Worthing CHC
Mr Neville RICHARDSON	Community Administrator	St Helens Hospital
Miss Joyce C RICKWORD	Member	Brentwood, Barking & Havering CHC
David ROBERTSON	Unit Administrator	Lenham Hospital
Mr Struan ROBERTSON	Committee Member	Friends of Winifred House
Miss Jane ROY	Staff Nurse	St Ann's Hospital
Jennifer F SMITH	Education Officer	ENB for Nursing, Midwifery & Health Visiting
Miss J S SPEARMAN	Charge Nurse/Sister	Bexley HA
Averil SWEET	Assistant Divisional Director	Dr Barnardo's
Ellis THACKRAY	Director of Nursing Services	Lenham Hospital

Mr J WARREN	Nursing Officer	Bexley HA
Yvonne WELLS	Social Worker	Harmston Hall Hospital
Alison WERTHEIMER	Director	Campaign for Mentally Handicapped People
Mr J WILKES	Senior Nurse	Lenham Hospital
Gillian P WING	Unit Administrator	Fleet Hospital
Heather WINTER	Houseparent	Bradford-on-Avon
Derek WINTLE	Administrator	Kingsbury Hospital
Gwen WORTHINGTON	Social Worker	Kent Social Services

Peter ALLEN	Development Officer	Dr Barnardo's Dehospitalisation Scheme
Frances BROWN	Senior Social Worker	Northumberland County Council
Paul CHAMBERLAIN	Senior Clinical Psychologist	Portsmouth & S E Hampshire HA
Rosemary HINDLE	Social Worker	Fostering Team, N W Division
Ann SHEARER	Writer & Journalist	London
Chris SPENCER	Social Worker	Fostering Team, N W Division
John WALLIS	Principal Clinical Psychologist	Portsmouth & S E Hampshire HA
Joan RUSH	Project Officer	King's Fund Centre