

## Smoothing the transition to adult care

*The most important need is for a change of attitude and approach*

Transition is “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems”.<sup>1</sup> The importance of transition of young people with chronic health conditions from paediatric to adult care is finally being recognised, but it needs to be addressed in a coordinated and integrated way. In Australia, as internationally, there are some well established and potentially effective transition programs. However, little is known about the efficacy of such programs, as there is little published evaluation.<sup>2</sup>

What is clear, both anecdotally and with some modest support in the literature, is that the journey faced by young people with chronic and disabling conditions is a complex one.<sup>3,4</sup> The majority will face obstacles that arise from the lack of infrastructure and precedent in this specialised area of health care. Current approaches are rarely ideal, the most likely options being abrupt transfer to adult services, staying in the paediatric setting longer than is appropriate, or leaving medical supervision altogether.<sup>5</sup>

The study at the Royal Children’s Hospital, Melbourne, reported by Lam and colleagues<sup>6</sup> in this issue of the Journal (*page 381*) revealed a doubling in admissions of young adults aged 18 and over between 1992 and 2001, along with an overall increase in the numbers of adolescents admitted. In a more detailed analysis of a cohort of 247 young adults admitted during 2001, the authors also examined disease complexity and discovered a paucity of transition planning, particularly in surgical units. While some medical services (eg, Endocrinology, Respiratory Medicine) appeared to effect transition of adolescents with complex health issues efficiently, this was definitely not the norm.

With increasing prevalence of some diseases and improved survival rates for previously fatal childhood conditions, pressures on all tertiary care facilities continue to rise. In paediatric hospitals, one possible outcome is pressure to improve facilities for adolescents. A psychosocial survey of Australian hospitals undertaken in 2004 by the Association for the Welfare of Child Health showed an

increase in the number of “adolescent units” since the previous survey in 1994.<sup>7</sup> Hospitalised and ambulatory young people require developmentally appropriate health care supported by psychosocial services — needs that are usually better served in dedicated adolescent facilities. While the impact of this trend on transition practices is yet to be determined, the broader challenge is to consider transition needs in the coordinated planning of health care services. Until transition to adult care is recognised by the adult health care system as requiring a demonstrable change in attitude and resources, little real progress will be possible.

Older adolescents deserve to be treated more as adults than as children. Keeping young adults in the paediatric system is working against this goal on many levels. A sense of maturity and hope for the future are implied in “moving on”,<sup>8</sup> but one of the prerequisites for an effective transition program is “an interested and capable adult service”. By allowing young adults to stay on in the paediatric system (which carries its own set of problems, including the inappropriate collocation of young children with “adults”), the development of such services is effectively stifled, and adult physicians and surgeons are not encouraged to develop their skills in the area.

The article by Lam et al asks, “Why are they there?” It has been proposed that paediatric services may hold onto patients because of mistrust of adult services<sup>9</sup> or through failure to promote independence and autonomy in health-care seeking.<sup>10</sup> Some other probable reasons are less strongly supported by the literature. One is that paediatric services are family-focused, while adult services treat patients as independent adults. This is problematic for young adults who still require family involvement because of the nature or severity of their disease or disability.

Doctors and other staff in adult services may have limited knowledge and understanding of childhood chronic illnesses in young people who survive into adulthood, or of developmental issues in adolescents. Furthermore, young people are “diluted” in

**Transition plan for young people and their families/carers\*†**

**Phase 1: Preparation**

The paediatric coordinating team (paediatric clinicians, young person, family/carers, relevant others)

- identifies the need for transition to adult care;
- identifies one member as case manager for continuity through the process;
- plans and prepares for active transition;
- ensures that a baseline "assessment of readiness" checklist is completed for and by the young person, family/carers and staff; and
- Identifies, selects, includes and contacts appropriate adult services.

**Phase 2: Active transition**

The case manager

- evaluates "assessment of readiness" checklist on an ongoing basis;
- engages a combined paediatric and adult transition team in partnership with the young person and family/carers; and
- ensures successful transfer to adult services.

**Phase 3: Integration**

The case manager

- ensures that transfer is completed and that care is integrated into adult services, including designation of a new case manager;
- evaluates quality outcomes; and
- evaluates "assessment of readiness" checklist for indicators of success.

\* Based on a strategy being developed by the Transitional Care for Young People with Chronic Childhood Illnesses Group of the Greater Metropolitan Clinical Taskforce. † This model will require adjustment to meet the needs of special groups.

Australia urgently needs to develop a national policy on transitional care that articulates the critical role of transition coordinators as well as the coordination of transitional care between paediatric and adult services. Success will also depend on educating health professionals and families about the value of coordinated transition; developing appropriate attitudes and expertise, particularly in adult services; comprehensively evaluating transition programs; examining health outcomes and cost-benefit issues; and involving consumer advisory groups.<sup>12,13</sup> While additional resources may be needed, the overwhelming need is for a change of attitude and approach.

**David L Bennett**

Head, NSW Centre for the Advancement of Adolescent Health  
The Children's Hospital at Westmead, NSW  
and Associate Professor, Discipline of Paediatrics and Child Health  
University of Sydney, Westmead, NSW  
Davidb3@chw.edu.au

**Susan J Towns**

Head, Department of Adolescent Medicine  
The Children's Hospital at Westmead, NSW

**Kate S Steinbeck**

Head, Adolescent Medical Consultancy Service  
Royal Prince Alfred Hospital  
and Associate Professor, Discipline of Medicine  
University of Sydney, Camperdown, NSW

**Acknowledgements:** We wish to thank Ms Anne Cutler, National Liaison Officer of the Association for the Welfare of Child Health Inc., for her helpful comments, and Ms Lynne Brodie, Program Manager, Transitional Care for Young People with Chronic Illness, Greater Metropolitan Clinical Taskforce, NSW.

- 1 Blum RWM, Garell D, Hodgman CH, Slap GB. Transition from child-centred to adult health-care systems for adolescents with chronic conditions: a position paper of the Society for Adolescent Medicine. *J Adolesc Health* 1993; 14: 570-576.
- 2 Viner R. Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Arch Dis Child* 1999; 81: 271-275.
- 3 Rosen DS, Blum RW, Britto M, et al. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. *J Adolesc Health* 2003; 33: 309-311.
- 4 Somerville J. Grown-up congenital heart (GUCH) disease: current needs and provision of service for adolescents and adults with congenital heart disease in the UK. *Heart* 2002; 88(Suppl 1): i1- i14.
- 5 Boyle PB, Faruki Z, Nosky ML. Strategies for improving transition to adult cystic fibrosis care, based on patient and parent views. *Pediatr Pulmonol* 2001; 32: 428-436.
- 6 Lam P-Y, Fitzgerald BB, Sawyer SM. Young adults in children's hospitals: why are they there? *Med J Aust* 2005; 182: 381-384.
- 7 Association for the Welfare of Child Health. 2004 National survey report on psychosocial care of children (and families) in hospital. In press.
- 8 Conway SP. Transition for paediatric to adult-orientated care for adolescents with cystic fibrosis. *Disabil Rehabil* 1998; 20: 209-216.
- 9 Fox A. Physicians as barriers to successful transitional care. *Int J Adolesc Med Health* 2002; 14: 3-7.
- 10 Rosen DS. Transition of young people with respiratory diseases to adult health care. *Paediatr Respir Rev* 2004; 5: 124-131.
- 11 Fleming E, Carter B, Gillibrand W. The transition of adolescents with diabetes from the children's health care service into the adult health care service: a review of the literature. *J Clin Nurs* 2002; 11: 560-567.
- 12 American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics* 2002; 110: 1304-1306.
- 13 Callahan ST, Winitzer RF, Keenan P. Transition from pediatric to adult-oriented health care: a challenge for patients with chronic disease. *Curr Opin Pediatr* 2001; 13: 310-316. □

the adult health care system and their special needs may be largely overlooked in individual services.

There are inherent difficulties in discovering, accessing and negotiating adult services for young people and their carers. The implications of "failed transition" for young people range from a lack of continuity of care and reliance on crisis services to "falling through the gap", with significant adverse health consequences.<sup>11</sup> We agree with Lam and colleagues that the solution to the problems of young adults in children's hospitals lies more in a greater focus on the infrastructure supporting transition than in admission policies *per se*.

Unfortunately, there are no established, evaluated transition programs described in the literature on which such an infrastructure could be based. In New South Wales, the Transitional Care for Young People with Chronic Childhood Illnesses Group (part of the Greater Metropolitan Clinical Taskforce) is developing a state-wide strategy to address transition, which may serve as a blueprint for a national process (Box). Data collection, "gap" identification and the use of transition coordinators based in adult hospitals are all part of this initiative.