

research snapshot

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How Can the Health Care System Better Work With Young Adults With Cerebral Palsy?

What is this research about?

Teenagers and young adults with cerebral palsy (CP) face challenges in healthcare. Common challenges are:

- Issues talking with service providers.
- Problems accessing basic health services.
- Breach of rights related to confidentiality.

Young people with CP experience trauma when health care programs have negative attitudes. Most studies have considered issues from a caregiver or clinician point of view. Understanding these issues from the youth's point of view is important in order to empower them.

What did the researchers do?

The researchers included young adults aged 18 to 25 with CP in their sample size. Information about name, age, and living arrangements was collected through a short survey. Then a semi-structured interview was conducted with each person. The interview was created to identify the challenges young adults with CP experience in the healthcare services.

What you need to know:

Young adults with CP often face challenges in the healthcare system. These issues all contribute to a negative experience for the patient within the healthcare sphere. Autonomy for young adults with CP needs to be respected and more research needs to be directed towards CP.

What did the researchers find?

Young adults had the following challenges when engaging with the health care system:

- Limits in access to the physical space and medical equipment in the location of the services.
- Practitioners who were unaware of the proper use of assistive devices, which are employed to help with daily tasks.
- Basic needs not being met when a hospital stay was necessary.
- Not enough personal support to access assistive devices, like wheel chairs.

Overall, young adults with CP had bad experiences with healthcare professionals that

led to adverse feelings. Being treated like a child was a common experience for young adults when accessing the health care system. They felt this caused service providers to dismiss their opinions, hindering their ability to make choices. A clear concern was that CP is neglected within the healthcare system. This caused young adults to believe that services, knowledge, experience, and expertise are lacking.

How can you use this research?

Practitioners can gain insight into why they should respect the opinions of young adults with CP when providing treatment.

Policy makers can ensure that policies related to patient care are upheld; especially when dealing with young adults with CP.

About the Researchers

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Citation

Lariviere-Bastien, D., Majnemer, A., Shevell, M. and Racine, E., 2011. Perspectives of Adolescents and Young Adults With Cerebral Palsy on the Ethical and Social Challenges Encountered in Healthcare Services. *Narrative Inquiry in Bioethics*, 1(1), pp. 43-54.

Available online at bit.ly/1iRHrrl

Keywords

Cerebral palsy, Disability, Neuroethics, Qualitative research, Transition

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