



**REVIEW OF
HARROW COMMUNITY TEAM FOR
PEOPLE WITH LEARNING
DISABILITIES
(HLDT)**

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INTRODUCTION

THE TASK

In February 2003, The National Development Team was commissioned to carry out a review of the Harrow Learning Disability Team in line with the Valuing People Learning Disability Review Toolkit and to link this to Harrow's Audit Commission Review, when results were available.

METHODOLOGY

A series of consultation meetings were held with people working for, being supported by and working in partnership with HLDT.

- Harrow Learning Disabilities Team
 - Two sessions
 - 32 participants
- Self- Advocates
 - Two sessions
 - 31 participants
- Family Members
 - Two sessions
 - 15 participants
- Service Providers
 - Two sessions
 - 11 participants

While each consultation session was designed and run to reflect the knowledge and background of participants, three key themes were addressed:

- The role of HLDT
- Participants experiences of HLDT
- Ideas for the future

Following the consultation meetings, a questionnaire was distributed to enable those people who were unable to participate in the consultation meetings to contribute to the review.

- 22 questionnaires were returned by family carers
- 7 questionnaire were returned by others connected to HLDT

THIS REPORT

The aim of this consultation process was to gather information to support the operation and development of HLDT.

In the first section of the Report, the authors have sought to highlight issues raised in the consultation under a series of headings appropriate to the operation of the Team in both the interactions with clients and delivery of objectives.

We have offered a summary of the findings of the questionnaires.

OUR THANKS

We would like to thank all the members of the Team, people using the team, families and associated staff for sharing their experiences and ideas for the future.

ROLE OF HLDT

Members of HLDT:

Members of the Team seek to offer a good quality service based on sound principles
There are a wide range of roles and expectations
The scope of roles for the team is large and may be unrealistic
The Team needs to set out clearly what they aim to achieve and what they cannot achieve

People with learning disabilities:

In the main, people with learning disabilities see the role of the Team in very practical terms, as a resource you go to when you need specific help/support, for example, to get help with housing or to get a job or to sort out problems

HLDT was one of a number of sources of help identified

Family Carers:

They also see the role of the team as providing practical information about services available and putting them in touch with the right person. Also providing specific/direct help with problem solving, especially in a crisis

Associated professionals:

Feel HLDT role should be comprehensive – for the whole of a person’s life and throughout their life.
Good intentions - colourful brochures
There are concerns about the split between Children’s & Adult Services
The Team should be ‘specialist’ resource, providing very specific expertise
They have an important role in commissioning/buying services/resources people need
There is not a clear profile of a joint team – still a split between Health & Social Services

Issues for consideration:

- To clarify roles of team members
- To ensure that the stated function of the team meets expectations/needs of users/other professionals
- To publicise roles and the specific aims of the HLDT

STRUCTURE OF HLDT

STAFFING LEVELS

Areas identified by the Team:

There is a shortage of staff in every department
The shortage is particularly in administration and care management
Post are frozen
There is a lack of applicants

People with learning disabilities:

Shortage of staff at weekends

Family Carers:

Management is not effective
Team resources are overstretched

Associated professionals:

There is a high turnover of staff with poor retention
Difficulties with roles identified in new legislation

Issues for consideration:

- Are staffing levels and skill mix appropriate for team's role?
- The recruitment and retention of staff
- Staff training
- The management of the team

ACCESSING HLDT

People with learning disabilities identified that in addition to using some of the access points below, they may use other people (families/service workers, etc) to access HLDT

TELEPHONE

Areas identified by the Team:

The phone is often the first point of contact
People can telephone to access the duty person or a particular worker
People can access the Team, for at least part of the day (4 hours)
People have to 'get through' the duty person
There is no duty person on some days
There are only two lines into duty
The duty service is not multi-disciplinary, only staffed by social workers
Callers are sometime distressed or annoyed before accessing the service, this may result in abusive calls

People with learning disabilities:

Need a list of telephone numbers
Phoning is frustrating – takes too long
Want the choice of talking to a man or woman
Some people would like access on the phone in their community languages

Family Carers:

Want to speak to the same person rather than start all over again
There doesn't appear to be a follow through – returning calls
Some people would like access on the phone in their community languages

Associated professionals:

Problems in getting phones answered
Lunch breaks
The first point of contact is not welcoming
Out of hours it is only the standard emergency number

Issues for consideration:

- Offering a greater number of telephone contact hours, including some none 'traditional' team hours – a 'help line'?
- Ensuring that phones are answered
- Ensuring a high quality of telephone contact and follow up
- Phone access with community languages

WRITING

Areas identified by the Team:

The team can be accessed through 'writing in'

Areas identified by others:

Being able to write into the team was hardly mentioned by any other group during the consultation process

Issues for consideration:

- Making people using services, family carers and other workers more aware of the opportunity to write to the team

ACCESSING THE OFFICES

Areas identified by the Team:

Being based in the Civic Centre people get to know where the team is and can 'walk in'

The internal design of the building creates barriers to accessibility

People with learning disabilities:

Know where the team is located

The lift does not always work

Areas identified by others:

The location needs to be more accessible

Issues for consideration:

- Offering physical access to the Team in a venue that is always physically accessible, both externally and internally

INFORMATION

Areas identified by the Team:

Promotion of the service includes information, leaflets and displays, but team are aware that this needs to improve

People with learning disabilities:

More written information about the team, which is easy to understand

Family Carers:

Information needs to be available in the main community languages
Information needs to be accessible to everyone

Associated professionals:

Information about the team and what they offer needs to be more widely available
Also information about other relevant services

Issues for consideration:

- The provision of written information in the most used community languages
- The provision of accessible information
- The distribution of information

THE OPERATION OF HLDT

REFERRALS

Areas identified by the Team:

There is an open referral system with people able to use the telephone, verbal, written, intranet and arriving in person

People are referred through others services including day services, GPs and other service providers

There can be separate referrals for the same person to different disciplines

The system is too bureaucratic

People with learning disabilities:

People need to be clear about whether they can help or not

Family Carers:

The process takes too long

Associated professionals:

Team responds to crisis but slow in responding to less urgent referrals

Issues for consideration:

- The effectiveness of current referral processes

ELIGIBILITY

Areas identified by the Team:

The Team has eligibility criteria

The current criteria eliminate a lot of people. For others who are on the 'borderline', for example people with Asperger's Syndrome, the criteria are unclear

People with learning disabilities:

If people cannot help they need to explain why

Family Carers:

The criteria excludes people, for example with autism

Too much bureaucracy

Associated professionals:

If the Team acts as 'a gateway' to other services, people who are excluded from the Team can be effectively excluded from the other services

Too much reliance on IQ

Fair Access to Care

Issues for consideration:

- Ensuring clear eligibility criteria
- Identified supports available to people who are not eligible

WAITING LISTS

Areas identified by the Team:

There are waiting lists

Waiting lists are long

Family Carers:

Can be weeks, months or years

Associated professionals:

Have been told that waiting time for psychology is a year and 8/9 months for social workers

People wait for assessments, when they have had an assessment, they wait for supports

Issues for consideration:

- Monitoring the length of time people spend on waiting lists
- Addressing, as resources allow, waiting lists
- Consider informing service users about probable waiting times

SPEED OF SERVICE

Areas identified by the Team:

There are delays in the work being processed

Areas identified by others:

It can take a long time to get a service

Sometimes it is possible to get a swift service by, for example, showing that placement is at risk. People are reaching 'at risk' when help could have been offered earlier

Some family carers identified waiting in terms of years

Issues for consideration:

- Opportunities for offering earlier support/interventions
- Reviewing priorities

CLOSED ‘CASES’

Areas identified by others:

There is a problem when, because of no perceived need, cases become closed, it is as if people have ‘fallen off the planet’

Cases should not be closed

You are a closed case!

Issues for consideration:

- The appropriateness of closing cases
- Contact with people whose cases are no longer ‘open’

PERSON-CENTRED PLANNING

Areas identified by the Team:

Person-centred planning to be available after April 2003

A person-centred approach is often prevented by a lack of money/resources

People with learning disabilities:

Some people have plans, but unaware of person-centred approach

Family Carers:

Other people decide what is important

Services need to be centred around the person not service led

Associated professionals:

Service-centred within narrow boundaries

Team lack capacity to get involved in individualised planning

There needs to be more regular planning to prevent crises

There is a ‘free for all’ on who takes the lead on PCP

Turnover means there is a lack of long-term continuity

There is conflict between Local Authority and Health assessments

Some have been told that the Team will only attend meetings if need for change is identified

Issues for consideration:

- Consider the role of Team members in Person-Centred Planning – is it the role of the Team to facilitate plans or to support their implementation?
- Developing Person-Centred Approaches in service delivery

RESPONDING TO NEEDS/WANTS/ASPIRATIONS

Areas identified by the Team:

Needs are being met in some but not all areas

Morale is low because of the inability to meet people needs

Team responds when an individual/family reaches crisis but, due to lack of funds, not good at crisis prevention

People with learning disabilities:

If the Team is not going to help, they should say so

If the Team say that they are going to do something it is important that they do it

There should be less 'jargon'

Family Carers:

The Team does not always understand important needs

Need to deal with someone they know and trust

Care managers don't have authority to make decisions

Areas identified by others:

For some people what they want is not available and there is not a willingness by services to be flexible

The Team should be less formulaic (going by the book) and more creative

The formulaic approach hinders opportunities to be culturally appropriate

There is a need for resources to offer more alternatives

It feels like there is a prescribed way for working, for example – if clients don't want day services they don't get offered anything else

Lack of front line or local budget control/authority

Issues for consideration:

- How the Team can offer the necessary person centred approach in response to individual plans
- Opportunities for supporting greater creativity and responsiveness through Direct payments and individualised purchasing
- Team member skills in offering individualised responses

‘VALUING PEOPLE’ OBJECTIVES

It is important to note here that there are many expectations about the Team meeting the major objectives set out in ‘Valuing People’, which is of course unrealistic – the HLDT cannot solve all the problems of each person who has a learning disability!

1. Children and young people:

Areas identified by the Team:

Team has much knowledge & expertise in this area
Uncertainty about the future of Children’s services
Lack of support for families

Associated professionals:

Discontinuity of service due to gap between Children & Adult Services

Issues for consideration:

- How to work more closely with Children’s Services

2. Transition:

Areas identified by the Team:

All 16 yr olds have been allocated a care plan, a social worker and a ‘transition plan’
Gap between Children’s and Adult Services
Lack of joint working
Lack of opportunities for employment

Family Carers:

Some family members feel that supports before/during transition have not been effective
Lack of clarity/information about transition

Associated professionals:

Discontinuity of service due to gap between Children & Adult Services
Once out of the education system a person can become isolated at home
Offering alternatives

Issues for consideration:

- How to establish a more effective transition service

3. Enabling control:

Areas identified by the Team:

Pathway is working well
User and professional forum established
Advocacy supports are limited
Inconsistent approach to PCP
Some good individual non-verbal communication systems being developed/supported

People with learning disabilities:

Knowledge about Direct Payments – ‘we are the customers’
Evidence of genuine advocacy supports
Sometimes to be treated with more respect and feel that the professional is listening to them

Associated professionals:

Pathway has long waiting lists

Issues for consideration:

- Advocacy development
- Communication supports
- Person-centred planning
- Direct Payments

4. Supporting Carers:

Areas identified by the Team:

Carer assessment offered to all carers (65-90)
Most elderly carers prioritised for resources
Difficult to separate client & carer needs
Lack of family support groups

Family Carers:

Gave examples where support to families was lacking or not forthcoming
Needs of carers not always understood
Consider the needs of carers who have their own health problems
Options for the future, when carer no longer alive

Issues for consideration:

- How the team can improve information/supports to family members
- Support Networks for family members
- A forum for including family carers

5. Health:

Areas identified by the Team:

Health Action Plans have been started, but limited staff resources to implement effectively
Primary Care more responsive to needs of people who have a learning disability
Psychosexual Therapy service has been a success
Shared nursing protocol as established with Northwick Park Hospital needs to be expanded to other hospitals

Family Carers:

Sometimes long delays before seeing a specialist
More preventative health care

Associated professionals:

More inclusive health service needed – Fair Access to Care
Health & Social Services need to work in genuine partnership

Issues for consideration:

- Health Action Planning

6. Housing:

Areas identified by the Team:

Housing strategy includes need of people who have a learning disability
Stanmore Housing Project and Supported Living has been a success
Good links with Benefits Agency
Care packages promote housing needs
Insufficient housing stock to meet identified need
Lack of awareness in private/independent sector about learning disability
People with complex needs are often excluded
More respite required than available

People with learning disabilities:

Assistance with moving home is seen as a key role of HLDT

Family Carers:

Commitment to provide accommodation for my relative when I'm gone
Plan housing resources at local level
Respite service too rigid – 3months notice only – no emergencies/short notice
Holiday option no longer available

'I want good respite – not any respite'
'We have to book our life through a respite booking system'
Expedite 'Home Care Service'
Had not heard about non-buildings based respite

Associated professionals:

More support for finding alternatives to residential services – sometimes used as threat

HLDT could take a lead in supporting people to move on
Social Services are not able to offer respite, which is what people want
Some parents go on the 'at risk' register, just to get respite

Issues for consideration:

- Review Housing Strategy – more prioritisation for elderly carers?
- More emphasis on alternatives to traditional residential services
- Develop flexible respite with more non-buildings-based options – eg. home supports/holidays

7. Fulfilling Lives:

Areas identified by the Team:

Services are/should be moving away from traditional day service model
Person-centred planning has a key role to play here

People with learning disabilities:

Assistance with changing day service and help with transport is seen as a key role of HLDT

Family Carers:

Need help with transport to college
Not much happens when college courses finish
Not enough staff at the day centres – to facilitate smaller groups
Better facilities at day centres – practical training for everyday living
More emphasis on learning – better computers
More choices for daytime activities
Residential & Day Services should meet together regularly to agree/share goals

Associated professionals:

More involvement from Education
Lack of creativity – if someone does not want day centre, they don't get offered any alternatives

Issues for consideration:

- Day Service Modernisation
- More emphasis on alternatives to traditional day services
- More creative use of current resources

8. Moving into Employment:

Areas identified by the Team:

Team attempts to explore/support available employment opportunities
Options for employment and supports are limited

People with learning disabilities:

Assistance with getting a job is seen as a key role of HLDT

Family Carers:

Local sheltered workshop

Issues for consideration:

- Strategy for developing/maximising employment opportunities
- Supported employment

RECOMMENDATIONS

AGENDA TO WORK FROM:

- **Clear information about the HLDT service**
- **Clear operating policy and what roles of team members are**
- **Review access criteria (more inclusive?)**

- **Sort out recruitment**
- **Sort out duty system/phone system**
- **Sort out sufficient admin/IT support**

- **Change location and ensure that it is accessible**

- **Improve communication with people with learning disabilities & their carers**
- **Establish effective ‘forum’ for listening to people with learning disabilities (‘user forum’/individual advocacy)**
- **Establish effective ‘forum’ for listening to carers**
- **Address needs of Asian community more thoroughly**

- **Integration of different services/lines of access/communication**
- **Sorting out what joint working/partnership means**
- **Address Children/Adult Services split**

- **Develop better understanding of ‘person-centred’ planning (including ‘health action planning’) and a strategy**

- **Explore and develop more alternatives to traditional service models: Residential/Day /Respite/ Employment**

- **Promote Direct Payments**

- **Improve evaluation/monitoring of what service needs**

**George Sapiets & Bill Love
National Development Team**

September 2003

HLDT REVIEW ACTION PLAN

| AREA OF WORK | TASK | DESCRIPTION OF TASK | BY WHOM | BY WHEN |
|---------------------|----------------------------|---|---|--|
| 1. Joint Working | Initial assessment form | Produce single integrated assessment form, to be used by all professionals when carrying out joint assessments. | David Proudfoot | End Dec 2003 |
| | | To be in user friendly pictorial format to enable client/carer to part complete prior to visit by professionals | David Proudfoot | ACHIEVED June 2004 |
| | Team building | To identify an outside facilitator to enable clarity and definition of roles of different professionals on team | Helen Keeble/ Dick Van Brummen | June 2004 |
| 2. Sorting Out | Administration team review | Revisit person spec/job description/advertising to enable retention of staff | Mona Christie/ Helen Keeble | Jan 2004 ACHIEVED |
| | I.T systems | To establish an integrated Health/People First I.T system | Malcolm Jeeves/ Dick Van Brummen Geraldyn Wynne | Ongoing as part of overall I.T strategy that has commenced |

| AREA OF WORK | TASK | DESCRIPTION OF TASK | BY WHOM | BY WHEN |
|-----------------------------------|---------------------|--|--|--------------------------|
| 2. Sorting Out (cont.) | I.T systems (cont.) | To have all relevant operational forms e-enabled | Themiya Haththotwa/ Helen Keeble | December 2005 |
| | Duty system | Revamp present system to enable operation via a newly established Customer Support Team | Mona Christie/ Helen Keeble | April 2004 |
| | | Recruitment of CST members | Mona Christie | Jan 2004 ACHIEVED |
| | Single file system | To consider active participation of all disciplines in new diaried appointment system based on requirement for joint assessments, commencing with care managers and psychology as first tranche. | Chris Roberts/ David Proudfoot/ Dawn Jackson/ Mona Christie | Jan 2004 ACHIEVED |
| To develop guidelines & protocols | | Helen Keeble/ Health Service Manager | December 2005 | |

| AREA OF WORK | TASK | DESCRIPTION OF TASK | BY WHOM | BY WHEN |
|------------------------|--|---|---|--|
| 2. Sorting Out (cont.) | Operational policy | Update present policy to reflect new legislation, Valuing People aims and principles and new practice requirements | HLDT Management Team | December 2004 |
| | Training | To identify an outside facilitator to look with the team at defining care elements of the service provided and teams vision | Helen Keeble/ Health Service Manager | March 2004 |
| 3. Location | Team accommodation specification | Compile a specification based on realistic needs | Helen Keeble/ Health Service Manager | June 2004 Already partly achieved |
| | Team to be split into Geographical Areas | Carry out a feasibility study | Helen Keeble | This is no longer an option that will be pursued |
| 4. Listening to people | Evaluation | To evaluate how well users/carers feel team members are listening to them via an audit tool and to then implement changes. | Juliet Holder/ Helen Keeble | August 2004 Work on this task has already started |

| AREA OF WORK | TASK | DESCRIPTION OF TASK | BY WHOM | BY WHEN |
|---------------------------------|------------------------------|--|---|------------|
| 4. Listening to people (cont..) | Outreach service | Feasibility study to establish whether the team has the required resources to operate an outreach service to be based in one of the community centres. | Helen Keeble/ Health Service Manager | March 2005 |
| 5. Recruitment and retention | Review care management tasks | To establish which areas presently carried out by care management are 'generic' tasks, which other specialist workers on the team could integrate into their working practice. | Dawn Jackson/ David Proudfoot | March 2004 |
| | Promote retention of staff | To identify the feasibility of acting up roles/gaining promotion/secondment opportunities. | Helen Keeble/ People First Human Resources/Union/ Health Service Manager/ Health Human Resources Unit | April 2005 |

| AREA OF WORK | TASK | DESCRIPTION OF TASK | BY WHOM | BY WHEN |
|---|--|---|----------------------------------|--|
| 6. Person centred planning | Audit | To purchase a set of tools for audit planning from the NDT | Helen Keeble | April 2004 |
| | HLDT input into person centred planning sub-group | Nominated HLDT rep. to feed into sub-group, views of team and keep team informed of progress | David Proudfoot | October 2003 ACHIEVED |
| 7. Alternatives to traditional services | Information gathering | Identify and produce a service resource list on all respite care provision in the borough | David Proudfoot Dawn Jackson | April 2004 This work has already commenced |
| | Provide information to users/carers on direct payments | Direct payment leaflet to be sent out with all information packs to users/carers. Direct payments information to be discussed with all users/carers during assessment appointment as an alternative to purchasing traditional services | Admin staff Care managers | October 2003 ACHIEVED October 2003 ACHIEVED |

| AREA OF WORK | TASK | DESCRIPTION OF TASK | BY WHOM | BY WHEN |
|-------------------------------|---|---|---|---------------|
| 8. Information about the team | To recruit an information officer | <p>Feasibility study on cost of employing an information officer to collate all information on relevant services/resources available to users/carers</p> <p>Or</p> <p>Appointing a media student for a time limited period.</p> | Helen Keeble/ Health service manager | December 2004 |
| | To provide a Boro-wide roadshow on HLDT | HLDT to discuss the pros and cons of setting up a roadshow, determine contents and timescales (one-off or rolling programme) | HLDT management team | June 2004 |

Helen Keeble
08/01/2004