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How to Ensure People With Neurodevelopmental Disabilities Have Independence in Their Medical Choices

What is this research about?

Autonomy is one of the main principles in medical ethics. Autonomy is the principle that affirms that a person should be allowed to make informed decisions about their health and treatment choices. The presence of cognitive impairments does not mean a person is not able to participate in decisions about their health care. To help people make informed choices, guidelines advise the use of communication tools or specialized human resources. As a result, some people's autonomy may include the support of other persons. When a person has a cognitive disability, it should not be assumed they are incapable of making health care choices. These assumptions can lead to a decrease in the autonomy a person is given. Talking about health care decisions with people who have disabilities will help identify any concerns with autonomy.

What did the researchers do?

14 young adults between the ages of 18 and 25 were interviewed. To be included in the study, they had to understand and respond to the interview questions, and had to be diagnosed with cerebral palsy. Each young adult completed a semi-structured interview and a brief survey.

What you need to know:

Autonomy is important in the adult healthcare system. When a youth with cerebral palsy moves to the adult healthcare system, their autonomy may be limited but can be fostered and enriched. These are some of the factors that need to be accounted for.

The topics covered during the interviews were:

- What is it like living with their disability?
- What was it like to move to the adult health care system?
- What are some of the ethical and social issues they have had in the adult health care system?

The interviews were conducted in French. The data were coded by 2 researchers and then analyzed using statistical software and translated into English.

What did the researchers find?

A number of issues were found in regards to respecting autonomy. Some of these concerns were:

- Little respect for the choices made by young adults about their health care.
- Varied involvement of parents in decisions made for the youth within the adult health care system.
- The ability of young adults to make an informed choice was not always promoted.
- No backup plan for when a support person is not present to keep youth independent.
- Change in behavior towards young adult when not accompanied to health appointments or clinics.
- Speech difficulties making it hard to communicate.
- Concern that health care providers are not sharing all information with youth.
- Barriers to being able to talk about private health concerns with a doctor.

There was a connection between the limited access to the physical healthcare space and the autonomy of choice. Problems getting to the health care space also decreased autonomy.

How can you use this research?

Policymakers will learn why plans for adults with disabilities need to be flexible. They will also be able to stress the need of training personnel to improve accessibility.

Healthcare providers need to be aware that access to the physical health care space impacts a person's autonomy.

About the Researchers

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Autonomy, Cerebral palsy, Ethics, Health services, Independence

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