

LB of Haringey - Access to Healthcare Project

Progress Report from National Development Team

Health Access Interviews:

1. Process:

- The aim of the project was to explore the quality of healthcare received by a number of individuals who live in LB of Haringey and have complex health needs (which include a significant learning disability and additional physical disability and/or major health need.). The group of people selected were also to be from a wide range of ethnic and cultural backgrounds
- Originally 10 people were selected by Haringey Learning Disability Service
- Interviews to be carried out October - November 2006
- 'Health Diaries' to be set up over a three month period (November 2006 to January 2007)

2. Progress so far: -

- We have interviewed eight families (two have cancelled)
- Families have been interviewed mainly at home but also some in the residential home where they live and we have been able to spend time with most individuals who are the subject of the project.

- Work on diaries has just begun and further work by telephone will need to be completed to follow-up/clarify information gathered at the interview stage
- The age range of the individuals seen is between 20-50 yrs old
- The range of health needs include significant learning disability for all, autism and also individuals who have an additional physical disability, epilepsy, diabetes etc.
- The backgrounds of families are English, Cypriot, Nigerian, Tanzanian and Iranian
- Family members interviewed have been mostly mothers

3 Initial feedback issues:

3 (a) Positives:

- Many GP's are seen as supportive – even if some surgeries are not accessible – will make appointments easily or arrange specially to suit individual and family or make home visits
- Community Dental Service has been very helpful
- Key individuals can make a difference – a community nurse/a physiotherapist/a speech therapist or a key worker
- Support from Day Services and Respite mainly seen positively
- A positive/respectful/understanding attitude and a good knowledge of the person can make all the difference!

3 (b) Key issues of concern:

- Lack of co-ordination of healthcare - named person
- Lack of knowledge or access to Health Action Plans or Person-Centred Plans
- Lack of information about how to access/co-ordinate health care
- Lack of regular health checks – especially if individual may require extra support during the appointment
- Low standard of appropriate support from hospital departments:
 - Outpatient and inpatient departments are not geared up to accommodate someone who has specialised needs
 - Long waiting periods/lack of ‘fast tracking’
 - Unwelcoming/insensitive attitude/lack of respect for expertise of parents
 - Lack of information/training about range of disabilities
 - Lack of appreciation of communication skills needed
 - Lack of basic support during period in hospital:
 - individual personal care needs such as help with eating/toileting and basic monitoring/supervision of vulnerable individuals who could be at risk if left alone – it is often assumed parents can provide this 24 hours a day!

- Some hospital services are difficult to access either by distance or transport
- Some surgeries are not accessible and not 'person-centred' in arranging appointments /waiting times
- Lack of input from some specialist health services (e.g. nursing/physiotherapy/speech therapy)
- Aids and adaptations need to be reviewed more regularly and upgraded/replaced
- Personal care supports to some families' homes are sometimes very inadequate and are not addressing the health needs of parents who may be getting older and have their own health needs
- Need for improved input/co-ordination from community dentist to local dental practices
- Historically treatment by some past clinicians and hospital staff has been very poor:
 - some stories of poor standard of healthcare in the past when subjects were much younger and were seeking clear diagnosis/treatment and ongoing support

4. Next stage:

- Should we interview two more families?
- Timescales – completion of diaries/feedback

NB: It has been agreed to initially feedback to families about information gathered.

George Sapiets & Bill Love

Senior Consultants

National Development Team

16/11/2006

