

# research snapshot

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## How Can Ethics Help Young Adults With Neurodevelopmental Disabilities as They Change Over to the Adult Health Care System?

### What is this research about?

There is little research on how clinical programs support young people as they change from the paediatric to the adult health care system. Yet, this topic is vital due to the complex needs of young adults who have neurodevelopmental disabilities (NDD). Some challenges that young people with NDD face when transitioning to the adult system are:

- Lack of training or experience with NDDs in the adult system.
- Limited plan for moving youth to the adult health care system.
- Loss of the trusted relationship with their doctor.
- Issues with communication between youth and adult health care system doctors.

Concerns related to when young people with NDD change over to the adult health care system may be lessened when ethics are brought into the process.

### What did the researchers do?

A review of the few research articles that deal with young adults with NDD as they change over to the adult health care system was done.

### What you need to know:

There is limited research on the complex issues of young adults with disabilities as they change over to the adult health care system. This paper focuses on the concerns of changing health care systems for youth with neurodevelopmental disabilities.

Then an interdisciplinary group of Canadian researchers and clinicians met. They discussed some of the key problems with transition to the adult health care system. The 4 goals for this meeting were to identify ethical issues, create plans for ethical issues, identify barriers, and find where knowledge is lacking.

### What did the researchers find?

Actively thinking about ethics means considering how we treat young adults with NDDs. Thus, thinking about ethics in the transition process will help manage problems when these young adults are entering the adult health care system. An example where ethics can help is when answering the questions of at what age a young adult with NDDs should be moved to the adult system.

It is important to acknowledge that independence is not the same for all people. Not all young

adults have the same expectations or desires about the change to adult health care. Moving to a personalized transition model would let independence be defined to suit each person. There are many ways by which young people can prepare, and be supported for, the transition to adult care. Healthcare provider attitudes can impact the transition process. Adapted models help to deal with the complexity of moving young adults with NDDs to the adult system.

### How can we use this research?

Practitioners will learn some of the main concerns of young adults with NDD transitioning to the adult health care system. They will also be introduced to how ethics can help manage these challenges.

Policy makers will learn about the importance of having flexible plans in place to help ensure that youth with NDDs are given the chance to succeed.

### About the Researchers

Dr. Eric Racine is Director of the Neuroethics Research Unit at the Institut de recherches cliniques de Montréal. He is also appointed at the University of Montreal and McGill University.

[eric.racine@ircm.qc.ca](mailto:eric.racine@ircm.qc.ca)

Dr. Emily Bell is an Associate Researcher at the Institut de recherches cliniques de Montreal and Adjunct Professor at McGill University.

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### Keywords

Ethics, Paediatrics, Adult health care system, Young adults, Neurodevelopment disability

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[KT@neurodevnet.ca](mailto:KT@neurodevnet.ca)

