

## **Annex B2: Review of Disabled Children**

### The key questions the review will address

The changing profile of disabled children, for example, due to increases in complex disability and rise in Autistic Spectrum Disorders, profound and multiple learning disabilities and low birth-weight babies and the challenges this poses to services.

1. *What progress has already been made in addressing the needs of disabled children and their families?*

A new partnership commissioning framework has been established locally to facilitate a whole systems approach to commissioning. (see attached chart)

Children's Trust service configuration model developed (see Q3 below)

Improved integrated working (see below re ADHD/ASD virtual teams, Willow).

Recent needs assessment completed for services for children with a learning disability.

2. *What are the barriers currently restricting access to services and therefore effective intervention?*

**The changing profile of need has led to an increase in demand in services, with no corresponding increase in resources to address this.** There are service pressures in across the pathway. This is against the backdrop of CaPL NHS savings and parallel financial difficulties in Local Authorities. New guidance (e.g. NSF for CYP and Maternity Services) has not provided the resources needed for implementation, apart from CAMHS.

Medical capacity is stretched (including psychiatry with the rise in ASD and ADHD in particular), leading to bottlenecks as a diagnosis is awaited, which, in turn, leads to delays in the provision of care plans. Much more formal assessments (in line with NICE Guidelines, etc) are required to confidently provide evidence based packages of care. This may involve assessment over more than one appointment.

There are significant pressures within therapies, particularly SALT and OT. Therapists provide training and support to school staff to build skills capacity to support children in school, but this brings with it increased demand to specialist therapists from school staff to maintain this approach. This is a similar dilemma for CAMHS staff.

3. *Are services sufficiently co-ordinated at local level to allow families to access sufficient support to meet their needs?*

The Children's Trust approach provides the framework for this. Locally, services are being configured so that locality networks are being formed

around Children's Centres and Extended Schools (tier 1 / 2). The aim is to support the locality networks through a handful of locality hubs across the borough (tier 2 / 3). Specialist hubs will provide integrated services at specialised level (tier 3 / 4). The Locality Hubs will provide the co-ordination of Locality Networks, however, each hub will require a Co-coordinator and identifying resources for this is proving difficult. Capital will need to be accessed to provide adequate accommodation for Specialist Hubs.

A virtual team model approach has been successfully implemented for ADHD and for ASD. This brings together a network of staff from different organisations, whose main area of work is either ADHD/ASD. Both services are led by a Co-ordinator, with the initial 6 months being spent on development of the service (criteria, pathways, building the virtual team, etc.). This model will also be rolled out for LD services during 2007.

The Croydon vision includes roll out of the Early Support Programme, for CYP aged 0-19 years, across the spectrum of need. This would need to be done in a phased way, starting with younger children (0-5 years) with the most complex needs. (see later question on keyworkers)

There are difficulties caused through lack of clarity of roles and financial responsibilities across integrated care pathways, e.g. a child discharged from hospital on a ventilator resulted in endless emails and discussion involving several people before it was negotiated who should fund the ongoing equipment needs. This situation is precipitated by the financial pressures within organisations.

4. *How does the system of support for disabled children and their families compare across the country and abroad? Are there lessons we can learn to improve outcomes?*

Continuing Care Criteria for CYP is being developed (due 2007). Currently, PCTs apply the adult criteria for children, in the absence of CYP specific criteria, and only resource on the grounds of medical needs. It is anticipated that this will (and should) include MH and LD and be based on the principles of the Establishing Responsible Commissioner Guidance (2006 – further children's guidance awaited) in that the originating PCT funds any health assessments required (and ongoing interventions in most cases). If MH and LD are to be included and ERC guidance applied, the costs would need to be predicted with financial transitional plans put in place to accommodate the otherwise potentially destabilising shifts in funding responsibilities between PCT and LA, and between out of borough partners.

Policy is not always joined up and this can cause difficulties at local level, e.g. there are tensions between the drive for Practice Based Commissioning and local joint commissioning. PCTs and GPs are concerned with the health needs of their total population, not just children and therefore children's services are at risk of being marginalised. Communication of, involvement with, and joining up of commissioning strategies can prove challenging. The

scale of the children's agenda alone is huge. The same challenges have also been heightened with the delegation of budgets to schools. Apart from the individual identities and cultures within schools, the PCT does not have the manpower to engage with them proactively, on an individual basis, with a view to encouraging investment in health services to support implementation of the NSF and Every Child Matters.

5. *What family support services i.e. key workers, short breaks, sibling support, behavioural management are currently available and how do these relate to other services?*

There are no formal key worker arrangements established locally yet. Again, this requires some additional resource that has not yet been identified. Although some existing staff have been identified to ring fence some of their time for keyworking, the key worker network requires training, co-ordination and support to establish and sustain it.

Opportunities to network with other services need to be taken wherever possible, e.g. the National Autistic Society recently had success with a bid to the Parenting Fund for a Family Support Worker for 12 months. Discussions are underway with the NAS to ensure the FSW is fully engaged with the ASD virtual team. This will help to alleviate some of the gaps in family support for the families of children with ASD over the forthcoming 12 months.

An award winning bereavement service has been set up in Croydon, the Willow service, funded through the Children's Fund. This service is particularly for the siblings of terminally ill children. Referrals are received at the Willow from the Children's Hospital at Home and Palliative Care services, but may also come from other sources occasionally, e.g. teachers.

The ADHD virtual team is led by an educational psychologist. The Team's membership also includes psychiatry, community paediatrician, SALT, OT, family support.

The ASD, ADHD and Willow developments are funded through the Children's Fund. The Palliative Care service through the New Opportunities Fund. All are running on time limited funding and there is real concern about the sustainability of the services beyond 2008.

There is normally a proviso with the provision of new development funds that funds should only be used for new and innovative services, and not be used for existing services. Whilst the sentiment of this is understood, in that new funds should not be used to prop up existing services, it is not helpful to exclude the mainstreaming of innovative projects with proven success that have been kick started through successful application to other time limited funding pots.

6. *What are the most cost effective interventions in delivering better outcomes?*

Families need to be supported to enable keeping their children within their communities, and for children to achieve the best quality of life. To reduce the number and duration of high cost placements, and to reduce and prevent parent/carer stress and risk of family breakdown, more of the following is needed:

- Key Workers
- Respite/short breaks
- Equipment
- Housing and adaptations
- Family Support
- Improved and timely information
- Transport

Quicker and more housing adaptations would enable children to be discharged earlier from hospital/placement setting. Locally, although OTs can carry out assessments for major adaptations to council owned homes fairly quickly, there are then long waits for the work to be carried out due to insufficient funding. Where re-housing is recommended, waits are even longer – several years are not unusual – due to lack of housing stock.

There is a welcome recognition (NSF, Improving Life Chances for Disabled Children, Removing Barriers to Achievement, etc) on the importance of equipment and the impact that it can have for children, their families and carers at home and at school. However, funding for equipment (supply, maintenance, servicing, training, storage, recycling) is a real issue. Demand for equipment has increased, due to the changing profile of need, and as more children are integrated into mainstream schools equipment (including lap tops, PCs, seating, hoists, height adjustable tables for science/DT, etc.) is needed to support them.

7. *Are there interventions which, if made earlier, could reduce more costly interventions later? How can we identify the need to intervene earlier?*

The Early Support Programme provides an excellent approach and set of tools to intervene early in an integrated and supportive way.

See also Q6.

8. *What lessons can we learn from the legal frameworks in other countries that might inform the review?*