

Equipment shortfall: How disabled children are being failed

Executive Summary

Figures released today illustrate the substantial difficulties faced by disabled toddlers and children just to obtain life-changing wheelchairs and medical equipment. The Muscular Dystrophy Campaign has published the findings of Freedom of Information requests and a patient survey, which show that:

- A shocking 50 percent of Primary Care Trusts (PCTs) will not fund the full cost of a powered wheelchair for a disabled child.
- A staggering 1 in 3 children do not receive any NHS funding for a wheelchair.
- Some of these children have life limiting conditions yet they are being forced by the NHS to wait up to 2 years to receive essential equipment which promotes their independence, allowing them to lead normal lives.

National Key Stats

- One in three of the UK's children, with muscular dystrophy, who need to use a wheelchair receive no NHS funding for this piece of equipment.
- Disabled children in England are forced to wait, on average, almost 5 months to receive a wheelchair from the NHS.
- The worst performing PCT, in the North West, has an average waiting period of 2 years for a child to receive a powered wheelchair.
- Over half of the children in England (58%) have to wait at least 3 months for a powered wheelchair and 14% are forced to wait more than 6 months,
- The postcode lottery of NHS equipment provision means that there is a difference in waiting times for equipment of up to 11 months for disabled children living just 4 miles apart.
- Almost all PCTs and Health Boards state that the average cost of a powered wheelchair is about £2,000. However the Joseph Patrick Trust, a grant giving organisation, calculate that the true average cost is in fact £17,500. In reality £3,000 would only pay for the most basic powered wheelchair, which would not meet the needs of most disabled children.

West Midlands Key Stats

- Two PCTs in the West Midlands have waiting times for a powered wheelchair of 18 months compared to a national average of just under five months.
- The average waiting time for a powered wheelchair for the West Midlands region as a whole stands at 33 weeks.
- None of the region's PCT offer wheelchairs with a sit-to-stand function that can maintain muscle strength.

- Just a third of PCTs provide riser wheelchairs which allow children to elevate their seat to be at eye level with their peers, aiding mental wellbeing.
- The 84 day average wait for an electric profiling bed in one PCT in the West Midlands is over three times the national average of 25 days.
- Children living in the West Midlands' face the longest average wait in the country to receive a portable hoist (31 days).
- One PCT in the West Midlands is the worst performing PCT in the country for providing portable hoists with an average wait of up to 56 days against a national average of just 13 days.

London Key Stats

- Only half of PCTs state that they will fully fund powered wheelchairs for disabled children, forcing families to pay out of their own pocket or rely on charities.
- The average wait for an electric bed in one London PCT is 4 months – more than 4 times longer than the national average. This equates to an extra three months where parents must wake up every hour throughout the night to turn their child in bed to prevent breathing difficulties and pressure sores developing.
- The postcode lottery of NHS equipment provision means that one PCT in London has an average waiting time of 1 year for a powered wheelchair, compared to 6 weeks in another inner London PCT, only 4 miles away
- Fewer than 10% of PCTs in London fully fund riser wheelchairs that allow children to raise their seat to be at eye level with their peers or sit-to-stand function that allows children to exercise their muscles and prevent pressure sores
- One PCT in London makes an average contribution of only £700 towards the cost of a child's powered wheelchair.

East of England Region Key Stats

- Only half of Primary Care Trusts in the East of England state that they will fully fund powered wheelchairs for disabled children, forcing families to pay out of their own pocket or rely on charities.
- One PCT contributes only £650 to the provision of a powered wheelchair despite acknowledging that the average cost of such a chair is between £2,000 and £3,000. However the Joseph Patrick Trust, a grant giving organisation, calculate that the true average cost is in fact £17,500. In reality £3,000 would only pay for the most basic powered wheelchair, which would not meet the needs of most disabled children.
- Disabled children in the East of England are forced to wait an average of three months to receive a powered wheelchair.

- The children in one PCT in the East of England must wait up to a year for their powered wheelchair.
- 83% of PCTs do not provide wheelchairs with the sit-to-stand function that allows children to exercise their muscles and prevent pressure sores.
- Fewer than one in five PCTs fund riser wheelchairs that allow children to raise their seat to be at eye level with their peers.
- One PCT in the East of England region will only fund half the cost of a £1,000 electric profiling bed that allows a disabled child to adjust their position in bed at night.

East Midlands Key Stats

- One PCT in the East Midlands has the longest average waiting time for an electric profiling bed with children forced to wait up to a year to receive their vital equipment.
- Responding to the Muscular Dystrophy Campaign's Freedom of Information request, the PCT said *"the PCT only provides profiling beds occasionally. The issues are always whether there is a specific medical/health needs [sic], or whether it would assist carers, or improve a child's independence. This then becomes a social care need. This argument often goes round in circles as it is normally both!"*
- Only 40% of Primary Care Trusts in the East Midlands region state that they fully fund powered wheelchairs for disabled children, forcing families to fund their own equipment or rely on charities.
- None of the region's PCTs provide powered wheelchairs with a riser or sit-to-stand function – essential features that vastly improve a child's physical and mental wellbeing.
- Disabled children must face a 53 day wait to receive an electric profiling bed, a figure more than twice the national average of 25 days. This equates to an extra month-and-a-half where parents must wake up every hour throughout the night to turn their child in bed to prevent breathing difficulties and pressure sores developing.

South East Key Stats

- Less than half the South East's PCTs state that they fully fund the cost of powered wheelchairs for disabled children, forcing parents to contribute large sums of money towards vital equipment or having to rely on the support of charities.
- A third of the region's PCTs do not provide tilt-in-space wheelchairs – which allow children to relieve pressure on their bottom and legs, preventing pressure sores – compared to 100% PCT provision in the North East and East of England.
- Only 23% of PCTs fund powered wheelchairs with a riser function which allows a child to raise their seat to be at eye level with their peers.

- Just one of the region's seventeen PCTs makes any financial contribution towards powered wheelchairs with a sit-to-stand feature which allows a child to exercise their muscles.
- Children living in two PCTs in the South East are forced to wait over three times as long for an electric profiling bed as children in the rest of the region (120 days against an average of 36).
- One PCT in the South East has an average waiting time for a portable hoist of up to 4 months nearly ten times longer than the national average waiting time of just 13 days.

South West Key Stats

- The South West region has the longest average wait as a region for a powered wheelchair in the country at 34 weeks.
- Children in three PCTs must wait almost a year to receive their wheelchair.
- Fewer than one in four PCTs fully fund wheelchairs which incorporate a riser or sit-to-stand function that can greatly aid a child's physical and mental development.
- One PCT in the South West has an average waiting time of 120 days for a child to receive an electric profiling bed – over four times longer than the regional average of 27 days.

Yorkshire and Humberside Key Stats

- Only two out of five PCTs fully fund powered wheelchairs for disabled children.
- Only 10% will fund wheelchairs with a riser function that allows children to elevate their seat to be at eye level with their peers, aiding mental wellbeing.
- None of the region's 14 PCTs fully fund wheelchairs with a sit-to-stand feature that can maintain a child's muscle strength while only one 1 PCT offers any financial contribution at all.
- The 39 week wait for a powered wheelchair endured by children in one PCT in the Yorkshire and Humberside region is more than twice the 19 week UK average.

North East Key Stats

- None of the North East's PCTs provide wheelchairs for disabled children which incorporate the sit-to-stand feature that is essential to help maintain muscle strength and prevent pressure sores.
- All but one of the region's PCTs rely on charitable funding to provide powered wheelchairs with the riser function that allows children to raise their seat to eye level with their peers and aid mental development.

- The average length of time for one PCT in the North East region to provide children with electric profiling beds (84 days) and portable hoists (42 days) are both more than three times the national average.

North West Key Stats

- The North West contains the country's worst performing PCT with an average waiting time of 2 years for a powered wheelchair.
- Fewer than half of the region's PCTs fully fund children's powered wheelchairs.
- Only 9% of the PCTs fund wheelchairs that incorporate a riser or sit-to-stand function that helps develop both physical and mental development.
- Children in one North West PCT must wait on average up to 56 days to receive a portable hoist.

Scotland key stats:

- Only half the PCTs in Scotland stated that they paid the full cost of a powered wheelchair for disabled children
- Children living in Scotland face a wait of 22 weeks to receive a powered wheelchair – two weeks longer than the average wait in England.
- Wheelchair services for a series of Scottish islands are provided by a rehabilitation service which only visits the region once every six months. This means that if a powered chair is necessary, an assessment for a powered chair could take place on one visit with delivery/handover only on the next visit 6 months later – **waiting time for a powered chair is a minimum of 6 months**
- Two Scottish Health Boards do not provide electric profiling beds for children under twelve.

Footnote

The data published by the Muscular Dystrophy Campaign has been gathered by a number of Freedom of Information requests to the relevant Primary Care Trusts (PCTs) and Local Health Boards in England and Scotland, with a 54% response rate. Information has also been taken from a UK-wide patient survey of 237 children under the age of 20, carried out by the Muscular Dystrophy Campaign.