

Healthcare a 'postcode-lottery' for children with cerebral palsy, new study shows

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Children with cerebral palsy face a 'postcode-lottery' in the healthcare they receive, new research has revealed.

A study, led by experts at Newcastle University and City Hospitals Sunderland NHS Foundation Trust, found stark differences in the quality of healthcare given to <u>children</u> and young people with this condition.

Judith Rankin, professor of maternal and <u>perinatal epidemiology</u> at Newcastle University, is co-author of the study, published today in the journal *Developmental Medicine & Child Neurology*.

The findings identified variations between geographical areas across a range of standards of care, including use of MRI brain scans, access to surgical expertise, and monitoring of pain.

Examining the records of 389 children and young people with cerebral palsy who were born in the North of England, researchers found that more than a third never received an MRI brain scan, which is important for understanding the cause and prognosis.

Although MRI provision did improve over time, the difference between districts was significant, with over 90% receiving an MRI in the best performing area, compared with less than 10% in the worst.

Similar disparities were observed in the management of pain, which is known to be an especially important influence of quality of life for



children with cerebral palsy.

A third of children had no record of being asked whether they were experiencing pain, but this ranged from everyone having a documented discussion about pain in the best performing area, to just one-in-five in the worst.

Prof Rankin, from Newcastle University's Institute of Health and Society, said: "The data used for this important study was derived from a long-standing cerebral palsy register. Collecting and reflecting on high-quality population based data is important for ensuring excellent and equitable clinical care is delivered to all disabled children and young people.

"Unfortunately, it is not currently possible to replicate this study in other areas of the UK as this data is not routinely collected."

The study also examined whether children and <u>young people</u> from deprived communities received poorer care than their more advantaged counterparts, and found that they were less likely to have had a documented discussion about their levels of pain.

Other key areas where variation was observed between areas was in the recording of the state of the spine, and whether an orthopaedic surgeon was routinely involved in the care of those with the most severe movement disorders.

Dr Karen Horridge, consultant disability paediatrician at City Hospitals Sunderland NHS Foundation Trust, who led the research, said: "There are always going to be areas of better practice and areas where there's room for improvement, but these findings show really alarming levels of variation across a range of factors.



"We looked at a number of key standards of care, and found that many children were missing out simply because of where they lived.

"Every disabled child deserves the best opportunity for the best outcomes, but that doesn't seem to be what was happening, at least not for children with <u>cerebral palsy</u> at the time of our study.

"No child should be left in pain. As clinicians and therapists we must proactively ask about it at every consultation and where present, make robust pain management plans.

"To avoid this kind of 'post-code lottery', we urgently need the development of national and international guidelines, and for these to be backed-up by policy."

A breakdown of the results has been shared with healthcare staff working in each of the study areas, so they can compare their own practice to that in other areas and make improvements where necessary.

More information: "Variation in health care for children and young people with cerebral palsies: a retrospective multicentre audit study." *Developmental Medicine & Child Neurology*. doi: 10.1111/dmcn.12740

Provided by Newcastle University

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