The Quest to Improve the Care of Children and Young People Who Undergo Transition from Child to Adult Health Services

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EDITORIAL

The Quest to Improve the Care of Children and Young People Who Undergo Transition from Child to Adult Health Services

ABSTRACT
Emeritus Professor Alan Glasper, University of Southampton, discusses how the transition experiences of children and young people from children’s to adult health services can be enhanced.

Introduction
Continuing new developments in health have resulted in greater numbers of children who in the past would not have lived beyond their early years surviving into adulthood. For example, there are now more than 40,000 people less than 18 years of age in England who have complex health needs, caused by physical disabilities, special education needs, or life-limiting or life-threatening conditions (Care Quality Commission, 2017).

In the United States the prevalence of adolescents between 12 and 18 years with special health care needs is 18.4% (Castillo & Kitsos, 2017) and in Australia 12% of young people aged 12–24 reported at least one chronic condition or disability. Good transition to adult health services is important for all these young people with special
health needs in order to maximize their lifelong access to health and their general well-being in society.

Such is the concern about the optimum management of these young adults as they transition into adult health services that various organizations in many countries have published policies that articulate strategies to ensure that adolescents’ health does not adversely deteriorate in the wake of transfer. For example, the American Academy of Pediatrics and others published a consensus statement on health care transitions for young adults with special health care needs which highlighted the importance of optimum transition of young people with long-term health care needs to adult health services (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians–American Society of Internal Medicine, 2002). Similarly, in response to the growing incidence of chronic illness and disability among the childhood population in the United Kingdom, the Royal College of Paediatrics and Child Health (RCPCH) recently published a new set of standards entitled “Facing the Future: Standards for Children with Ongoing Health Needs” (Royal College of Paediatrics and Child Health, 2018) which attempts to improve transition of children with long-term conditions to adult health services.

Likewise in 2014, the Sydney Children’s Hospitals Network in Australia published key principles for the transition of young people from pediatric to adult health care (Agency for Clinical Innovation and Trapeze, the Sydney Children’s Hospitals Network, 2014).

Transition from child to adult mental health services has also come under significant scrutiny in England after an 18-year-old boy who suffered from autism committed suicide after displaying anxiety over the prospect of his forthcoming transition to mental health services and the loss of his long-term child and adolescent mental health care co-coordinator. The subsequent investigation by the English Healthcare Safety Investigation Branch (HSIB) found that many mental health organizations lacked standardized tools or appropriate methodologies for the transition of young people suffering from mental health disorders to adult services. The report by HSIB estimated that only a small percentage of the 25,000 young people in England who undergo transition from child to adult mental health services and experience an optimum transition (Healthcare Safety Investigation Branch, 2018).

**Background**

The number of published policies pertinent to young people’s transition to adult services by health authorities in many countries is indicative of the concerns and debates about the process, which have become more strident over the years.

It is because the young adult thinks and functions so differently from the mature adult that there is a case for developing young adult health services that meet the developmental needs of young people to ensure that they optimally receive the health care they need to reach full adulthood without mishaps.

For certain groups of young adults, the transition from children’s services to adult services can cause significant worry and anxiety, not only for the child but also for the parents and guardians of that child. It is important to stress that many children with long-term conditions may have been cared for by individual pediatricians and children’s nurses since birth. The prospect of leaving the familiarity of these partnerships when the adolescent reaches 16 or thereabouts to enter the world of adult medicine, where in some cases they are expected to behave beyond their actual developmental age, is concerning for many families. In the case of young people with learning disabilities, transition is
often very challenging and occurs at a period in their lives when they are also undergoing other profound physiological and psychological changes (Mencap, n.d.).

Similarly young people with specific mental health disorders such as attention deficit hyperactivity disorder (ADHD) are particularly vulnerable during the transition period, and disruption of care during transition can adversely affect the health, wellbeing, and potential of this vulnerable group (Young et al., 2016)

**Strategies that aspire to improve transition to adult health care**

There continue to be inequalities in health status among childhood populations around the world. A collaborative report by the Royal College of Paediatrics and Child Health and Royal College of Adolescents (2003) recognized all the shortcomings within the health system for young people undergoing transition, but the implementation of the report’s findings was meager despite the report highlighting that mortality among young people in the UK did not decrease significantly in the second half of the twentieth century and the early years of the twenty-first century—in contrast to all other age groups. It was the publication of the English Department of Health’s “You’re Welcome—Quality criteria for Young People Friendly Health Services” in 2011 (updated in 2017) that helped commissioners and providers of health services improve health services for young people approaching transition (Glasper, 2011). The “You’re Welcome” criteria had been designed as an audit tool to allow organizations to reflect on how young person friendly they were. The principal aspiration of the audit tool, intended for all organizations that provide care for young people, is that young people should be entitled to receive appropriate health care wherever and whenever they access it. One of the sections of the audit tool specifically examines transition to adult health services

Although there is a wealth of guidance about transition, young people actually making the transition journey from child to adult services are still in many cases inadequately or inconsistently supported. Singh, Anderson, Liabo, and Ganeshamoorthy (2016) believe this can lead to disrupted care and, if young people subsequently disengage from services, be financially costly both for the young person and for care providers.

In 2016 The UK National Institute for Health and Care Excellence (NICE) published a standard on transition from children’s to adults’ services (see National Institute for Health Care Quality and Excellence, 2016) with five quality statements:

1. Young people who will be moving from children’s to adults’ services should start planning their transition with health and social care practitioners by school year 9 (aged 13–14 years) or immediately if they enter children’s services after school year 9.
2. Young people who will be moving from children’s to adults’ services should have an annual meeting to review transition planning.
3. Young people who are moving from children’s to adults’ services have a named worker to coordinate care and support before, during, and after transfer.
4. Young people who will be moving from children’s to adults’ services meet a practitioner from each adult service they will move to before they transfer.
5. Young people who have moved from children’s to adults’ services but do not attend their first meeting or appointment should be contacted by adult services and given further opportunities to engage.

In responding to national and international guidance on transition for young people some health authorities such as the University Hospital in Southampton England have developed and implemented specific transition programs. Southampton’s “Ready
Steady Go” initiative is a structured and adaptable transition program designed to empower young people to take control of their lives and equip them with the necessary skills and knowledge to manage their own health care as they prepare to leave children’s services and enter adult services (Nagra, McGinnity, Davis, & Salmon, 2015).

The role of health care regulators

The Care Quality Commission (CQC), which is the health care regulator for England, now recognizes that health care transition for young people to adult services is problematic. Hence the CQC is increasingly examining transition arrangements for young people when they inspect children’s and young people’s services in English health care organizations (see Care Quality Commission, 2014). In future the CQC will place greater emphasis on transition arrangements, and health care providers will be encouraged to improve their services and, importantly, castigated when inadequate care is revealed which fails to meet the needs of this vulnerable group.

Conclusion

All young people have to undergo the challenges of adolescence as they prepare for adulthood. For young people with long-term health conditions both physical and mental these challenges can be far more complex. There are now a number of international policies and standards to help health care professionals such as children’s nurses to work with young people and their families to enhance the process of transition to adult health services. To increase nursing knowledge about transition, Comprehensive Child and Adolescent Nursing has commissioned a special issue of the journal which will publish in 2020.

Key points

- The number of young people throughout the world who have complex health needs is increasing.
- In many countries concerns have been raised about the optimum management of young people as they transition into adult health services.
- Although there is a wealth of guidance about transition, young people actually making the transition journey from children’s to adults’ services are still in many cases inadequately or inconsistently supported.
- Health care regulators such as the English CQC are taking an increased interest in transition arrangements for young people when they inspect children’s and young people’s services in hospitals.

References


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