

## Access to the Community

Session Notes, 7<sup>th</sup> Feb 09

### External barriers:

- Health service support
  - Levels of provision of services
  - Adequate, appropriate levels of funding for services?
  - Waiting lists: delays in diagnosis, access to therapies, such as physiotherapy

### **Recommended:**

- Medical practitioners should focus on therapies early on – and beyond school arena – to ensure that all disabled children get the extra help they require, and at the most appropriate time.
  - Greater awareness amongst GPs – of therapies and accessing info/support
  - Greater numbers of health visitors and therapists
- **LEA SEN provision**
    - Difficult Statementing procedure: “constantly having to reapply – having to justify”

(Health and LEA) parents find it difficult to initiate procedures that would give their child access to medical or SEN provision – and, once initiated, face long waiting lists – for example, to access Speech and Language therapy

### **Recommended in both cases:**

Professionals in Health and LEA provision must listen and respond sensitively to parents.

Also, how might public awareness of disability be raised? - To avoid the looks and comments of people who don't understand.

### Personal (“self-imposed”) barriers:

Having to accept diagnosis of disability in the first place – and then having to make a “public admission” of it (e.g., filling in I-Count and other forms) and “having to tell [your child's] story over and over” is;

- “Stigmatising”
- “Off-putting”

For these reasons, people may not elect to access services - even though these might be timely and appropriate.

## General barriers:

Lack of awareness of services available:

A variety of information is accessed in a range of ways, depending on individual awareness, contacts and familiarity with info providers around the borough, such as:

- Disabled Children's Information and Advice Service (DCIAS)
- Talking to other parents (Tuesday Special Club, ASD parents support group)
- Health visitors – **but appear to be fewer available, are these being cut back?**  
**Concern that children can "fall through the gaps"**
- Maple practitioners
- Portage
- Surbiton Hill Nursery
- Libraries
- RBK website: Recommended: this should be easier to navigate, and should offer more, and more in-depth, information – including phone numbers that actually respond to your call. Clear information and helpful contacts, trained to advise and support effectively and sensitively.

It can be difficult to access a range of information without a computer – so how can a good range of information be disseminated as widely as possible? - e.g., as on the back of Kingston Connections.

## Issues to accessing information and services

How could services be streamlined? At present, various difficulties create barriers to accessing appropriate services:

- Form-filling: having to provide the same information over again; parents would rather be spending time with their children.

**Recommended:** information be stored electronically (e.g., CAF)

- Knowing who's in charge of your child's "case" – who to contact for appropriate advice and support.

**Recommended:** This key person could be responsible for providing information, advice and support drawn from multi-agency sources, including updates on national legislation that benefits disabled children.

- Transition times are stressful: require particular support/advice to prepare and go through transitions. **Concern:** for example, though parents understand that, with regard to school options, agencies (such as Parent Partnership Officer) can't recommend – but where and how can they get the information they need to make informed and appropriate choices? Parents need to be aware of the possible repercussions of their choice of school (and services).

**Recommended:** someone (a caseworker?) who knows child over time and can advise on school options.

- Statementing process: **Concern:** to provide information and to feel able to encourage proceedings without biasing LEA professionals against child's case.

**Recommended:** SENCo should be a job in itself, focussed solely on SEN provision.

- Accessing “cross-border” services: why is there a variation in services (levels; quality) on offer from one borough to the next?

**Recommended:** a “Memo of Understanding” between boroughs (in order to offer proportionate service provision).

### Concluding remarks:

- ✓ Parents’ greatest concern is how to know what’s available, and whether their children are eligible for various elements of service and support on offer. More information is required, and it must be clear and comprehensive.
- ✓ Parents would like greater personalisation of services, which would call for their ability to access a range of professionals in both service and information provision.
- ✓ Identify a lead professional to “be in charge” of child’s case over time – someone who can give a clear idea of what to expect along the “journey.”
- ✓ Address the lack of basic services at key points: diagnosis, early years, school transitions and puberty.
- ✓ Simplify forms – and minimise need for form filling by creating a central database.

EnhanceAble was cited as being good at providing information that enables parents to access appropriate services and support - “Ring EnhanceAble!”

**Recommended:** raise community awareness of EnhanceAble’s DCIAS.