

# Contextualized Autonomy in Transitional Care for Youth With Neurologic Conditions: The Role of the Pediatric Neurologist

Journal of Child Neurology  
1-7

© The Author(s) 2020

Article reuse guidelines:

sagepub.com/journals-permissions

DOI: 10.1177/0883073820918454

journals.sagepub.com/home/jcn



Aline Bogossian, MSW, PhD<sup>1</sup> , Annette Majnemer, OT, PhD, FCAHS<sup>2,3</sup>, and Eric Racine, PhD<sup>4,5</sup>

## Abstract

Youth with neurologic conditions experience multiple life transitions. The transfer from pediatric to adult health care systems exemplifies one such complex and multifaceted transition that occurs in parallel with developmental, legal, and social changes that may influence the roles and responsibilities of youth and their caregivers. As a result, ethical situations, questions, and challenges may surface in transition care to which pediatric neurologists may be confronted. In this article, we focus on the topic of autonomy and situations that may arise in transition care in the context of pediatric neurology. Building from a clinical case, we present the concept of contextualized autonomy to work through the questions that arise in the case and propose ways of thinking through those challenging situations in transition care.

## Keywords

youth, cerebral palsy, health care transition, autonomy, pragmatic health ethics

Received October 7, 2019. Received revised February 17, 2020. Accepted for publication March 4, 2020.

## Case Illustration

Box 1: A young woman with cerebral palsy and epilepsy facing autonomy issues at the time of transition [*The case study presented in Box 1 has been developed from an aggregate of clinical cases and is for educational and reflective purposes only.*]

Liz is a 16-year-old with a diagnosis of cerebral palsy and a history of co-occurring epilepsy that is currently controlled. Liz presents with a mild to moderate intellectual disability, requiring moderate support for self-care and planning daily living activities. Liz is nonambulatory, though she has learned to use a motorized wheelchair. She attends a community high school where a specialized aide provides in-class support, and she receives physical and occupational therapy to help her with daily living adaptations and maintaining motor abilities. Liz has learned to travel between home and school on an adapted school bus and receives supervision from her parents to manage her other travel needs such as making online arrangements for transit on the public, adapted transit system. She is a bright, cheerful, and creative young person who enjoys writing stories, connecting with friends on social media, and has begun to express romantic interest in a classmate who reciprocates this interest. She lives with her biological parents and her older sister in a suburban setting near a large, Canadian metropolitan city.

During her annual visit to the neurologist, transitional care was discussed. Liz's parents had many questions about the continuity of neurologic follow-up and medications and were provided with answers by the neurologist who warned that it would likely be difficult to receive the same type of support in the adult system. When Liz spoke about her future academic plans, she told the neurologist that she hopes to attend a creative writing program she had learned about that was being offered at a local university. She then began to mention that

<sup>1</sup> School of Social Work, Faculty of Arts and Science, Université de Montréal, Pavillon Lionel-Groulx, Montréal, Quebec, Canada

<sup>2</sup> School of Physical & Occupational Therapy, McGill University, Montréal, Quebec, Canada

<sup>3</sup> Montreal Children's Hospital and RI-McGill University Health Centre & Centre for Interdisciplinary Research in Rehabilitation, Montréal, Quebec, Canada

<sup>4</sup> Pragmatic Health Ethics Research Unit, Institut de recherches cliniques de Montréal, Montréal, Quebec, Canada

<sup>5</sup> Department of Neurology and Neurosurgery, Biomedical Ethics Unit and Division of Experimental Medicine, McGill University, Montréal, Quebec, Canada

## Corresponding Author:

Aline Bogossian, MSW, PhD, Université de Montréal, Faculté des arts et des sciences, École de travail social, Pavillon Lionel-Groulx, 3150, rue Jean-Brillant, Bureau C-7116, Montréal, Quebec, Canada H3T 1N8.

Email: aline.bogossian@umontreal.ca

she would like to live on campus but quickly stopped as she could see that her parents were uneasy and disconcerted about upcoming changes to health care provision in the adult sector.

How can the neurologist engage Liz in discussions about her health, safety, and independence? Is the fact she is not actively participating or even leading the conversations a sign that she is not interested in managing her own care or prepared to do so? Should the neurologist prepare her for autonomous decision making, and if so how? In the event that Liz experiences difficulties (barriers) in communicating and expressing her wishes and preferences (eg, familial, psychological, social), how should the neurologist advocate for her?

## Introduction

Advances in neuroscience as well as in medical and surgical care have led to the increased likelihood that youth with childhood-onset neurologic conditions survive and thrive into adulthood.<sup>1</sup> Youth like Liz, who are survivors<sup>2</sup> of complex medical conditions, live with an array of associated and sometimes overlapping neurologic diagnoses and neurodisabilities that will require long-term follow-up and support across different spheres of development and activities of daily living.<sup>3</sup> Simultaneously, youth like Liz will also have hopes and aspirations for their future lives, alongside changes and challenges associated with their health condition.<sup>4,5</sup> Similarly, parents and caregivers, like Liz's parents, experience the joys of parenthood along with worries about their child's health condition as well as concerns about locating appropriate supports, making efforts to ensure that their child is provided equal life opportunities for participation and happiness.<sup>6</sup> Pediatric neurologists, over the course of their encounters with children and families, including during transition planning have to address the various biological, medical, developmental, and social transitions of these youth, thereby being exposed to the multiple experiences and needs that touch the lives of their young patients and their families over time.<sup>1,7</sup>

Pediatric to adult health care transitions in the context of neurology are multifaceted and complex. They involve the collaboration and involvement of many actors and institutions, with different professionals assuming leadership for the smooth trajectory. Within pediatric health care transitional care services more generally, and within transition care services in pediatric neurology more specifically, multiple situations may evoke ethically problematic situations occurring in parallel with developmental, legal, and social changes, influencing the roles and responsibilities of youth,<sup>8,9</sup> their caregivers,<sup>1</sup> as well as pediatric neurologists.<sup>10</sup> As a result, smooth and uninterrupted transitional care requires "interdisciplinary collaboration . . . and positive interaction of 2 or more health professionals who bring their unique skills and knowledge to assist patients/clients and families with their health decisions."<sup>11</sup>

In this article on ethical aspects of health care transition, we define youth as people aged 15-24 years, aligned with the categories used by the World Health Organization.<sup>12</sup> We focus

on the value and ethical principle of autonomy and the role of the pediatric neurologist, as an integral member of an interdisciplinary transition support team. An important goal of most health care transition programs is the development of autonomy and independence of youth to promote transition readiness, to support youth to gradually manage their own health care needs and to advocate for themselves in the adult health care system.<sup>13</sup> Although autonomy may be a valued goal, the literature suggests that this goal may not be equally valued by all actors in the same way.<sup>14,15</sup> Indeed, functional and social complexity that might accompany conditions like cerebral palsy may influence the quality of youths' transitions, including their ability to become autonomous and independent in the traditional sense.<sup>5,16</sup> In this article, we take into account that individuals vary in their autonomy preferences (irrespective of their level of functioning)<sup>15,17</sup> and that, based on recent clinical guidelines,<sup>7,18-20</sup> the pediatric neurologist, as a specialized member of an interdisciplinary transition team, has an important role to play in advocating for, facilitating, and supporting youth autonomy for youth with neurologic conditions. In our case analysis, we assume Liz to be a youth in the process of developing into an autonomous adult and propose our framework in support of her "anticipatory autonomy rights" (ie, rights that she will come to have as she grows up).<sup>21</sup> In our exploration of the value and ethical principle of autonomy in the context of health care transition of youth with neurologic conditions, we draw guidance from pragmatic ethics, to offer an account of autonomy as a composite ability that can be strengthened and reinforced.<sup>22-24</sup> In this way, we suggest an empowering role of the pediatric neurologist as advocate for supporting the emerging and contextual autonomy of youth like Liz.

## Autonomy and Healthcare Transitions

Autonomy, as an ethical principle in the context of health care is a highly valued principle for human life and for ethics.<sup>15</sup> In health care and social service settings, autonomy designates the ability to make informed and free decisions<sup>25,26</sup> Respect for autonomy, a foundational principle in biomedical ethics,<sup>25</sup> is built on the positive valuation of an ability and related experiences, consistent with modern psychological literature.<sup>27</sup> However, structural and contextual factors may impact the development and exercise of autonomy for youth with chronic health conditions such as philosophical or cultural differences in health care delivery between pediatric and adult health care delivery models.<sup>1</sup> Paternalistic models of care may also hinder the promotion of self-determination, creating dependencies among young neurology patients<sup>28</sup> who may feel unprepared to move to the adult health care system where limited family involvement and patient autonomy in decision making are the norm. Changes to legal status may also create opportunities as well as tensions as youth will have the opportunity and the right to participate in their care decisions<sup>5,29</sup> in a manner that may not align with the wishes of their parents, who made those decisions on their behalf.

Understanding or unpacking the concept of “autonomy” to work with youth with neurologic conditions, like Liz, requires a holistic approach that pulls from rich accounts of people’s lived experiences as well as the philosophical scholarship. Philosophical pragmatism offers an expanded and dynamic entryway into the analysis of autonomy for it draws on multiple sources of knowledge (eg, psychological theory on autonomy and human flourishing) and acknowledges the importance of lived experience in its analysis (R.E., unpublished data).<sup>30</sup> From this perspective, spurious dichotomies and fallacies of false alternatives such as “respecting or not respecting autonomy” can be avoided. Rather, autonomy can be viewed much more broadly, avoiding the pitfall of considering individuals as static agents whose existing and/or desired autonomy does not vary in time and in different contexts. Through the pragmatist lens, autonomy is viewed as a dynamic concept where people, such as Liz, or her parents, or the pediatric neurologist, all have an empowering role to play in the development of Liz’s autonomy.

The pragmatist account of contextualized autonomy recognizes autonomy as a composite “ability” that is experiential (R.E., unpublished data) and that can be empowered and enacted by a moral agent, like Liz. Autonomy is described as contextualized because it is an ability of the agent that is exercised in interaction with a number of contextual factors. It is valued because it contributes to positive development, well-being, and health.<sup>27,31</sup> A number of *component abilities* (eg, voluntariness, self-control; see explanations below) make up the broader notion of autonomy though there is no hierarchy among these. Decisions or actions are considered more or less autonomous from this perspective based on the exercise of certain component abilities. Weakness in these component abilities point to areas that can be explored and supported such that an individual can experience autonomy and enrich his or her experiences in the world. In a contextualized account of autonomy, agent- and context-related factors combined lead to a fuller understanding of how autonomy can be empowered or diminished. For example, examining the interaction between Liz (the agent) and her social context (family, school, formal support systems such as the pediatric neurologist and the interdisciplinary health care transition team, professionals in physical rehabilitation services, informal support systems such as peers) can offer fruitful information for work with her. Full descriptions of each component ability presented below and in Table 1 will be presented elsewhere (R.E., unpublished data). The discussion below explains how the model can be interpreted and applied in the case of Liz in the context of a neurologic encounter in which the topic of transition is discussed.

In Table 1, we offer an outline of how to work with Liz in an exploration of her goals using the framework of contextualized autonomy as a guide for practice.

*Ethically problematic situations in transitional care related to autonomy.* In our case example, a number of ethically problematic situations can be encountered. An ethically problematic situation is a “worrisome stake that needs discussion, attention

and to be answered and surmounted via a concrete response taking into account specific agents and context involved”<sup>13</sup> in contrast to an ethical issue, which does not necessarily designate a lived experience in a given context.<sup>13</sup>

The context within which autonomy is exercised makes a difference to how empowered or, alternately, how diminished autonomous actions can be. If we consider Liz’s context, we would explore factors that support or inhibit her ability to learn and develop skills that will enhance her ability to live independently while attending university, while remaining cognizant of any needed protections. Drawing from this case, the pediatric neurologist and the broader interdisciplinary team of actors can play an advocacy role through an awareness that Liz’s autonomy needs are important and relevant by providing space and opportunities for joint or private discussions when they notice her reticence, and by providing opportunities for Liz to take ownership of expressing her choices. This requires the sensitive task of respecting the important relational bonds and interdependence of Liz and her parents,<sup>32,33</sup> and the bonds of trust that they themselves have built over the years of working with Liz and her parents. How can the neurologist balance parents’ discomfort and acute need for information as well as their need to stay involved and informed about Liz’s health care while also providing Liz the attention and opportunity to express her needs and questions as an emerging adult?<sup>34,35</sup>

In the case above, the pediatric neurologist - in collaboration with team members - with an eye toward enhancing Liz’s developing sense and need for autonomy, may want to think about the most profitable way to hold discussions that will provide space for everyone’s concerns, in the manner that makes sense. For instance, the neurologist can seek collaboration from members of an interdisciplinary transition team in order to structure and to provide space for joint family concerns as well as time for individual meeting with Liz.<sup>32</sup> In parents’ presence, the neurologist can signal to Liz that her opinions matter by speaking directly to her and inquiring about her thoughts about future independent living goals. In doing so, the neurologist would be signaling to Liz that her needs beyond health care are important and that there is a space where conversations about those broader needs can happen. The neurologist can solicit the support of team members, such as a social worker to guide Liz (and her parents) to prepare for future independent living, if that is the goal.<sup>36,37</sup> For example, the neurologist and team can open up dialogic spaces for Liz to discuss practical needs for accessible housing, self-care, medical care, and insurance in order to increase her practical knowledge on what she might need to have in place. In these discussions, the pediatric neurologist may also want to work with Liz, her parents, and the broader health care team (eg, social worker, occupational therapist) to identify the individuals and service provider agencies who have experience with working with youth with disabilities in the pursuit of independent living. Using the contextualized account of autonomy as a guiding concept and tool, the pediatric neurologist can walk through issues in this case to address Liz’s autonomy support needs.

**Table 1.** Contextualized Autonomy Framework and Guidance for Practice.

Component Ability	Description	Practice Considerations	Guiding Questions
Voluntariness	The ability and degree to which an action or decision emerges from the individual, and not through coercion	Set the stage for Liz to think freely about her life goals and preferences. Acknowledge that Liz may have questions beyond health care that she may want to discuss freely in private (or in collaboration with parents)	What does Liz want to be able to do on her own at this time and in the future? What aspects of her life beyond health care does she want to discuss with the neurologist?
Information	The ability and degree to which individuals have legitimate information required to take decisions or action	Explore Liz's understandings about the types of goals she seeks to achieve. Refer Liz to support services and sources of information to help her to address and achieve her goals. Follow up with Liz about the meaningfulness of information and usefulness of information that she has received and ensure that the support received is useful for achieving those goals.	Given Liz's goals, what does she understand about what she needs to do? Who and what can help her to obtain the information she requires? Given Liz's goals, what types of supports and services does she already have in place to help her? What types of supports and services does she need to seek? Who can she consult and work with to find this information? How useful is this information and what else does she need to explore?
Control	The ability and degree to which individuals experience themselves as able to take actions toward desired goals	Explore with Liz the factors that could undermine the ability and degree to which she controls her life. Refer Liz to appropriate and desired support services to help her gain control over her life.	Are there contextual (eg, physical, interpersonal) factors impeding the ability and degree to which she has a handle on her own life? Does Liz want complete control over her decisions or does she prefer to delegate some decisions to her parents?
Deliberation	The ability and degree to which individuals have thought about the motivation and reason for a choice	Explore the elaboration of goals and their implications with Liz. Explore with Liz the various means and outcomes she has been thinking about, including alternatives to her current plans.	What are the kinds of facts and perspectives that would help Liz mature in her deliberation about her goals and the means to reach them? If ever Liz's plans feature significant challenges, has she considered alternative means of achieving her goals and aspirations?
Authenticity	The ability and degree to which actions reflect the self, individuality, character, personal integrity, and coherence	Explore the meanings of decided actions for Liz, and the meaningfulness of these decisions with who Liz is as a person as well as who she hopes to become. Create opportunities to follow up with Liz about the steps she has undertaken and how those line up with previous articulations and/or alternative views about the meaningfulness of her goals. In follow-up meetings, explore whether the proposed actions continue to align with her goals and preference.	What are Liz's hopes for herself and how do those line up with her articulated preferences and values? Why does this goal matter to her and can she be helped to explain it to others?
Enactment	The ability and degree to which a decision can be actualized, and in the event of the contrary, can result in frustration	Explore realizability of the decided action with Liz.	Is this goal realizable at this moment? What is concretely needed to realize this goal?

#### Analysis using contextualized account of autonomy

*Voluntariness.* A first component ability of contextualized autonomy is *voluntariness*, referring to the ability and degree to which an action or decision emerges from the individual, and

not through coercion. Drawing from the case, an acknowledgment that Liz is an emerging adult who has goals that span beyond health care management may be a good place to start an exploration of the supports she might need in order to

nurture her autonomy, even if she appears indifferent. Respect for autonomy of patients is demonstrated when patients are informed, engaged in discussions and decisions, and supported in developing their health care preferences and choices.<sup>38</sup> These actions will signal to the patient that they are invited and encouraged to take initiative in matters that concern them. Moreover, these actions will also signal to the patient that their perspectives matter, that they should be discussed and embedded in a plan that supports their choices. Therefore, in these discussions, the neurologist may want to explore what Liz wants to do on her own in order to help her locate supports in line with her goals and preferences. Her responses will help the neurologist understand her preparedness, her current supports, as well as her desires. This will also allow the neurologist and team to ally with Liz and her parents and ensure safe progressive transition planning.

**Information.** *Information*, another component ability of the model of contextualized autonomy, refers to the ability and degree to which individuals have correct, legitimate information required to take decisions or actions. Referring to our case, the neurologist takes an advocacy role to support Liz to explore resources available for university students with disabilities who seek independent living options. An unintended consequence of growing up with a chronic health condition may be the lack of opportunities youth are offered in order to experience age- or development-appropriate life choices.<sup>39</sup> The pediatric neurologist [and team], beyond coaching youth to prepare to enter the adult health care settings, may also take the opportunity to expand the definition of transitional care beyond health care management to incorporate personal, holistic life, and existential questions.<sup>40</sup> Pediatric neurologists (as members of interdisciplinary teams), in acknowledging and respecting youths' choices, values, desires, and decisions<sup>5,41</sup> can offer opportunities to young people to think about, ask about, and articulate broader lifestyle preferences and choices (eg, independent living, higher education, employment, leisure, sexuality). In doing so, they can also seek opportunities to evaluate how youth, like Liz, may understand what they need to do to prepare for the goal, and to help them seek supports and sources of information to address those needs as well. The recognition of the autonomy of these youth as a staged process may involve discussions with parents about the graduated transfer of responsibility from parent to youth.<sup>39,40,42</sup> This imperative points to the need for sensitivity on the part of the pediatric neurologist and team to empower both Liz and her parents through the provision of information and coaching<sup>28,38</sup> in a way that respects youth's right to self-determination in a context where practice from the perspective of youth's best interest<sup>40,43</sup> prevails. This infers the duty of the pediatric neurologist to be a partner in assisting youth to develop skills to manage self-care, to self-advocate<sup>38,40</sup> about matters that may influence their health, well-being, and quality of life.

**Control.** In the conceptualization of contextualized autonomy, *control* refers to the ability and degree to which individuals experience themselves able to take effective actions toward

desired goals. The pediatric neurologist (as members of interdisciplinary teams) acting as an advocate to support Liz may seek out indications of autonomy needs, goals, and preferences in discussions with her and then examine the obstacles (both personal and contextual) that can be addressed in order to support her to achieve her desired goals. For instance, if Liz appears timid or reticent to discuss her own needs because she worries about their impact on her parents, strategies can be used to signal that her needs are important (example: using active listening techniques to identify concerns and then taking the opportunity to speak directly to her at the utterance of a concern or question or encouraging her to ask for what she needs by providing the space for her to do so). Asking Liz what she would like to do and what she thinks she needs to achieve her goals provides her with a signal that she is in control of decisions about herself.

**Deliberation.** *Deliberation* refers to the ability and degree to which individuals have thought about the motivation and reason for their choices. The ethical principles of autonomy, self-determination, and the rights of young people with neurodisabilities to articulate preferences and make their goals known may be challenged within a culture where young people with neurologic conditions have traditionally been viewed as less capable to be involved in these decisions. However, young people can make valuable contributions regarding their health care and life decisions<sup>14,15,32,44</sup> and can be assisted to do so through innovative shared decision-making interventions geared to elicit and integrate youth values, goals, and concerns with accurate and age-appropriate information. One way to accomplish this is by acknowledging that young people have goals that are meaningful and appropriate. Being poised to ask Liz about how she imagines her transition to university and independent living will be and demonstrating sincere curiosity about what she would like to do to arrive at those goals and offering supports are ways that will show Liz that her goals are acknowledged and supported. Such practices serve to preserve, promote, and ensure dignity and respect for youth's deliberated choices<sup>38,42</sup> and should be at the forefront of transition care.

**Authenticity.** *Authenticity* refers to the ability and degree to which actions represent individual personal preferences, taking into account individuality, character, personal integrity, and coherence to self (R.E., unpublished data). Clinicians working with Liz can demonstrate awareness and acceptance that Liz has a vision of herself and has hopes for who she wants to become in the future. There are different pathways through which the pediatric neurologist can play an important role that fosters authenticity.<sup>18</sup> Working toward the best interests of the patient, the pediatric neurologist can enter conversations with openness, curiosity, and acceptance of her goals through open and purposeful communication. These exchanges may, in turn, provide opportunities for Liz to articulate her authentic desires and choices that can then be articulated to the team by the pediatric neurologist. Moreover, by eliciting her goals and preferences and locating supports to build competence in expressing her preferences,<sup>5,38,40</sup> the neurologist will be signaling that

her hopes for her future matter, thereby demonstrating respect for her dignity and worth as a person.

**Enactment.** The component ability of *enactment* refers to the ability and degree to which a decision can be actualized, and on the contrary, can lead to frustration. Exploring the realizability of Liz's decisions can be done at the individual level by examining, for instance, whether Liz, with her current set of skills and knowledge, can indeed actualize her goals. It can also be done at the systemic level by monitoring patterns and gaps in the broader health, social service, and educational systems that may lead to unfulfilled goals. At the individual level, where gaps in knowledge or ability are demonstrated, the pediatric neurologist and team can problem-solve by determining adaptations and competencies required in order to perform the tasks needed to attain her goal and making appropriate referrals. The pediatric neurologist can also advocate for patients at the systemic level by identifying trends and patterns in their practice that demonstrate gaps in broader social policies and programs that have hindered their patients from enacting their goals.

## Conclusion

Transition is a complex period for youth and those surrounding them where ethical aspects of health care surface. In this context, the value and ethical principle of autonomy takes considerable importance because of the growing aspirations of youth for independence and adulthood. The pediatric neurologist (and team) has an important role in advocating for, facilitating, and supporting youth autonomy, and can take on an advocacy role for supporting the autonomy of emerging adult patients like Liz. We employed a new model of contextualized autonomy to work through a clinical case and suggest how clinicians can promote the autonomy of their young patients. We recognize that the ideas put forth are a first attempt at addressing issues associated with autonomy based on a more elaborate model of autonomy and that further specification and validation will need to be undertaken. Hopefully, they provide direction and inspiration toward this goal and opportunities for discussion.

## Authors' Note

Eric Racine is also affiliated with Departments of Medicine & Social and Preventive Medicine, Université de Montréal, Montréal, Quebec, Canada. Aline Bogossian is also affiliated with Pragmatic Health Ethics Research Unit, Institut de recherches cliniques de Montréal, Montréal, Quebec, Canada.

## Author Contributions

The manuscript was conceptualized by AB, AM, and ER. AB and ER drafted the manuscript. AB, AM, and ER participated in critical revisions and provided final approval of the version to be published.

## Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: ER received a career award from the Fonds de recherche santé - Québec (FRQ-S). Support for the writing of this manuscript comes from the IRCM Foundation (Fonds Le Royer).

## ORCID iD

Aline Bogossian, MSW, PhD  <https://orcid.org/0000-0002-9816-5887>

## References

1. Tilton AH. Transition of children with neurologic disorders. *Curr Neurol Neurosci Rep.* 2018;18(4):14.
2. Arim RG, Miller AR, Guèvremont A, Lach LM, Brehaut JC, Kohen DE. Children with neurodevelopmental disorders and disabilities: a population-based study of healthcare service utilization using administrative data. *Dev Med Child Neurol.* 2017;59(12):1284-1290.
3. Morris C, Janssens A, Tomlinson R, Williams J, Logan S. Towards a definition of neurodisability: a Delphi survey. *Dev Med Child Neurol.* 2013;55(12):1103-1108.
4. Shikako-Thomas K, Lach L, Majnemer A, Nimigon J, Cameron K, Shevell M. Quality of life from the perspective of adolescents with cerebral palsy: "I just think I'm a normal kid, I just happen to have a disability." *Qual Life Res.* 2009;18(7):825.
5. Lariviere-Bastien D, Bell E, Majnemer A, Shevell M, Racine E. Perspectives of young adults with cerebral palsy on transitioning from pediatric to adult healthcare systems. *Semin Pediatr Neurol.* 2013;20(2):154-159.
6. Shikako-Thomas K, Bogossian A, Lach LM, Shevell M, Majnemer A. Parents' perspectives on the quality of life of adolescents with cerebral palsy: trajectory, choices and hope. *Disabil Rehabil.* 2013;35(25):2113-2122.
7. Brown LW, Camfield P, Capers M, et al. The neurologist's role in supporting transition to adult health care: a consensus statement. *Neurology.* 2016;87(8):835-840.
8. Hamdani Y, Proulx M, Kingsnorth S, et al. The LIFEsplan model of transitional rehabilitative care for youth with disabilities: healthcare professionals' perspectives on service delivery. *J Pediatr Rehabil Med.* 2014;7(1):79-91.
9. Lindsay S, Proulx M, Maxwell J, et al. Gender and transition from pediatric to adult health care among youth with acquired brain injury: experiences in a transition model. *Arch Phys Med Rehabil.* 2016;97(2):S33-S39.
10. Affdal AO, Moutard ML, Billette de Villemeur T, Duchange N, Hervé C, Moutel G. A difficult transition from childhood to adult healthcare: the case of epilepsy. *Arch Pediatr.* 2015;22(4):337-342.
11. Orchard C, Bainbridge L, Bassendowski S, et al. *A National Interprofessional Competency Framework.* Vancouver, BC: The Collaborative; 2010.
12. WHO Technical Report Series 886. *Programming for Adolescent Health and Development.* Geneva: World Health Organization; 1999.

13. Bogossian A, Gorter JW, Racine E. Protocol for a scoping review about ethics in transition programmes for adolescents and young adults with neurodisabilities. *BMJ Open*. 2018;8(8):e020914.
14. Racine E, Bell E, Yan A, et al. Ethics challenges of transition from paediatric to adult health care services for young adults with neurodevelopmental disabilities. *Paediatr Child Health*. 2014;19(2):65-68.
15. Racine E, Larivière-Bastien D, Bell E, Majnemer A, Shevell M. Respect for autonomy in the healthcare context: observations from a qualitative study of young adults with cerebral palsy. *Child Care Health Dev*. 2013;39(6):873-879.
16. Larivière-Bastien D, Racine E. Ethics in health care services for young persons with neurodevelopmental disabilities: a focus on cerebral palsy. *J Child Neurol*. 2011;26(10):1221-1229.
17. Zizzo N, Bell E, Lafontaine AL, Racine E. Examining chronic care patient preferences for involvement in health-care decision making: the case of Parkinson's disease patients in a patient-centred clinic. *Health Expect*. 2017;20(4):655-664.
18. Shevell M. The role of the pediatric neurologist in the care of children with neurodevelopmental disabilities. *Pediatr Neurol*. 2018;88:3-9.
19. CAPHC Community of Practice in Transition. *A Guideline for Transition From Paediatric to Adult Health Care for Youth With Special Health Care Needs: A National Approach*. Ontario: Children's Healthcare Canada; 2016.
20. McManus M, White P, Barbour A, et al. Pediatric to adult transition: a quality improvement model for primary care. *J Adolesc Health*. 2015;56(1):73-78.
21. Feinberg J. The child's right to an open future. In: Aiken W, LaFollette H, eds. *Whose Child?* Totowa, NJ: Rowman & Littlefield; 1980.
22. Friedrich O, Racine E, Steinert S, Pömsl J, Jox R. An analysis of the impact of brain-computer interfaces on autonomy. *Neuroethics*. 2018;(Online first):1-13.
23. Racine E, Aspler J, Forlini C, Chandler J. Contextualized autonomy and liberalism: broadening the lenses on complementary and alternative medicines in preclinical Alzheimer's disease. *Kennedy Inst Ethics J*. 2017;27(1):1-41.
24. Racine E, Dubljevic V. Porous or contextualized autonomy? Knowledge can empower autonomous moral agents. *Am J Bioethics*. 2016;16:48-50.
25. Beauchamp TL, Childress JF. *Principles of Biomedical Ethics*. 5th ed. New York, NY: Oxford University Press; 2001.
26. American Academy of Pediatrics Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics*. 1995;95(2):314-317.
27. Ryff CD. Psychological well-being revisited: Advances in the science and practice of eudaimonia. *Psychother Psychosom*. 2014;83(1):10-28.
28. Bailey S, O'Connell B, Pearce J. The transition from paediatric to adult health care services for young adults with a disability: an ethical perspective. *Aust Health Rev*. 2003;26(1):64-69.
29. Gorter JW, Gibson BE. Independence in adulthood: ethical challenges in providing transition services for young people with neurodevelopmental impairments. In: Rosenbaum PL, Ronen GM, Racine E, Johannesen J, Dan B, eds. *Ethics in Child Health: Principles and Cases in Neurodisability*. London, UK: Mac Keith Press; 2016.
30. Racine E. *Pragmatic Neuroethics: Improving Treatment and Understanding of the Mind-Brain*. Cambridge, MA: MIT Press; 2010.
31. Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *Am Psychol*. 2000;55(1):68.
32. Carnevale FA, Teachman G, Bogossian A. A relational ethics framework for advancing practice with children with complex health care needs and their parents. *Compr Child Adolesc Nurs*. 2017;40(4):268-284.
33. Gorter JW, Gibson BE. Independence in adulthood: ethical challenges in providing transition services for young people with neurodevelopmental impairments. In: Rosenbaum PL, Ronen GM, Racine E, Johannesen J, Dan B, eds. *Ethics in Child Health: Principles and Cases in Neurodisability*. London, UK: Mac Keith Press; 2016:335-348.
34. Catena G, Rempel GR, Kovacs AH, Rankin KN, Muhll IV, Mackie AS. "Not such a kid thing anymore": young adults' perspectives on transfer from paediatric to adult cardiology care. *Child Care Health Dev*. 2018;44:592-598.
35. Hislop J, Mason H, Parr JR, Vale L, Colver A. Views of young people with chronic conditions on transition from pediatric to adult health services. *J Adolesc Health*. 2016;59(3):345-353.
36. Bagatell N, Chan D, Rauch KK, Thorpe D. "Thrust into adulthood": transition experiences of young adults with cerebral palsy. *Disabil Health J*. 2017;10(1):80-86.
37. Coyne I, Prizeman G, Sheehan A, Malone H, While AE. An e-health intervention to support the transition of young people with long-term illnesses to adult healthcare services: design and early use. *Patient Educ Couns*. 2016;99(9):1496-1504.
38. Racine E, Bell E, Shevell M. Ethics in neurodevelopmental disability. In: *Handbook of Clinical Neurology*. Vol 118. Philadelphia, PA: Elsevier; 2013:234-263.
39. Hudsmith LE, Thorne SA. Transition of care from paediatric to adult services in cardiology. *Arch Dis Child*. 2007;92(10):927-930.
40. Berg Kelly K. Sustainable transition process for young people with chronic conditions: a narrative summary on achieved cooperation between paediatric and adult medical teams. *Child Care Health Dev*. 2011;37(6):800-805.
41. Ronen GM, Dan B. Ethical considerations in pediatric neurology. In: Dulac O, Lassonde M, Sarnat HB, eds. *Handbook of Clinical Neurology*. Vol 111. Amsterdam: Elsevier B.V.; 2013.
42. Kaufman H, Horricks L, Kaufman M. Ethical considerations in transition. *Int J Adolesc Med Health*. 2010;22(4):453-459.
43. Cohen MH. Ethical issues in discharge planning for vulnerable infants and children. *Ethics Behav*. 1995;5(1):1-13.
44. Montreuil M, Carnevale FA. A concept analysis of children's agency within the health literature. *J Child Health Care*. 2016;20(4):503-511.