

## Integrative Framework of Ethics in Transitional Care

Ethical principles and tensions in transitional care services	Proposed strategies and duties
<p><b>Autonomy</b></p> <p>Respect youth capacity for participation in decision-making<sup>1,2</sup></p> <p>Recognition of autonomy as a staged process or gradual transfer of responsibility from parent to youth<sup>3-5</sup></p> <p>Youth's right to self-determination versus youth's best interest<sup>3,6</sup></p> <p>Family's right to self-determination versus youth's best interest<sup>1,4,6,7</sup></p>	<p>Duty to empower autonomous decision-making through coaching and information<sup>1,2</sup></p> <p>Duty to help youth develop skills in youth to manage self-care, to self-advocate<sup>1,3</sup></p> <p>Duty to provide all necessary information and consequences of opting out of care<sup>3</sup></p> <p>Duty to provide developmentally appropriate information<sup>3,5</sup></p> <p>Duty to acknowledge and respect youths' choices, values, desires and decisions<sup>8,9</sup></p>
<p><b>Trust and relationships</b></p> <p>Recognition that paternalistic models of care may create dependencies<sup>2</sup></p> <p>Recognition of physical and developmental fragility of some children and impaired capabilities of some caregivers<sup>6</sup></p> <p>Recognition of differences in communication styles of youth/young adults and older patients<sup>3</sup></p> <p>Considerations regarding truth-telling to youth and family regarding availability of resources<sup>5,9,10</sup></p> <p>Considerations regarding truth-telling to youth about medical history and need to maintain family relationships<sup>10</sup></p>	<p>Duty to respect family values and autonomy of family<sup>1,9</sup></p> <p>Duty of paediatric and adult care sites to ensure cooperation and communication and to build competence in transition planning for specific populations<sup>1,3,8</sup></p> <p>Duty of adult health systems to foster and support trusting relationships<sup>1,5,8</sup></p>
<p><b>Confidentiality</b></p> <p>Parents' right to self-determination and youths' right to self-determination (e.g.: explaining or concealing parents' past decisions regarding the health care of their child)<sup>6,10</sup></p> <p>Youths' decisions to opt in/out of services and parents desire to be informed<sup>7,10</sup></p>	<p>Duty to train and educate youth to be involved in discussions and decisions about their own health condition<sup>10</sup></p>
<p><b>Equality and justice</b></p> <p>Citizenship rights of youth (right to participate)<sup>7,8</sup></p> <p>Recognize long term medical vulnerability and its impact on life choices<sup>4</sup></p> <p>Recognition of hidden ethical issues related to dominant culture, values, institutional practices, clinical standards</p> <p>Mismatch between capacity of young person and available clinical, community and social resources to increase autonomy<sup>7</sup></p>	<p>Duty to develop tailored and available services<sup>4,10</sup></p>
<p><b>Human dignity and human rights</b></p> <p>Need to expand definition of transitional care beyond health care management to incorporate personal life and existential questions<sup>3</sup></p>	<p>Duty to preserve, promote and ensure dignity and respect for youth<sup>1,5</sup></p>

Reference:

1. Racine E, Bell E, Shevell M. Ethics in neurodevelopmental disability. In: Bernat JL, Beresford R, editors. *Ethical and Legal Issues in Neurology. Handbook of Clinical Neurology.* 118: Elsevier; 2013. p. 234-63.
2. 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. *Australian Health Review : A publication of the Australian Hospital Association.* 2003;26(1):64-9.
3. 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 and Development.* 2011;37(6):800-5.
4. Hudsmith LE, Thorne SA. Transition of care from paediatric to adult services in cardiology. *Archives of Disease in Childhood.* 2007;92(10):927-30.
5. Kaufman H, Horricks L, Kaufman M. Ethical considerations in transition. *International Journal of Adolescent Medicine & Health.* 2010;22(4):453-9.
6. Cohen MH. Ethical issues in discharge planning for vulnerable infants and children. *Ethics & Behavior.* 1995;5(1):1-13.
7. Gorter JW, Gibson BE. Independence in adulthood: Ethical challenges in providing transition services for young people with neurodevelopmental impairments. In: Rosenbaum PL, Ronen GM, Dan B, Johannesen J, E. R, editors. *Ethics in Child Health: Principles and Cases in Neurodisability.* London, UK: Mac Keith Press; 2016. p. 335-48.
8. Larivière-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. *Seminars in Pediatric Neurology.* 2013;20(2):154-9.
9. Ronen GM, Dan B. Ethical considerations in pediatric neurology. *Handbook of Clinical Neurology.* 2013;11 (3rd series)(Pediatric Neurology Part 1).
10. Woldorf JW. Transitioning adolescents with special healthcare needs: Potential barriers and ethical conflicts. *Journal for Specialists in Pediatric Nursing.* 2007;12(1):53-5.