

# Transition care in Hong Kong

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Hong Kong Med J 2016;22:408–9

DOI: 10.12809/hkmj165060

The main objective of the transition from paediatric to adult health care services is to ensure that all adolescents continue to receive coordinated care after reaching adulthood.<sup>1</sup> Medical personnel understand that when children grow up, there are adulthood-related issues such as pregnancy or drug-related illnesses that many paediatricians are not equipped to deal with. Thus, transferring patient care to adult facilities is often an essential and unavoidable event in the medical journey for children.

There is now ample evidence that children who acquire a major physical illness at an early age, such as chronic kidney disease, are also at risk of cognitive developmental delays.<sup>2</sup> Thus, while all youths eventually experience transition in health care, paediatricians are particularly concerned about youths with physical and/or cognitive disabilities. Medical care for these individuals is often more complex: they will generally also need long-term therapies and require extra attention due to the accompanying suboptimal cognitive maturity. In order for their health care to successfully transition to adult facilities, it is crucial that these vulnerable youths receive sufficient and appropriate preparation.

Although the literature suggests that many children with physical and cognitive disabilities suffer profound and prolonged morbidities due to ineffective health care transitioning, paediatric caregivers in Hong Kong face wide-ranging predicaments both within and outside the health care system. Problems include the lack of a comprehensive health care policy, scarcity of transition programmes, inadequate physician training, and inadequate education and preparation of patients and/or their family. In “A proposal on child health policy for Hong Kong” published by the Hong Kong Paediatric Society in August 2015,<sup>3</sup> paediatric health care professionals expressed their desire to set up and implement a comprehensive, yet effective child health care policy to address the many health care challenges in Hong Kong. The professional panel pointed out that among all major concerns, there was ultimately a lack of coordinated and uninterrupted care for children with special care needs and medical complexities. In particular, the transition of care for such children was especially fragmented.

Transition preparations for children with

special needs have been a public concern in many developed countries.<sup>4</sup> The US Government has also identified the need to involve more physicians in transition planning as a public health objective in the Healthy People 2020 project.<sup>4,5</sup>

Efforts have been made to develop transition programmes, for example, with the establishment of transition clinics that are directed by transition coordinators in conjunction with adult-care physicians.<sup>6</sup> During the past decade, more and more organisations have taken the initiative to set up ‘Family-Centered Medical Homes’ in order to integrate care for children with special needs.<sup>4</sup>

In 2011, the Transitions Clinical Report Authoring Group, along with representatives from the American Academy of Pediatrics, the American Academy of Family Physicians and the American College of Physicians, issued a clinical report on the practice-based implementation of transition for youth.<sup>7</sup> The report offered a framework for training not only for the medical team, but also for educators, assistants, and families of youths in medical homes. This year, the National Institute for Health and Care Excellence in England also published their guidelines on the transition of care for young people.<sup>8</sup> They provide practical advice for caregivers attempting to improve young people’s engagement with services.

There are also some other transition tools available through the Internet that may be able to be adapted for use in education for the general public or even as a means to assess whether patients are ready for health care transitions.<sup>9</sup> One such tool that could be particularly beneficial is the MyHealth Passport,<sup>10</sup> as well as other tools listed in the Health Care Transition Resources.<sup>11</sup> Since children with special needs are heterogeneous in nature, there is currently no universal tool although most tools can potentially be customised for each individual child and his/her family according to cultural background and underlying disabilities.

In 2007, approximately 10 900 adolescents with disabilities between the ages of 14 and 17 years took part in the Survey of Adult Transition and Health.<sup>12</sup> The results showed that only 21.6% of adolescents had undergone successful transition to adult care. This finding reflects the dire fact that despite all the efforts made, the health care system in its current state still fails to support the majority of youths with

special needs who are exiting paediatric care. There remains a great need for research and evaluation on the outcome of the transition of children with disabilities into adult facilities.

In the current issue, Pin et al<sup>13</sup> reports on their local pilot data on the clinical transition of adolescents with developmental disabilities. Among the surveyed children and their families, approximately 60% considered the transfer process to be suboptimal. Although the study was confounded by many limitations and the findings are far from conclusive, it sheds light on the underlying causes of dissatisfaction and hurdles associated with youth transition in Hong Kong. Since a solid understanding of the underlying problems is important in finding a solution, we desperately need more local and relevant information on how to improve the effectiveness and success of health care transfer for children with special needs.

One of the six core goals of the care of children with special needs, as identified by the Maternal and Child Health Bureau, is to ensure that these individuals continue to receive the support necessary for transitioning to adulthood.<sup>14</sup> The ultimate goal is not just to provide the necessary medical care during transition, but also to enable individuals to succeed in all aspects of life so that they are able to work, to assimilate into society, and to achieve independence.

Now that the deficiencies have been identified, it is time for medical professionals to take the initiative and work together to help shape the future of health care for children with special needs.

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