

Annex A – Covering Template for Responses

Please complete the attached cover sheet when sending evidence, indicating the set of questions to which a response is being provided and contact details of the person for any follow-up queries.

| Contact details for respondent | |
|--|---|
| Name | |
| Job title | Integrated Service Manager for Children with Disabilities |
| Do you represent an organisation? (if so, name of organisation and type: e.g. voluntary, public body, private company). | Tower Hamlets Children's Services |
| Postal address | 62 Roman Road London E2 OPG (Attended review event hosted by the Treasury on 4 th July 2006) |
| Telephone number | |
| Email | |

| | Which area of the review are you responding to? (please mark X) |
|---|---|
| Prevention strand | |
| Review of disabled children | X |
| Strategy for youth services | |
| Review of high cost, high harm families | |

– **Annex B2: Terms of reference for the Review of Disabled Children**

Objective:

To improve outcomes and life chances of disabled children through the development of effective and accessible services for disabled children and their families.

The scope of the review will cover:

- services specifically for disabled children, including how specialist services for disabled children support access to universal services, specialist services provided in a universal setting and how universal services refer children to specialist services;
- childcare services, which are of particular importance in the early years for children's development and to support their parents;
- appropriate support for disabled children during the school years and in making the transition into adulthood;
- how expenditure by one service/department can avoid or reduce concurrent or later expenditure by another department.

The Government recognises that financial support and benefits have played an important role in reducing the risks of poverty and delivering economic wellbeing. This provides the foundation on which families, communities and government can work together to secure better outcomes for disabled children and their families. Although financial support and benefits will not be a focus, the review will consider the interrelationship between poverty and service delivery needs.

The review will consider the actions that can lead to better outcomes for those children already with a disability, including family support e.g. respite provision, rather than prevention and risk factors, which will be considered as part of the wider Children and Young People's Review.

The key questions the review will address include:

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.

Context Note:

The primary reason for an increase in children with a disability were identified by C Glendinning et al 1991 as follows:

Medical advances - children with disabilities are living longer. Better medical care and treatment has extended life expectancy.

Technological developments - more children can be supported at home with aids and adaptations to family homes.

Policy developments - there has been movement away from institutional support. In addition families are more aware of their needs and more able to voice them.

Nationally and locally there has been an increase in children diagnosed with severe communication disorders. For example, the prevalence of autistic spectrum disorders (ASD) is rising. This is because of changes in diagnostic practice and public and professional awareness.

Tower Hamlets

The prevalence of severe learning disabilities among South Asian communities is up to three times greater than in the general population (Hatton et al, Supporting South Asian families with a child with severe disabilities, Institute of health research, Lancaster University, 2002). As third of Tower Hamlets community is of Bangladeshi origin (One of South Asian Country) we have a high prevalence of this in this borough. 2001 Census figures 4% of disabled children received a service .

2003 Census figures 10% of disabled children received a service.

2005 Census figures 15% of disabled children received a service

85 children over 3 years have a diagnosis of ASD (SEN register 2006).

31 disabled children are looked after permanently

26 disabled children receive overnight respite care

91 disabled children receive a package of care

357 disabled children are known to children with disability team

The average caseload is 22 per Social Worker

70 children with a disability requiring tube feed at home

90 children with complex needs

£1,260,078 budget for family support for disabled children

£738,000 pooled budget for care packages

Challenges:

IT support to capture accurate data between the PCT and Children's Services (e.g. children with disabilities register and financial information).

Securing pooled funding to co-locate and train staff as lead professionals to ensure a single assessment process and care plan process is in place, (with shared files).

Reprioritise services in line with demographic changes and agreeing joint eligibility criteria with a balance of universal, inclusive provision as well as targeted, specialist services. (E.g. threshold criteria for respite and OT services. A majority of resources is focused on children with complex needs).

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

The Council and its partners completed a "Best Value" review of services to disabled children in 2003. This identified a number of areas for improvement. It particularly highlighted the need for greater integration between service providers.

Following this consultation, the Council, Primary Care Trust and the voluntary sector providers established a pooled budget for an integrated service. They brought together a range of teams under a single accountable manager and management structure. This has re-energised the service and enabled it to build more effective joint working processes to meet the needs of disabled children in a timely manner.

Care pathways are being developed to improve user experience of integrated service delivery (e.g. ASD, Palliative care and ADHD).

To compliment consultation events, Tower Hamlets undertook a Needs Analysis with Dartington i, (to inform commissioning priorities). Data was gathered on 80 disabled children known to the integrated service, across professional disciplines. A statistical cluster analysis of children's needs was then undertaken. This identified three discrete groups of children and families with similar needs. They were:

Group One

The need for services that support families coping relatively well with learning disabled children and the problems associated with this disability, especially challenging behaviour.

Group Two

The need for services to help families coping relatively well with caring for children whose disability arises from a serious medical condition, often compounded by restricted mobility.

Group Three

The need for services that support families with children with multiple disabilities - learning, behavioural and emotional - compounded by parents' mental health difficulties and limited parenting capacity.

The Council undertook a review of commissioning priorities to meet the gaps in services. Three themes emerged from the audit:

- i) Need for more work with families to come to terms with having a disabled child (bereavement).
- ii) Need for services that developed parental skills at home, with high numbers of children from single-parent families.
- iii) The need for a clearer distinction between family support work and respite-short-break care, coupled with a better understanding of the complementary relationship between them (address the dynamics of family relationships).

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

The Borough in partnership with key agencies has completed a Best Value Review of services to Disabled Children. A detailed action plan has been produced 7 key areas were identified within the review:

- Action Area 1: To address the needs of children with disabilities in housing and transport plans
- Action Area 2: To work with families & stakeholders to design and implement holistic provision for children and their families through the Pathfinder Children's Trust, including development of a communications strategy.
- Action Area 3: To ensure assessment and review processes are co-ordinated and efficient and place the children and their families at the centre, through the development of IRT process.
- Action Area 4: Senior Managers in all Service areas to ensure that evaluation and improvement of services for children with disabilities are a key priority
- Action Area 5: To include specific 'Workforce to Reflect the Community' targets for people with disabilities, recognising diverse communities
- Action Area 6: To support children and their families to maximise the use of available services and to develop the confidence to tackle poor service delivery, where it exists.
- Action Area 7: To support children with disabilities in the transition to adulthood

The integrated Service has taken forward aspects of the Best Value review in Action area 2,3,4,6 and 7.

Other areas for development include:

There is a national shortage of workers who are sufficiently qualified in communication skills within different disciplines are limited (e.g. BSL, Brail & dual impairment (deaf/blind)).

Families consulted wanted more information about the range of services. Word of mouth and the internet is favoured (avoiding a pile of leaflets).

Two families have expressed disappointed that direct payments cannot be used for health care (medical care).

Some families require door to door transport prior to taking up services.

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

Services for children with disabilities in the borough are provided via an integrated team across health, and children's services with the aim of building an effective joint working process to meet the needs of disabled children in a timely manner. As part of the development of this service, an Integrated Screening Panel has been established to process referrals concerning children with disabilities more effectively.

The Integrated Screening Panel has the following role and functions:

- To prevent duplication
- To share information at an early stage
- To gather information
- To ensure timely access to appropriate services, Including:
 - a) Advice and consultation to referrers
 - b) Assessment of specific children
 - c) Provision of direct intervention
 - d) Identification of lead professional

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?

Building the capacity of mainstream services to meet the needs of disabled children is a priority. Tower Hamlets has a firm foundation with the Third Sector Strategy, and Commissioning framework.

The Best Value review identified Housing as a critical factor, as did the Matching Needs and Service audit.

School playgrounds could be open for public use outside of school hours and term time as in other countries. More open spaces should be designed for disability access.

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.

The Council has a range of provision including local respite, play provision after school and weekend's provision. A sibling support group is run by Spark, (Barnardo's).

Areas for commissioning development include an outreach, parent engagement service, offering practical support and respite care provision for Autistic children.

We could do more to improve the links between specialist and mainstream services to build capacity.

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

Pooled budgets and matrix management

Employ disabled people and parents due to their added value, (as role models)
To create cultural changes within teams

Plan for integrated assessment and care planning and single communication strategy.

Families value practical advice on sleep and diet, and lifestyle help to access services such as libraries and leisure centres.

Respite services are valued.

Care pathways and lead professionals have made a significant difference.

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

Respite provision

ICT Services to promote communication, so children with disabilities can exercise choices (pooled equipment budgets).

Practical support and lifestyle advice re routines, such as sleep management to prevent challenging behaviour difficulties when the disabled young person becomes bigger.

Couple and family relationship counselling at the point of diagnosis and transition.

Sibling and befriending support programmes

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

USA legislation promotes inclusion.

The existing experience of post code lottery is of concern.

