

Helping young adults with neurodevelopmental disabilities

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In a study published today by the medical journal *Paediatrics & Child Health*, IRCM researchers address shortcomings in transitional care in the Canadian healthcare system. The team led by Eric Racine and Emily Bell, Montréal neuroethics experts, identified important challenges in the transition from paediatric to adult health care, especially among youth with neurodevelopmental disabilities (such as autism spectrum disorders, fetal alcohol spectrum disorders and cerebral palsy).

"Health care transition is a crucial process in the lives of youth with neurodevelopmental disabilities and their parents," explains Dr. Racine, Director of the Neuroethics research unit at the IRCM. "Transition challenges are likely to be greater among these adolescents because of the complexity of their [health care](#) needs and the stigma associated with physical and intellectual disabilities that may accompany their disorders. Some individuals believe they were suddenly removed from paediatric care and thrust into a foreign system for which they had not been adequately prepared."

Transition in health care is the process during which adolescents gradually prepare for and shift toward care in the adult system. Several challenges exist in this transition process, including the lack of preparation for the transfer; adult health care providers' lack of experience, training and expertise in traditionally paediatric diseases and conditions; the loss of a longstanding and trusting relationship with the paediatrician; and poor relationships and communication between adolescents and their adult health care physicians.

"We focused on the important issues that arise during transition for youth with neurodevelopmental disabilities," says Dr. Bell, Research Associate in the IRCM's Neuroethics research unit. "From an ethics perspective, a fundamental component of transition is whether individuals with disabilities feel respected, and how their values and autonomy are integrated, developed and supported within the transition."

Several studies have reported problematic attitudes and behaviours by health care providers in their communication and interaction with youth with neurodevelopmental disabilities. These reports suggest that health services and transition programs may respond inadequately to the needs of these individuals.

"Our study confirms that health care providers should play a constructive role in the transition process, and that failure to fulfil this role can cause potentially harmful and frustrating situations," adds Dr. Bell. "Ethics considerations may help transition programs become more responsive to the needs, perspectives and expectations of different stakeholders and lead to the integration of a personalized approach."

A common practice in the transition process is upholding a firm age for transition, in contrast to a developmentally appropriate time for transition. This introduces significant challenges when independence is potentially forced on youth, when the adult system is unable to cope with unprepared patients and when parents are inappropriately left out of shared decision making.

"Developing policies regarding the appropriate time for transition is one example in which ethics challenges could be diminished," concludes Dr. Racine. "We hope our reflection will be useful to both practitioners and scholars, and that further practical policy and scientific developments will bridge existing gaps in the transition process for youth with neurodevelopmental disabilities."

"CIHR is pleased to partner in furthering the work of Drs. Racine and Bell," says Dr. Anthony Phillips, Scientific Director of the CIHR Institute of Neurosciences, Mental Health and Addiction. "Their research will help to ensure access to the continuum of care so important to ensuring significant support for youth living with neurodevelopmental disabilities. It is essential that [health care providers](#) consider these findings carefully as they may guide improvements to the transition process from paediatric to adult health care services."

Provided by Institut de recherches cliniques de Montreal

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