



- n Children with complex disabilities or an acquired brain injury have exceptional needs
- n The Children's Trust provides expert care, therapy and education for these children
- n This care transforms the lives of children with complex disabilities
- n Private funding could help the Trust support more children with complex disabilities

## Issue: Children with complex disabilities or an acquired brain injury have exceptional needs

There are around 700,000 disabled children in the UK. The number of children with complex and/or multiple difficulties is unknown. Mencap estimates that around 65,000 children have severe and profound learning difficulties. An estimated 6,000 children are technology-dependent and use medical devices to compensate for the partial failure or loss of a vital body function.

Children with complex difficulties have many needs, including: rehabilitation (for those who have suffered acquired brain injury through accidents or illness), therapy (including speech and language, occupational therapy and physiotherapy), as well as other health, education and social needs. Given the intense care requirements of some children, a single child may need a rota of up to five staff to provide care.

Most of the services for these children are funded by the government, however many have needs that go beyond the minimum standards which health authorities are prepared to pay for. This might be additional specialist staff or equipment which improves a child's quality of life but may not be considered essential treatment.

Although the actual number and spread of children with complex needs remains unclear, it is apparent that the number is increasing. This is partly due to enhanced neonatal care and improved acute medical care leading to increased survival rates. Provision for these children needs to grow in line with the growth in numbers.



A child with complex difficulties may need a rota of up to five staff to provide care.

### Case study: Ollie's story:

In August 2006, two-year-old Ollie suffered severe brain injury when he choked on a grape, cutting oxygen to his brain. He was rushed to hospital and placed in intensive care. In just a few hours he had become unresponsive. He constantly cried and could no longer walk, eat, sit up, hold a toy, or communicate. The brain damage also caused blindness and he was completely dependent on 24-hour care.

Once discharged, Ollie needed specialist, intensive treatment. At The Children's Trust Ollie was given his own therapy and nursing programme and made remarkable progress. He learned how to eat again, his movements were strengthened by regular sessions in the hydrotherapy pool and his vision recovered using the multi-sensory room. In June 2007 Ollie returned home. His parents say that the Trust made a huge difference and that he 'returned home a transformed child'.

### Response: The Children's Trust provides expert care, therapy and education for these children

The Children's Trust provides care to children with exceptionally complex disabilities. Established in 1984, the Trust is based in Surrey and provides services for over 180 children per year, with an average occupancy of 76 children on site. Services include:

- **Residential rehabilitation** for 30 children. The Trust runs the UK's largest rehabilitation centre for children who have an acquired brain injury (see box).
- **Transitional care** for technology-dependent children who are ready to leave hospital intensive care but are not ready to go home.
- **Education at St. Margaret's School** for 43 children with profound learning difficulties.
- **Short-break care** for around 58 disabled children with complex health needs.
- **Continuing and palliative care** for 17 children with life-limiting conditions.
- **Outreach support** including care for children with acquired brain injuries.
- **End of life and crisis care** is a new service which provides an emergency on-call service and respite in the family home. When a child reaches the end of his or her life, the service offers 24-hour care at home followed by bereavement support to members of the family as required. Up to 600 children in the area could benefit.

The Children's Trust is unique in providing all of these services from one site. It employs over 400 staff and uses around 350 volunteers. Total income in 2007 was £17.5m, 75% of which came from fees for services.

## Results: This care transforms the lives of children with complex disabilities

The Children's Trust develops individually planned programmes of care and education for each child, that develop their ability, personality and talents. Progress is tracked against individual objectives, and feedback from parents suggests a huge degree of satisfaction and gratitude with the care provided (see box).

Outside the classroom and treatment sessions, The Children's Trust provides a home-like environment in which the children can have dignity and autonomy as well as involvement with the local community. It also supports families of disabled children through emotional support, outreach services and short breaks.

The Children's Trust is a centre of excellence. It has won a number of awards, including the 'Healthcare and Medical Research Award' in 2007, and is active in sharing its expertise with the sector. For example:

- The Trust's scientific research programme conducts, publishes and peer reviews research. The Trust also regularly hosts and presents at conferences.
- St Margaret's School's unique curriculum has been sold to around 50 special schools across Europe. Teachers from the school have also provided training to special needs teachers in the UK and in Sweden.

Existing children's services cost between £120,000 per annum per child for 48-week residential schooling and £450,000 for a year of technology-dependent residential nursing and medical care. The costs of the Trust's services are high because many of the children require round the clock care from highly skilled nursing and care staff. But the costs are less than the alternative of paediatric intensive care in an acute hospital.

### Feedback from parents:

*'As well as being highly professional and experienced the nurses are so loving and giving that we immediately felt at ease with them.'*

*'The staff made it possible for Elisha to have fun doing the things any teenager would enjoy... Thanks to the Trust she lives every day to the full.'*

*'St Margaret's doesn't just help students, it helps their families too... The whole family has benefited from knowing that Jack is having such a wonderful time at school and receiving the best possible care and education.'*

### Geographical coverage

Local ..... National



### Focus of approach

Indiv- Comm- Services Society  
idual- unity



### Life stage

Innovation ..... Established  
or pilot approach



### Replicability or scalability

Little ..... Considerable  
scope scope



### Annual income (£'000s)

2005	2006	2007
13,627	14,957	17,523

### Staff

Full-time	Part-time	Volunteer
278	194	350

## Recommendation: Private funding could help the Trust support more children with complex disabilities

The Children's Trust has an established record of providing high quality care, treatment and education to children with exceptional needs and profound disabilities. It has significant assets in terms of state-of-the-art facilities, skilled staff and dedicated volunteers, all of which are centred on the needs of the children.

The Trust is currently building a new rehabilitation centre for children with acquired brain injury. This will cost £7.2m, of which half has already been raised. Private funding of up to £3.5m would help meet the remaining costs. Specifically:

- £25,000 could fund a quiet area in the new rehabilitation centre where children can read, relax, have time away from their programme of therapies, and spend time with their family and friends.
- £50,000 could build, equip and furnish a child's bedroom.

In the long term, the Trust's goal is to support many more children and families, partly by developing outreach services but also by seeking opportunities to expand its residential services outside the current catchment area. For this work:

- £250,000 would help develop the Trust's community support team—including nursing staff, therapists and social workers—working with children and their families at home and at school.

Supporting The Children's Trust represents a low risk. The charity has an established approach, an experienced management team and a good strategy.

**The Children's Trust improves the lives of severely disabled children by providing the highest levels of care.**

[www.thechildrenstrust.org.uk](http://www.thechildrenstrust.org.uk)

New Philanthropy Capital (NPC) is a charity that advises all types of donors on how to ensure their money has high impact.

This document describes one of the charities recommended by NPC in its report on disabled children in the UK. For more information see our report *Ordinary lives* at [www.philanthropycapital.org](http://www.philanthropycapital.org). Names and potentially identifying details in case studies have been changed.

To discuss this or any of our other recommendations, please contact Harry Charlton on 020 7785 6309. Last revised on 26/02/2008. Matthew van Poortvliet.

#### Notice and Disclaimer:

- The content of this report is the copyright of New Philanthropy Capital ("NPC").
- You may copy this report for your personal use and/or for that of your firm or company and you may also republish, retransmit, redistribute or otherwise make the report available to any other party provided that you acknowledge NPC's copyright in and authorship of this report.
- To the extent permitted by law, NPC shall not be liable for loss or damage arising out of or in connection with the use of this report. This limitation applies to all damages of any kind, including (without limitation)

---

## Glossary

Page 1

<b>Funding needed</b>	amount or range of funding required
<b>Results</b>	impact of this charity's work on people's lives – NPC looks at results in terms of three dimensions:  <b>Breadth</b> – number of people affected <b>Depth</b> – intensity of results for each individual affected (greatest depth means a life-saving intervention; lowest means a minor interaction) <b>Change</b> – degree of systemic change brought about by this work; equivalently whether it tackles causes (high) or treats symptoms (low)
<b>Risk</b>	level of risk threatening the delivery of specified results
<b>Difficulty of fundraising</b>	level of difficulty associated with fundraising for this charity (may be due to unpopularity of field of work or lack of fundraising capacity)

Page 2

<b>Geographical coverage</b>	charity's area of work – local, regional or national – or a number of these levels
<b>Focus of approach</b>	main groups with which the charity works:  <b>Individual</b> – working directly with individuals, providing services and support to improve their quality of life <b>Community</b> – working with communities and/or families, providing activities to strengthen community life <b>Services</b> – working with organisations, funders and policymakers to improve services <b>Society</b> – working at a national level to change attitudes and tackle causes
<b>Life stage</b>	organisation's developmental stage – from pilot/start-up to mature, established organisation
<b>Replicability or scalability</b>	potential for replication of the charity's model, or growth of the charity itself

---

## Good giving principles

- **Pro-active selection of charities based on results:** Donors should support charities that are achieving excellent results for the people that they serve, rather than charities that have the most effective and professional fundraising teams or the lowest administrative costs (all organisations need administrative costs in order to be effective; low admin costs may in fact be a sign of an inefficient organisation).
  - **'Light touch' engagement with charities:** In most instances we recommend that donors minimise the demands on the time and resources of the charities they fund. In practice, this means not imposing arduous reporting requirements and limiting visits and contact with charities.
  - **Funding organisations, not projects:** As a donor, it is tempting to stipulate that a grant can only be used for a particular project, because this makes it much easier to see the direct charitable impact of the donation. However, we believe that this practice can limit the impact of the donation. Firstly, it may cause charities to propose projects that meet the donor's objectives but which stray from their core mission. Secondly, if circumstances change then charities are unable to respond. We believe that the charities we recommend can and should be trusted to make decisions in the best interests of the people they serve, and so in general we recommend that donors fund organisations, not projects. Practically, this means giving unrestricted funding.
  - **'Just right' donations - not too big, not too small:** Judging the right size for a donation to a charity is an art, not a science. If a donation is too big, there is a risk that rapid growth will create significant organisational problems, particularly when the donation runs out. At the other end of the scale, if a donor makes a small donation and requires a charity to go through application and reporting processes then the administrative burden may outweigh the benefit of the donation. Of course, small donations with no strings attached are always welcomed by charities. Our researchers work with charities to understand their financial needs, and recommend a suitable size for a donation. In general, we work on an assumption that contributing more than a third of an organisation's annual income may create problems. However, if a charity is looking to grow significantly and it has a robust strategy for growth, a larger grant may be entirely appropriate.
  - **Multi-year support:** We recommend that donors should provide multi-year support for charities, rather than giving them a lump sum in a single year. Choosing the right length for a grant depends on the specific case – as a guide, grant-making trusts often give three-year grants. Multi-year support gives charity leaders the opportunity to make long term plans to improve their organisations and build projects that will create and sustain improvements in the lives of the people they serve. It also allows donors to build longer-term relationships with the charities, if they wish.
-