KINGS FUND COLLEGE

Hillingdon Health Agency

Rview of Learning Difficulities and Mental Health Services

by

King's Fund College

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I. INTRODUCTION

The preparation for and implementation of the NHS and Community Care Act, has provided individuals serving or representing disability groups an opportunity to join with consumers in reflecting on current practice and advancing innovative ways forward. Dramatic organizational and service changes have been envisioned within a climate of restricted or dwindling resources. Such challenges call for visionary leadership, joint working, informed commissioning and cost containment.

During the past year, many changes have occurred within Hillingdon. The Hillingdon Health Agency was initiated on 1 April 1993. This combined management scheme brings together the commissioning activities of the District Health Authority and the Family Services Health Authority; although both Authorities continue to function as two separate statutory entities. [1] Social Services has undergone combined management arrangements with a single Director being appointed to manage a merged Education and Social Services.[2] In addition, the Local Authority has had to initiate severe cuts in some Social Service provision. Further structural change is evidenced with the establishment of four Trusts and four GP Fundholders.

The objectives adopted by the Hillingdon Health Agency call for, in part:

- "Continuously improving our understanding of the . . . needs of the people in Hillingdon and the degree to which they are being met.

- Listening to and communicating with the people of Hillingdon to develop services which are responsive.

- Creating strategies and plans for improving the delivery of care by working effectively with other care agencies."[3]

In and effort to be a more informed commissioning partner, the Hillingdon Health Agency commissioned the King's Fund College (herein after referred to as the Project Team) to conduct a review in line with these Objectives. The review focused on services to adults with mental ill health and people with learning difficulties.

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[1] *Corporate Contract, 1993/94, Hillingdon Commissioning Agency, February 1993.*

[2] *Caring for People in Hillingdon, The Community Care Plan, 1993.*

[3] *Hillingdon Commissioning Agency Corporate Vision and Proposed Management Structure, A Consultation Document.*

II. METHODOLOGY

A. Process

In harmony with objectives previously listed, this project was conducted in three Phases.

Phase I: Constituent[4] Input and Service Visits

The project began with a focus on constituent perceptions and on sight reviews of existing services. Information was gathered from individuals receiving services as well as carers, advocates, providers, Local Authority/Social Service, Trusts, GP's, and the Health Authority. Questions were designed to acquire information regarding:

- o where best practice was currently taking place in Hillingdon and why the interviewed individual perceived this as best practice;
- o gaps which exist in current service provision;
- o duplication perceived to exist;
- o resettlement process, plans and projections;
- o specific descriptive and financial information regarding existing or proposed services.

Over 90 individuals from throughout Hillingdon participated in the interview or on site review process. Those specific individuals/groups which were interviewed and locations toured are listed in Appendix A. Interviews and sight visits were conducted during the month of June.

Phase II: Data Gathering and Document Review

The KFC Project Team received and reviewed over 70 documents[5]. These document assisted in better understanding:

- o purpose, mission, goals and outcome expectations of services and agencies;

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[4] *Constituent in this context refers to those 'parts of the whole' who have great interest or a 'stake in' what happens through the delivery of services/care. Constituents which most naturally come to mind are those included in the JCG's: users, carers, advocates, friends, neighbours, providers, GP's, Health, Education/Social Services, Housing, etc.*

[5] *A listing of most of the documents reviewed can be found in Appendix B.*

- o quality assurance procedures and practice;
- o information available (demographic, service specific and financial) to the commissioning agency from which to make funding decisions;
- o joint working documents/reports on "best practice", gaps, duplication or needed services;
- o general needs of service users through interviews and limited file/care plan review; and
- o best practice and innovative models within Hillingdon, from the U.K., and internationally.

This report was not intended to include a detailed audit of available financial information regarding mental health and learning difficulties services. Therefore, a brief questionnaire was developed to gather broad general information. There was significant difficulty in acquiring data, therefore the following explanation is offered so data provided can be viewed in proper context.

Some Data Was Complete and Detailed: Some of the questionnaires returned were complete and detailed in content. Information provided for statutory services such as hostels and group homes was much more complete than information provided for voluntary or privately provided provision.

Some Data Reported As Not Available: Some of the returned questionnaires, contained portions indicating information was not available. Follow up provided some additional information but significant gaps remained.

Questionnaire Not Clear Enough To Gather Detail: The questionnaire was not specific enough to gather appropriate detail regarding source and proportion of funding. The Costs Section asked, "Total cost of service, cost per person and funded by". The question was inadequately stated. It should have requested, "who funded the service and in what amount". Again, some additional detail was provided through follow up.

Conflicting Data: Follow up conversations were initiated by the Project Team and Health Agency in an effort to confirm data and gather additional detail. In many cases, this effort provided extremely beneficial by adding information which complemented the data already received. Unfortunately, all too frequently, the data received in these follow up conversations conflicted with the data provided on the questionnaires.

The Project Team attempted to clarify financial information contained within the 1993 Hillingdon

Community Care Plan. The perception of many within Hillingdon services who are responsible for financial tracking and reporting lead the Project Team to conclude the financial information contained within the plan for mental health and learning difficulties services could not be reliably used.

The financial data contained within this report must be understood in context and intent. The context has been explained. Some information was complete, however, portions were contradictory and incomplete. The intent in providing this information is to offer examples of what information might be reported and how it might be used to foster a greater understanding of where money is going and why.

By portraying the information as provided, the Project Team hopes the limitations point out the need to agree protocols on information tracking and reporting.

Phase III: Analysis and Initial Drafting

Significant time was spent on gathering written and verbal information. This information in turn was reviewed and analyzed for common themes and conclusions.

B. SCOPE OF WORK

Services offered to people with learning difficulties as well as people with mental health challenges are all critical and deserving of thoughtful, detailed attention. Unfortunately, given limited time and funding, specific services had to be identified and selected for review.

For people with learning difficulties, this report focuses on services to adults and the implications surrounding resettlement.

For people with mental ill health the review was limited to the needs of adults with mental ill health.

III. CHALLENGES TO COMMISSIONING AGENCIES

The challenges faced by commissioning agencies such as the Hillingdon Health Agency (HHA) are significant and complex. In reality, the HHA serves multiple 'masters' many of whom have conflicting interests. The customer, families/advocates, providers, other statutory agencies, government, public, media and the courts: all have direct or potential interest in decisions made by the commissioning agency. As a result, the commissioning agency must continue to develop extremely sophisticated skills directed towards meeting the customers needs in partnership with sister agencies. Often this is accomplished through:

- o reinforcing joint working & consensus strategies;
- o agreeing customer centred outcome measures;
- o promoting incentives which stimulate creativity, innovation and best practice measured against jointly established values and outcome expectations;
- o establishing customer driven internal and external safeguards from which the service system learns and adapts;
- o identification of how aggregate need will be fed into the system;
- o creation of new and use of existing generic community providers;
- o stimulation of voluntary and private providers;
- o development of cost containment approaches which maintain desired services; and
- o redirect resources captured by ineffective models and direct limited new resources to models which best capture the vision of the future and are effective and efficient.

The HHA has a strong commitment to improve customer health through the provision of quality services and the wise use of limited resources. Therefore, each of these skills becomes key to successfully influencing the provision of services for customers of Hillingdon. Further, accomplishing these objectives requires a system where values, policies and procedures interlock to ***inform*** and ***modify the practice*** of the Agency.

There is no one model of commissioning. Each response must be designed to fit the unique environment and needs of those whom it supports. There are, however, practical, basic, procedural steps commissioning agencies can initiate with their constituents to facilitate the development of an uniquely responsive purchasing approach.

Commissioning, as envisioned here, is a reflection of the whole system and a window to the organization's values. How purchasing agencies conduct their business sends strong messages reflecting how they view their customers, carers, advocates, staff, independent providers, sister agencies, GP's, . . . virtually everyone with whom they come in contact. 'Getting it right' becomes essential because getting it wrong can hurt so many.

The following system design for commissioning envisions an inter-related and co-dependent approach which begins with and continually includes the customer/user and related constituents.

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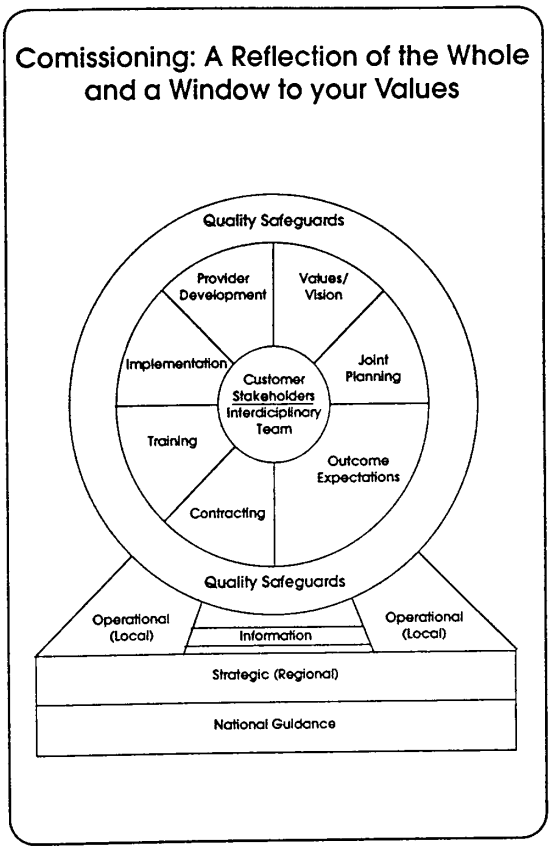

Clear Values/Vision for the Delivery of Customer Service: One of the most important steps in broadcasting what you want is the articulation of those principles/values against which all services and funding decisions will be measured. The key is to develop customer centred values which reflect a consensus amongst constituents so there is a joint vision of how people are regarded and treated by the service system. Once such consensus has been reached, these principles can be incorporated into the fabric of all services provided. Further, they can be incorporated into contracts and used to describe outcome expectations.

The following statements offer an example of what principles for services to people with disabilities might include:

- "each individual has the capacity for growth and development;

The following statements outlin
disabilities might include:

- "each individual has the capacity to grow

- each individual should have access to services and opportunities that enhance his or her development, autonomy, independence, productivity, well-being, and capacities for social interactions with others, including those without disabilities;

- each individual should have access to the most culturally sensitive and least intrusive social, medical and physical environments which are consistent with his or her needs and present him or her as a valued member of society;

- each individual's services should be provided, as far as possible, in settings integrated into the community and that promote interaction with family members, friends and with other persons without disabilities; and

- each individual's services should be delivered in accordance with a single individual plan that is developed, monitored, coordinated, and revised by members of a team of which the individual and, where appropriate, the family are a part." [6]

Joint Planning: Once the values and vision are clear, constituents can begin the planning process. With unlimited need and limited resources, planning and prioritising goals is a part of managing all parties expectations. It can not all be done, it can not all be done now. Consensus must be reached on what will be done, when it will be done and who must assist to see it is successfully accomplished. A broad base of planning participants bring a reservoir of talent, creative thinking and resources which can be dedicated to accomplishing jointly held goals.

Defining Outcome Expectations: Commissioning agencies are responsible for knowing what customers need and meeting those needs. Accountability and preserving the public trust is essential, therefore both the purchaser and provider must be clear as to what is being purchased and what it (the service) is expected to accomplish. Often, outcomes focus on the activity of the provider with little or no regard for the outcome (achievement, learning, healing) to the customer. Few businesses in the "real world" would survive for long using such an approach. Imagine taking your car in to have a flat tyre repaired only to come back, be charged for the repair but find the tyre remained flat. Would the argument "we really worked hard on it all day" be compelling enough to pay the bill? Granted, health and social service commissioning agencies are not in the business of simply repairing tyres, however, they are in the business of knowing what users want and buying the most effective outcomes for them. Agreeing and establishing principles such as those above work to focus service outcomes for the customer on increased independence, productivity and community integration.

Contracting, Service Specifications/Standards: With Clear principles, goals, and outcome expectations, specific service specifications/standards can be crafted using existing guidance from

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[6] *Standards and Interpretation Guidelines for Services for People with Developmental Disabilities, National Quality Assurance Program, Accreditation Council on Services for People with Developmental Disabilities (ACDD), 1990 Edition, Page 3.*

- each individual should have access to services
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Contracting, Service Specifications: Clear
expectations, specific service

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* Standards and Interventions Guidelines for Services for
Family Services Program, Australian Council on Children and
Any Issues, Page 3.

local, regional and national sources. A joint process assists in the development of a common language, manages expectations and clarifies misunderstandings by providing insights from multiple user, clinical, professional, and lay perspectives.

Service specifications/standards become even more important in the "Community Care" environment where multiple providers (statutory, private or voluntary) may come to deliver the service. Consequently, specifications must ensure reliability, validity, and credibility in the provision of services. They should be written to apply regardless of who the provider might be.

Service specifications apply to WHAT is being provided not WHERE. Focusing on where a service is provide may limit creative thinking and responses to very human problems. An example of a specification or standard for Mental Health Community Housing Programme is provided in Appendix D. [7]

Contracts and service specifications can miss the essence of what users and carers are saying about outcomes or specific providers. As with all the other steps, users and carers must inform this critical step in the commissioning process.

Training: Training for and by constituents on all aspects of the system facilitates understanding, communication and sets expectations. Contrary to the uni-dimensional portrayal of this commissioning model, the system is three-dimensional and never static. The experiences and learning gained through commissioning and service provision must continually inform the entire system and the training which is conducted on the various components.

Implementation: The actual implementation of services is where the 'rubber hits the road' so to speak. A car can have the finest engineering and state-of-the-art design and still not be able to move. All the planning, joint working and training in the world can still result in poor quality of life and poor quality of care. Often times the key to a creative, energized commissioning agency is what it learns from its implementation successes and failures. Encouraging risks and reinforcing new ideas (even when they don't work) will help keep the commissioning of services inspired and the implementation of services user focused.

Provider Development: Expanding and strengthening providers is central to the commissioning role. Commissioning a broad provider market provides an opportunity for development of long term relationships, building strength from diversity, spreading risk, building trust and developing varied arrangements to solve problems. Part of developing a pattern of accumulated good will with providers is not only telling them what they have got wrong, but providing technical assistance to be sure they have it right. A programme of built in incentives to stimulate more 'best practice' is a must. For example, limited (one-year) contracts can be issued to providers

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[7] *Adapted from Standards Manual for Organizations Serving People with Disabilities, Commission on Accreditation of Rehabilitation Facilities, 1993. For illustrative purposes, only a few of the actual standards are listed.*

local, regional and national scenarios. A [illegible]
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[1] Adapted from Southwark Alliance [illegible]
Accreditation of Rehabilitation Facilities, 1994. For [illegible]
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with marginal or outdated services. Three-year contracts could be used as incentives for providers who were responsive, moving towards state-of-the-art provision and who met the purchaser's user-centred criteria.[8]

Quality Safeguards: A system of quality safeguards which supports and informs the entire system is essential. Assuring quality is not an event, it must become a way of thinking and acting for every constituent within and outside the system.

Traditionally, organisations have assembled the pieces of a quality safeguard system (eg. users directly reviewing services, consumer satisfaction surveys, care management, information systems, certification, licensing, budgeting, contracting, external monitoring, advisory committees, complaints, etc.). Once in place, the challenge becomes how these individual components will inform each other and in turn the behaviour of the organisation as a whole. It is not unusual for a purchasing agency to continue to purchase services from an agency users and others have determined to be quite inadequate. This leaves an impression the 'right hand doesn't know what the left is doing'. Pulling the various components of a safeguards system together to inform and influence outcomes becomes a part of an over all quality management approach to the delivery of responsive services.

As evidenced by the work of the Community Health Council and others, users, carers and advocates bring a common sense approach and a keen eye for equity when building a quality safeguards system. External constituents must continue to play a central role in quality review and reporting. Further, all constituents have a role to play in constructing the content, process, consequences and incentives built into the safeguard system.

Information Required: The tool which keeps the system informed and working, vertically and horizontally, is information. Information is another key to success for purchaser and provider alike. Given limited resources, what information you seek and analyze becomes very important. From the purchaser perspective, it is essential to have the information necessary to meet individual need, ensure best value for money, stabilise service provision and provide incentives to stimulate best practice. Baseline data becomes critical when attempting to measure movement towards strategic goals or attempting to redirect resources to unmet needs. Asking, "who", "what", "when," "where," and "how," questions becomes a simple guide to stimulate discussion and reach agreement on what must be reported and how this information will be used.

* Who (how many) receives supports/services?
* Who is waiting for supports/service?
* Who will require supports/services in future?

* What do they receive?
* What are they waiting for?

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[8] *Rucker, L., Powell, D., Being User Led: From Rhetoric to Practice, King's Fund Newsletter, June 1993.*

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[illegible]

* When do they receive these supports/services?
* When will they require services?

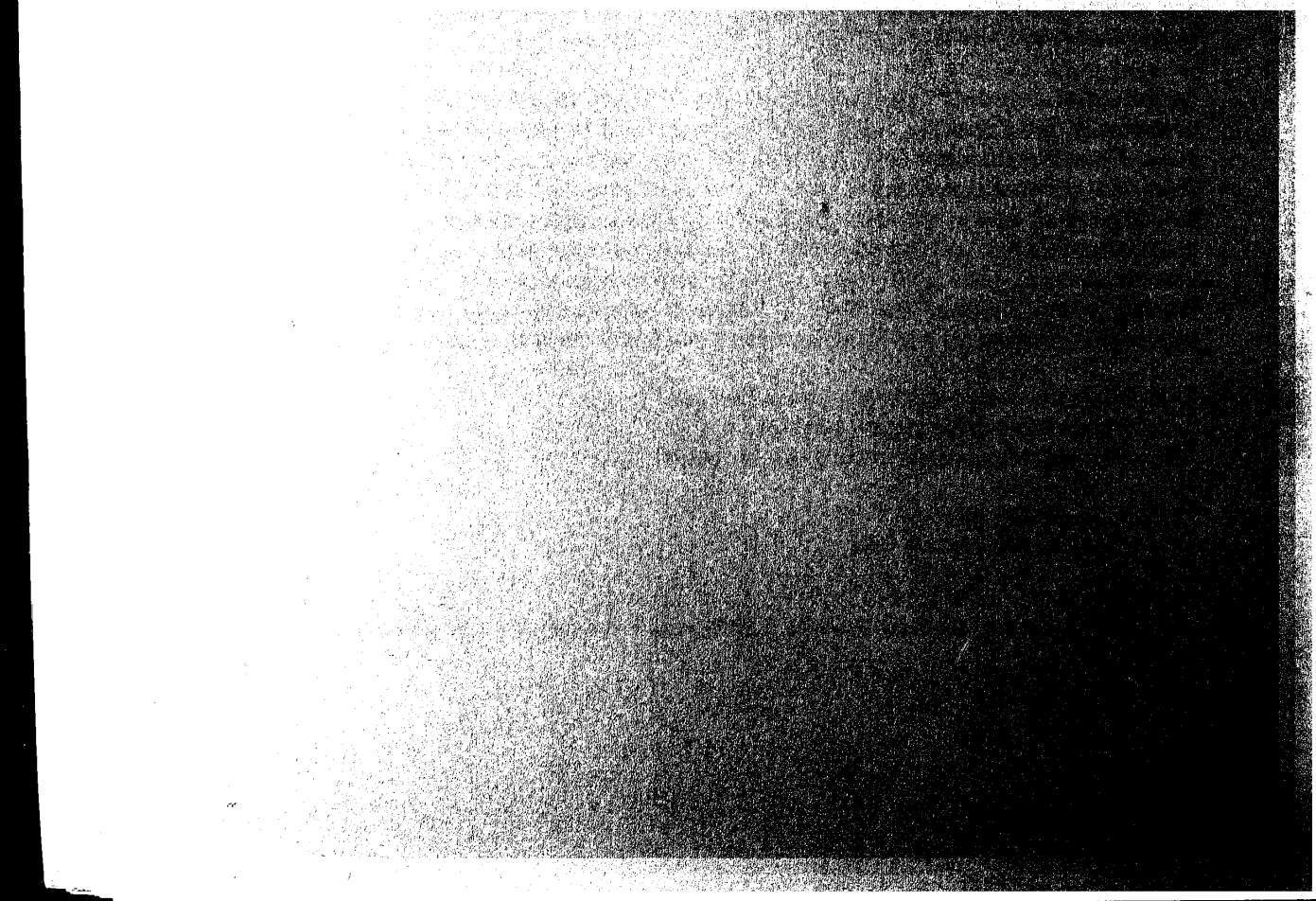
* Where (from whom & geographical location) do they receive services?
* Where will they require services?

* How much do they receive (of the service)?
* How much does it cost?
* How much did it cost?
* How much will it cost?

Without detailing further examples, let us summarise by saying what is perhaps the obvious: commissioning agencies along with their customers and constituents must know:

- what they wish to purchase;
- what the outcome expectations are; and
- how they intend to measure the outcomes.

Working through and resolving these issues is certainly not the exclusive challenge or responsibility of the HHA. With the establishment of Joint Commissioning Groups (JCG's), Hillingdon has forged ahead in its efforts to turn the 'joint commissioning rhetoric' into practice.



IV. GENERAL OBSERVATIONS

During the review process, several issues impacting both adult mental health as well as learning difficulties services became obvious. Those issues are addressed within this section.

A. Consumer Involvement in User Led Services[9]

Action towards consumer involvement and user led services is based on the belief that decisions which affect the lives of individuals and their families are best made by them. To ensure decisions are relevant and workable, the individual must have opportunities to learn decision-making skills and experience opportunities to use those skills in all aspect of day-to-day living. If an individual is not able to make an informed decision and does not understand the consequences of the decision, then the individual should learn to exercise choice in other situations that are appropriate to his/her level of functioning.

A commitment to consumer empowerment means individuals wishes and desires are viewed as important and those individuals participating in services have a leadership role in service design and delivery.

Hillingdon can proudly point to examples of flexible consumer focused services in both mental health and learning difficulties. For example:

- The operations at the both the Moorecroft and Pembroke Centres are seen as focused on the user where the people who attend play a major role in choosing what they want/receive from the centre.
- User representatives participate in the management board of the Pembroke Centre;
- The beginning of a self advocacy scheme for persons with learning difficulties;
- There are active user committees functioning within both mental health and learning difficulties day centres;
- Principles into Practice: exploring ways of consultation with users in influencing day services to persons with learning difficulties;
- The family placement schemes in both learning difficulties and mental health support people in integrated family settings within the community.

In addition, there are examples where external organisations have been invited in to hear

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[9] *Adapted from The Accreditation Council on Services for People with Developmental Disabilities, Standards and Interpretation Guidelines, 1990 Edition, Pages 12-60.*

and Integration Challenges

Adapted from The Partnership Challenge, 2009 Edition, pp. 24-25

In addition, there are examples of [illegible]

- **The Family Placement [illegible]**
  people in integrated [illegible]
- **The Family Placement [illegible]**
  services to persons [illegible]
- **Principles and Practices [illegible]**
- **The Deployment & [illegible]**
- **There are service [illegible]**
  difficulties day [illegible]
- **The operations [illegible]**
  the user [illegible]
  [illegible]
- **User Engagement [illegible]**

Health and Learning Disabilities

Highlights and Challenges

A commitment to [illegible]
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Action towards community [illegible]
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A Community Dentistry [illegible]

Dealing the review process [illegible]
difficulties services persons [illegible]

complaints (MH Unit, MIND); conduct consumer satisfaction surveys (MH Unit, CHC), begin individual advocacy programs (PLD & MH, DASH), etc.

Hillingdon has initiated, and should be commended for its initiation of greater user involvement in influencing service provision. These efforts should be encouraged, recognised and expanded. If Hillingdon is to aggressively address the issue of direct user involvement, the following questions may assist in moving forward:

- o Are we moving one person at a time (during resettlement) using a person centered planning method involving those who know and care the most about the individual?
- o Are users employed (paid) to train other users on how to understand user rights, responsibilities and how to impact on the services they receive?
- o Are the users reimbursed for their participation in self advocacy or other 'official' meetings (like staff are paid to go to these meetings, eg. JCG)? Costs might include transport, meals, day care, compensation for lost income if during the day, etc.
- o Are all users involved in a meaningful way in the evaluation or hiring of staff who work or live with them?
- o Are users involved in a meaningful way in the evaluation of existing services?
- o Do all users pick their own roommates (if they have one)?
- o Are users prepared in advance of meetings regarding them, so their wants drive the meeting?
- o During resettlement, is person-centered planning occurring or are people being moved en mass because capital is available to refurbish an existing large residence. How are existing friendships being preserved through resettlement?

The positive steps Hillingdon has already taken should be built upon and expanded.

B. An Overburdened Yet Dedicated Work Force

One of the prevailing strengths of the Hillingdon system is its staff. Throughout the system of services to persons with learning difficulties and mental ill health we experienced hard working, throughtful, dedicated and caring staff. Given limited and now dwindling resources where some administrative staff carry responsibility for 2 sometime 3 jobs, we marvelled at what they were able to accomplish. The question for everyone in the system must be, "for how long?" Having an overburdened staff 'rise to the occasion' is cause for recognition and celebration. It is also cause for concern if it goes on too long.

cause for concern if it does on the long

B. An Overlapping Yet Independent Ombudsman

The positive steps Hillingdon has already taken towards having an independent

- Are we making the best use of resources?
- Do we have a business plan?
- Are there clear objectives for the service?
- Are we monitoring the service to see if it is meeting its objectives?

These staff work with vulnerable people. Their errors, due to fatigue or lack of ability to attend to task as they should, could result in tragic human consequences.

C. Depend Less On Buildings

Given the current ability to receive large sums of money for capital improvements or purpose built sites, it is tempting to go for money regardless of the actual needs of the user. Once buildings have been built or remodeled, the temptation to 'keep them full' in order to keep revenue coming in may supersede the actual need of the users. The following quote emphasizes this trend, "Over half the current spending is tied up in old institutions and much of that is being spent on servicing the building - heating, cleaning, portering, maintenance, etc." [10]

While some buildings may be needed, many sites can (and are in Hillingdon) be provided through contracts and agreements with the voluntary and non-statutory sector[11] or through provision of services in the home of users/carers. As the user develops skills the numbers of hours of staffing required can be phased out.

The primary focus must be on the needs of the user and how staff can meet those needs regardless of where the user lives. Having resources tied up in facilities limits the organisations ability to be flexible and responsive to changing user need.

D. Think In Terms of *Hours of Services* Not Just *Models of Service*

Part of a person-centred approach calls for purchasing specific skill training/services instead of 'models' of service. Traditionally the system has conditioned people to ask for 'models' of service like 'group home', 'hostel', 'day centre', etc. Once a model, such as group home, is purchased a commitment of over 80 hours of staff time (based on shifts with multiple staff it is likely you are buying over 100 hours) has been made. In reviewing the actual amount of training each individual receives to learn tasks which will assist him/her live a more independent life, often less than 5 hours is provided per person per week. (Some research has show it is actually less than 1 hour).

If the focus shifts to buying hours of service many more individually tailored options are created. For example:

- o Some carers may be requesting group homes because their son/daughter requires assistance with personal hygiene needs (bathing, dressing, etc.) and the carer can no longer lift or manage these tasks. Rather than a group home, the carer may be quite happy with someone coming into their home in the mornings to assist in getting their son/daughter

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[10] *Managing Mental Health Services, The Institute of Health Services Management, 1991, p.10.*

[11] *Ibid.*

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[9] Managing Major ...

[11] Ibid.

up and off to day centre and then again at night to assist in bathing and going to bed. The level of skill required would not require a 'professional'. Perhaps a neighbour or friend already acquainted with the family would assist for reimbursement. Naturally, training and monitoring of the individual would be required. On the other hand, what might be needed are one time expenses for environmental adaptations, bath lift, etc.

- o Some individuals need assistance with learning to clean their home, shop for food, make simple meals, manage money, etc. This type of training can occur during the day with small groups of people actually learning these tasks 'out in the real world' which helps with situational learning. These skills can also be taught at (or out of) day centres or the individuals home.

- o Some individuals may require room and board accommodation. Purchasing this type of support should be quite inexpensive compared to staffed group homes.

- o Other individuals may need some supervision at first, but the amount of hours can be phased out as skills and confidence grows. This can be done in their own home or in a home shared by housemates. Some very successful schemes include one flat where "staff" (individuals under contract or who are actually staff) live. Users in flats close by are seen daily or as the user feels the need and they work on the skills required by each user. The staff are paid by the hours they are needed and actually engaged with the users.

- o Some individuals actually need hours of supervision because they can not be left alone or have no family able to care for them. If the agency values include statements such as "each individual has the capacity for growth and development" some training will also be going on during hours of basic supervision. Buying general hours of basic supervision and specific training does not require high paid professional staff. The staff need to be trained and monitored properly, but they do not need to be a specific professional.

- o Other individuals will require specific hours of support which only qualified professionals can provide. While most staff can be taught to do range of motion exercises during the day and evenings, only Physical or Occupational Therapists should design and monitor those programs and train the staff on how to do the exercises. While most staff can be taught to regularly initiate communication interaction, language stimulation, sign, etc., Speech Therapists are required to set up the specific method of intervention and monitor its implementation and success.

E. Preserving User Credibility Through The Complaints Process

When looking at complaints procedures for Hillingdon users, several procedures apply. Specifically:

[illegible] at night to assist in bathing and going to bed [illegible] require a "professional". Perhaps a neighbour [illegible] would assist for reimbursement. Natur[illegible] would be required. On the other hand, [illegible] environmental adaptations, bath lift, [illegible]

[illegible] to clean their home, shop for food [illegible] of training can occur during the [illegible] those tasks 'out in the real world' which [illegible] can also be taught at (or out of) day centr[illegible]

[illegible] and board accommodation. Further[illegible] compared to staffed group homes.

[illegible] supervision at first, but the amount of [illegible] grows. This can be done in their [illegible] very successful schemes include [illegible] who are actually staff) live. Users [illegible] and they work on the skills [illegible] they are needed and actually [illegible]

[illegible] because they can not be [illegible] values include statements [illegible] development" with training [illegible] Buying general [illegible] high paid professional staff. [illegible] they do not need to be [illegible]

[illegible] which only qualified [illegible] range of motion exercises [illegible] should design and [illegible] the exercises. While most staff [illegible] language stimulation, sign [illegible] method of intervention and [illegible]

[illegible] Schemes

[illegible] several procedures [illegible]

- o those followed by the FHSA (formal);
- o those followed by the FHSA (informal);
- o those followed by Education and Social Services;
- o those followed by voluntary organisations;
- o those followed by private providers;
- o Health Authority and issued by the Department of Health and Social Security (HC(88)37, HN(FP)(88)18;

  - one safeguard built into the NHS process is the Ombudsman. While there are limitations regarding what the Ombudsman can investigate, s/he is available to pursue lack of statutory provision and maladministration.

  - also, Health Authority has chosen to observe the requirements of the Hospital Complaints Procedure Act 1985 by setting up a District complaints Panel whose services are available to Trusts within the Hillingdon Borough.

Clearly an abundance of methods of voicing concerns are in place. A review of complaints filed between January 1992 and March 1993 and being tracked by the Hillingdon Health Authority was conducted. A summary of the types being follows:

o Complaints: Health Authority

- 3 regard sectioning issues
- 1 detoxification
- 3 EMI, discharge issue
- 1 EMI
- 2 EMI admissions issue
- 1 CPN service
- 1 Access to Psychologist
- 1 Absent with out leave issue
- 1 Treatment question

o Complaints registered and handled by the Hillingdon Hospital Trust but which reached the Health Authority:

- Delay in moving person with a label of EMI out of St. Bernards back to Hillingdon. Registered by family.
- Problems over the treatment of person with both learning difficulties and mental health challenges. Registered by family.
- Restrictions of catchment area for Hillingdon/St. Bernards. Registered by individual.
- Support lacking for relatives whilst relative is in-patient. Registered by family.
- Anorexia care inappropriate in St. Bernards. Registered by family
- Brain damaged patient inappropriately cared for in medical ward: Registered by family

- o those followed by the PASA (formal);
- o those followed by the PASA (informal);
- o those followed by Education and Social Services [illegible]
- o those followed by voluntary organisations;
- o those followed by private providers;
- o Health Authority and issued by the Department of [illegible] and Social Security (HC(88)37, HN(FP)(88)[illegible]);

- one safeguard built into the NHS process [illegible] limitations regarding what the Ombudsman [illegible], s/he is [illegible] lack of statutory provision [illegible]

- also, Health Authority [illegible] requirements of [illegible] Complaints Procedure [illegible] District complaints [illegible] services [illegible] Hillingdon Borough.

Clearly an abundance of [illegible]. A review of [illegible] between January 1992 and March 1993 [illegible] the Hillingdon [illegible] was conducted. A [illegible]

- o Comp[illegible] Health Authority [illegible]
  - 3 [illegible]
  - 1 [illegible]
  - 3 EMI [illegible]
  - 1 EMI [illegible]
  - 2 EMI admissi[illegible]
  - 1 CPN service[illegible]
  - 1 Access to [illegible]
  - 1 Absent with [illegible]
  - 1 Treatment question[illegible]

- o Complaints registered and [illegible] Trust but [illegible] Health Authority:
  - Delay in moving person with a [illegible] St. Bernards back [illegible]. Registered by family.
  - Problems over the treatment of person with [illegible] difficulties and [illegible] challenges. Registered by family.
  - Restrictions of catchment area for Hillingdon [illegible]. Registered by [illegible]
  - Support lacking for relatives whilst relative [illegible]. Registered by family.
  - A[illegible] care inappropriate in St. Bernards [illegible] by family
  - Bath[illegible] patient inappropriately [illegible] ward. Registered by [illegible]

- Services for young persons with dementia. Registered by family.
- Proximity of day nursery to MH unit. Registered by nursery staff/parents.
- Concern regarding therapist approach. Registered by parent.

The statutory and Citizens/Patient Charter responsibilities to implement a complaints procedure are well developed and implemented. The creation of a review panel to track complaints and monitor for trends is excellent.

However, there is a strongly held view that registering formal or informal complaints can and has resulted in retaliation. This view is certainly not universal, especially with staff interviewed who indicated they welcomed recommendations and criticism. Nevertheless, in the mental health arena particularly, some advocates and users were vocal in citing examples of retaliation following suggestions or complaints.

In addition to retaliation, feelings of being caught in the proverbial 'catch 22' situation were frequently expressed. The logic perceived goes something like: If you are labeled mentally ill, you can not be competent or perceive the world accurately. If you can not perceive the world accurately, you can not file a credible complaint, therefore complaints filed by people with mental ill health are not believable.

Again, not all users or advocates expressed a similar view. However, the majority did. This is a serious perception, if not fact, and needs to be acted upon with haste.

F. Information

As mentioned earlier, information is an essential component of a well informed and managed system of care. As a pivotal part of an over all safeguards system, the information system specifications must anticipate the requirements of its multiple and diverse users. The main purchasing authorities (Health and Education/Social Services) currently labor with incompatible information systems. Yet, they must account for and wisely disburse human and financial resources in an environment where practice has out paced the systems ability to define expectations and how it wants to measure service outcomes.

Persons with mental ill health and learning difficulties use all types of services in various combinations. In order for teams to provide 'seamless' services which are blind to geographical or provider barriers, access to financial, service and generic information is key. Carers and advocates require accurate and current sources of information to facilitate referrals to available generic and specialized resources.

The Project Team is aware of joint working between Health & Education/Social Services which has anticipated both short and long term solutions to information difficulties. A detailed review of the information system being developed was not within the purview of this project but we offer comments for consideration.

- Services for young persons with [illegible]
- Proximity of day nursery to [illegible]
- Concern regarding increase in [illegible]

The statutory and [illegible]
are well developed [illegible]
monitor for trends [illegible]

However, there is [illegible]
has resulted in [illegible]
who indicated they [illegible]
stems particularly [illegible]
following suggestions [illegible]

In addition to [illegible]
frequently expressed. [illegible]
you can not be [illegible]
accurately, you can put [illegible]
mental ill health [illegible]

Again, not all users [illegible]
[illegible] perceptions if not [illegible]

F. Information

As mentioned earlier, [illegible]
system of direct [illegible]
specifications must [illegible]
purchasing authorities [illegible]
information systems. [illegible]
resources in an [illegible]
expectations and how it [illegible]

Persons with mental ill [illegible]
combinations. In order [illegible]
or provider barriers. [illegible]
advocates require [illegible]
generic and specialized [illegible]

The Project Team is aware of [illegible]
has anticipated both short [illegible]
of the information system [illegible]
offer comments for consideration.

- o Consensus amongst relevant parties (Health, Education/Social Services, Housing, GP's, users, carers, advocates, elected officials, care managers, multi-disciplinary team members, quality assurance staff, contracting personnel, etc.) who need or want information should be reached regarding what information is required, when and for what purpose. Information for information sake is expensive and a waste of time and resources for both purchasers and providers.

- o A standardised reporting and retrieval system to simplify data collection and eliminate duplication of requests for information is desirable.

- o Protocols for collecting information and handling requests should be designed for the planning and coordination of services and for the identification, not only of available services, but also those that are needed and not provided in the community should be developed.

What ever system is adopted (manual or computer based) it must meet the needs as perceived in Hillingdon. Naturally, that may take several years to accomplish given limited resources. It should, however, continue to be a very high priority for Commissioning Agencies to refine standard information routinely required.

V. SERVICES TO PERSONS WITH MENTAL ILL HEALTH

". . . Hillingdon (has) been unanimous in a desire to see a wide range of local facilities being provided to support mentally ill people and their carers in the community. . . the range of overall facilities required span from long term residential care to supporting and enabling people to play an active role in society.
. . . in order to do this it is necessary to have a set of principles on which to base the planning:

- *o To treat mentally ill people as full citizens. This entitles them to:*
  full rights and responsibilities;
  - full consultation on planning proposals in order to contribute to the future service. . .
- *o To encourage mentally ill people to contribute to their own care by planning a service which gives a choice of facilities and resources which cater for their individual needs.*
- *o To allow the development of a range of provision from support to longer term care from all interested agencies.*
- *o The service will promote independence for the user but will also have ready support available for people in need. . ."* [12]

Those who drafted these principles and many others within Hillingdon have made the commitment to a user-led array of disbursed community support services complemented by acute and well staffed 'homes for life'.

This report picks up these values and goals with a primary focus on the supports and services required to prevent the need for admission to an acute or long stay hospital. Therefore, rather than starting with a 'facility' focus, we begin with an eye to those supports and services required in the community to support users within their most natural networks and environments.

A. Building Support Services Around Primary Care

Primary care is traditionally the first point of contact for individuals experiencing psychological disorders. [13] With the emphasis on resettlement from long stay hospitals and the desire to create integrated, less intrusive methods of supporting people in community the emphasis on the role of general practitioners and those professional services/supports available within the community must become sharper.

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[12] *Into the 1990's, A Multi-Agency Strategic Framework for Mental Health in Hillingdon, Hillingdon Health Authority, London Borough of Hillingdon Social Services Department, February 1989, Page 2. The quote used here is an incomplete summary of Section 1.2 "Putting the User First".*

[13] *Wright, A.F., A Blueprint for Shared Psychiatric Care in the Community, British Journal of General Practice, June 1993.*

Many methods and models exist which may facilitate and expand existing moves in this direction within Hillingdon. The following is offered for consideration and discussion amongst those most interested in services to persons with mental health needs.

The Wise Use of Professional Skill & Talents: Providing quality care in the community has required a change in how and where we support people. With these changes has come the need to re-examine what users need professionals to do, which professional should do what and where their practice might best be located. Matching what users need with the appropriately skilled individuals prevents duplication and wasted money and talent.

If one were to design a process which would facilitate a fresh look at what functions are needed in light of the Community Care Act, a consultative process with all concerned (especially users) would be in order. It may be appropriate for the JCG or other group to consider such a review. A review of such detail was not part of this remit, however, the Project Team offers MH Table 1 as a sample intended to stimulate comment and discussion. The duties and responsibilities listed represent a sample of those identified by professionals during interviews and a limited review of job descriptions currently in force within Hillingdon. [14]

MH Table 1
PROFESSIONAL RESOURCES AND SUPPORT PROVIDED

Professionals / Functions Performed	Community Based	Hospital Based	Assessment	Diagnosis	Information Referral	Care Coordination	Benefits Coordination	Social Support	Visit in Home	Carer Support	Work Support	Counselling	Psychotherapy	Med Administration	24 Hour Call	Follow up Case	#s in Hillingdon
Care Manager	●			●		●	●										1
Counsellors	●			●		●						●					2 *
CPN	●	●		●		●	●		●	●	●		●		●		37
Day Centre/Work Staff	●			●		●	●		●		●	●					N/A
GP	●			●	●	●	●			●	●			●	●	●	125
MH Nurse		●		●		●					●		●	●	●		61.5
MH SW	●	●		●		●	●	●	●	●	●	●			●	●	15
OT	●	●		●		●				●						●	8.8
Psychiatrist		●		●	●	●				●				●	●	●	4.5
Psychologist		●		●	●	●				●						●	12.5 **
Residential Staff	●			●		●	●	●	●					●	●		N/A

N/A - Data not available
* Not including those hired by GP Fundholders
** Including EMI

[14] *See Appendix B for a complete list of documents reviewed.*

Obviously, not all professionals sharing a common title have exactly the same practice. Variations are expected based on personality, preference and user circumstances. The challenge is to examine with a new eye the roles and responsibilities of the key professionals in light of the values, goals and vision held by key contributors within Hillingdon.

An examination of the functions currently done compared with what the users really need and what the users say they need should stimulate lively questions and discussion. Are there other functions which should be added? Are there some which are no longer required? Should there be additional lists for social, recreational, legal or advocacy needs? Once there is agreement on what needs to be done, lack of resources would force some prioritisation undoubtedly. The final question is who has the best skill match to perform each function? Does it differ depending on the persons level of need? While many individuals CAN perform a given function, the question remains: SHOULD they?

Advantages/Disadvantages of Moving The Mental Health Unit and Its Resources To The Community: When considering the provision of a comprehensive array of support services in a 'seamless system', some discussion regarding how best to organise and manage such services is required. With the emphasis on the provision of supports and services in the least restrictive setting, the need to re-evaluate where resources are 'held' and how that helps or hinders the provision of flexible 'needs led responses' becomes more critical.

Several individuals interviewed expressed concern over the perceived management fragmentation within mental health services. With the Mental Health Unit continuing to be a part of the Hillingdon Hospital Trust and separate from the Community Health Trust, concern was expressed over the ease with which some resources of the Unit might be creatively used to build the capacity of the community and help reduce the need for inpatient acute care. Advantages and disadvantages of such a consolidation of available resources should be considered. The elimination of artificial barriers which may limit the creative and efficient use of resources is key.

Emphasis on Community Inter-Disciplinary Teams:[15] Expanding a disbursed community system of supports and services managed by multiple statutory, voluntary and private providers creates the potential danger of fragmentation and duplication. Coordination and continuity of care become issues for planners, managers and quality assurance personnel. From the users perspective, however, this integration into the generic fabric of the community can offer expanded choice, improved quality and an opportunity for greater influence over provision.

One of the keys to 'user friendly' access to this more complex system of services is the provision of appropriate member(s) of a inter-disciplinary team. Often, a single person (key worker, link worker, care coordinator) is assigned to be a type of personal assistant or professional advocate for the individual. This person, in turn, relies on multiple people who

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[15] *Description of the inter-disciplinary team process and function adapted from Standards and Interpretation Guidelines for Services for People with Developmental Disabilities, The Accreditation Council on Services for People with Developmental Disabilities, 1990 Edition.*

make up an interdisciplinary team for support and guidance. A brief discussion of the 'community team' approach is offered for comparison with the Hillingdon approach.

The Community Team is a group of persons whose participation is required in order to identify the needs of the individual and to devise ways to meet those needs. No standard composition of the Team is required. At a minimum, the team might include the coordinator, the individual and a service provider. However, for an individual whose only assessed need is to find semi-supervised accommodation, the team might be limited to the individual and those persons required to assist in acquiring housing, benefits and limited supervision/counselling. For an individual requiring ongoing therapy, medication monitoring and job placement, the team might be expanded to include psychologist, job placement specialist, residential living staff (if any), CPN (of appropriate grade depending on what level of intervention is required) and, as appropriate, the individual's family, guardian, or advocate.

In each case, the composition of the team is determined and modified in light of the assessed strengths and needs of the individual. As the individual needs change the composition of the team may shift.

In such a planning processes, one person should be designated to be the coordinator. In some cases that person may be the individual receiving services. In others it may be the CPN or Social Worker. Who coordinates the team/plan for a given individual depends on the users preferences and abilities. Responsibilities of the coordinator might include: assembling the group as necessary for assessment and reassessment of needs and services, gathering relevant information for the Team's review, monitoring progress of programme implementation and assisting, when necessary, the individual/family.

Advantages for the user of such an approach include: crisis/admissions prevention, anticipation of needs/events, continuity and the provision of a network of supports.

Advantages of a Community Team for the GP is access to and back up by a Team of skilled support available in proportion to the needs of individuals living in the community.

Hillingdon has a similar approach for those who qualify for the Care Programme Approach. There are others who would benefit from such support, especially those not requiring acute care but need more than un-staffed accommodation. Such Teams could be housed in or near GP surgeries or in Neighbourhood Health Centers.

Developing Neighbourhood Health Centres: A discussion of such an individualized approach to supporting people in the community inevitably leads to the discussion of where such resources should be located. In many respects Hillingdon has answered that question with the successful implementation of the Pembroke Centre. If supports and services are to meet the needs of individuals, those supports/services must be available where people live and at a time when they need them. Developing similar Centres is one option whether or not money is available for building a facility. Without capital funding an option might be the co-location of support services in or near GP practices known to actively support persons with mental health needs. Joint working with Housing Authorities may make smaller

neighborhood centres accessible and cost efficient.

B. Day Services: *Work Training, *Employment and *Day Centres[16]

When exploring the options of day services offered to individuals with mental health challenges, an array of services designed to meet a variety of needs is desired. Few of these services need be facility based or restricted to any one type of provider. What is important is the support they offer and the skills they teach. Some of those services might include:[17]

Vocational Evaluation: a comprehensive process which utilizes work, either real or simulated, as the focal point for assessment and vocational exploration. The purpose of this is to assist the person in vocational development or redevelopment.

Work Adjustment Support: would offer transitional, time-limited, systematic training program which assists individuals toward their optimal level of vocational development. Utilizing real or simulated work, the intent of the programme is to assist individuals to understand the value, and demands of work; to learn or re-establish skills, attitudes, personal characteristics, and work behaviours.

*** Job Club/Job Placement:** assists individuals to identify, obtain, and or maintain employment commensurate with their vocational, social, psychological, medical needs and personal abilities.

Sheltered Work: services designed to provide remunerative work. Sheltered Work typically includes subcontract work or prime manufacturing. Some persons may be involved in Sheltered Work services on a full-time basis, while other persons may be involved for only a few hours a week, choosing to spend their time in other services or programmes.

Employment Support/Supported Employment: Employment Support is provided for people within an industrial/business setting and is intended to maintain or result in paid employment in the community. Such services are designed to enable the person served to integrate into and stabilise within the work place. Support is provided to those who require ongoing support, on or off the job, in order to choose, obtain, and retain paid employment in integrated settings.

*** Personal, Social, and * Community Supports:**[18] offer goal-oriented opportunities in which skills and supports are developed and maintained in a variety of functional settings. Opportunities are provided to support individuals in becoming valued members in the community. These services are designed to maximise a person's independence in such areas

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[16] *All services marked with an asterisk (*) are services provided within Hillingdon.*

[17] *Adapted from Standards Manual for Organizations Serving People with Disabilities, Commission on Accreditation of Rehabilitation Facilities, 1993 Edition.*

[18] *Personal care in Hillingdon is offered by Home Carers. Community Support is, generally, offered through CPN's and Mental Health Social Worker's.*

as activities of daily living, personal health and safety, socialisation, communication, education, recreation, and work attitudes and skills exploration.

Personal, social, and community services may include domiciliary services, opportunities for older adults, and/or may complement employment or other community services.

Outpatient or Transitional Therapy Programmes: a series of time-limited, structured, face-to-face sessions with the purpose of attaining defined goals as identified in the individual's plan. Outpatient Therapy may be provided in a specific facility or in the individuals home or neighborhood.

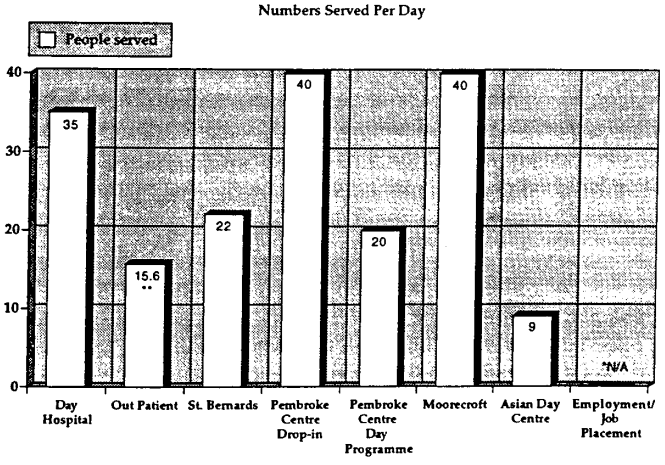
* **Day Centres:** provide a variety of craft, social and leisure activities from which to choose. Activities are individually chosen and designed to maximise learning and practice of appropriate social skills, enjoying crafts, music and the arts, learning about resources available within the community.

Hillingdon does not currently offer such a wide array of options. This variety becomes extremely important for users as their needs and ability to cope may fluctuate.

Information regarding the more traditional Day Centres was more readily available than information regarding work or volunteer related activities. The users and carers guide [19] offers specific information regarding job placement and work related services provided. It was not possible to learn the numbers who benefit from such work related programmes as records are not kept/available of how many people are served each year or their costs.

Available day services and location follow in MH Table 2 and Map 1. The Map does not display locations of job related placements since that information is not available at this time.

MH Table 2
LOCATION 1993/94 - DAY SERVICES
Numbers Served Per Day



* Data not available
** 5.2 Average attendances per clinic / 3 clinics per working day

[19] *The Mental Health Handbook, a users and carers guide for Hillingdon, Hillingdon MIND and Hillingdon Education and Social Services, 1993.*

Local Authority Day Services &
Voluntary Support Groups - Mental Health

Access and distribution of existing services becomes important when considering future location and funding. The preceding map helps provide substance to user, carer and professional concerns regarding the clustering of services in the south of the borough. As we can see, this is true for both day services as well as voluntary support groups. That is not to say the southern part of the borough has an over abundance of services. With only three centres (The Asian Day Centre, Mental Health Day Hospital and Moorecroft) serving a total of 89 persons on a given day, *over provision* is not an issue.

It is reported that unemployed people are 2 1/2 times more likely than employed people to have greater mental distress. [20] All seven of the wards in Hillingdon where more that 17.5% of the population are in Social Class iV & V are in the south. Eighty percent of the wards with 12% to 17.4% of people in Social Class iV & V are in the south. Unemployment is not the single contributing factor to mental ill health, however, Hillingdon has done well to consider and respond to the needs in the south of the borough. In addition, the needs of those in the north of the borough must also be considered.

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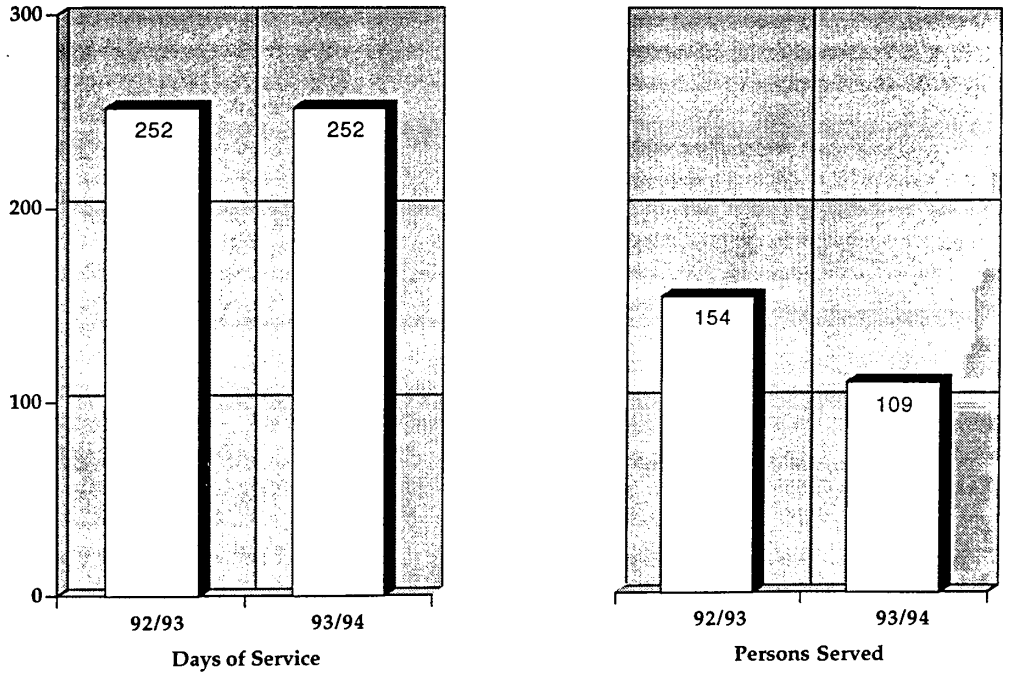
[20] *The Community Care Plan, 1993, Page 37.*

A review of day services would be incomplete without reference to the recent reductions in numbers of individuals served. There were no cuts in day services to those attending the Asian Day Centre, out patient services at the Acute Mental Health Unit or long stay hospital. As MH Table 3 illustrates, the total days the other centres are open has not been reduced either. However, the total numbers of persons attending have been reduced by 45 or 29%.

MH Table 3
COMMUNITY DAY SERVICE
Days of Service and Persons Served
1992/93 compared to 1993/94



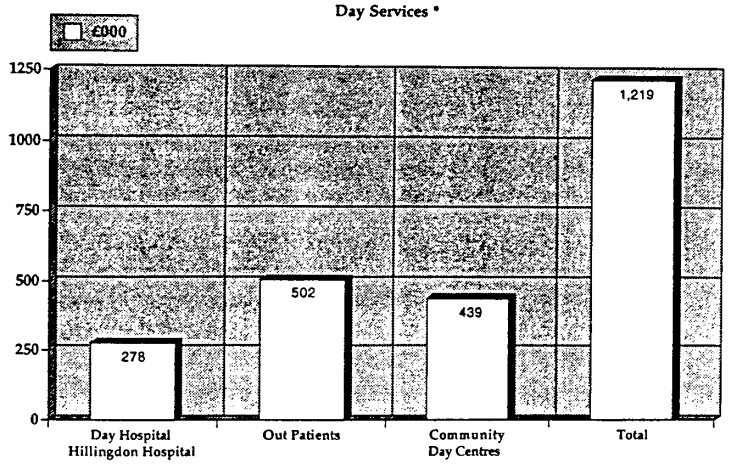
Costs: Attempting to gather financial information regarding the exact cost of services presented a significant challenge.[21] MH Table 4 provides estimated expenditures for mental health day services throughout Hillingdon. The figures for Hillingdon Hospital Outpatient and Day Hospital were provided by the Hillingdon Hospital. The figures provided for the community day centres (Asian Day Centre, Pembroke and Moorecroft) were provided by Education/Social Services.

The figures included in the Community Day Centres category include a total of £43,713 for the Asian Day Centre (an estimate figured by taking the total costs divided by the total

[21] *See explanation contained in Methodology section.*

numbers in attendance for a per person cost. Nine of the individuals who attend have mental ill health, therefore the total cost is a rough estimated only.) £275,000 for Pembroke (£48,00 Social Services, £50,000 Mental Illness Specific Grant and £177,000 Health Authority) and £100,000 for Moorecroft (including £20,000 from the Mental Illness Specific Grant for weekend drop in services).

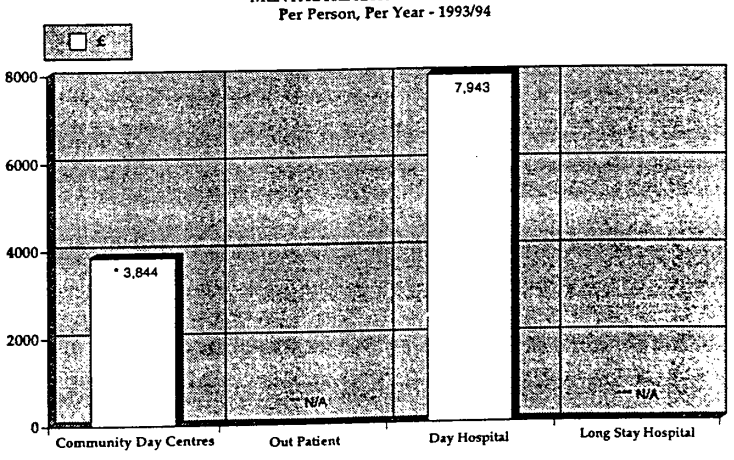
MH Table 4
ESTIMATED EXPENDITURES 1993/94
Day Services *



* Long stay day services expenses not included

MH Table 5 reflects a comparison of the estimated cost per person per year for day services. Costs for day services within long stay hospital are not reported separately from a per day total including residential. Out patient figures are calculated by the numbers of attendances. With out an unduplicated count of those served, it is not possible to project an average per person per year cost.

MH Table 5
MENTAL HEALTH DAY SERVICES
Per Person, Per Year - 1993/94



* Does not include £20,000 for Moorecroft drop-in weekend service
** Out Patient figured at £90 per attendance per Hillingdon Hospital
*** Data not available

From a commissioning perspective, questions regarding the reason for the approximate 107% difference in yearly cost per person are natural. There may be quite well reasoned explanations why costs vary so significantly. Hopefully, they would be *user need* rather than *model of service* based. How costs are allocated also plays a major role in understanding exactly what costs include. Such significant differences in cost, if accurate, emphasizes the need to know:

- o what specific service are being purchased;
- o who are they designed to serve;
- o what are the expected outcomes;
- o what is a reasonable cost for the service;
- o how do those costs compare to other similar services;
- o is the cost variance justified; and
- o is the purchaser willing to pay that price?

Gathering accurate, relevant financial data assists in establishing a baseline of information from which comparisons and management decisions can be made. Looking at trends over time assist in factually determining progress towards values and goal attainment.

The provision and management of a comprehensive community support system must become the priority if more intrusive alternatives are to be phased down. The 'community system' must expand to include related service components, specialised and generic, which are directed towards meeting the general and extraordinary needs of people who live in the community. [22]

The following MH Table 6 offers one way of considering equitable distribution of resources based on individuals served. What is obviously missing is information on individual level of need which would be required to complete the picture. The information points out that 75.7% of persons served receive services in the community. 61.3% of estimated expenditures are spent on community services. 24.3% of those served receive services in Day Hospital with 38.7% of estimated expenditure supporting those services. The numbers do not include those individuals who receive services through the outpatient clinics and would also be included in the hospital numbers.

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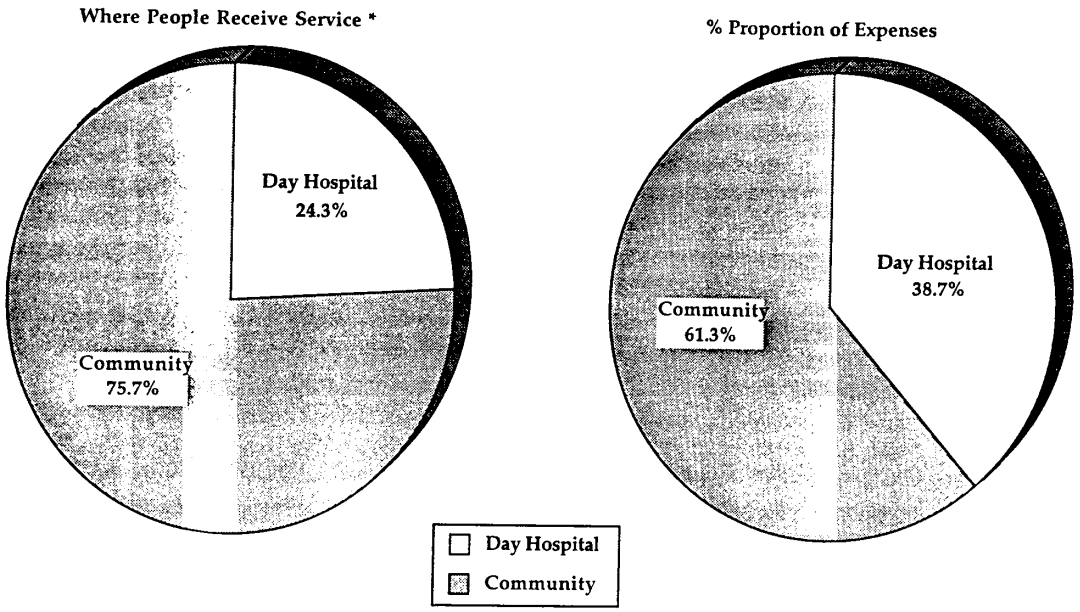
[22] *Standards and Interpretation Guidelines for Services for People with Developmental Disabilities, National Quality Assurance Program, The Accreditation Council on Services for People with Developmental Disabilities, 1990.*

MH Table 6
Numbers Served and Proportion of Estimated Expenditures
Adult Mental Health Day Services 1993/94



* Does not include Long Stay Hospital or out patient numbers

C. Residential Supports

When considering the range of supported living options for persons with mental ill health, we begin exploring what is offered in the least intrusive environment: where the person lives. Such programmes should be designed to enable the individual served to have the best possible quality of life through a programme which strives to integrate the person served into the fabric of community life.[23]

Service options range from 'community living schemes' to inpatient psychiatric programmes. A description of some successful models follow:

Emergency/Crisis Intervention Programme: offering services aimed at the assessment and rapid stabilisation of acute symptoms of mental illness and/or emotional distress.

*** Supported Independent Living:** A programme which provides support to persons who are primarily independent, enabling them to maximise and maintain their independence and self-direction. Staff members are available as needed and are present on a planned, periodic basis to offer assistance and support in the homes in which these persons live.

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[23] *Service descriptions with this section are adapted from those described in the 1993 Standards Manual for Organizations Serving People with Disabilities, Commission on Accreditation of Rehabilitation Facilities.*

* **Supervised Living:** programmes which provide individualised care, supervision, support, and training to promote and maintain self-sufficiency of one or more persons. Such services are provided in homes in which staff are present nightly and usually at other times when the persons served are at home.

* **Family Placement Scheme:** through a contractual relationship, a family environment to maximise the potential of the person(s) served through enhanced belonging, acceptance, and continuity of relationships. The setting for the programme is the home of a family. This home includes one or more persons with challenges who are unrelated to the family but participate as family members. Family living arrangements are initiated, monitored,and supported by an external agency.

* **Group Living Programmes:** provide for residential services in larger communal living arrangements that are basically self-sustaining. These services provide individualised care, supervision, support, and training to maintain and promote self-sufficiency of one or more persons with disabilities.

Residential Treatment Programmes (Rehabilitation Programme): organized and staffed to provide 24 hour per day general and specialised interdisciplinary services for persons who have a psychiatric disorder and for whom there is reasonable expectation of benefitting from the programme within a length of stay of approximately 24 months. May be provided in freestanding facilities or, like Victoria House, part of a larger unit. This approach is appropriate for persons whose acute symptomatology has been stabilised, although not resolved, and who have persistent dysfunction in several major life areas. The extent of the person's dysfunction requires a total, therapeutically planned group living and learning environment.

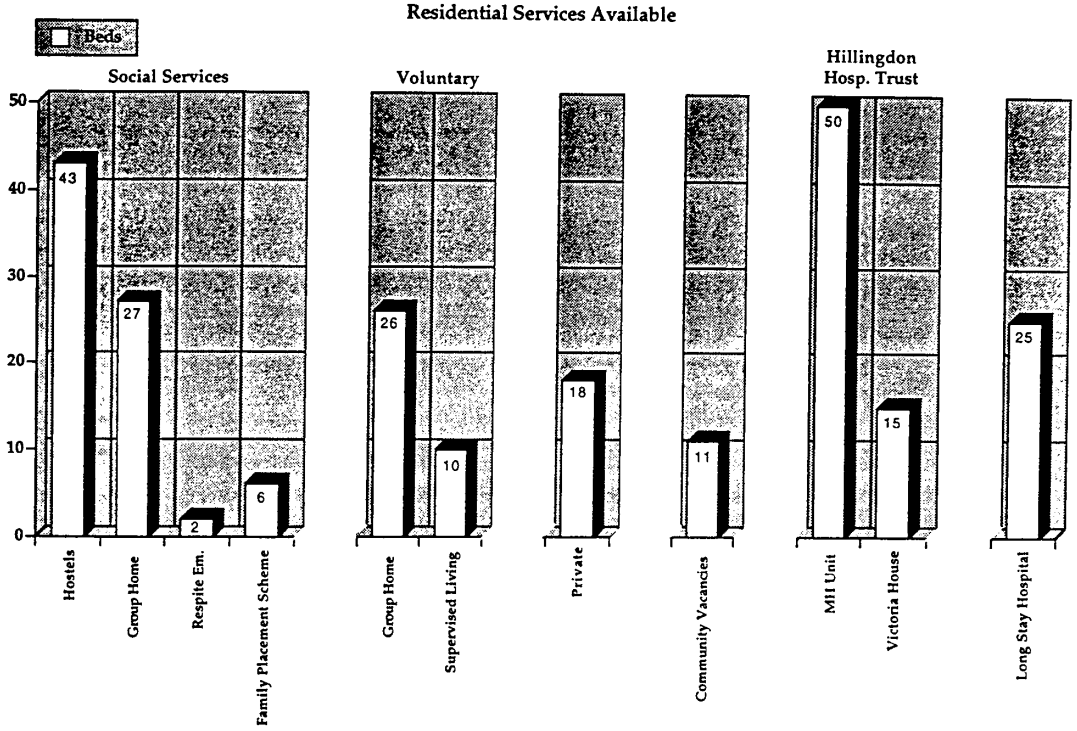
Partial Hospitalisation Programmes: Partial Hospitalisation programmes are timelimited (generally less than six months), episodic treatment programmes that offer comprehensive, intensive, coordinated and structured services within a stable therapeutic milieu. The goal of the partial hospitalisation programme is to provide an acute care facility to minimise or avert the need for inpatient care. The programme may function in one or more of the following ways; 1) as an alternative to inpatient care; 2) as transitional care following inpatient status in order to facilitate return to the community and to reduce the length of inpatient stay; 3) as a more intensive form of outpatient therapy when traditional office visits are not meeting the needs of the person; and 4) as a therapeutic setting for comprehensive assessment.

* **Inpatient Psychiatric Programmes:** Inpatient programmes for people with psychiatric disorders are programmes of coordinated and integrated services that include, but are not limited to, psychiatric evaluation and treatment. In addition, there are daily therapeutic activities in which the person served participates. The inpatient psychiatric programme is provided 24 hours per day in a protective environment that provides support and supervision. The goal is the stabilization, control and/or amelioration of acute dysfunctional symptoms or behaviors that result in the earliest possible return of the person served to a less intrusive environment.

Hillingdon tends to have services clustered at either end of the 'continuum'. That is, long-stay and acute provision at one end, then a gap in services. The less intrusive end of the continuum are supports such as the Family Support Scheme, self catering hostels with unstaffed group homes. Gaps exist in individually tailored supports and those partial hospitilization programmes similar to 'hospital hostels'.

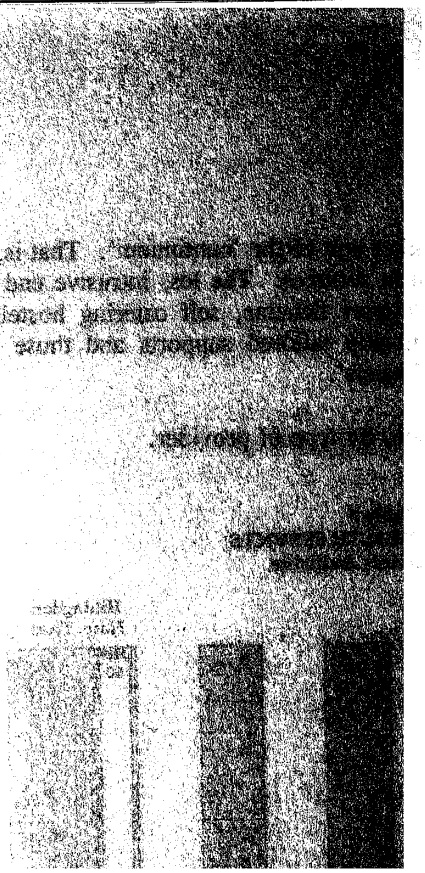
MH Table 7 shows the numbers of beds available, by type of provider.

MH Table 7
ADULT MENTAL HEALTH SERVICES
Residential Services Available

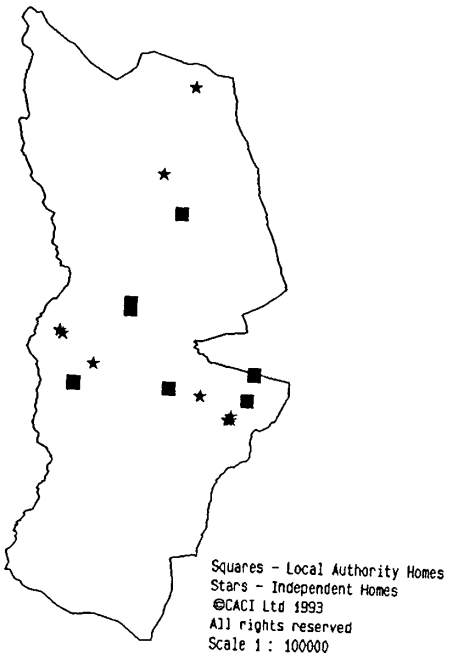


With Local Authority and independent residential provision, there is a greater number of residential accommodation as well as people served in the south. The north of the district has 5 group homes and one 10 person facility. It is also important to note that inpatient beds at the Mental Health Unit of the Hillingdon Hospital actually serve persons from throughout the borough. Specifically, Windsor Ward serves people living north of the A40 and York Ward supports people from the south.

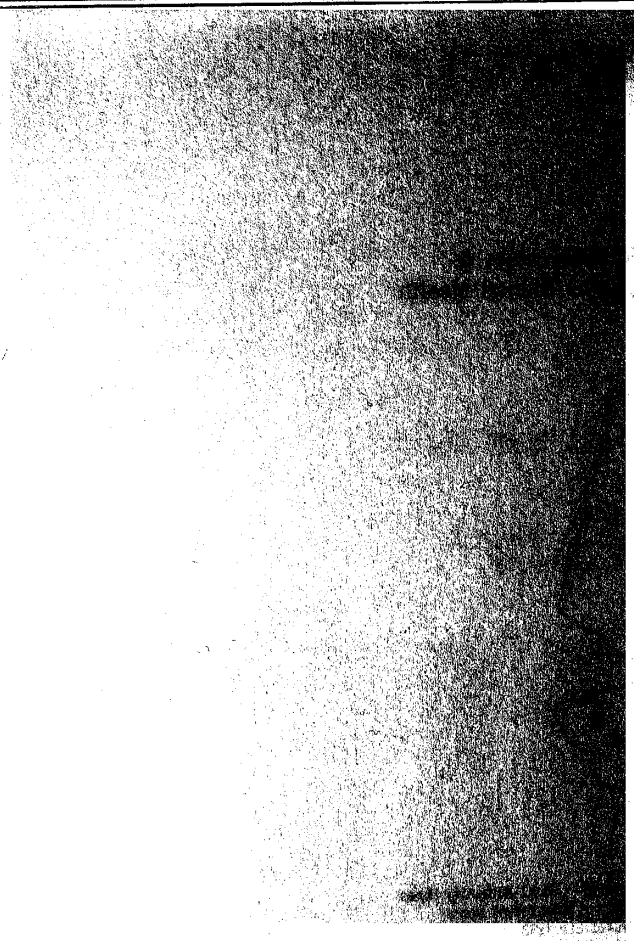
The following map provides perspective on hwere these options are located within Hillingdon.



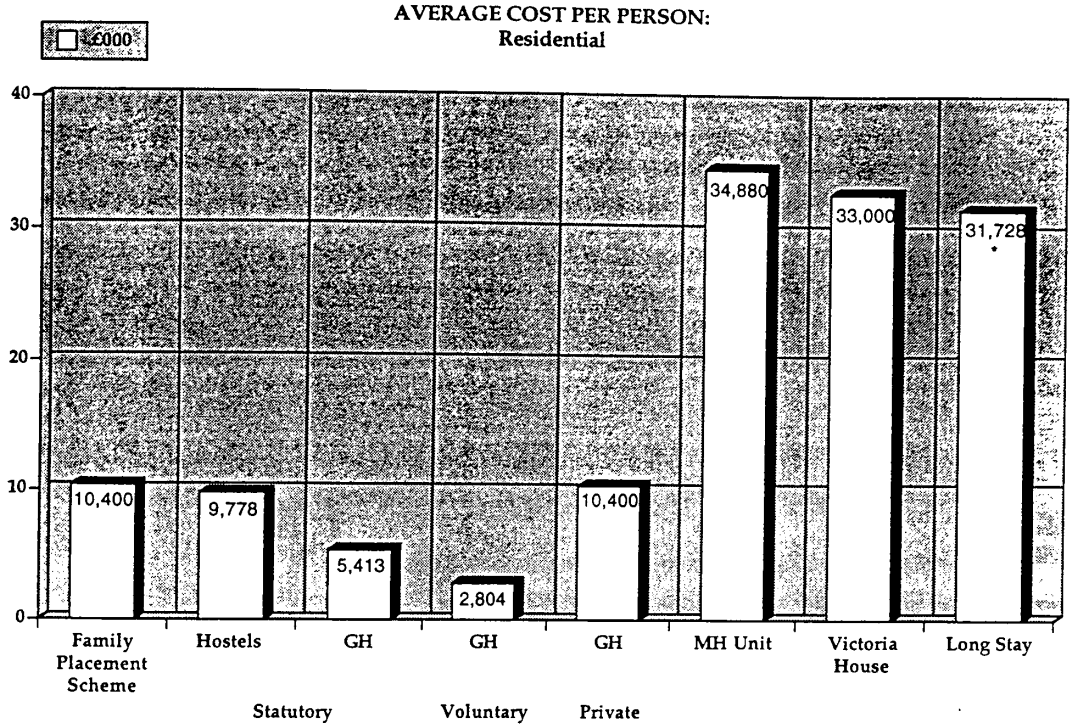
Local Authority Residential Homes &
Independent Residential Homes - Mental Health



Providing a comparison of the exact cost per service/location or cost per person is not possible with out some detailed explanation of the limitations of the information portrayed. MH Table 8 reflects the average cost per person by size of home or type of provider. Hostels include Hayes Park and Tasman House. Their costs include Housing Benefits, client contribution and £6,000 per home of Local Authority base budget. Other costs for these homes were not identified. The Group Homes were figured in the same manner: housing benefit, client contribution and £6,000 of the Local Authority base budget. Voluntary group home costs also include housing benefits and client contribution. No top up money was identified. Private homes cost were reported at £200 per person per week, as were the Family Placement Scheme costs.



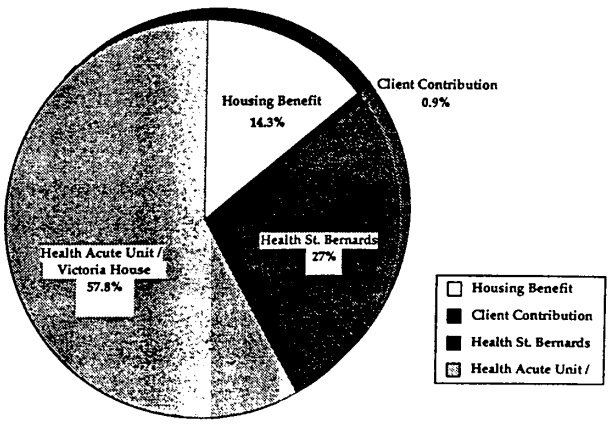
MH Table 8
AVERAGE COST PER PERSON:
Residential



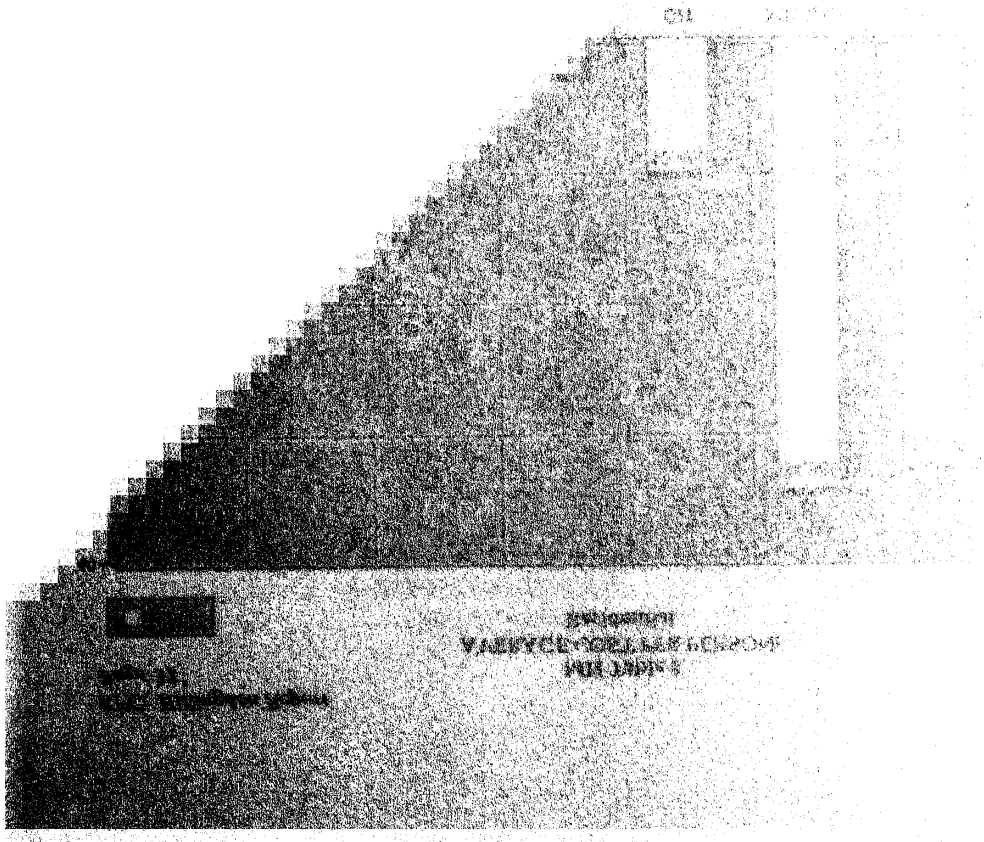
* Contract Rate

Based on the information provided, some revenue sources can be more readily identified than others. Health provides approximately 85% of the funding through provision at St. Bernards, Acute Mental Health Unit and Victoria House. Housing Benefit, client contribution and Local Authority make up the remaining 15% of identified revenue. It should be pointed out that these projections do not include Family Placement scheme (6 people), or private providers (18 people).

MH Table 9
SOURCE OF REVENUE:
Residential

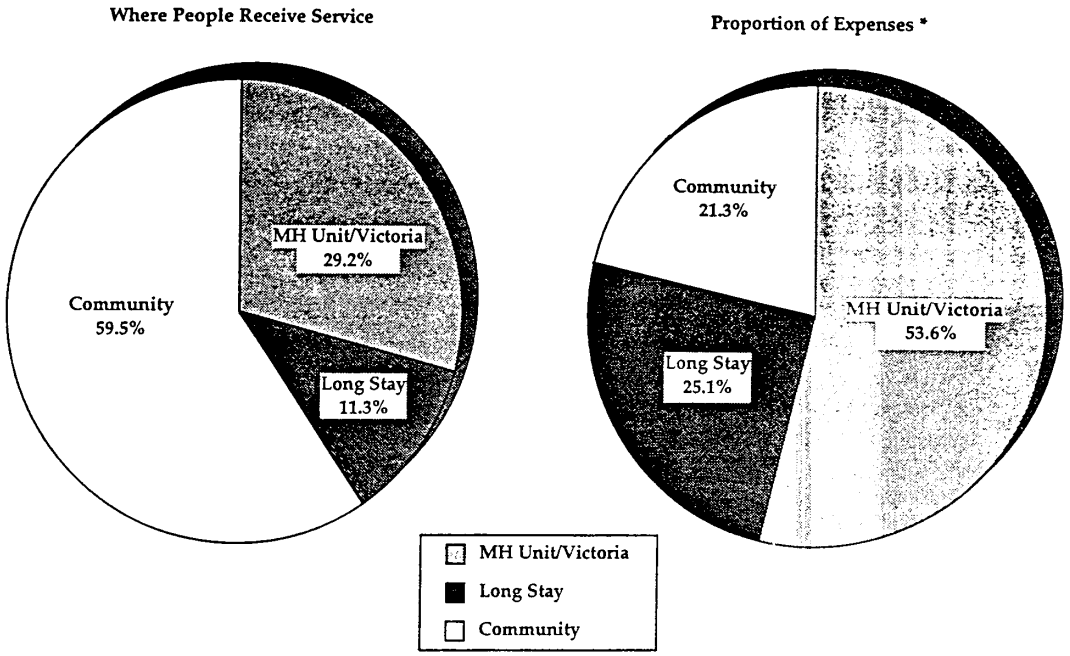


* Does not include Family placement scheme (6 people), private providers (18 people) or Merrimans (2 people)



MH Table 10 provides another look at the numbers served and the corresponding proportion of expenditures being made for their support.

MH Table 10
NUMBERS SERVED AND PROPORTION OF
ESTIMATED EXPENDITURES
Adult Mental Health Residential Services



* Does not include £14,000 LBH Out-of-Borough Est. Expenses per 1993 Community Plan (all for one person)

D. Ethnic Representation:

An effort was made to acquire numbers of individuals from culturally diverse backgrounds being served in both day and residential services. Unfortunately, the information is not tracked or reported system wide. Information was available from 3 locations (Asian Centre, Mental Health Placement Scheme and Moorecroft) which provided information on 74 individuals in residential (4 persons served are black, 3 from Asian background and 67 white).

E. Services To Persons With Learning Difficulties & Mental Ill Health

Virtually everyone interviewed recognised serious gaps in services for those individuals who have mental ill health and are also learning disabled. Enormous amounts of time can be spent attempting to determine which diagnosis supersedes the other (and therefore 'who is really responsible') or who should have done something but did not. None of which is very helpful.

Learning difficulty experts require the assistance of mental health experts and visa versa. Resources required need to be jointly identified and pursued.

F. Perceived Strengths, Gaps and Needs Of The System

Each person interviewed was asked to provide their perspective on the strengths, gaps and needs of the current system. While every opinion registered can not be listed, those most often cited along with reasons, if given, are summarized in Appendix E.

Learning difficulty experts require the assistance of [illegible]
Resources required need to be jointly identified and [illegible]

Perceived Strengths, Gaps and Needs in The [illegible]

[illegible] was advised to provide [illegible]
[illegible] current system. While every [illegible]
[illegible] with reasons. If given, are [illegible]

VI. SERVICES TO PERSONS WITH LEARNING DIFFICULTIES

A. MESH[24]

In May 1986, Hillingdon Health Authority transferred the management of its community services for people with learning difficulties to the (then) London Borough of Hillingdon Social Services Department which resulted in the creation of MESH (Mental Handicap Services in Hillingdon). The creation of MESH involved the transfer of management, staff and budgets for mental handicap services provided by the District Health Authority. Included in the transfer were Merchiston House, the Community Mental Handicap Team and 3 Colham Road.

The purpose of MESH was to provide an integrated and coordinated service across the borough/district and to provide a balanced range of services with unified service principles, avoiding duplication and gaps. MESH was designed to achieve a more efficient use of budgets by having a single management structure. In addition, MESH was to be a flexible arrangement for resettling people from long stay hospital into the community, ensuring that people with varying levels of need and type of handicap were among those resettled.

B. Values

MESH and those in Education/Social Services who run day services strive to keep a focus on user centred values as it implements and/or contracts for services. While the values and assumptions guiding this review of services was not specifically 'lifted' from a MESH document, they do reflect many of the values articulated in correspondence and other documents authored by MESH or Social Services Staff (eg. Principles into Practice). [25]

Aims and Philosophy of Service: To provide a quality service to people with learning disabilities which improves their experiences and opportunities, and allows them to have their own chosen way of life. This will be accomplished through the provision of ordinary work, leisure, their own homes and clubs within local communities, complemented by staff support to meet the needs of each individual. The following values and outcome expectations guide service provision:

Family, Friends and Social Networks: During values clarification exercises completed by over 100 individuals from throughout the U.K.,[26] the most frequently identified 'critical components to maintaining a good quality of life' were family, friends and social networks. Services provided must focus on ensuring non-paid people (friends, club members, family) are in the lives of persons with learning difficulties. These people include friends, family,

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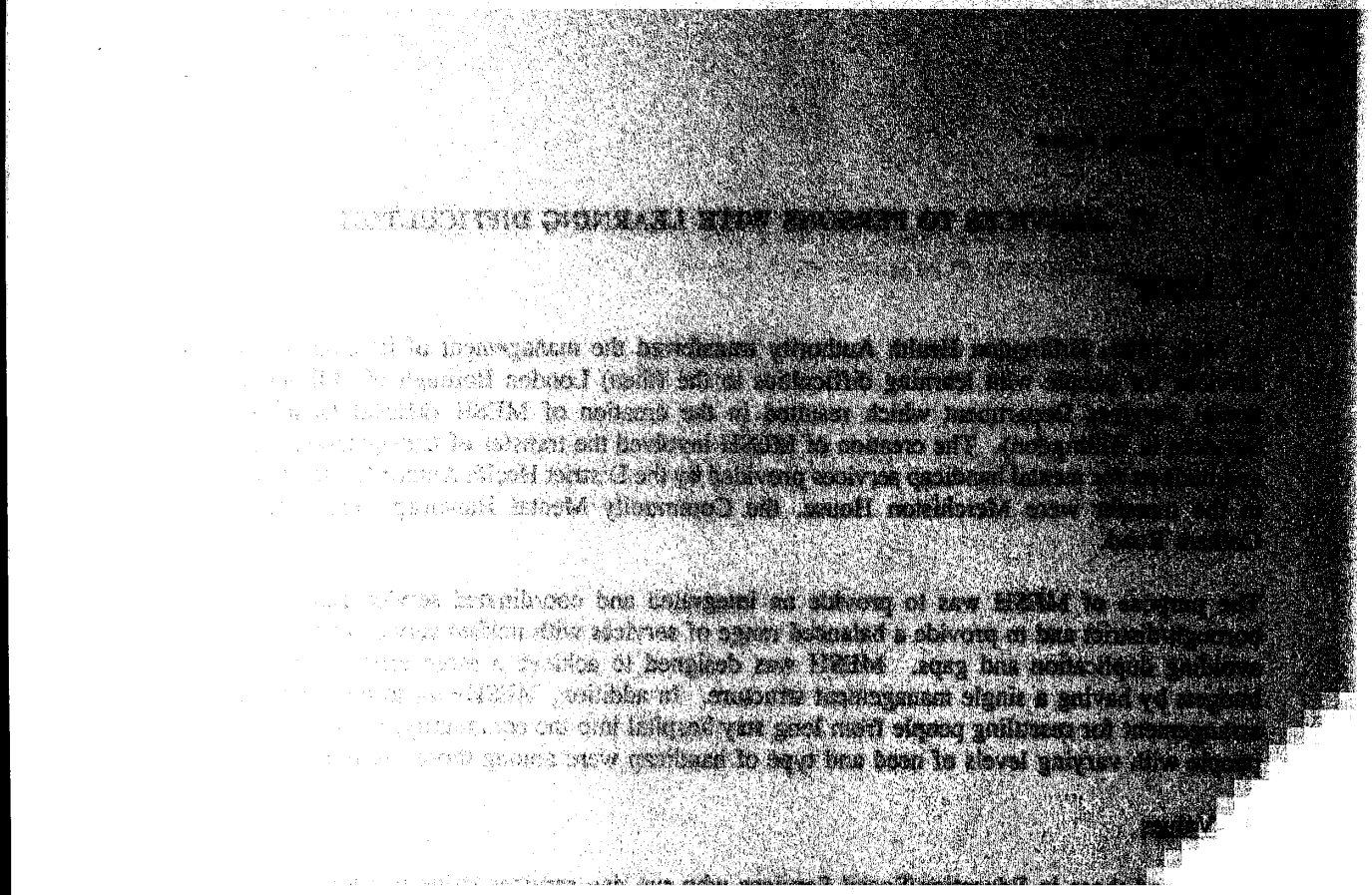
[24] *Adapted from "M.E.S.H. A Report on the Development of Services in Hillingdon by Liz Spencer and Ian Macdonald, Brunel University of West London, April 1989.*

[25] *Adapted from ELCAP Aims and Philosophy statements, East Lotian, Scotland.*

[26] *Individuals participating in the Care Management Course offered through the King's Fund College from 1988 through 1993.*



housemates, co-workers, neighbours, fellow club members and many others. People like spending time with others who respect them, those who take time to listen and appreciate what they do as important. Therefore, particular attention must be given to:

- o Arranging time for each person to spend time with people whom he/she enjoys;
- o Creating opportunities for each individual to meet new people and make more friends (including non-disabled);
- o Ensuring continued contact with his/her family.

Community Participation and Integration: Living in the community does not automatically mean the individual is a part of the community. Further, moving from long stay hospital to another large or small "home-like" facility in the community should not be the singular goal of resettlement. The emphasis must also include community participation and integration. Specifically, those arrangements that enable individuals to live, work, learn, and play side-by-side in the community with people who do not have disabilities. Therefore:

- o Each person should have the opportunity to visit new places and try new things in an effort to expand their knowledge, skills and emotions;
- o Each person should have the opportunity to go to places they enjoy;
- o Each person should be able to go into any public place and help should be provided if there are any difficulties with this.
- o Each person should be helped to go to places were they might not be able to manage on their own.

Communication: The ability of an individual to communicate and interact with the world is one of the most essential components in living a quality life. Since 70% of any persons communication is done non-verbally, learning to read communication cues as well as to listen is essential for anyone. For persons with learning difficulties who also have communication challenges, the provision of adequate attention to speech, language and communication abilities and methods is vital. Teaching an individual to communicate through methods which reduce their isolation from others including adaptive communications devices, alternatives forms of manual communication and culturally sensitive methods is essential.

Choice: Through learned methods of communication conveying what we want or do not want - like or do not like. Some people do this by speaking, using signs or pointing; by sharing their feelings (smiling, frowning, or looking angry); and voicing their feelings by laughing, crying, shouting out loud or screaming. Through what ever means the individual has learned or is being taught to communicate:

- o Every person should get to do things and learn about things that have to do with the choices they must make and be helped to understand the choices they have. Then they will know better what to choose - what they really want and

the consequences of making those choices.

- o Every person should get the help they need to make others understand that they have made a choice and what that choice is.

Respect: Each person should be treated with respect and dignity. People show respect when they:

- * Speak with the person, not about them as if they were not there;
- * Listen to the views and opinions of individuals regardless of how long it takes;
- * Respect the views, opinions and life experiences of individuals no matter how different from the listener's;
- * Assist individuals to do the best they can do;
- * Assist individuals to manage their own lives, and then reduce that assistance as the person can manage more.
- * Each person is seen as an individual with strengths, likes and dislikes;
- * Each person is given the chance to do the things that will cause others to respect their talents and abilities;

Using these guiding principles, services were reviewed.

C. People With Disabilities Team[27]

February, 1993 the People with Disabilities Team (PDT) was formed as a result of the amalgamation of the People with Physical or Sensory Disabilities (PPSD) Team and the Mental Handicap Resource Centre (MHRC).

This Team serves the whole of the Borough and has the lead responsibility for access to services by adults with a physical (including HIV/Aids) or learning disability up to the age of 60, and people with a sensory disability of all ages.

The Team is located in the Civic Centre which is accessible for people with disabilities.

Purpose of the Team: The PDT is a 'fieldwork' team which has a multi-disciplinary approach. The PDT is designed to respond to the needs presented by people with disabilities. Their work is focused around: meeting future expectations; understanding relationships within the family and social group; resolving issues of training and employment,

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[27] *Taken from "People with Disabilities Team Operational Policy," Hillingdon Social Services Disability Division, May 1993.*

rehabilitation, physical and emotional care where disability puts people in a situation of temporary or permanent dependency; support in achieving maximum independence and empowering people to take control of their lives whenever and where ever possible. Services are designed around the needs of people ranging in age from school leavers to those approaching retirement.

Structure and Services Offered By The Team: The majority of the staff are Social Workers or Occupational Therapists, there are a number of specialist posts which offer:

- o communication skills with people who are deaf or hard of hearing;
- o rehabilitation of people with a visual impairment,
- o community nursing;
- o psychology services for people with learning disabilities
- o facilitation of a number of groups and clubs of people with specific disabilities;
- o adaptations and equipment for daily living; and
- o advice and counselling.

Services Purchased or Managed by The Team:

- o in-borough residential placements:
  - Adult Care Scheme
  - Private Landlord Schemes: Person Specific
  - Personal Care at home
- o out-borough residential placements;
- o contract for: equipment for people with physical disabilities;
- o liaison with wheelchair assessment and supply centre based at Hillingdon Independent Living Centre;
- o maintains the register for people with learning difficulty; and
- o two small houses owned by the Shepherds Bush Housing Association for 6 people with learning difficulties.

D. Day Services: Work Training, Employment and Day Centres

As articulated in the Principles into Practice document [28] a great deal of time has been devoted to the development of those principles which drive day services provision for persons with learning difficulties within Hillingdon. Steve Battley and those who contributed to this document are to be congratulated for its content and the current efforts underway to put those principles into practice, particularly those efforts to increase consumer participation.

Concepts underlying service provision continually evolve. Attitudes towards work for individuals with learning difficulties evolved from assumptions that they were incapable of performing work to hopes that some could produce in sheltered settings, and then to the recognition that most can be integrated into the work force. Accordingly, a review of day services anticipates that individuals are given opportunities to function in normal work

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[28] *Battley, Steven., Day Services for People with Disabilities in Hillingdon, Principles into Practice.*

settings and be provided alternatives in segregated settings only when conventional placement is clearly not possible.

In addition to job training and work alternatives, there should be a variety of supports and training available for those individuals who would benefit from structured skill training. Also, those who wish to participate in more social activities or clubs should have the opportunity to join others from their community in doing so in age appropriate environments and activities.

Samples of such an array of services includes:[29]

* **Vocational Evaluation:** a comprehensive process which utilizes work, either real or simulated, as the focal point for assessment and vocational exploration. The purpose of this is to assist the person in vocational development or redevelopment.

* **Volunteering Time:** people with learning difficulty are often seen as individuals who need support rather than individuals who can offer support and contribute to their community. Enabling individuals to volunteer provides exciting opportunities for individuals to make new friends, improve feelings of self-worth in addition to the actual accomplishment of the volunteer tasks.

* **Self-Employment:** many individuals have developed a talent or skill which enables them to work at home or for themselves. Some users have become home helps, personal care attendants for friends, home visitors for elderly or home bound individuals, etc. Support offered these individuals can come in the form of marketing and selling products, for those unable to do so, bringing supplies to their place of employment, arranging transport, etc.

* **Work Adjustment Support:** would offer a transitional, time-limited, systematic training programme which assists individuals toward their optimal level of vocational development. Utilising real or simulated work, the intent of the programme is to assist individuals to understand the meaning, value, and demands of work; to learn or re-establish skills, attitudes, personal characteristics, and work behaviours; and, to develop functional capacities.

* **Job Club/Job Placement:** assists individuals to identify, obtain, and or maintain employment commensurate with their vocational, social, psychological, and medical needs and abilities.

* **Sheltered Work:** services designed to provide remunerative work. Sheltered Work typically includes subcontract work or prime manufacturing. Some persons may be involved in Sheltered Work services on a full-time basis, while other persons may be involved for only a few hours a week, choosing to spend their time in other services or programmes.

* **Employment Support/Supported Employment:** Employment Support is provided for people within an industrial/business setting and is intended to maintain or result in paid

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[29] *All services marked with an asterisk (*) are services provided within Hillingdon.*

employment in the community. Such services are designed to enable the person served to integrate into the work place. Support is provided to those who require ongoing support, on or off the job, in order to choose, obtain, and retain paid employment in integrated settings.

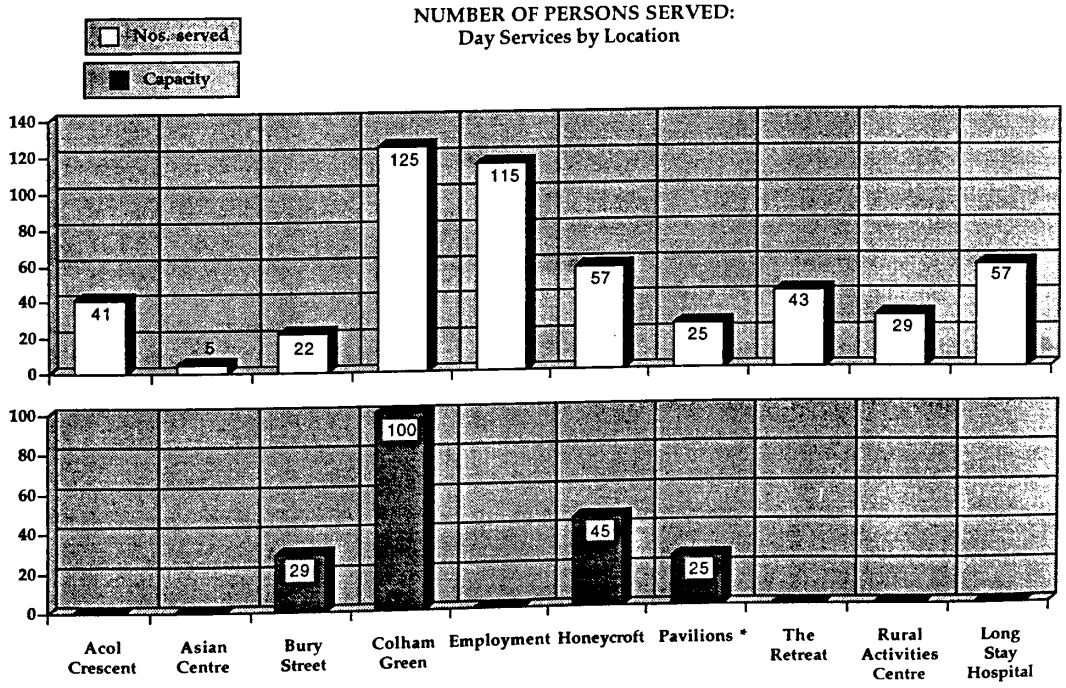
* **Personal, Social, and Community Supports:** offer goal-oriented opportunities in which skills and supports are developed and maintained in a variety of functional settings. Opportunities are provided to support individuals in becoming valued members in the community. These services are designed to maximise a person's independence in such areas as activities of daily living, personal health and safety, socialization, communication, education, recreation, and work attitudes and skills exploration.

Personal, Social, and Community Services may include domiciliary services, opportunities for older adults, and/or may complement employment or other community services.

* **Day Activities:** provides a variety of craft, social and leisure activities from which to choose. Activities are individually chosen and designed to maximise learning and practice of appropriate social skills, enjoying crafts, music and the arts, learning about resources available within the community and maintaining or improving mobility, speech/language and other needs as required.

Current Provision: Hiliingdon currently provides day activities and employment training, support and placement. Day services are currently provided in eight community based locations as identified in PLD Table 1.

PLD Table 1
NUMBER OF PERSONS SERVED:
Day Services by Location



* Due to close

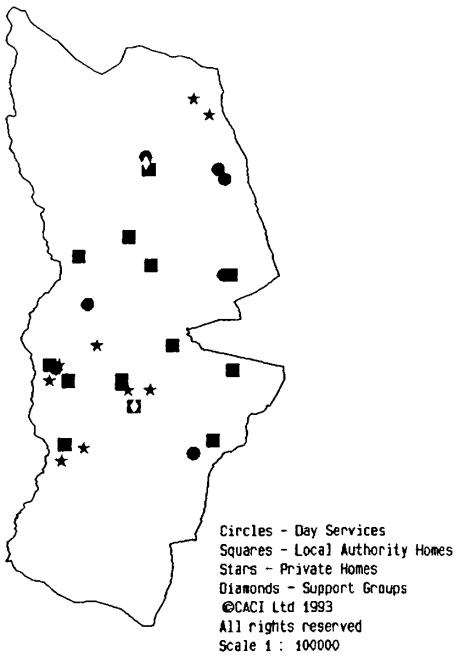
A total of 462 individuals are attending the community centres. One centre, Pavilions is scheduled to close. Three others (Bury Street, Colham Green, and Honeycroft) are currently operating above capacity. This, presumably, as a result of some individuals attending only certain days each week, therefore, the centre is able to serve more than its set capacity.

The bulk, 75%, of the provision occurs in day centres which are more oriented to day activities. However, the employment services are flexible, individualized and supporting people to try new options and to be integrated into the work environment. Ten individuals have moved out of employment/job training provision into paid employment during the past year.

The emphasis on user involvement and increasing the role of users on the Principles into Practice Group is to be commended. Centres are now in the process of reconstituting their user committee to incorporate new participants entering as a result of the cuts.

The following map provides perspective on where services are actually provided throughout Hillingdon. The locations of the centres are actually fairly evenly distributed throughout the borough.

Service Provision For
People with Learning Difficulties

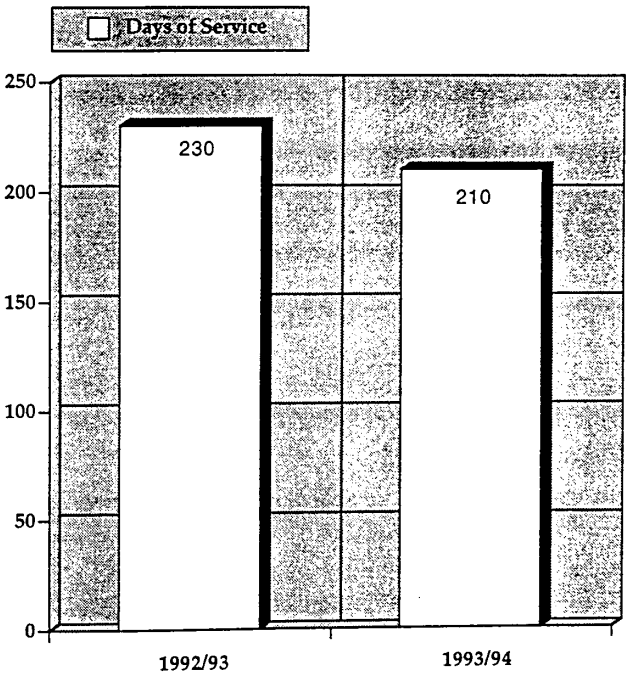


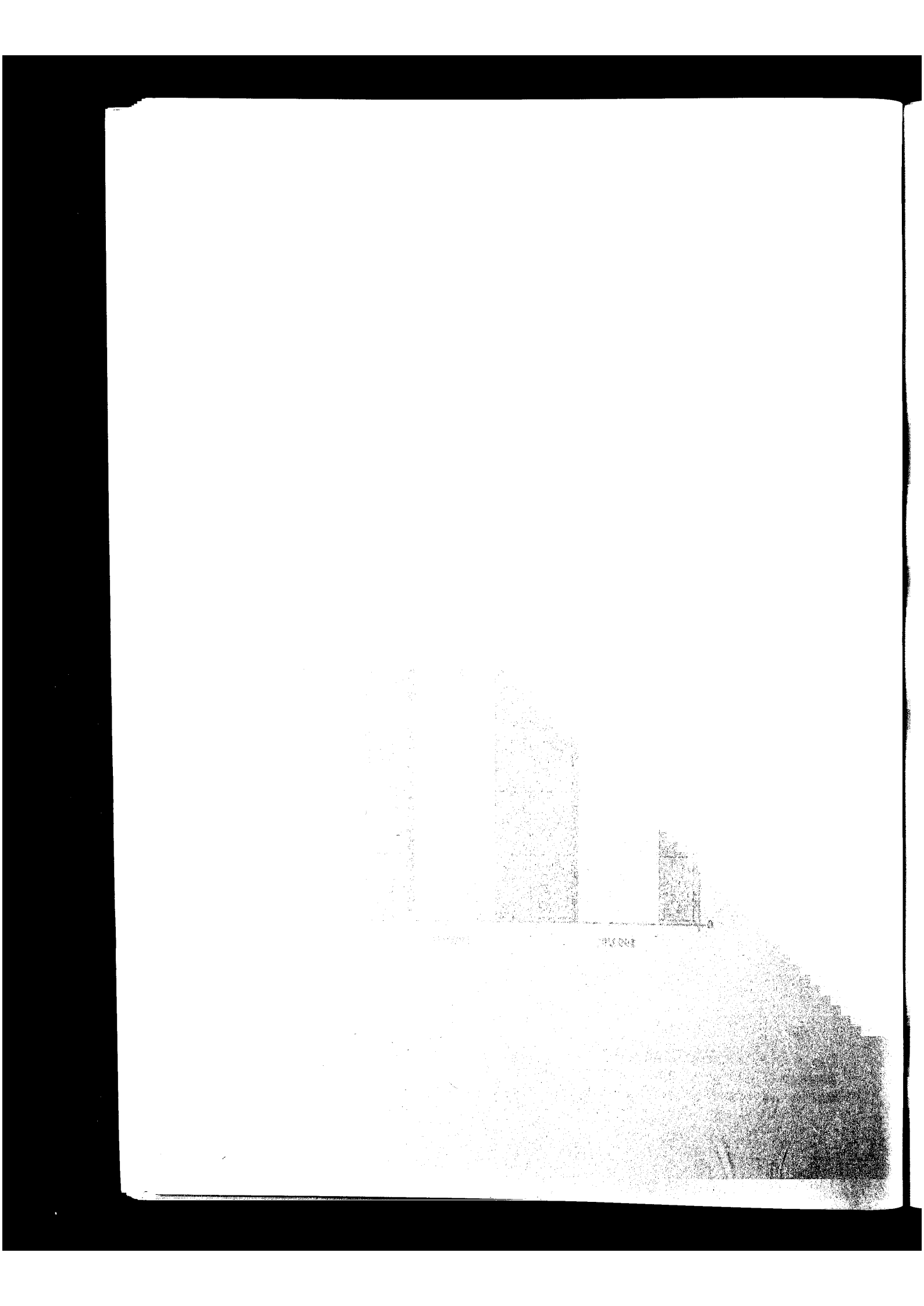
Day services within Hillingdon have been seriously impacted as a result of the London Borough of Hillingdon's cuts. Both the actual numbers of days of provision as well as the numbers of individuals receiving a 5 day per week service has been reduced significantly.

As demonstrated in PLD Table 2, the numbers of days the centres are open each year has been reduced from 230 in 1992/93 to 210 days in 1993/94. Of those attending day services, PLD Table 3 illustrates the percentage who participate from one to five days per week. In the past, the majority of individuals received a 5 day per week program.

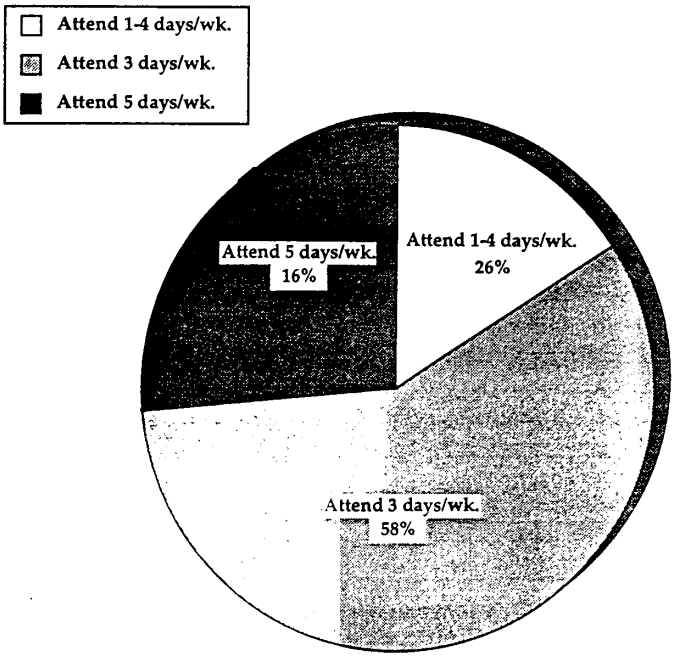
Recent cut backs in days of attendance and the reassignment of day centres for some individuals is most unfortunate. Some individuals who were reported to have gained skills and therefore 'promoted' to more independent settings have been returned to their previous day centre. Consumers and parent/carers are confused and angry about the changes which have been made and unclear as to what influenced these decisions. Assuming the best of intentions in most difficult of circumstances, many consumers can be expected to regress and in some cases demonstrate behaviours not previously seen or resume behaviours once extinguished.

PLD Table 2
NUMBER OF DAYS OF SERVICE
1992/93 to 1993/94





PLD Table 3
DAY SERVICE:
Days of attendance



Gaps in Service: While there is no reported waiting list, there is a need for more services and more varied services. Some of the most urgent needs follow:

- Carers and users alike are united in their desire to return to a 5 day work week;
- The provision of individually tailored supports and services needs to be expanded;
- Services provided to persons with challenging behaviours[30] require greater resources in terms of both numbers of staff and technical assistance;

Costs:[31] PLD Table 4 provides some information regarding the cost per person of the various centres. As noted, the costs for individuals attending Pavilions, Retreat Centre and Rural Activities Centre are included in the Employment figure. The total cost for community

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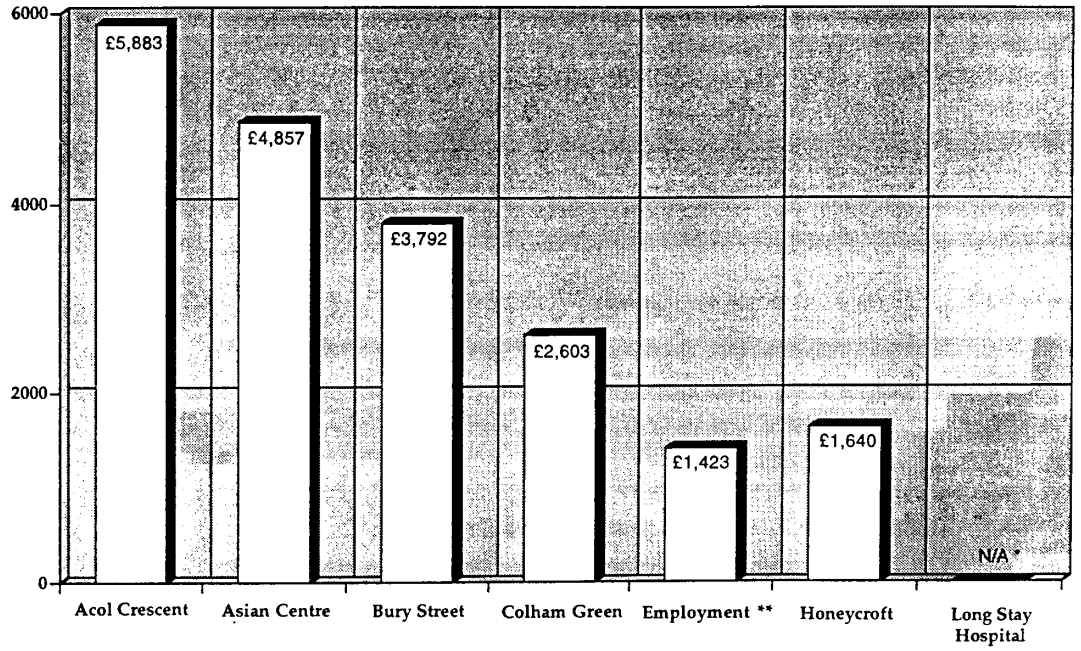
[30] *See Section E which addresses issues surrounding persons with challenging behaviors.*

[31] *On 7 July it was learned that £100,000 had been resored to the PLD Day Centre budget. While that remains £200,000 short of what was originally cut, it is a welcome addition. While plans are not complete, it appears the restoration of this revenue will allow the weeks the Centres are open to be extended from 42 to 48 weeks per year. In addition, some individuals will have their work week extended from 3 days per week to the original 5.*

day centres is approximately £1,250,000 per year for staffing and non-staffing costs excluding Hospital Transfer Scheme (HTS) money. Debt charges and training costs are also included in this figure. Transport costs are also included and average £8,000 per week. Some individuals are charged a fee for transport which provides limited revenue to off-set this cost.

PLD Table 4
ESTIMATED COST PER PERSON
Day Services



* Data not available
** Included in the employment costs are services to people at Pavilions, Retreat Centre and Rural Activities Centre

D. Residential

Environment: The environment impacts significantly on the lives of people with learning difficulties as it does on the lives of all people. Organisations should strive to support individuals in the community and to improve the quality of environments used by and for those individuals. Three important considerations follow:[32]

- o individuals should be provided with options and be supported in making decisions regarding the environments in which they live, work and interact with others;

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[32] *Adapted from The Accreditation Council on Services for People with Developmental Disabilities Standards and Interpretation Guidelines, Page 240.*

- the individual's experience should be increasingly defined in the context of a community environment of generic settings rather than a service environment of specialised and segregated settings; and

- agencies should strive to assist the community to make those environmental adaptations - physical, attitudinal and others - that promote successful experiences. Such adaptations should lead to maximum opportunities, integration and accessibility of services, and these should be accomplished with a minimum restriction and interference.

Physical environments should be accessible, comfortable, and attractively designed and decorated from the perspective of the individual. They should be comparable to the environments of persons who do not have learning difficulties. Such environments can provide valuable exposure to and training in, cultural values and/or opportunity for self-expression by the individual.

Individuals should be helped to locate living, learning, and working environments in the community that will promote their personal goals, and to the extent they may desire, their integration into the life of the community and interactions with all members of the community, including those who do not have a disability. In addition, the agency should seek and welcome assistance from, safety and health officials to ensure the safety and well-being of individuals served.

Accessibility: Accessibility and mobility enhance the individual's opportunities for development. Accessibility contributes to the development of adaptive behaviours and self-care skills, improved communication with others, better appearance and attitudes, improved physical functioning, more satisfying use of leisure time, and participation in the political process.

Standardised symbols make the environment more accessible to individuals who cannot read. Identifiably coded surfaces such as pavements and textured floors make the environment more accessible to individuals with visual impairments. Services to enhance mobility should include helping individuals who are immobile to become mobile or partially mobile, as well as enabling them to use public and private transport systems.

Facilities should be accessible to and usable by people who require adaptive equipment (such as wheelchairs) to be mobile or who have multiple disabilities, so that such individuals are not denied services or programmes solely because of their physical disabilities.

Array of Residential Support: When reviewing the provision of residential supports and services, the 'array' of services one would expect to be provided would include:

* **Emergency/Crisis Intervention Programme**: offering services aimed at the assessment and rapid stabilisation of behavioural challenges, acute symptoms of mental illness and/or emotional distress.

* **Domiciliary Support:** support provided in the individuals home or the home of his/her parent carer. This may include assistance in getting up in the morning, taking care of personal hygiene needs, home help activity, bathing, lifting and preparing the individual for bed at night. Services to the individual may resemble personal care attendants since from the elderly carer perspective, they perform duties age and physical limitations of the carer may no longer allow them to do.

* **Supervised Living:** support provided based on individualized needs and may include: supervision, support, and training to promote and maintain self-sufficiency of one or more persons. Such services are provided in homes in which staff are present nightly and usually at other times when the persons served are at home.

* **Supported Independent Living:** support provided based on individualized needs to persons who are primarily independent, enabling them to maximise and maintain their independence and self-direction. Staff members are available as needed and are present on a planned, periodic basis to offer assistance and support, in the homes in which these persons live.

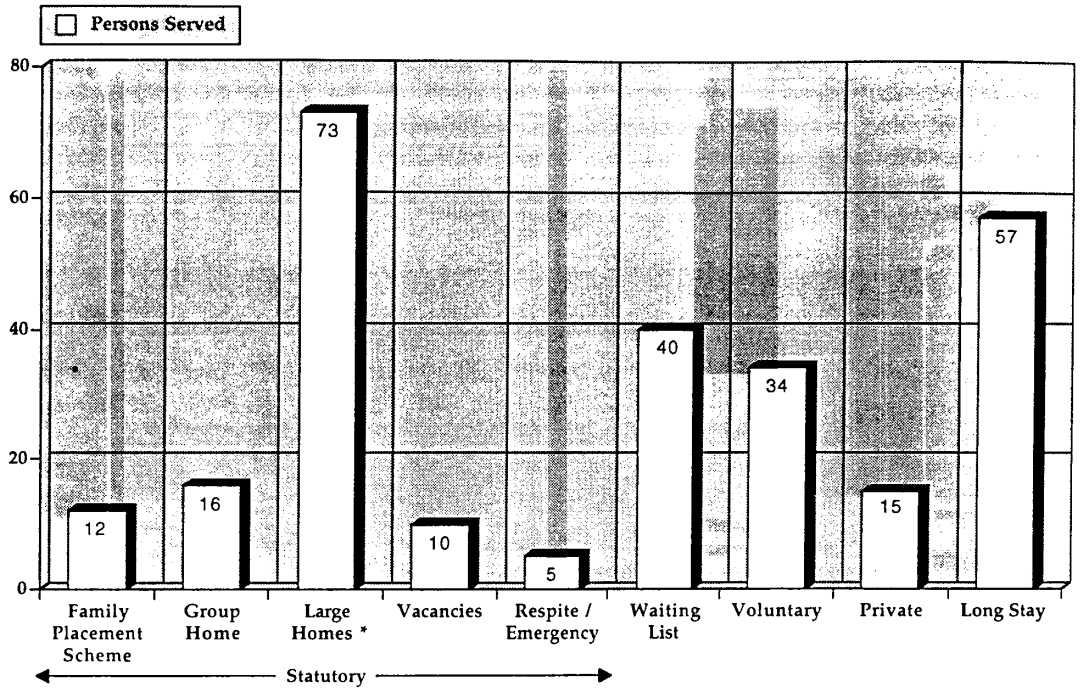
* **Family Placement Scheme:** through a contractual relationship, a family environment to maximise the potential of the person(s) served through enhanced belonging, acceptance, and continuity of relationships. The setting for the program is the home of a family. This home includes one or more persons who are unrelated to the family but participate as family members. Family living arrangements are initiated, monitored,and supported by an external agency.

* **Group Living Programmes:** provide for residential services in larger communal living arrangements that are basically self-sustaining. These services provide individualized care, supervision, support, and training to maintain and promote self-sufficiency of one or more persons with disabilities.

Current Provision: There are currently 150 individuals (PLD Table 5) receiving community residential support in over 24 locations throughout Hillingdon (PLD Map 2). This includes homes operated by both Local Authority and independent providers. 56 individuals remain in long stay hospitals, however, 26 of those persons are scheduled to move during 1993/94. The issue of distribution of services between the north and south of the borough does not appear to be an issue.

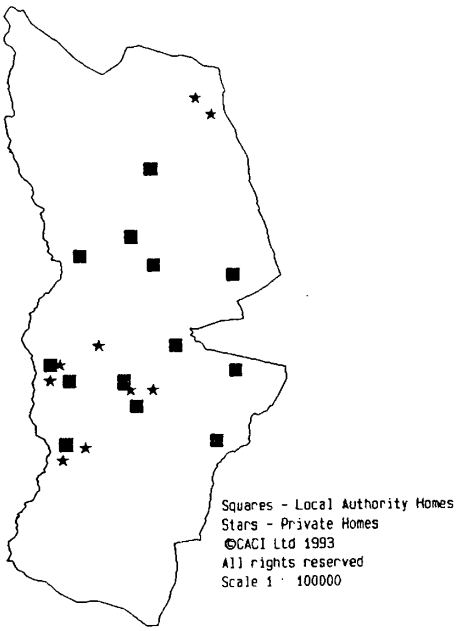
Provision of services to persons living in large or medium size accommodation are very well developed. Most of the individuals are reported to be involved in picking out the colors for their own rooms, have well appointed bedrooms and involved and caring staff.

PLD Table 5
PEOPLE WITH LEARNING DIFFICULTIES
Residential Services Persons Served



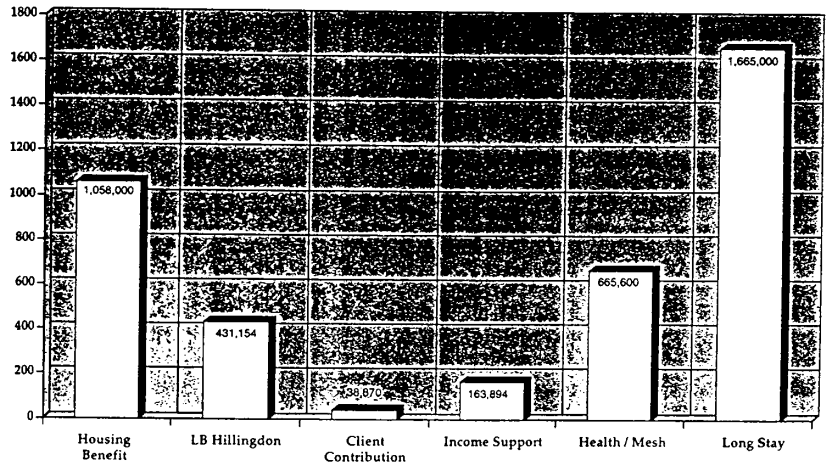
* 4 Homes, 10 or more persons

Local Authority Residential Homes &
Independent Homes - Learning Difficulties



Costs: PLD Table 6 portrays information received regarding source of income for residential services. Based on information provided, Health contributes £2.3 million through its support of services managed by MESH as well as those contracted for with long stay hospitals (Cell Barnes: 3 people, Harpersbury: 22 people, Leavesden: 30 people and Bromham: 2 people). Housing benefit, client contribution, income support and Local Authority make up the remaining £1.7 million.

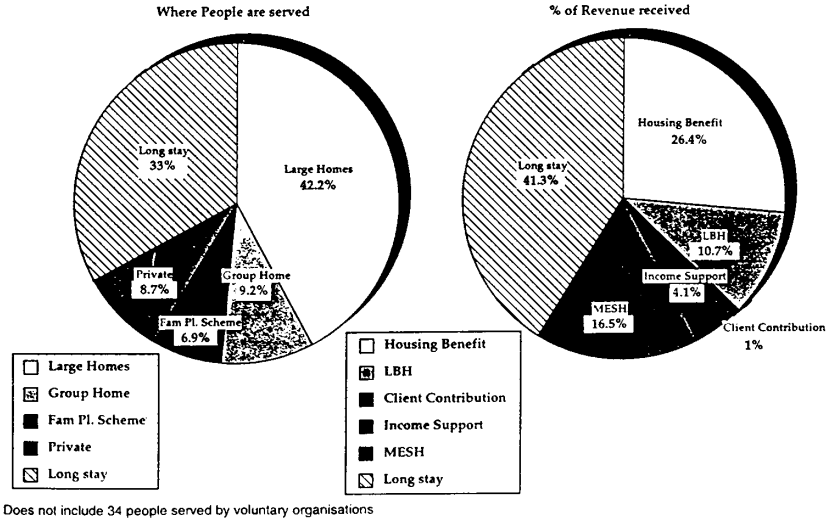
PLD Table 6
SOURCE OF REVENUE**
1993/94: Residential



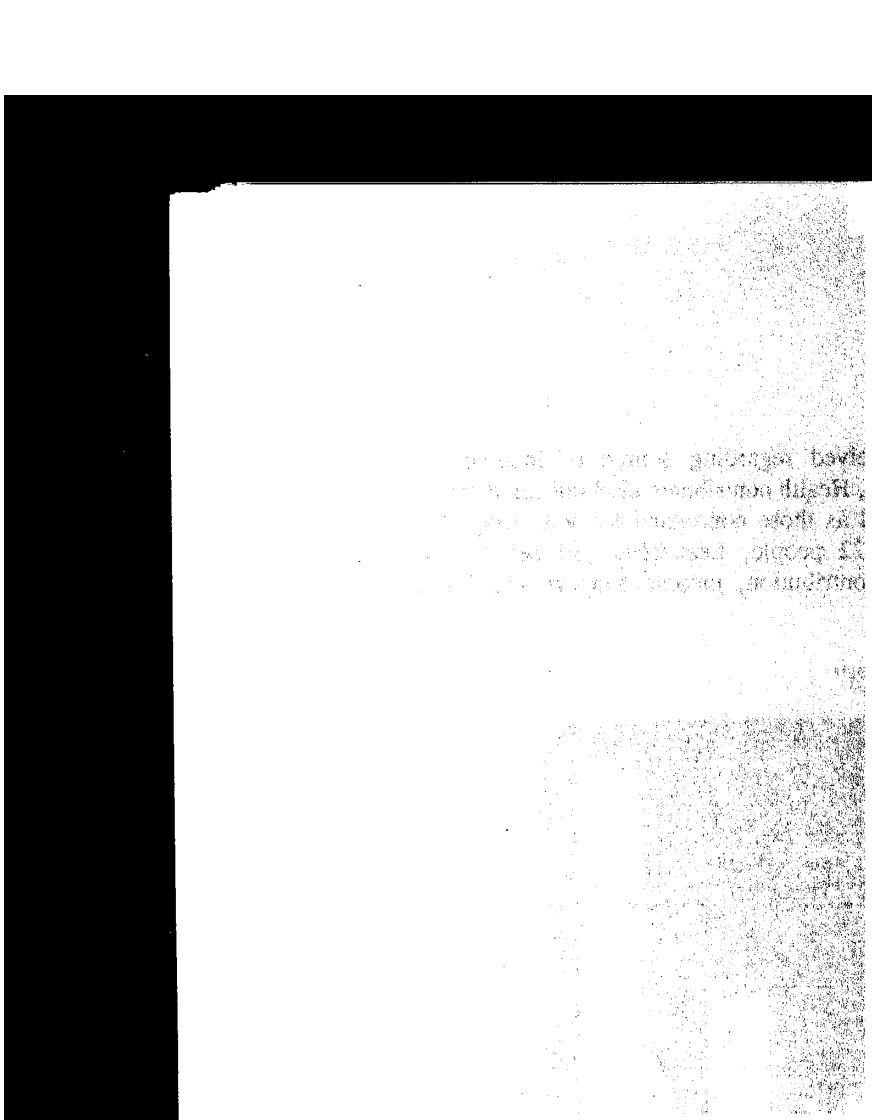
* Includes £124,800 of revenue received for 12 people in family support scheme
** Does not include revenue or expenses for voluntary organisations

PLD Table 7 indicates that 67% of the individuals served are supported in the community. 58.8% of the revenue reported goes for their support. Neither pie chart includes the revenue or numbers of persons (34) served by the voluntary organisations as that information was not available.

PLD Table 7
PROPORTION OF REVENUE RECEIVED *
% of people served - 1993/94

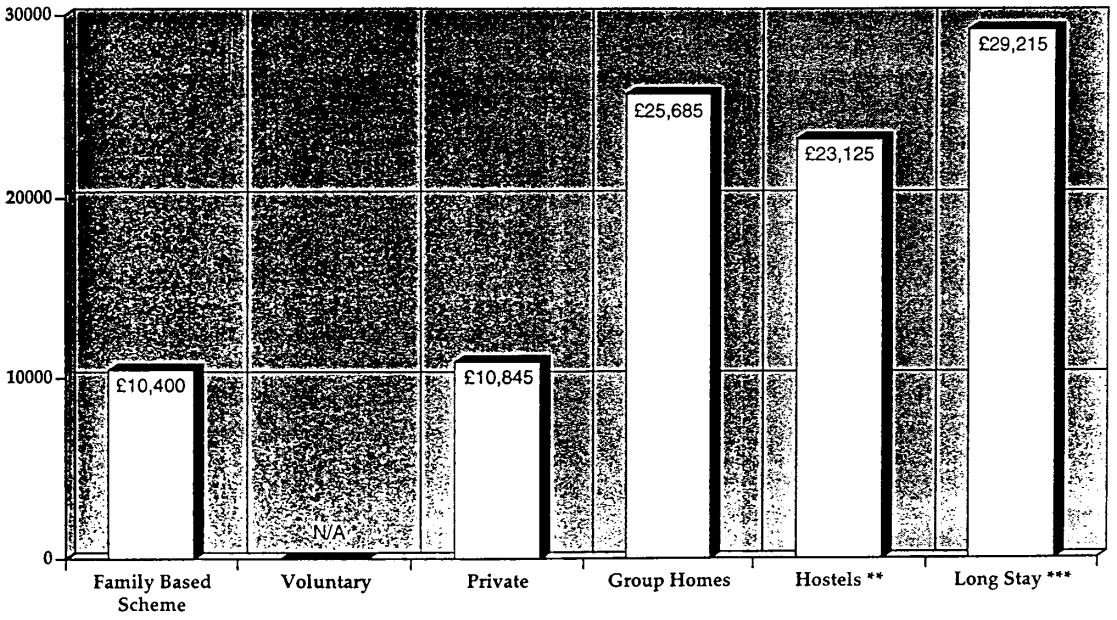


* Does not include 34 people served by voluntary organisations



PLD Table 8 shows the estimated average cost per person per year by type of residential support they receive.

PLD Table 8
RESIDENTIAL
Average cost per person per year - 1993/94



* Data not available
** 10 persons or more
*** Based on contract rate

Ethnic Representation: As with mental health, an effort was made to acquire numbers of individuals from culturally diverse backgrounds being served in both day and residential services. Unfortunately, the information is not routeinly tracked or reported.

E. Resettlement: Services to Persons With Challenging Behaviours

The following comments regarding services to persons with reputations for "challenging behaviours" are predicated upon the following principles of positive behaviour building.[33]

"1. Behaviour occurs all the time.

2. You influence a person's behaviour, whether you realise it or not.

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[33] *Behavior Building Curriculum, Department of Economic Security, Division of Developmental Disabilities -District V, Arizona, U.S.A. 1991.*

3. Every interaction is either therapeutic or not -- you make the difference.

4. Bonds and friendships develop from interactions with people.

5. The environment influences behaviour 24 hours a day.

6. How you structure the environment determines whether it is therapeutic.

7. At any given moment, there is a desired behaviour to promote.

8. A person's needs are identifiable through his/her behaviours.

9. There are constructive ways to respond to needs.

10. The individuals who receive services have preferences which may be different than staff preferences.

11. People who are (learning disabled) can and do change/learn."

A few individuals with learning difficulties may exhibit behaviorus that impede their development and acceptance. An even smaller number of individuals have developed a reputation for severely aggressive or destructive behaviours.

Maladaptive or socially unproductive behaviors, including severely aggressive or destructive behaviours, may be attributed to: patterns of life which lack meaningful, stimulating, or positively reinforcing environments, conventional human contact, positive peer models or teaching strategies; lack of success experiences; histories of extreme boredom or punishing experiences; lack of ability to communicate needs or desires in a conventional manner; neurologically based impairments, or other physiological determinants including pain.[34]

Research results have confirmed the efficacy of environmental manipulation in teaching positive behaviours and replacing behaviours that are maladaptive. In addition, the efficacy of positive programming, including the use of positive behaviour interventions in shaping socially productive behaviours and the efficacy of environmental manipulation in extinguishing behaviours that are maladaptive have also been demonstrated.[35]

Successful efforts have been undertaken within Hillingdon to address the needs of people with learning difficulties who also have challenging behaviours. While they should be considered as being in their infancy, the attitude and thrust of the interventions have a strong positive base from which to develop. Some examples of Hillingdon's strengths and remaining challenges follow.

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[34] *This section regarding services to persons with challenging behaviours borrows from Standards and Interpretation Guidelines followed by The Accreditation Council on Services for People with Developmental Disabilities, 1990 Edition.*

[35] *Ibid.*

3. Every interaction is either reinforcing or punishing for the learner.

4. Bonds and friendship develop from reinforcing activities.

5. The environment influences behavior by providing [illegible]

6. How you structure the environment determines what [illegible]

7. At any given moment, there is a limited number of [illegible]

8. A person's needs are hierarchically arranged from [illegible]

9. There are constraints ways to respond to [illegible]

10. The individuals who [illegible] have [illegible] preferences.

11. People who are learning [illegible]

A few individuals with learning [illegible] development and acceptance. [illegible] reputations for [illegible]

[illegible]
[illegible]
[illegible]
[illegible]
[illegible]
[illegible]

[illegible]
[illegible]
of positive [illegible]
socially [illegible]
extinguishing [illegible]

[illegible]
learning [illegible]
as being in their [illegible]
base from which to [illegible]
challenges follow.

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* This section regarding [illegible]
Interpretation Guideline [illegible]
Dimensions, 1990 Edition.

Attention to What The Person Is Communicating: The focus of provision should be on equipping individuals to communicate their needs and desires and on providing environments and experiences that are reinforcing.

Behaviour assumed to be maladaptive should be analysed to determine the communicative intent of the behaviour, the antecedents of the behaviour, and whether environmental alterations would reduce or eliminate it. If maladaptive behaviours are present, they should be targeted for reduction and replacement, but not without specifying the adaptive behaviours with which they are to be replaced. Programmes to change maladaptive behaviours should specify procedures for building positive behaviours which are socially useful. Reliance on reactive procedures which serve only to control the individual or the situation are unacceptable.

Acol Crescent and Colham Green staff were demonstrating a variety of communication techniques designed around the individuals they were serving. Two individuals were observed using picture cards to communicate with staff and others. Other individuals were using sign language.

Some residential staff of both statutory and voluntary providers were observed using both verbal and sign as a method of communication with users present. The methods employed would assist users in communicating with those outside the service system in some cases. Other staff indicated they knew what the individual wanted so no specific form of communication which would enable the individual to communicate outside that closed environment was being taught.

Other forms of augmentation devices such as acustical boards and head pointers were not observed.

Implementation of A Plan of Active Intervention: Given the complex needs of individuals with challenging behaviours, a structured plan of active and consistent intervention should be agreed. This plan should be based on a functional analysis[36] which includes observation and baseline documentation. Active, consistent intervention is vital for people with severe/profound learning difficulties and those with challenging behaviours. This approach incudes:

1. empowering all involved staff with the understanding, skills and resources to provide meaningful training activities;

2. holistic inter-disciplinary intervention planning;

3. a plan which attends to:

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[36] *refers to a process that includes an assessment of behaviour and context, communicative intent of behaviour, reinforcement which have been successfully (or not) used, contingencies used, observed or documented antecedent and consequential variables, known situational responses, motivational and other factors that might increase or decrease the likelihood of positive or undesirable behaviour.*

...amour as Ideal Has Failed to Communicate. The focus of problem ...
enabling individuals to communicate their needs and desires and ...
and experiences that are satisfying.

Behaviour assumed to be maladaptive should be analysed to ...
... of the behaviour, the antecedents of the behaviour, and ...
... would reduce or eliminate it. If maladaptive behaviours ...
... for reduction and replacement, but not without ...
... are to be replaced. Programmes to change ...
... for modelling positive behaviours which ...
... which serve only to control the ...

... Green staff were ...
... individuals that ...
... communicate with staff ...

... involving ...
... through ...
... values ...

- structured and purposeful activities which offer an opportunity to reinforce desired behaviours and avoid undesirable ones; and

- a physical environment conducive to growth and learning.

Observations in both day and residential programmes were limited, therefore, sweeping conclusions would certainly be inappropriate. However, there appears to be a need to develop plans with active interventions which are consistently employed through purposeful activities. Periodic data recording (frequency of behavior, level of skill attained on tasks being taught, etc.) in line with Team recommendations is essential for learning about what is working and what is not.

Acol Crescent staff indicated plans were used which included types of interventions staff were to use with specific individuals given specific behaviours. However, some residential staff indicated 'the plans they had were not practical, therefore they didn't really use them, and this is their home so if they don't want to do anything, they shouldn't have to'. An opposite view might be that the system has an obligation to teach people the skills necessary to reach their full potential. That should include learning behviours and skills which enable people to interact with the community, at large, appropriately.

Behaviour Consultation Committee: Consideration should be given to the establishment of a behaviour consultation committee. Along with the staff who will implement the plan of intervention, the committee would review the proposed intervention, reinforcers and reporting methodology. The purpose of the committee would be to offer advice and suggestions on the method of intervention being proposed. This could be seen as an additional opportunity for learning and training of staff in emerging techniques designed to teach positive behaviours.

Such a committee might include a psychologist or other professionals qualified by training and experience to evaluate published behaviour intervention research studies and the technical adequacy of proposed behaviour interventions, and a physician, pharmacist, or other professionals qualified to evaluate proposals for the use (and elimination) of drugs to manage behaviour. In addition, users, carers and advocates should be members.

Method For Ethical Review: Imposition of restrictive procedures on individuals should be subjected to careful ethical consideration. The agency should have written policy and procedure statements that define interventions that may be used. These should be ordered according to their relative degree of restriction and departure from conventional human behaviour. The principle of least restriction should be followed. When more restrictive interventions are used, the specificity with which they must be explained increases, as does the intensity of the control established by the agency.

Staff Training: Many individuals with learning difficulties not only need to learn new skills (how to brush their teeth, plan a nutritious meal, wash their clothes, etc.) but also need to develop more positive attitudes towards themselves and towards the people around them. They must learn to like themselves, develop a feeling of self-confidence. They need to know that someone likes and cares about them.

The responsibility for helping individuals develop good feelings about themselves lies with the people who support/train them. The need to develop a positive relationship with the individual must be stressed to all staff, but especially those who work most directly with each individual. The work and action of those who come into contact with each individual must convey a strong message of, "I like you", "You are a worthwhile person," "I know you can do this!" [37]

This attitude coupled with specific competency based training for staff who work with persons labeled as having "challenging behaviour" is essential. The emphasis of this training is critical when shaping the intervention approach. Is the emphasis of building positive behaviours or extinguishing inappropriate behaviours?

Persons who implement behaviour intervention procedures should receive competency-based training in more than just one technique or approach. Safeguards and review procedures should be in place.

Provision of A Technical Support Team (Parapetic Team): Hillingdon has provision for a team of individuals with whom the responsibility to provide technical assistance to day and residential staff rests. Unfortunately, 2 of the 3 posts remain unfilled. If people are serious about supporting people with challenging behaviours in the community (with a zero failure expectation) active attention and support must be given to providing the proper resources. Resources must be available after hours and on weekends, they must assist in the design of structured, consistent methods of intervention and then train direct care staff in its implementation. Part of the task is technical assistance. The other part is developing the confidence and capacity of community staff.

General Observations For Service Models: For a variety of specific reasons, Hillingdon is planning to move 12 persons identified as having 'challenging behaviours' into one location: Bourne Lodge.

Bourne Lodge is an existing facility originally serving 24 people. Currently there are 19 people living at Bourne Lodge.

This building was opened in 1963 and is a traditional hospital configuration. Therefore, it will need substantial alterations to provide discreet living units and will need other work (rewiring and replumbing) which may have to come from Local Authority central funds. The building will have to be closed for this work.

Day Service will be developed for people with challenging behaviour who are resettled. Hillingdon owns a site adjacent to Bourne Lodge and contemplates little difficulty in obtaining planning permission. Provision of this service is seen as vital to successful resettlement of this particular group.

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[37] *During the tour of Acol Crescent Challenging Behaviour Programme, the staff clearly demonstrated this positive, "we genuinely like being here with you and you can do great things" attitude.*

Experience has shown the grouping of individuals with challenging behaviours together as, generally, unsatisfactory. This model of isolating "like behaviourally challenged individuals" usually results in an untherapeutic or less than adequate learning environment: an environment where individuals imitate deviant and unacceptable behaviour instead of learning new skills and how to interact successfully with others. Often, the failure of these environments is usually blamed on the user instead of a faulty support design, which often results in the user being moved and/or carrying a lifetime label of 'difficult or impossible to serve'.

Keys to successful placement of individuals with such reputations include:[38]

- o the placement of such individuals into homes of their own, alone or in very small groups; (additional roommates who are not behaviourally challenged can be added once the individual has learned new more appropriate behaviours. This usually happens quickly so per person costs drop rapidly) or

- o the placement of such individuals into homogeneous (no other individual has a challenging behaviour) small groupings;

- o if difficulties arise where the user currently lives (own home, group living, etc.) staff who are trained to deal with the behaviour should be provided in the home. Those in the home should receive technical support for the purpose of seeing how confrontational situations can be avoided, how to reinforce and teach the user new more appropriate behivours, etc.

- o Individuals with challenging behaviours should not be segregated into isolated service models (day and residential away from everything else or congregated in a type of 'behavioural getto');

- o As individuals with challenging behaviours are identified to move into the community, the receiving staff should be trained in skill building techniques specifically designed for the individual. Professionals with expertise in successfully designing environments that are conducive to positive behaviour should be made available to these staff. These staff should be a part of the placement planning process and available to the receiving staff throughout placement or until such time as the staff indicate they are only required on an on-call basis.

- o The same level of support should be made available to families who wish to keep their son/daughter at home.

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[38] *Adapted from "We have changed, we have learned together", a Review of the Bedfordshire Strategic Plan, Rucker, L., Peters, G., Powell, D., April, 1992.*

B. Improved Staffing During Resettlement:

The expectation is that 26 individuals will move from long stay hospital to community during this year. That number should not pose any particular problem in an environment with a team of individuals dedicated to:

- o (along with the long stay hospital direct and professional staff) developing person-centred plans for those moving;
- o finding appropriate accomodation within the community which will meet the needs of small groups of individuals who choose to live together or who have common interests;
- o initiating creative schemes with voluntary, private, housing authorities and others which will meet individual needs in a cost effective way;
- o working with the receiving community staff (both day and residential) in advance of the actual move, including them in the planning process so the training is complete and accurate information regarding each individual conveyed;

C. Perceived Strengths, Gaps and Needs of the System:

Each person interviewed was asked to provide their perspective on the strengths, gaps and needs of the current system.[39] Every opinion can not be listed, however, those most often cited are summarised in Appendix F.

[39] *The list provided from the Parents Action Group is provided in Appendix C.*

APPENDIX A

Interviews

Steve Battley, Day Services Coordinator, Department of Social Services

Suchi Bhatt, Ethnic Minority Laison, Social Services

Phillip Brown, Chief Executive Officer, Hillingdon Health Trust

Mark Budding, Resettlement Coordinator

Cath Calen, Development Officer, Community Care Forum

Dr. Daly, GP

Dr. Das, GP, Yiewsle

Maureen Dalziel, Cheif Executive Officer, Hillingdon Health Agency

Roger Freeman, Clinical Director, Mental Health Unit

Kate Gammon, DASH, Advocacy Program

Adrian Hayward, Mental Health Unit, Hillingdon Hospital

Audrey Jacobs, Chair of Community Health Council

Madeline King, Director of MIND

Mike Lewis, Pembroke Centre, Team Leader Social Services

Steve Lynch, Former Finance Officer, Hillingdon HA

Ann Malkin, Clinical Phycologist, MH Unit

Ian Milne, Division Director, Social Services, MH

Marie Pettman, Community Health Council

MIND Advisory Group (9 users, 4 staff)

Julia Palmer, Consultant Phycologist, Woodlands (EMI)

Parent Action Group Meeting (30 parent/carers, two users)

David Pashley, Regional Community Care, Northwest Thames Regional Health Authority

Jane Rice, Director of Finance, Hillingdon Health Agency

Kiran Seth, Asian Befrenders, MIND

Dr. Singh, Physiatric Consultant, persons with lerning difficulities.

Liz Skelhorn, Associate Director of Family & Community Care

Nezlin Sterling, Director of Nursing Services, Quality Assurance, Hillingdon Hospital Trust

John Spargo, Divisional Director of Social Services for People with Learning Difficulty.

Sue Taylor, Complaints, HHA

Jean Templeman, Carers Association

Dr. Vaughn-Smith, GP, Uxbridge Health Centre

On Sight Tours

Acol Cresent Day Care Centre, persons with learning difficulities and challenging behaviors

Charles Curran House. Paula Stevens, Officer-in-Charge, Lorraine Garlic, Assistant, Sandra Taylor, Assistant. Local Authority, residential care for persons with learning difficulties.

Colham Green, Day Centre, persons with learning disabilities

3 Colham Road, Residential, persons with learning difficulities

Hatton Grove, Residential: people with lerning difficulities

Hayes Park House, Residential: people with mental health challenges

Leavesden: tour, file review, met users

Mental Health Unit, Hillingdon Hospital Trust

Mental Health Joint Commissioning Group Meeting

Merchiston House, Residential, people with lerning difficulities

Money Lane, people with learning difficulities, Mencap

Moorcroft Day Centre, people with mental health challenges

Pembroke Centre: Mental Health Resource Centre.

Principles into Practice (Users, carers, providers, staff) Day Services.

Rickmansworth, Residential, persons with learning difficulities, Wallsingham Homes

Special Needs Housing Seminar

St. Bernards

Tasman House, MH

Wallsingham Homes, people with learning difficulities

Co

APPENDIX B

Documents Reviewed

Annual Public Health Report, 1992.

Annual Review '92, SENSE, The National Deaf-Blind and Rubella Association.

Barnet Scheme: Potential Hillingdon Residents for Barnet

Barnet Service Operational Policy, Second Draft, February 1993, SENSE.

Brunel University Report on MESH, 13 September 1989

Care Programme Approach - Policy and Procedures, hillingdon hospital Mental Health Directorate and Hillingdon Social Services Department, May 1992.

Caring for People in Hillingdon, The Community Care Plan, 1993.

Complaints:

A Policy for Handling Complaints, Hillingdon Hospital, August, 1991.
Complaints filed with Health Authority: on issues relating to learning difficulties or mental health services.
General Procedure for Dealing with Complaints, Hillingdon Health Authority, 16 June 1993.
Summary of Complaints Policy, Hillingdon Community Health Services, August, 1991.
Summary of Complaints being tracked by the Hillingdon Health Agency for 1993.

DHA Project: Research Programme, Epidemiologically Based Needs Assessment, Report 6 Mental Illness, J.K. Wing, Provisional Version, commissioned by the NHS Management Executive, August 1992.

Developing A Joint Strategy for Training in Local Mental Health Services, NHS Training Directorate, 1991.

Discussion Paper: Day Services for persons with mental health difficulties & persons with learning difficulties with additional mental health problems, Steve Battley and Linda Milner, April 1993.

Education and Social Services, Mapping Exercise, May 1993 for the following services:

ACOL Crescent Day Service (Special Care) South Ruislip
Adult Placement Scheme
Barker House
Beeches, Uxbridge
Bourne Lodge, South Ruislip
Bury Street Day Service, Ruislip

Charles Curran House, Ickenham
Colham Green Day Service (Special Care) West Drayton Road, West Drayton
Employment Services, Hayes Careers Office, Hayes
Goshawk Gardens, Hayes
Honeycroft Day Services, Uxbridge
Independent Living Schemes
Merchiston House
Out-Borough Placements
Peripatetic Service
Personal Carers Scheme
Private Landlords Scheme
Respite Care
    Merrimans House
    Hyde House
Standale Grove, Ruislip

Evaluation of A Service Development Group, Sue Macdonald, Health Manpower Management, Vol. 18, nO. 3, 1992, PP. 20-21. MCB University Press.

Goodbye to all that?, The Socialist Health Association, A Policy for Mental Health, 1989.

Guidelines for Empowering Users of Mental Health Services, Jim Read and Jan Wallcraft, MIND Publications, COHSE, October, 1992.

Health Service Guidelines, NHS Management Executive:

    Health services for people with learning disabilities (mental handicap) HSG (92)42

Hillingdon Commissioning Agency, Corporate Contract, 1993/94, February 1993.

Hillingdon Commissioning Agency, Corporate Vision and Proposed Management Structure, A Consultation Document.

Hillingdon Health Agency: Capital Bid, Development of Residential and Day Services for People With Challenging Behaviour, and Development of Service For People Who Have Learning Difficulties With A Mental Health Overlay, 18 March 1993.

Hillingdon Hospital Mental Health Directorate Corporate Philosophy & Objectives. Also:
    Summary of bed availability 1 April 92 to 31 March 1993
    Consultant Outpatient Clinic Activity page 4 of 6
    NHS Day Care: Availability and Use of Facilities page 2 of 4
    Legal Status of Patients: Legal Status on Admission page 2 of 3
    Patients Legal Status: Changes in Legal Status page 2 of 3
    Total finished consultant episodes page 3 of 5
    Clinical Psychology Korner Professional Activity Record 92/93
    Summary of Clinical Psychology Services, page 4 of 4

Initial Contacts: Source of Referral page 3 of 4
Face to Face Contacts page 2 of 4
Summary of Clinical Psychology Services, page 1 of 4
Patient Care in Community: Community Psychiatric Nurses page 1 of 5
Face to Face Contacts: page 2 of 5
First contacts in the Year page 3 of 5
initial Contacts (New Episodes of Care) page 4 of 5
Contacts with Patients, Drug & Alcohol pg 5 of 5
Occupational Therapy Services, page 1 of 4
Face to Face Contacts, page 2 of 4
Initial Contacts: Source of Referral, page 3 of 4
Summary of OT Services, page 4 of 4
Summary of OT Services
Individual Patient Data: Print out by person, by DOB for patients admitted between 1 April 1992 and 31 March 1993

Hillingdon Social Services, Disability Division, People with Disabilities Team Operational Policy.

Job Descriptions:

Community Psychiatric Nurse
Senior Nurse Manager
Nurse Therapist
Clinical Practice Specialist
Community Psychiatric Nurse - Ethnic Minority (Asians)
CPN - Community Drug Team
Community Mental Health Nurse - Care of the Elderly Mentally Ill

King's Fund Organisational Audit review of mental health services provided by the Hillingdon Hospital Trust,

Letter: Hayward, A. to Skelhorn, L., 7 April 1993 regarding a general overview of services offered through the mental health unit and perceived gaps in service.

Letter: Jacobs, A. to Bellamy, M. 27 March 1991, regarding the "provision of mentally handicap services for the residents of Hillingdon".

Letter: Spargo, J. to Jacobs, A. 15 April 1991, response to 27 March 1991 Jacobs letter.

Letter: Jacobs, A. to Bellamy, M., 7 August 1991, regarding "mental handicap unit - NW Herts".

Local Authority Circular, Social Care for Adults with Learning Disabilities (mental Handicap) LAC (92)15

London Borough of Hillingdon Services for Adults With Disabilities, March 1993 summary.

Managing Mental Health Services, The Institute of Health Services Management, 1991.

MENCAP: Royal Society for Mentally Handicapped Children & Adults Homes Foundation, 1 Money Lane, Operational Policy.

MENCAP: Royal Society for Mentally Handicapped Children & Adults Homes Foundation, 4 & 6 Precinct Road, Hayes, Operational Policy.

MIND Publications:

Anti-Depressants, Special Report, First Choice... or last resort?
Anxiety brochure
Caring brochure
ECT: Pros, Cons and Consequences
Mental Illness brochure
Your Rights in Hospital brochure

Out of Sight, Out of Mind. Mental Illness: Who Cares? Proceedings of the 1990 MSD Foundation Symposium on Mental Illness.

Proposal: For A Mental Health Service Review.

Psychiatric Services Beyond The White Papers, A Guide To Key Organisational and Staff Development Issues, NHS Training Authority in Collaboration with Nuffield Institute for Health Services Studies.

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Recommendations: J.M. and G.J. Spooner regarding the Principles into Practice Document.

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Report to Mental Health Joint Commissioning Group on Eating Disorders in Hillingdon, 15 June 1993.

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Survey of the Acute Mental Health Unit at the Hillingdon Hospital, by the Mental Health Services Working Group, Hillingdon Community Health Council, May 1993.

Tasman House: Users handout
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APPENDIX C

Parents into Action Group Meeting
23 June 1993

The following represents a summary of the ideas and issues brought up by the Parent Action Group during their June meeting. The listing was developed by 30 parent/carers and two users breaking into three groups to discuss the strengths of the current system, the gaps which exist and recommendations. The following list is not presented in order of priority as that was not requested of the groups.

Strengths of Current System:

* Good quality staff.
* Individual programmers - User participation
* College
* Contract Work
* Day care & respite is provided
* Transport
* Good support from day centre staff/individuals
* Day services which are still available are generally satisfactory to most users who continue to receive the service.
* Respite care, when available, is excellent. (3 Colham Rd. & Merrimans)
* Transport is generally O.K., drivers and escorts are friendly and helpful in most instances. It is an asset if the escort can be more permanent.

Gaps in Existing Service:

* The loss of 50 week/year service and a 5 day week for all.
* Future and even existing residential care for our sons & daughters is nonexistent.
* Respite care is grossly inadequate.
* Continuity of staffing dealing with the users is of prime importance, i.e. familiarity between staff & user should be maintained.
* For users who are doing work and were getting paid - this payment should be reinstated. 1 £ per day is slave labor.
* Dinners should be provided for all those who want one.
* No security for clients or parents.
* Shortage of staff.
* Lack of stimulation for clients.
* Staff over estimate the clients abilities.
* Clients put at unnecessary risk.
* Procedures to be taken when clients go out alone.
* Staff don't get enough support from management.
* Transport: clients arrive late and go home early (from day service) so what little day service they receive is cut even shorter.
* No Social Workers for families.
* Insufficient day & respite care

* Lack of social, key & link workers.
* More efficient transport
* Lack of organised social activities (voluntary)
* No midday meals
* Ignoring of parents/carers.

Recommendations:

* All the above should be resolved to our satisfaction. i.e. more financial input.
* More attention to carers.
* More day and respite care
* More qualified and less temporary staff
* More communication with, and consideration of parents/carers.
* Improvement of individual programmers & variety of work.
* Better transport timekeeping. Better transport service.
* More personnel with knowledge of learning difficulties.
* Provide more social workers.
* More liaisons between day services & respite and parents/carers.
* Better meal provision.
* No charge for tea/coffee.
* Return to 5 day week for all.
* Better communication for parent/carers from the centres - PAG
* Trust parents judgement.

* Lack of social log
* More efficient
* Lack of organized
* No middle man
* Ignoring of

Recommendations

* All the above
* More emphasis
* More day
* More qualified
* More communi
* Supervision
* More trainings
* More positive
* Provide more
* More flexible
* Better
* Not charge
* Some in
* Better
* Less

APPENDIX D

Sample: Mental Health Community Housing Programme Specification

Description of Mental Health Programmes (in general): A Mental Health Programme is organized to develop, support, and maximise the quality of life and functional abilities of persons with severe and/or persistent psychiatric disabilities. Whenever possible, services involve significant others. The daily interaction of all employees of the Mental Health Programme are considered essential to the provision of an interactive therapeutic environment.

Definition (specific service): Rehabilitation Programmes are organised to develop, support, and maximise the quality of life and functional abilities of persons with severe and/or persistent psychiatric disabilities. Such programmes are community-based and have a commitment to community integration, normalisation, and self-determination by the persons served. Therefore, Rehabilitation Programmes are organised to prevent unnecessary use of psychiatric hospitalisation and to promote the utilisation of the least restrictive settings.

Services offered by Rehabilitation Programmes seek to help the persons served to maximize the vocational, social and personal skills necessary for them to live successfully in the community. Programme participation is of unlimited duration and is determined by the needs of the person served.

The persons served are active participants in all aspects of the programme. Therefore, the setting of a Rehabilitation Program is purposefully informal to reduce the psychological distance between staff members and other personnel and the persons served.

Sample of applied standards:

1. "The organisation should have a written programme plan to guide the operation of its programme and the delivery of its services. The plan should include a programme description that:

   a. Reflects the philosophy of the programme.
   b. Delineates the goals of the programme.
   c. Describes the persons served.
   d. Identifies the services provided.

2. The programme should provide core services in the following areas that are organised around the needs of the persons served, their preferences, and their stated goals:

   a. Enhancement of the person's understanding of and ability to cope with his/her psychiatric disability.
   b. Entitlement/benefits programmes.
   c. Socialisation and use of leisure time.
   d. Vocational development.

3. In addition to core services and dependent on the needs and preferences of persons served, the programme should provide or make formal arrangements for:

Sample of applied standards:

1. "The organization should have a written philosophy statement that guides the operation of its programme and the delivery of its services. The organization should include a programme description that:

   a. Defines the philosophy of the programme
   b. Delineates the goals of the programme
   c. Describes the persons served.
   d. Identifies the services provided

2. The programme should provide core services in the following areas: [illegible] organized around the needs of the person served. These programme areas include:

   a. Assessment of the person's understanding of and [illegible]
   b. [illegible] psychiatric disability.
   c. [illegible] psychosocial programmes.
   d. [illegible] and use of leisure time.
   e. [illegible] development.

3. [illegible] or more written guidelines on the needs and problems of [illegible] the programme should provide or make formal arrangements [illegible]

a. Advocacy services.
b. Alcoholism and other drug dependency education and/or services.
c. Educational services.
d. Family support and education.
e. Food, clothing, and housing.
f. In patient psychiatric services.
g. Job placement.
h. Medical services including psychiatric, pharmacological, health maintenance, and dental services.
i. Mental health services
j. Transportation.
k. 24-hour crisis intervention.

4. Situational assessment should reflect the direct involvement of the persons served.

5. A written plan should be developed with and for each person served. The plan should include:

a. The desires and choices of the person served.
b. Methods to develop and foster friends and other supports in the community.
c. Methods to foster family relationships as appropriate.
d. Services to be provided by the programme.
e. Services to be provided by other organisations.
f. The strengths, abilities, needs, and preferences of the person served.

6. The outcome evaluation systems of the rehabilitation programme should address a variety of measures, some of which should be:

a. Movement toward social integration.
b. Frequency and duration of psychiatric hospitalisation.
c. Movement to a more independent vocational environment.
d. Movement to a more independent residential environment." [40]

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[40] *Adapted from Standards Manual for Organizations Serving People with Disabilities, Commission on Accreditation of Rehabilitation Facilities, 1993. For illustrative purposes, only a few of the actual standards are listed.*

APPENDIX E

Mental Health Services
Perceived Strengths of the System

- The Pembroke Centre
  - operations are focused on the user, people who attend have a major role in choosing what they want/receive from the centre;
  - there is an active user committee with representatives on the management board of the Centre;
  - it provides a variety of services, a variety of skilled workers in a neighborhood resource centre;
  - has dealt creatively with some of the cuts. They use to offer weekly welfare benefits classes. They were eliminated so they are now offered by a volunteer.
- Family Placement Scheme, small group homes and MIND's 2 Sharing Placement were mentioned as "best practice" by several.
- Placing CPN's in GP practices has increased the expertise and effectiveness of services offered.
- Emergency psychiatric treatment is responsive. If referred in the morning, the patient is seen by the SHO that afternoon.
- MIND and all of its services/supports were often seen as best practice.
- The provision of multi-disciplinary service and planning for individual needs of persons.
- No one is in danger at the Mental Health Unit. It is a safe service and closely managed.

Perceived Gaps in Existing Service:

Those interviewed were also asked to share their perspectives on what they saw as gaps or duplication within the system. A summary of those most frequently mentioned follow:

- People stay in hospital longer than they have to because alternatives with 24 hour support in the community which could be used for transition from hospital do not exist.
- Proper follow up is not always maintained after discharge from hospital. "That is why so many people have to return to hospital."
- Prevention and early warning/intervention practice is inadequate in the community. Lack of support and detection leads to hospital admission which could have been prevent ed.

- Psychotherapy is a shortage not a gap. "Now we have a 6 month waiting list for people who need psychotherapy. Can you imagine needing psychotherapy and being told you have to wait 6 months?"

- Services to persons with a dual diagnosis of learning difficulties and mental health challenges are extremely difficult to acquire. "No one wants to own them".

- Need real work and decent work. Many individuals can and want to work. "What they are offered is boring and leads no where".

- People from ethnic minorities are under-represented as service users. Social Services need to understand more fully what the specific needs are in order to respond appropriately.

- We do no know enough about the outcomes or success of our service.

- Proper planning for the use of resources is not done well.

- Occupational Therapy is only offered to inpatients.

- CPN's and MH Social Workers duplicate efforts. They do very much the same jobs. They are beginning to sort this out.

- Not enough home care.

- Not enough support of carers.

- People with the same level of need are everywhere: home, day hospital, MH Unit, Pembroke . . . information on what and why we are doing things is not available.

- Advocacy is lacking and greatly needed.

- Role of the user has not changed much.

- Reliance on "beds" instead of looking at mental health needs in the community.

Perceived Needs of the Service System:

Those interviewed were also provided with an opportunity to share their opinions regarding what the system needs to improve services and supports to users. Some of those suggestions are offered here:

- Need day and evening care.

- Need care plans for individuals based on needs led assessments. Is not happening yet.

- Need more MH Social Workers.

- Need to restore the cuts made to the Citizens Advice Bureau.

- Need a 'safe house', a service between home and hospital with 24 hour support.

- Need someone to talk to. Self help groups, group therapy.

- Need crisis line for users where the person at the other end of the phone can act, not just listen. A crisis line for carers also.

- Need to develop schemes with Housing Associations using Housing corporation funding to enable the transition from homebased/hospital based care.

- More money.

- More community centres like Pembroke throughout the borough.

- More clinical psychologists.

- Need to access better information. Need to know what routine information is kept and what is available.

- Need better joint working with MESH to better serve persons with both learning difficulties and mental ill health.

- Need MH community crisis intervention capability.

- Need 2-3 beds for 3+ days during crisis. Would help reduce hospital admissions and allow people to calm down before they have to consider moving.

- Need Training:

    - geared to identification and intervention; and
    - on what criteria GP's should use for referral to specialist/hospital.

- Need an integrated multi-disciplinary team, properly trained in assessment.

APPENDIX F

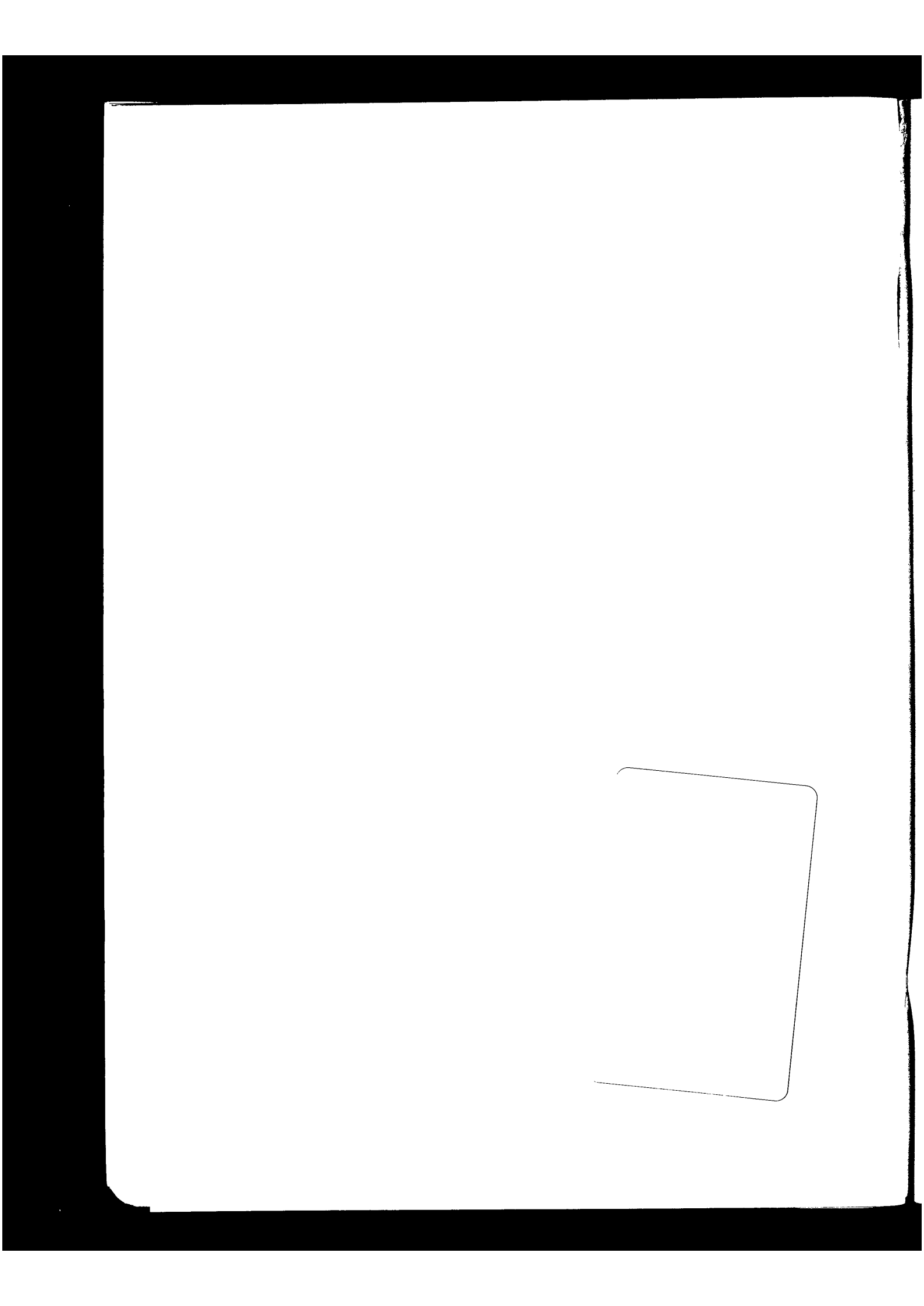
Summary: Perceived Strengths, Gaps and Needs of Services
Persons with Learning Difficulty

Strengths

- a mechanism for the development of Self Advocacy is being put into place.
- principles into Practice demonstrates a way of consulting with users and carers about the ways forward in day services.
- 3 Colham Road: inventive, enthauestic staff, individuals are valued, individuals working there are valued.
- specific examples of individuals who are now more independent and have progressed significantly since being in community services.
- joint working;
- good placements have occurred for individual users.
- continually attempting to improving our working relationships with parents.
- Social Education Centre, receive individual attention, use of generic services rather than bringing in and making more artificial.
- Employment services for people and placing people into jobs.
- use of public transport where possible rather than using Local Authority provision.

Gaps In Service:

- in Mental Health services to persons who also are learning disabled. Have difficulty gaining access to proper supports and early identification is lacking.
- provision for people with challenging behaviours.
- ability to respond to the needs of aging carers is limited. Need a plan of action so crisis can be anticipated and limited or avoided.
- Employment Services: have good opportunities for more able individuals but not for people with higher need or physical limitations.
- People from ethnic minorities are under-represented as service users. Social Services need to understand more fully what the specific needs are in order to respond appropriately.
- GP's are not involved in resettlement, "until the day the person walks through the door".



- provision is too slow and too expensive.

- are not serving people with high needs in employment services, too understaffed to do so.

Service Needs

- Day services should be locally based - in smaller sites - "not large based institutional holding type environments designed to relieve carers but not meeting user needs or wants."

- Communication needs improvement.

- Need to develop the use of generic services so that resources available to other people are used by persons iwth learning difficulities.

- Need to do a full evaluation of MESH. It has not had a complete evaluation since 2 years after it started. Need to develop a regular monitoring mechanism as well.

- Restore money cut from day services. Day services were not adequate prior to cuts.

- Transport: Health and Education/Social SErvices need to get together to cover this in a more user friendly way.

- Daytime services need to be more flexible and responsive to the needs of people within the community.

- Respite services need to be more accessible, and the allocation of respite care clearly understood.

- Need specific needs of people with learning difficulities in ethnic communities to inform the strategic planning for future services.

- Carers Needs:

    - respite: identify a range of options for both planned and unplanned respite; to include home respite, day respite and holiday respite. analyze uptake of respite provided by Crossroads for this care group. Feasibility study on the independent management of respite care.

    - information: ensure carers are offered maximum information on which to make decisions.