



# Transitions

Our frequent inability to ensure older adolescents experience a seamless transition

# Tools for Addressing Systems Issues in Transition

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**M**oving from pediatric to adult healthcare is a time of stress and opportunity for adolescents with special healthcare needs (ASHCN) and their families. With over 90% of children with special healthcare needs surviving into young adulthood, there is an increasing imperative to actively engage youth in preparing for the adult system (Betz and Smith 2011; Pai and Schwartz 2011). The goal of transition care is to provide young people with a coordinated, uninterrupted and developmentally appropriate transfer to adult healthcare (Kaufman and Pinzon 2007). This is often complicated by the complex medical, social and psychological tasks and requirements that adolescents experience as they navigate their healthcare and their lives as young, developing people.

There is extensive evidence that transition is risky business and that healthcare transition programs for ASHCN are a way to reduce the risks involved (Kennedy and Sawyer 2008; Rapley and Davidson 2010). In addition, there are many international and national position statements and policy documents that call for transition planning and evaluation of transition outcomes (e.g., American Academy of Pediatrics et al. 2002; Kaufman and Pinzon 2007). Despite this, there remain many issues that impede the successful transition of ASHCN to adult care, including barriers related to the patients, parents, organizations and providers (pediatric and adult; Shaw and DeLaet 2010; Tucker and Cabral 2005). If these barriers can be overcome, the

transition process will support ASHCN to gain a greater sense of independence, a feeling of graduating or “moving on,” a more positive sense of self and expertise in managing their health and their life. Transition into the adult system can provide an opportunity to focus on self-management and on adolescent issues (Dempsey et al. 2009), such as sexuality, reproduction, substance use, body image and violence prevention, all of which can be magnified in adolescents with chronic health conditions.

## Issues for Patients and Parents

A number of studies have examined the attitudes and perceptions of ASHCN and their parents in an attempt to identify barriers and facilitators associated with transitions and to ultimately support the development of successful healthcare transition planning (McDonagh 2007; Wong et al. 2010, 2011). Common themes emerge in all the populations studied. Adolescents' attitudes can differ from those of their parents, seeing transition as “no big deal” and even appearing apathetic to the process (Anthony et al. 2009). In contrast, parents generally report anxiety about transfer of care (Reiss et al. 2005), worry they will no longer be able to participate in the care of their child and believe that providers of adult healthcare are not knowledgeable about pediatric-onset conditions. Parents expect to have to re-educate providers of adult care and feel less confident in these providers compared with their pediatric counterparts.

Parents and youth often have very specific negative impres-

sions of care in the adult system (Reiss et al. 2005). The adult system is seen as unsupportive and less nurturing. Providers of adult healthcare are viewed as busier, with less time to answer questions or provide individualized care for their patients. Treatment and services are seen as fragmented and lacking an integrated multidisciplinary approach. Finally, the adult system is seen as neither collaborating nor communicating with the pediatric system. While some of these issues are based on real challenges faced by youth in transition, these negative attitudes are often fostered in the pediatric system. There are benefits or positives to transferring into the adult healthcare system, at a time when the patients' needs are becoming those of adults, but parents and youth are often unaware of these benefits. Although it is clear that adult survivors of childhood-onset health conditions may develop co-morbid conditions with which pediatricians are not familiar, it may not be made clear to young people and their parents that they will be best cared for by adult specialists.

Having entered the adult system, young adult patients and their parents identify additional issues: the system serves older adults and is not designed for emerging adults; many of the comforts of children's hospitals (e.g., private rooms, entertainment systems) are not automatically available; and they are required to build trusting relationships with new healthcare teams. At this time, patients and parents also often report feeling abandoned by their pediatric institution if they did not have the opportunity to prepare emotionally for the change.

Entry into adult healthcare highlights the lack of early preparation for transitions as an issue that affects both patients and parents. Patients are unlikely to be independent self-managers of their health at the time of transfer, given that time-of-transfer decisions are based on "aging out of treatment" versus factors of illness severity or emotional and cognitive maturity (Reiss et al. 2005). As pediatric age limits are unlikely to change in Canada, transition should be a process that begins in childhood and ends sometime in adulthood. This will help support youth and young adults achieve their optimal self-care capacity, but it requires education and training of adult-focused providers.

### **Systems Issues**

There are issues with transition at all levels – the individual patient and parents, the family within Canadian cultures, pediatric institutions and adult-focused care. At the most basic level is the adolescent brain, a highly complex system that is in the process of developing during the period of transition. Many of the underlying causes of poor adherence (a major barrier to successful transition) are due to incomplete acquisition of executive functions, including limited insight into the impact of poor adherence and a lack of impulse control. This immaturity of the prefrontal cortex is probably also linked to difficulties with self-advocacy and self-management skills (Casey 2000).

Within Canadian culture, there are many demographic,

economic and societal changes that have resulted in youth and young adults living at home longer, thereby keeping their parents involved in many aspects of their lives, including their interactions with adult healthcare. Not surprisingly, parents often experience difficulties relinquishing control and also feel reluctant to leave the pediatric environment and staff (Reiss et al. 2005).

The biggest transition issue within the healthcare system is that there is no real *healthcare system*. Communication, collaboration and coordination between pediatric and adult hospitals (not to mention home care, educational institutions and assisted living) are inconsistent and sometimes nonexistent.

People are at the centre of systems, and pediatric providers may experience difficulty letting go of their patients, feeling they provide better care than adult specialists can. The current focus on family-centred care can result in patients always being seen with a parent and not being coached to develop self-management skills. Although, in general, ASCHN with more complex conditions receive healthcare transition services more often than do those with less complex conditions (Scal and Ireland 2005), ASCHN with mental health diagnoses have few services available to them.

In adult healthcare facilities, there is inadequate knowledge of congenital and pediatric-onset conditions, fewer inter-professional teams, difficulty in accessing mental health services and a feeling that pediatric patients are difficult because they have been coddled by pediatric institutions. Procedures must be developed to improve the communication between pediatric and adult providers and to recognize the differences in each other's healthcare delivery mode while working collaboratively to promote the development of patient self-management skills.

Currently, there is an inability to track and measure healthcare transition planning outcomes. By definition, transition outcomes cannot be measured while young people are still in pediatric care. Betz and Smith (2011) have recommended that outcomes include (1) access to adult healthcare providers; (2) a medical summary from the referring provider; (3) enrolment in an adult health insurance program; (4) competency in self-management; (5) enrolment in training or educational programs leading to employment with healthcare benefits; and (6) the acquisition of independent living skills. Other than competency in self-management, these are all measurable but do not reflect the richness of the transition experience. Few studies have addressed the measurement of broader developmental and bio-psychosocial outcomes such as adherence, resiliency, quality of life, coping and self-efficacy. There are multiple issues that hinder our ability to measure these outcomes. First, single discrete events are easier to measure than events that take place over time and across healthcare facilities. Outcomes related to medical transfer are more easily measured than developmental changes that occur over longer periods of time. There is no consensus on what constitutes readiness and successful transi-

tion, and few reliable and valid measures of assessment (Betz and Smith 2011).

### Solutions

Interventions to improve the transition process include the following:

- Educating adult providers regarding the unique attributes of youth
- Creating an interest in adult-centred institutions about pediatric-onset diseases (Tuchman et al. 2010)
- Designing procedures for collaboration between adult and pediatric programs (Taylor et al. 2006)
- Creating teams that focus on particular diagnoses rather than age groups, with pediatric and adult providers collaborating on treatment plans and protocols (Sable et al. 2011)
- Allowing co-access to electronic health records for pediatric and adult centres
- Creating “young adult” clinics jointly staffed by pediatric and adult providers (Nakhla et al. 2009)
- Having clear protocols for the sharing of information at the time of transfer (Peter et al. 2009)
- Preparing young people for adult care (and adult life)

Many of these solutions require the administrations of pediatric and adult centres to collaborate, while others can be generated at different levels of these organizations.

### Tools for Transition

The Good 2 Go Transition Program was established in 2006 at The Hospital for Sick Children (SickKids) in Toronto. Its goal is to prepare all youth with chronic health conditions to leave SickKids by the age of 18 with the necessary knowledge and skills to advocate for themselves (or through others), maintain health-promoting behaviours and use adult healthcare services successfully and appropriately. Although the team has been involved in the education of, and negotiations with, adult providers, much of the work of Good 2 Go involves preparing youth for transition. The team offers direct transition service to high-risk patients, education and consultation with hospital programs and has developed a number of tools that can be used as is or customized to individual program requirements. Tools have also been developed by other programs within the hospital with input from Good 2 Go, and new tools are continuously created to further support transitioning families. Efforts are being made to ensure that tools, outlined below, are useful for the broad diversity of the populations we serve.

These tools can be as simple as a **transition poster** (displayed in all ambulatory clinics) that is a visual reminder of the expectation for healthcare providers to prepare patients to leave pediatrics and enter adult care.

**FIGURE 1.**  
**Getting Ready for Adult Care booklet**



**Readiness checklists** are self-reported (and parent-reported) measures of a youth’s medical knowledge, autonomy and skills needed to self-manage healthcare. This tool helps the healthcare provider create a plan for skill development and can be used to monitor change over time. A summary of the checklist can be included in the transfer summary.

As adult self-management models are often not appealing to young people, a manual has been developed in collaboration with an adult centre. This is being tested for a two-day **self-management group** for adolescents and young adults with chronic health conditions.

The **three-sentence summary** (with corresponding reminder bookmark) encourages young people to develop a succinct summary of their health history by learning what is most important to report in an interaction with a healthcare provider.

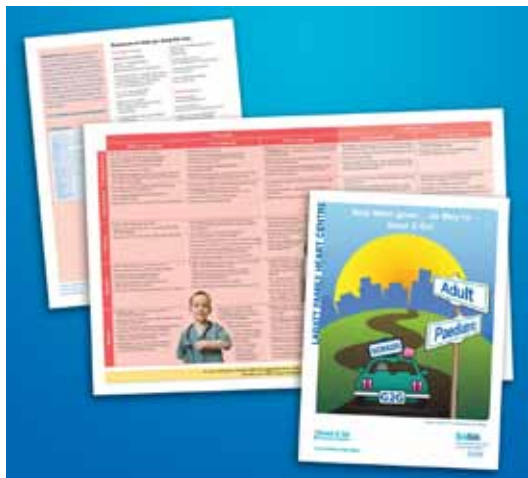
ASHCN are able to learn how to independently communicate with healthcare providers – a crucial skill in adult healthcare. Clinics are encouraged to set an age at which they will begin seeing children without parents for part of their visit in a **solo interaction**.

The **Getting Ready for Adult Care booklet** was developed with feedback from current and recently graduated pediatric patients, as well as adult providers. It gives general information about preparing for adult healthcare and checklists for adult clinic appointments and has customizable program-specific inserts (Figure 1).

“**Help them grow...so they’re Good 2 Go**” timelines (handout and poster) highlight how a child with a chronic health condition can move along a developmentally appropriate continuum from birth toward increased self-management. Program-specific timelines are developed collaboratively, with



**FIGURE 2.**  
**Good 2 Go Timelines – handout and poster**



expertise from inter-professional care providers, patients and families and sometimes adult healthcare providers. The posters are placed in clinic waiting areas and examination rooms. The handouts are given to families at time of diagnosis and reviewed at follow-up appointments (Figure 2).

**Online** self-management and education programs have been developed and are being tested for a number of conditions (Stinson et al. 2009). Several applications (“apps”) are in development, including one for young people with inflammatory bowel disease and one for transplant recipients.

**Transfer clinics** provide a structured meeting between patients and the new adult care team. Patients participate in small group discussions facilitated by Good 2 Go team members, meet their new adult provider, complete a MyHealth Passport and receive a graduation certificate.

**MyHealth Passport** ([www.sickkids.ca/myhealthpassport](http://www.sickkids.ca/myhealthpassport)) is a free online program that helps a young person to create a wallet-sized card with important health information. It was developed following recommendations that ASCHN have healthcare passports as an essential element for successful transition (Knauth et al. 2006). MyHealth Passport was originally designed to improve adolescent patients’ knowledge of their health history, to give them a sense of ownership of this information and to ensure that important information is communicated in a new or emergency situation. Early evaluation revealed that a number of parents were making MyHealth Passports for their younger children and that many users were above the pediatric age limit (up to age 91 years), so the passport templates have been expanded to the needs of a wider population. There are currently 40 templates, many of which are for congenital or childhood-onset conditions. A generic template can be used for

**FIGURE 3.**  
**Bookmark detailing MyHealth Passport**



conditions that do not yet have a specific template. Templates have lists of common medications, interventions and diagnostic tests that can be checked off and spaces for activities of daily living and names of healthcare providers, pharmacies and emergency contacts for the condition. When evaluated, MyHealth Passport has been shown to be easy to create and portable, to increase knowledge and to improve communications with providers and emergency personnel (Wolfstadt et al. 2011; Figure 3).

## Conclusion

Collaboration between adult and pediatric services is crucial to a seamless transfer of care in many pediatric-onset conditions. Adolescents and families can also be prepared to take on new roles and responsibilities after transfer. Barriers to the adoption of transition tools include a perception that staff are too busy to use them and the potential inappropriateness of the tool for a particular population (e.g., complex care patients with severe intellectual disabilities will not be able to complete the checklist). However, tools can be an effective adjunct in the quest to address the systems issues that interfere with successful transition. A well-planned, coordinated and developmentally appropriate transitioning program, along with a proper transfer from pediatric to adult healthcare, can improve adherence to treatment in ASHCN and decrease loss to follow-up. The long-term impact of these tools on the systems issues discussed in this article remains to be seen, and the results of evaluations are optimistically awaited. **HQ**

## References

American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians–American Society of Internal Medicine. 2002. “Consensus Statement on Health Care

- Transitions for Young Adults with Special Health Care Needs." *Pediatrics* 110: 1304–6.
- Anthony, S.J., M. Kaufman, A. Drabble, M. Seifert-Hansen, A.L. Dipchand and K. Martin. 2009. "Perceptions of Transitional Care Needs and Experiences in Paediatric Heart Transplant Recipients." *American Journal of Transplantation* 9(3): 614–19.
- Betz, C. and K. Smith. 2011. "Measuring Health Care Transition Planning Outcomes: Challenges and Issues." *International Journal of Child and Adolescent Health* 3(4): 463–72.
- Casey, B.J., N.J. Giedd and K.M. Thomas. 2000. "Structural and Functional Brain Development and Its Relation to Cognitive Development." *Biological Psychology* 54: 241–57.
- Dempsey, D., D. Singer, S. Clark and M. Davis. 2009. "Adolescent Preventive Health Care: What Do Parents Want?" *Journal of Pediatrics* 155: 689–94.
- Kaufman, M., J. Pinzon and the Adolescent Medicine Committee. 2007. "Canadian Paediatric Society, Position Statement. Transition to Adult Care for Youth with Special Health Care Needs." *Paediatric Child Health* 12(9): 785–88.
- Kennedy, A. and S.M. Sawyer. 2008. "Transition from Pediatric to Adult Services: Are We Getting It Right?" *Current Opinion in Pediatrics* 20: 403–9.
- Knauth, A., A. Verstappen, J. Reiss and G.D. Webb. 2006. "Transition and Transfer from a Pediatric to Adult Care of Young Adults with Complex Congenital Heart Disease." *Cardiology Clinic* 24(4): 619–29.
- McDonagh, J.E., T.R. Southwood and K.L. Shaw on behalf of the British Society of Paediatric and Adolescent Rheumatology. 2007. "The Impact of a Coordinated Transitional Care Programme on Adolescents with Juvenile Idiopathic Arthritis." *Rheumatology* 46: 161–68.
- Nakhla M., D. Daneman, T. To, G. Paradis and A. Guttman. 2009. "Transition to Adult Care for Youths with Diabetes Mellitus: Findings from a Universal Health Care System." *Pediatrics* 124: E1134–41.
- Pai, A.L. and L.A. Schwartz. 2011. "Introduction to the Special Section: Health Care Transitions of Adolescents and Young Adults with Pediatric Chronic Conditions." *Journal of Pediatric Psychology* 36(2): 129–33.
- Peter, N., C. Forke, K. Ginsburg and D. Schwarz. 2009. "Transition from Pediatric to Adult Care: Internists' Perspectives." *Pediatrics* 123(2): 417–23.
- Rapley, P. and P.M. Davidson. 2010. "Enough of the Problem: A Review of Time for Health Care Transition Solutions for Young Adults with A Chronic Illness." *Journal of Clinical Nursing* 19: 313–23.
- Reiss, J. G., R.W. Gibson and L.R. Walker. 2005. "Health Care Transition: Youth, Family, and Provider Perspectives." *Pediatrics* 115: 112–20.
- Sable, C., E. Foster, K. Uzark, K. Bjornsen, M.M. Canobbio and H.M. Connolly. 2011. "Best Practices in Managing Transition to Adulthood for Adolescents with Congenital Heart Disease: The Transition Process and Medical and Psychosocial Issues: A Scientific Statement from the American Heart Association." *Circulation* 123: 1454–85.
- Scal, P. and M. Ireland. 2005. "Addressing Transition to Adult Health Care for Adolescents with Special Health Care Needs." *Pediatrics* 115: 1607–12.
- Shaw, T. and D. DeLaet. 2010. "Transition of Adolescents to Young Adulthood for Vulnerable Populations." *Pediatrics in Review* 31: 497–505.
- Stinson, J, R. Wilson, N. Gill, J. Yamada and J. Holt. 2009. "A Systematic Review of Internet-Based Self Management Interventions for Youth with Health Conditions." *Journal of Pediatric Psychology* 34(5): 495–510.
- Taylor, L., A. Tsang and A. Drabble. 2006. "Transition of Transplant Patients with Cystic Fibrosis to Adult Care: Today's Challenges." *Progress in Transplantation* 16(4): 335.
- Tuchman, L., L. Schwartz, G. Sawicki and M. Britto. 2010. "Cystic Fibrosis and Transition to Adult Medical Care." *Pediatrics* 125(3): 566–73.
- Tucker, L.B. and D.A. Cabral. 2005. "Transition of the Adolescent Patient with Rheumatic Disease: Issues to Consider." *Pediatric Clinics of North America* 52(2): 641–52.
- Wolfstadt, J., A. Kaufman, J. Levitin and M. Kaufman. "The Use and Usefulness of MyHealth Passport: An Online Tool for the Creation of a Portable Health Summary." *International Journal of Child and Adolescent Health* 3(4): 499–506.
- Wong, L., F. Chan, F. Wong, E. Wong, K. Huen, E. Yeoh et al. 2010. "Transition Care for Adolescents and Families with Chronic Illness." *Journal of Adolescent Health* 47: 540–46.
- Wood, D., J.G. Reiss, M. Ferris, L. Edwards and J. Merrick. 2011. "Transition from Pediatric to Adult Care." *International Journal of Child and Adolescent Health* 3(4): 445–47.

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