Essential elements in transitional care for youth with chronic conditions

CORE PRINCIPLES 'ON YOUR OWN FEET'	*Six core elements of health care transition (Got Transition, 2014)*[1]	*Key elements for, and indicators of, a successful transition (Surís & Akré, 2015)*[2]	*NICE guideline on transition (2016)*[3]	*Proposed beneficial features (Colver et al., 2017)*[4]	*Consensus statement on successful transition (Mazur, Dembinski, Schrier, Hadjipanayis & Michaud, 2017)*[5]	*Components of interventions that improve transitions to adult care (Schultz & Smaldone, 2017)*[6]
FUTURE-ORIENTED	▪ The practice has an individual transition flow sheet or registry for identifying and tracking transitioning youth, ages 14 and older, or a subgroup of youth with chronic conditions as they progress through transition processes. ▪ The practice consistently offers clinician time alone with youth after age 14 during preventive visits. Clinicians use a standardized transition readiness assessment tool, and self-care needs and goals are incorporated into the youth's plan of care beginning at ages 14 to 16.	▪ Starting planning transition at an early age (and at least 1 year before the transfer boundary). ▪ If developmentally appropriate, seeing the adolescent alone at least for part of the consultation.	▪ Ensure a smooth and gradual transition. ▪ Collaboration between paediatric and adult care providers. ▪ Start early (13 years at latest). ▪ Make a transition plan. ▪ Meet adult care providers in advance (a transition clinic could help to facilitate this). ▪ Provide information about services and support available in adult care.	▪ Meet adult team before transfer: this could be in a joint clinic where pediatrician and adult physician consult together; or the adult physician might visit the child clinic to be introduced; or the young person might be taken to the adult clinic by a member of the child team to meet the adult physician. ▪ Promotion of health self-efficacy: the clinic has a written policy about how they will encourage the young person to take responsibility for their health and give them information about their condition.	▪ A structured, written policy involving child and adult healthcare providers. This should be available to adolescents and their family or caregivers. ▪ Starting to create a healthcare transition plan as early as possible, for example by the age of 14 or below or at least one year before the transfer itself. ▪ The transition process and timing should be individualized.	Transition clinics can provide a tailored approach to young adults, addressing issues specific to this age group.

				▪ Written transition plan, which should be created some time before transfer. It should include plans for wider transition, not just the transfer to adult health services. The young person should have a copy of it and it should be updated.		
COORDINATION		Assuring a good coordination (such as timing of transfer, communication, follow-up, remaining available as a consultant, etc.) between pediatric and adult professionals.	Appoint a named worker to coordinate the transition care and support.	▪ Key worker: a single person known to the young person whom they could easily contact or go to if there were any problems of co-ordination or misunderstandings that needed to be sorted out. ▪ Transition manager for clinical team who facilitates good working relationships between adult and child services; ensures that there are appropriate materials available for things such as health education or the transition plan; and monitors whether the young person has a suitable		A transition coordinator may be helpful in optimizing clinic attendance. They could provide assistance with scheduling appointments and following up if appointments were not attended.

				appointment in adult services and whether the appointment is kept.		
CONTINUITY OF CARE	▪ The practice has a written transition policy or approach, developed with input from youth and families that includes privacy and consent information, a description of the practice's approach to transition, and age of transfer. Clinicians discuss it with youth and families beginning at ages 12 to 14. The policy is publicly posted and familiar to all staff. ▪ The practice sends a complete transfer package (including the latest transition readiness assessment, transition goals / actions, medical summary and emergency care plan, and, if needed, legal documents, and a condition fact sheet), and pediatric	▪ Identifying an adult provider willing to take on the young patient before transfer. ▪ Patient not lost to follow-up.	▪ Ensure a smooth and gradual transition. ▪ Collaboration between paediatric and adult care providers.	Age-banded clinic: an intermediate clinic setting such as a young person's clinic or a young adult team.	▪ A structured, written policy, involving child and adult healthcare providers. ▪ Continuity of care and cooperation, i.e. using common medical guidelines, keeping proper medical records, and performing follow-up evaluations. ▪ Continuity of financing.	

	clinicians communicate with adult clinicians, confirming pediatric provider's responsibility for care until young adult is seen in the adult practice. ▪ The practice confirms transfer completion, need for consultation assistance, and elicits feedback from patients regarding the transition experience.					
YOUNG PERSON	The practice ensures equal representation of youth and families in strategic planning related to health care transition.	Including young person's views and preferences to the planning of transition.	▪ Involve young people and their caregivers in service design, delivery and evaluation of transition care. ▪ Transition support must be developmentally appropriate. ▪ Transition support must be strengths-based.		▪ Procedures should be available to adolescents and their family or caregivers, and should allow for some flexibility, depending on the adolescent's developmental stage as well as the expectations and needs of the patient and relatives. ▪ Active participation of the adolescents and the parents or caregivers should be sought.	

					▪ The transition process and timing should be individualized.	
TEAM	The practice has incorporated transition into its plan of care. All clinicians are encouraged to partner with youth and families in developing transition goals and updating and sharing the plan of care. Clinicians are also encouraged to address needs for decision-making supports. The practice has a vetted list of adult providers and assists youth in identifying adult providers.		▪ Collaboration between paediatric and adult care providers. ▪ Meet adult care providers in advance (a transition clinic could help to facilitate this).	▪ Age-banded clinic: an intermediate clinic setting such as a young person's clinic or a young adult team. ▪ Meet adult team before transfer: this could be in a joint clinic where pediatrician and adult physician consult together; or the adult physician might visit the child clinic to be introduced; or the young person might be taken to the adult clinic by a member of the child team to meet the adult physician. ▪ Coordinated team of which the members need to work together and communicate well together, and demonstrate to the young person that this is happening. Coordination of appointments on the	▪ Adequate staff training and sensitization to the needs and concerns of adolescent patients. ▪ Interdisciplinary teams.	

				same day demonstrates this.		
PARENT INVOLVEMENT	The practice ensures equal representation of youth and families in strategic planning related to health care transition.	Discussing with patient and family about self-management.	Involve young people and their caregivers in service design, delivery and evaluation of transition care.	Appropriate parent involvement in their child's care, but with changing responsibilities. Involvement concerns what happens in the clinic (parent being present or not and who does the talking) and also discussions at home about the young person's health and how to manage it.	Active participation of the adolescents and the parents or caregivers should be sought.	
SELF-MANAGEMENT	The practice consistently offers clinician time alone with youth after age 14 during preventive visits. Clinicians use a standardized transition readiness assessment tool, and self-care needs and goals are incorporated into the youth's plan of care beginning at ages 14 to 16.	▪ Discussing with patient and family about self-management. ▪ If developmentally appropriate, seeing the adolescent alone at least for part of the consultation.		▪ Promotion of health self-efficacy: the clinic has a written policy about how they will encourage the young person to take responsibility for their health and give them information about their condition and the young person is asked *"Have you received enough help to increase your confidence in managing your condition?"* ▪ Holistic life-skills training for education,	The extent to which the adolescent has acquired some skills for self-management should be taken into account.	Psychological support may help youth learn how to balance their multiple priorities as well as cope with challenges such as understanding how their illness affects their self-image and avoiding becoming isolated from their social circles.

				relationships, finances, employment, housing, social relationships etc. as well as health maintenance. The health service may not provide such training but staff in consultations inquire about such matters and referrals are made to other agencies as needed.		
PSYCHOSOCIAL CARE		Although having a holistic approach to prepare young people for adulthood was not unanimously considered as essential or very important, it is an important part of transition. In fact, it seems that the consensual elements in the study of Surís and Akré (2015) are mainly limited to health outcomes.	▪ Using a person-centered (holistic) approach. ▪ Involve primary care (general practitioner).	▪ Written transition plan, which should be created some time before transfer. It should include plans for wider transition, not just the transfer to adult health services. The young person should have a copy of it and it should be updated. ▪ Holistic life-skills training for education, relationships, finances, employment, housing, social relationships etc. as well as health maintenance. The health service may	▪ Young patients should not be transferred until they have the skills to function in an adult service and have finished growth and puberty. The extent to which the adolescent has acquired some skills for self-management should also be taken into account, as well as their own expectations. ▪ Adolescent patients with chronic conditions have specific needs that go far beyond treating their condition. These concerns are usually	Transition clinics can provide a tailored approach to young adults, addressing issues specific to this age group including taking responsibility for their diabetes, experimenting with drugs or alcohol and managing diabetes away from home. Transition clinics can also give adolescents / young adults an opportunity to meet with providers of different disciplines.

				not provide such training but staff in consultations inquire about such matters and referrals are made to other agencies as needed.	better addressed by an interdisciplinary team.	

[1] Got Transition (2014). *The Six Core Elements of Health Care Transition (2.0).* Retrieved from http://www.gottransition.org.

[2] Surís, J. C. & Akré, C. (2015). Key elements for, and indicators of, a successful transition: an international Delphi study. *Journal of Adolescent Health, 56(6),* 612–618.

[3] National Institute for Health and Care Excellence. (2016). *NICE guideline: Diabetes (type 1 and type 2) in children and young people: diagnosis and management.* Retrieved from nice.org.uk/guidance/ng18.

[4] Colver, A. et al. (2017). *The Transition Research Programme: How can health services contribute most effectively to facilitating successful transition of young people with long term conditions from childhood to adulthood?* Newcastle, United Kingdom: Newcastle University, Community Child Health. Report in preparation.

[5] Mazur, A., Dembinski, L., Schrier, L., Hadjipanayis, A., & Michaud, P. A. (2017). European Academy of Paediatric consensus statement on successful transition from paediatric to adult care for adolescents with chronic conditions. *Acta Pædiatrica, 106,* 1354–1357.

[6] Schultz, A. T., & Smaldone, A. (2017). Components of Interventions That Improve Transitions to Adult Care for Adolescents With Type 1 Diabetes. *Journal of Adolescent Health, 60,* 133-146.

Conclusions

MACRO LEVEL

- **FUTURE-ORIENTED:** A written protocol or policy helps to create future-oriented and planned transition processes. It is important to start early with preparation (by the age of 14) and to work towards more responsibility and independence for the young person step by step. Also, meeting adult care professionals in advance is important.
- **COORDINATION:** Appointing a named worker to coordinate the process; the communication and collaboration between professionals from pediatric and adult care; and the logistics around transition. Such a coordinator, known to the young person and his/her parents whom they could easily contact or go to if there were any problems that needed to be sorted out, is recommended.
- **CONTINUITY OF CARE:** A shared vision on transition and proper transfer of information (both oral and written), whereby pediatric professionals know to whom the young person is being transferred, contribute to continuity of care in the transition phase. Also, monitoring and evaluating follow-up and adequate financial coverage are important elements in ensuring continuity of care.

MESO LEVEL

- **YOUNG PERSON:** Transition requires tailoring and needs to be adapted to the individual situation/development of the young person. Young persons have to become actively involved in their care. Their wishes, needs and preferences need to be investigated and must be taken seriously. The key message is: *"Listen to young person's voice."*

- **TEAM:** Interdisciplinary coordination and collaboration between professionals from pediatric and adult care, and meeting new professionals before transfer are essential elements in providing transitional care.

MICRO LEVEL

- **PARENT INVOLVEMENT:** Parents need to be involved in their child's care during the transition phase and must be supported when their child takes over responsibilities.

- **SELF-MANAGEMENT:** To optimally support young persons in their transition, a person-oriented and holistic approach must be applied. Medical aspects require attention, but also psychosocial developments and challenges young persons face during the transition phase need to be addressed. Young persons need to be prepared for independence and self-management from a broad perspective. Developmentally appropriate care to promote self-efficacy and to reach optimal readiness for transfer is of high importance.

- **PSYCHOSOCIAL CARE:** During the transition phase young persons have to deal with various challenges. Therefore, it is important for professionals to apply a person-oriented and holistic approach. This means attention for achieving optimal participation goals and optimal transition into adulthood. If necessary, young persons can be referred to relevant professionals (e.g. psychologist, social worker, dietician).