Principles of transitional care for young people with longstanding continence problems

More children with long term conditions are surviving into adulthood. This article discusses how to prepare young people and their families for transitional care.

INTRODUCTION
The National Service Framework for children and young people recommends that young people with long term health problems are supported to make the transition to adulthood and work towards achieving their maximum potential in terms of education, health, development and wellbeing (Department of Health, 2004).

Achieving these goals is problematic as research into effective models of transition is limited (Jones and Hamilton, 2008). As a result, both the Department of Health (2008a; 2006) and the Royal College of Nursing (2004) have produced documents to aid the development, management and implementation of transitional care.

BACKGROUND
Adolescence is a period of physical, psychological and social change that can be a difficult time for young people. As they move through adolescence, there is an expectation that they will seek increasing independence and autonomy (DH, 2008a). For those with a medical condition requiring long term management, adolescence can be even more stressful or difficult (Friedman et al, 2009; Social Care Institute for Excellence, 2004).

There is limited research on the impact that moving from children’s to adult services has on health related quality of life in young people with voiding dysfunction or neuropathic bladder. Many adolescents may have ongoing incontinence, despite having had several operations (Baird et al, 2005). Studies have reported that social exclusion or isolation and loss of dignity can be associated with urinary incontinence in adolescence (Mohn et al, 2010; Dockter et al, 2008), while Barf et al (2009) reported that up to 40% of young people (16-25 years) with spina bifida identified physical challenges, such as incontinence, as a barrier to social inclusion and relationship development.

Transitional healthcare services need to be based on patient need in order to promote positive health, educational and social outcomes for young people (DH, 2008a) and improve the quality of care they receive (Royal College of Paediatrics and Child Health, 2003).

WHAT IS TRANSITION?
Healthcare transition is defined as the “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated healthcare systems” (Blum et al, 1993). For young people with ongoing health needs, an early approach to preparing for transition is integral to building confidence and competence in the young person and their family unit, as well as in the professionals within both their existing and future services (de Beaufort et al, 2010). Preparation, along with good communication, is crucial if young people are to engage and participate in the process of transition (Viner, 2001).

Transitional care involves the ongoing education of young people in several areas. This includes developing an understanding of their diagnosis and management of any problems. Clarizia et al (2009) found that patients who were more knowledgeable...
about their condition were more confident in their ability to care for themselves and negotiate adult healthcare independently of their parents. Challenges or barriers may exist if young people are reluctant to become involved in managing their own care, especially if parents continue to play a significant role in managing physical healthcare needs (Clarizia et al, 2009).

Those who have had bladder surgery in childhood may have forgotten some of their experiences or have a limited understanding of the rationale for surgery. There is an expectation that parents will collaborate with healthcare professionals and share information with adolescents as they mature (Antle et al, 2009). However, parents themselves may not recall early surgery, fully appreciate the lifelong need for healthcare review or be able to explain the condition to their child.

Education, under the umbrella of health promotion, includes the topic of sexual and relationship health, as well as general health issues, such as the need to exercise and to avoid substance abuse. These areas need to be discussed with all young people, however, both professionals and parents may be reluctant to discuss such sensitive issues (RCN, 2004). Good transitional planning and the establishing of clinical boundaries by service providers, based on the needs of young people, may help to avoid power struggles between adolescents and their parents (Bowen et al, 2010), as well as facilitate the discussion of sensitive issues, such as sexual health.

As well as dealing with medical issues, successful transitional care may help young people to achieve independence and act as their own advocates. This is a positive step for those who have been dependent on their families for physical and emotional support throughout their childhood.

**PREPARING FOR TRANSITION**

Planning transitional care as early as possible may help to prepare children and their families for the transfer to adult services. This is supported by the DH (2008a) document Transition: Moving on Well, which states that “the process of transition should start while the child is being cared for by the children’s services and may, subject to the needs of the young person, continue for a number of years after the transfer to adult services”. The key components are outlined in Box 1.

A transitional care service that is collaborative and well organised can promote patient safety and high quality care, which are key goals in health service delivery (DH, 2008b). Transitional care services within organisations are often associated with specific healthcare teams and include specialists in areas such as diabetes, rheumatology and cystic fibrosis.

The DH (2008a) recommends that a health transition plan is developed by the young person and supported by the most appropriate healthcare professional available within the paediatric service. Considering individual young people’s readiness to transfer to adult services, rather than their age, can be helpful in determining a time frame for the transfer of care (Bowen et al, 2010). Transition planning should involve all members of the multidisciplinary team involved with the young person as well as those who will in the future be the gatekeepers to services (Tan et al, 2009).

**YOUNG PEOPLE WITH CONTINENCE ISSUES**

Regular follow-up for young people with long term conditions is important (Wong et al, 2010). This includes follow-up for those who have been treated for urological conditions as a result of congenital conditions, such as spina bifida. Finding ways in which to respond to the multitude of health, developmental, and psychosocial needs for those affected, for example, by spina bifida throughout their lifespan is important. Addressing these needs may improve their future quality of life and help them to achieve their full potential.

Similar to any young person with long term health issues, young people with ongoing continence needs are at risk during the transition process (DH, 2006). Risks to physical health include deterioration in renal function or missed opportunities to screen for possible bladder problems in young adults who underwent bladder augmentation in childhood (Austin, 2008). Specifically, bladder augmentation in childhood is associated with a number of potential long term risks. For example, there may be a need for further surgery, and there is a small risk of adhesive small bowel obstruction, bladder perforation, bladder stones, metabolic changes and bladder cancer (Austin, 2008).

Successful transition to the adult service may help with future patient concordance with care (Alpay, 2009) and the early recognition of any potential problems.

Developing a transitional pathway and access to teams, such as urology, for ongoing management will give young people with dysfunctional voiding the opportunity to access emerging treatments as they become available. These may include interventions that were not suitable or available for a paediatric population, such as in-depth pelvic floor training with a physiotherapist, new pharmacological treatments or surgery.

**THE NURSE’S ROLE**

There are many barriers to the successful transition of adolescents to adult healthcare, including a lack of coordination between services, problems relating to patient and/or family resistance to transfer, lack of planning, lack of service delivery support and lack of adult service providers (Alpay, 2009).

The long term implications of failing to develop transition services include compromised health outcomes for young people that have the potential to incur costs to health economies and waste health resources. Nurses are crucial in the care and management of young people with complex health needs (DH, 2008a). In some areas, including paediatric urology and continence, specialist nurse roles have developed over the last two decades; evaluation of the impact, effectiveness and quality of these roles continues (Muller et al, 2009). Nurse led services are integral to the delivery of care within acute care (Williams et al, 2010), including urology and continence clinics. Paediatric nurse specialists have a key role to play in acting as health promoters, educators, support and service providers to young people and their families (Chisanga, 2009).

A range of services are available nationally in community settings (Hagglund, 2009). However, there are no standards for service models and some regions do not provide a paediatric continence service or a dedicated transition service for young people with urological issues.

The urology transition service within our clinical area was developed by building links with adult service providers. This resulted in the appointment of a consultant surgeon in adolescent urology with clinical accountability to both paediatric and adult environments. The acute, community, adult service, continence and urology nursing teams are striving towards
collaborative and partnership working to enhance continuity of care for adolescents. Service evaluation and ongoing development are crucial areas that are often nurse led. Within the transitional urology service, the information needs of young people and their experiences of the transition process are being updated and evaluated. An action research project is underway across the organisation, which aims to explore transition as a process and identify minimum standards.

INFORMATION AND ADVISE
Young people and their families need information, especially at times of change. In our service, adolescents are given a detailed questionnaire before transition to the adult service, with the aim of assessing their understanding of their healthcare needs and their ability to manage healthcare and daily activities of living independently. This questionnaire may then be used as a tool to assess suitability for transfer.

Nurse specialists have a vital role in the transition by ensuring that young people and their families are fully involved in the process (Chisanga, 2009). Information needs to be easily accessible and readily available in a variety of formats (Wong et al, 2010).

Within our clinical area, transitional clinics aim to provide a comprehensive service and many groups are involved, including voluntary organisations and educational, physiotherapy and community continuity teams. The clinics aim to offer information about health needs, as well as employment and educational opportunities.

Both patients and their families are invited to attend. The transitional clinic also gives young people the opportunity to be seen without their parents. Direct communication between the agencies and young people rather than parents promotes autonomy and demonstrates a move away from family centred care.

In our clinical experience, young people have used the transitional clinics as an opportunity to build social networks with others who have shared similar experiences. Peer interaction and support during the transitional process may reduce feelings of being abandoned by their healthcare provider (Bowen et al, 2010).

A study by Anthony et al (2009), which examined the perceptions of transition, highlighted young people's desire for information about the transitional process to be available online.

Other ways to improve information sharing include email, text messaging and online forums. If they are to take the transitional process forward, healthcare providers need to be innovative to ensure that information is presented in ways that are meaningful to this group.

CONCLUSION
Although the best approaches to transitional care are as yet unknown (Bowen et al 2010) a review of current literature indicates that early preparation, promotion of independence, adequate information, education, continuity of care and the use of assessment tools are all vital components of a successful transitional process (Jones and Hamilton, 2008).

While guidance is available (DH, 2006; 2004; RCN, 2004), the challenge is in putting it into practice. In our clinical area, collaborative working between paediatric and adult services has started to bridge the gap between care providers.

Transitional healthcare plans are based on the adolescent's individual needs and there is ongoing support and coordination by nurse specialists. Future developments will be based on the findings of current research exploring the transitional process.