

Submission from The Children's Trust, Tadworth, to the Review of Services for Disabled Children by the Treasury and Department for Education & Skills, September 2006

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	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	

Introduction: Background Experience Underpinning this Response

The Children's Trust at Tadworth is an independent charity with over twenty years experience in the provision of residential and other very specialised services for children with multiple disabilities and complex health needs. Most of the children referred to the Trust cannot walk or talk, have impaired hearing or vision or both. Many cannot swallow and require feeding by tube; some cannot breathe independently and depend on artificial ventilation. The majority have severe or profound learning difficulties. Most have epilepsy and other significant health needs. What distinguishes this population is having some combination of all or most of these problems.

Some of these disabling conditions are congenital, perhaps profound cerebral palsy as a consequence of very early pre-term birth and low birthweight. Some of the children have progressive metabolic disorders of genetic origin so that their care needs will increase as they grow older. Perhaps as many as half or more of these children with multiple needs have acquired their neurological damage either through some traumatic accident like a fall or car crash or as a result of an illness such as viral encephalitis, meningitis or poorly controlled diabetes. Some children referred to us have residual brain damage following surgery to remove a tumour.

The Trust's services include residential special education, residential nursing care; short break or 'respite' care and continuing or palliative nursing care for children with complex health needs who are unable to live at home at all. We offer transitional care to provide children with a more appropriate, stimulating and therapeutic environment as an alternative to long term hospitalisation, while arrangements can be made to train a family and support living at home. The Children's Trust is also the leading provider of intensive residential rehabilitation programmes for children with acquired brain injuries. These residential services are complemented by an outreach care service to support families in their own homes (giving parents a good night's sleep) and a new support service for children with an acquired brain injury who have been discharged from hospital back to home and school but who may present with learning and behavioural problems later on.

These services are funded for each child individually by negotiation with the home PCT or social services or educational authority and often by all three.

Issues Arising from the Changing Profile of Disabled Children

It has been our experience over the past twenty years that the profile of the population of disabled children using our services changes at a fairly rapid pace, with considerable consequences for planning and delivery of services. One of the features of life here has been to encourage and train staff to adapt their skills to the next new need. Conditions we saw twenty years ago are not here today but others have always taken their place. In round terms the number of children in receipt of our services has doubled over twenty years while the number of staff has quadrupled. This is not a measure of inefficiency but rather of the increasing complexity of need which can only be met by increasing personal care and attention. For instance, the Trust has recently invested in a small unit to provide transitional care for children who are ventilator dependent or who have 'difficult' tracheostomies which require round-the-clock nursing care. Providing such children with trained nursing care,

therapies, opportunities for play, all in a reasonably home-like, non-institutional environment costs over £1,000 per day per child, less than the cost of paediatric intensive care, but more than the cost of support for living at home if that is manageable. These children are 'new survivors'. Technological advances have reduced the gestational age at which a new-born can survive but there has been insufficient attention to the development of appropriate facilities and resources for meeting their longer term care needs. Indeed, a high proportion of these children will now survive into adulthood. Managing the transition to adult services presents well documented difficulties for any family bringing up a disabled child but where a child has multiple needs and there seems to be no well resourced and appropriate adult care service available the challenges are much greater.

These changes are by no means solely a consequence of very early pre-term birth. Improvements in treatment at the scene of a road accident and in the operating theatre afterwards mean that more children are surviving traumatic accidents with multiple impairments. The nature of the long term conditions faced by these children with acquired damage is poorly understood and opportunities for therapeutic treatment and support woefully inadequate.

Some degenerative conditions: the muscular dystrophies, cystic fibrosis, Batten's Disease, Rett Syndrome used to be thought of as diseases of childhood. The development of new and better treatments is now seeing these children survive well into adulthood.

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

What has changed for the better in recent years is that goals, aspirations and intentions to do better by disabled children are now explicit. A series of important policy statements and some new legislation means that the needs of disabled children and their families are now much better acknowledged, but there is still too great a gap between the rhetoric of, say, 'Every Child Matters' or 'Improving the Life Chances of Disabled People' and the realisation of the highly desirable standards published in chapter eight of the National Service Framework. The Children Act 2004 introduced Directors of Children's Services and children's trusts to be established in each local authority by 2008. The National Service Framework describes some of the things which should be in place and children's trusts, accountable to a director of children's services, ought to provide a mechanism for linking local services closely to need. The kind of joined-up, holistic and well-planned access to relevant services that seemed to be envisaged has certainly not yet been realised for the children with multiple needs whom we are concerned with. This may be partly because of skill and manpower shortages in certain specialised fields, it may be a combination of high cost cases and budget shortfalls or it may be because of a certain wrong-headedness and inflexibility of approach. Certainly, this organisation has yet to have a funded referral from any local authority children's trust.

Frequently children who need multiple equipment items (wheelchairs, soft chairs, sleeping systems, splints, hoists, standing frames, etc) are subject to scandalous delays while different agencies argue about who is responsible for quite small amounts.

Arrangements to encourage mainstream schools to improve access for disabled children has increased choice for families but the so-called 'inclusion' argument has sometimes clouded

pragmatic judgements about what is best for children with very specialised needs. So-called 'out of county' placements are regarded as a bad thing but a regional facility such as our residential special school with specialised teaching methods and good medical cover is likely to offer the best educational prospects to children with complex health and social needs. The regional partnerships in SEN between local authorities are a useful development.

The development of children's hospices has created some welcome and high quality capacity for short term care for disabled children and their families. However this development may have some important disadvantages. Because they are dependent on voluntary fundraising and a public relations message which focuses on the palliative care needs of 'life limited' children they may have impeded wider awareness of the need to develop respite care services, whether funded publicly or privately, for families bringing up children with all kinds of disabilities.

The prominence given to 'Every Child Matters' seems to have taken some attention away from the challenge of implementing chapter eight of the National Service Framework. Similarly, after the initial fanfare with which children's trusts were launched the Government's enthusiasm seems to be focused elsewhere. It is as though local authorities are not being called to account for the progress they have made or not made in implementing children's trusts.

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

The lack of good epidemiological and other data is a problem. There is no reliable data to tell us how many children with multiple disabilities and complex health needs there are in the country. Census data is out of date and local authority registers do not give us the answers. Dr Janet Read and colleagues at the University of Warwick are reviewing existing data sources but we should be investing in new and high quality research to understand the numbers better. Having reviewed such sources as there are, my guess is that our population is in the range of 15,000-30,000.

Manpower resourcing is a key issue. There are chronic shortages of therapists and other professionals able to support disabled children both in hospital and, particularly, in the community to help them after they have returned home. There is a lack of psychological support for families in situations of considerable stress. One important problem in this area is the lack of specialist attention given to children with acquired brain injuries, particularly those who can benefit from some form of therapeutic rehabilitation. These children really should be recognised as a distinct group. This seems not to happen and yet I would guess that they may account for around half of all children with multiple disabilities and complex health needs.

Families grieving for the child they knew, and coming to terms with the different child they now have, are often in a very intense emotional state and need skilful support and, where rehabilitation back into school and family life is possible, they are the ones who will need to be trained and skilled up. A child with a brain injury is likely to have quite specific psychological and social needs.

The kinds of rehabilitation programme that we provide over a 9 or 12 month period is not widely available elsewhere. This is partly because neither professionals nor parents know what questions to ask about the child's needs nor about what is possible. They do not know what they are looking for in many cases. Rehabilitation can make a big difference but it seems very expensive, particularly when going home from hospital is a practical alternative. Some of these children go home after making a good physical recovery but with hidden or subtle cognitive and emotional difficulties which may not become obvious until later on. These children can slip right through the net but they are at risk of serious problems.

More work needs to be done to demonstrate the long term beneficial outcomes of therapeutic rehabilitation both in social and economic terms. The arguments seem clearer for adults where it is a question of getting back to work but less forceful for a child starting out on life.

Apart from the need to demonstrate value for money, funding is a barrier in other ways. Commissioning specialised health services seems unnecessarily complex because decisions about relatively low incidence needs are taken locally by a PCT or local authority, there is sometimes great resistance to meeting a cost which could have been planned for regionally or nationally on some actuarial basis. For a relatively small population of up to two hundred children each year, it is necessary for us to have a department of five people dedicated to negotiating and chasing appropriate funding. Sometimes problems and delays are exacerbated by a lack of specialist knowledge in commissioning the services.

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

No. One parent said their family's experience of their daughter's admission into our residential special school was 'like falling into a bed of cotton wool'. Suddenly their vulnerable child was in a place where an experienced doctor was on hand; specialist consultants visit the school (compared with having to chase a multitude of appointments when she was at home), and services such as physiotherapy and even music therapy are accessed as part of school life. It is all in one place. It would be a big undertaking but part of our ambition is to see this place replicated in parts of the country where no such service exists.

There is one important example of un-coordination which we see quite frequently. This is the failure of housing departments to engage early on with the needs of a family whose child has become disabled following an acquired brain injury. Housing adaptation or even re-housing is sometimes essential if the child with all necessary equipment is to live at home. These needs can and should be planned for at an early stage of the child's treatment. If the housing department fails to engage in the planning process until a child is ready to be discharged the PCT is then forced to bear the cost of a continuing but unnecessary service while housing re-provision is sorted out. There have been cases of children remaining here long after a residential rehabilitation programme is finished, simply because a housing department would only become involved in discussions about re-provision at the latter stages of a child's stay.

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?

There are a variety of different models of funding for services for both children and adults who have had a road traffic accident in countries such as Australia and New Zealand. For example in New South Wales the Motor Accident Authority also makes contributions to ensure all receive emergency care, rehabilitation and follow-up treatment as required. This means there is a better understanding of both incident statistics and needs. It also means that there is a better chance of children who often do not fit the specific criteria here in the UK getting picked up.

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?

All these support services are desirable but not available in sufficient quantity or quality.

Allocation of effective key workers is patchy. Sometimes a social worker's job description can include a duty to provide a key worker service to families, but with a case load so huge that the service is unlikely to make much practical difference to the lives of the families concerned. An expectation that key workers will make a real difference to families should be taken more seriously and efforts should be made to ensure a more uniform national standard of service delivery. Parents should be allocated a key worker at an early stage after the birth of their child or after a brain damage caused by accident or illness. Parents setting out on the next stage of their lives have no idea of the journey ahead and it would make a huge difference to have a plan and some reassurance based on experience.

In order to access different services parents are forced to repeat over and over their child's name, address and date of birth as well as complex medical histories, sometimes to professionals within the same agency. A key worker would help but some kind of accredited 'passport' system could save time and stress.

Children with acquired brain injuries do not necessarily fit into CAMHS services and, again, more should be done to recognise the needs for family support amongst this distinct population.

Many families complain of the paucity of available opportunities for short breaks. The Children's Trust provides a residential short break care service led by experienced children's nurses and supported by an in-house team of doctors. During term time children attend classes on our site. This service, mostly funded by social services, is highly unusual in its ability to reassure anxious parents that the complex medical and health needs of their child will be attended to, that their child really is in safe hands however complex the need. It is important that we do not end up with an exclusive reliance on the model of service developed by voluntary children's hospices, however good they may be. We must expand and sustain capacity for diverse needs.

We organise regular 'siblings days' with a range of learning and play activities, giving them a sensitive outlet to express their own experiences and needs in being brought up alongside a

disabled brother or sister. We have also organised similar workshops for grandparents. This autumn we shall have a one day conference for parents, partly to offer practical advice, partly to create a networking opportunity and partly to hear from them how we might shape our services better to reflect family needs.

Better family support during the difficult period of transition to adulthood would also benefit many families. A good key worker would help. We need to increase the capacity of provision of services designed to meet the needs of these 'new survivors' with multiple impairments. Seeing a child move from a child-centred residential setting such as this to an old people's home because there is nowhere else available causes heartache for everyone concerned. Most services stop dead when the child is eighteen or nineteen. Where the child is extremely dependent, extending the remit of a paediatric social worker through to twenty-five years would help to carry forward skill and experience to adult provision. We are experimenting with staff exchanges, bringing staff from an adult care home into our residential school for three months to get to know their new client before the move and sending some of our care staff onto the adult facility to help further smooth the process of transition. We would also like to see more funding available for the extension of educational opportunities for young adults with profound learning difficulties.

**What are the most cost effective interventions in delivering better outcomes?
Are there interventions which, if made earlier, could reduce more costly interventions later? How can we identify the need to intervene earlier?**

Here are three examples from our experience of areas where early and appropriate intervention can improve outcomes and save long term costs.

Preventing Deformity

Provision of physiotherapy and associated items of equipment can provide twenty-four hour postural management for children with multiple disabilities, improving a child's quality of life and longer term health and avoiding the need for costly hospitalisation later on. Many children are frequently admitted here having had very little physio or other therapy intervention and we are faced with a need to provide therapy and equipment to undo problems caused by lying for long periods in a hospital bed. An adult patient is likely to find an occupational therapist to support their rehabilitation in hospital but because of the relatively low incidence of these children with multiple disabilities there is no such equivalent service for children in hospital.

The sort of interventions which should be made available through appropriately skilled therapists include:

- a) **Spinal jackets**. These cost approximately £350 and need replacing on an annual basis. The jackets help to protect a child's internal organs and prevent deformities developing which may otherwise require spinal surgery in the future, costing many thousands of pounds.
- b) **Ankle Foot Orthoses (AFO's)**. These hold a child's foot in a 90° position to avoid developments such as a 'dropped foot' which can prevent them from standing. The lack of an AFO (which costs approximately £500 and needs replacing on an annual basis) can result in

bone density problems and can confine the child to a wheelchair which, in turn, necessitates more intensive care.

c) Sleep systems. A sleep system costs approximately £1,000, but generally lasts for the duration of childhood. The sleep system not only helps a child to sleep through the night, but also helps to prevent the development of postural problems such as scoliosis. We are currently working with a child who was experiencing up to 30 seizures per night, causing major distress and disruption to his sleep patterns. After a sleep system was introduced the number of seizures reduced to nil.

d) Seating. Specialised seating is vital for many children with multiple disabilities particularly with the 'add-ons' of supports and knee-blocks. These cost approximately £2,000 but last for about two years and do much to prevent muscle and bone deformities from forming.

In all, a collection of equipment for a typical child with multiple disabilities including a wheelchair, comfy chair and other equipment for postural management costs a total of about £8,000. In our experience, much time is taken up in arguing about funding of these items separately. These needs can be planned for with a considerable degree of certainty and the necessary funding should be set aside in the name of each child from an early stage. We should be taking a more long term holistic view of needs.

Preventing Family Break-up

Adequate short breaks and other forms of family support can help prevent the huge social and financial costs associated with family break-down. Just last week one of our rehabilitation beds was taken by the emergency admission of a child needing continuing care. The child's mother had been requesting extra help from her local social services department but it was not forthcoming. In desperation she let them know that she had reached her wit's end and was contemplating 'putting him out of his misery'. Forced to act swiftly they found a placement with us costing over £4,000 per week and will now have to find and fund a more permanent residential placement. One of the child's brothers has been excluded from his school because of behaviour no doubt related to all the stress at home.

Our short break care costs around £265 per night for the home or outreach service and just over £400 per night for residential nursing care. These services help to put off or prevent the need for long term residential care, the cost of which starts at around £160,000 per annum. The average allocation of respite care for children coming to The Children's Trust is thirty-nine nights – an annualised cost of £15,873 – just 10% of the cost of one of our residential continuing care packages.

Rehabilitation for Children with Acquired Brain Injury

More work needs to be done to prove incontrovertibly that investment in intensive therapeutic rehabilitation programmes will reduce the lifetime costs of care for a child with severe acquired brain damage. The arguments have been rehearsed more fully with the adult population, yet children with a lifetime ahead of them and grieving families to support them have even more at stake.

Individual packages of therapeutic rehabilitation can restore children's mobility, communication, ability to feed themselves and techniques for learning and counteracting

memory problems. Multi-disciplinary assessment of need and better understanding of the consequences of brain damage can help families to manage the tasks which lie ahead.

The Children's Trust has recently invested in a small team of experienced brain injury therapists to support young people who have been discharged from hospital back to school. This community based service is helping to give teachers, parents and children themselves the tools to adapt to their altered state following a brain injury. Quite small behavioural changes following an injury can lead to social exclusion and educational failure. Relatively infrequent and low-cost interventions can help prevent serious problems from manifesting themselves later on in a population of children whose needs are poorly recognised and understood.

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