



## **Literature review**

### **Young people's transition from children's to adult services in primary and community care settings**

by Chloe McCallum, Policy Officer, The Queen's Nursing Institute

#### **Introduction**

The Queen's Nursing Institute (QNI) was funded by the Burdett Trust for Nursing to deliver a comprehensive programme of work to improve the experience of a young person transitioning from children's to adult services, with a specific focus on district nursing and general practice nursing. This project will involve identifying evidence-based approaches to improve the transition experience of young people and developing resources and 'transition champions' to promote learning and embed best practice.

To inform the work, the QNI undertook a literature search at the beginning of the project to identify relevant research. It was recognised that the literature would need to be reviewed throughout the project in order to maintain an up-to-date understanding of the evidence. The initial search comprised UK literature published within the last ten years.

The following databases were searched: British Nursing Index, Social Policy and Practice, Royal College of Nursing Library and Heritage Centre Catalogue. Key words used in the search included: transition, adult, adolescent, community health, community nursing, district nursing, primary care, general practice, teen transition. There was a paucity of relevant literature as much of the research on transition was hospital-focussed and was therefore excluded. Whilst some articles made a general mention of community services and primary care, no research was identified that specifically referred to district nursing or general practice nursing.

The research that was identified is considered below in relation to three themes: the role of the key worker in the community, the role of community nurses more generally, and the role of primary care; followed by a review of relevant policies and best practice guidance.

#### **The role of the key worker**

Guidance from the Department of Health (DH, 2008) recommends that a named individual, often called the key worker, co-ordinator or lead professional, works with the young person to co-ordinate their transition process. The health or care professional who undertakes this role should be agreed with the young person and should either be a transition key worker, a professional from the children's services, or a professional from the adult services. If the young person has a life-limiting condition and needs support to maintain their quality of life or manage at home, their health transition plan might be coordinated by a therapist or community nurse, for example a

nurse in a palliative care team or hospice, a district nurse, community matron or a Macmillan nurse.

In *Adolescent transition care: RCN guidance for nursing staff*, the Royal College of Nursing (RCN) noted that whilst in most hospitals the key worker is likely to be a children's nurse specialist, or even an adolescent specialist nurse, this role could also be undertaken by another professional, such as a community nurse, social worker, GP or occupational therapist (RCN, 2013a).

Kelly (2014) described the role of the transition nurse coordinator in Hertfordshire as 'an effective key worker, facilitator, coordinator, communicator and advocate' for young people with complex health needs until they are established in adult services. In this case the transition nurse coordinator was based in Hertfordshire Young People's Health Transitional Service, open to young people aged 14-21, rather than within either children's or adult services. The transition nurse facilitated the transition process over several years by working together with the young person, their family and a range of professionals in both acute and community health services, social care, education and other agencies.

Kelly noted that the transition nurse coordinator must identify the training needs of professionals within the receiving adult services, such as the district nursing team, and ensure these training needs are addressed during the transition process. Another part of the role was to encourage the young person to engage with their GP before transition from children's to adult services, so the GP can become familiar with their health needs. Unfortunately, no assessment was made in this article of the impact of introducing a dedicated transition nurse coordinator on outcomes for young people.

Whilst their review was specific to cancer services, Farrell and Law (2015) described the role of specialist liaison nurses who supported the transition of young people with cancer to adult services and facilitated information sharing between hospital and community services. The specialist liaison nurse in this case could be a registered children's or adult nurse, who was based in hospital but also provided care in the community by visiting the patient and their family at home.

### **The role of community nurses**

Barron *et al* (2013) conducted a study into the transition of young people with intellectual disability and challenging behaviour in London and identified a lack of access to community specialist nursing, such as nurses trained in learning disability or mental health. The authors stated that to assess the physical and mental health needs of young people with challenging behaviour, the 'full range of relevant professionals and specialist supports' should be available, although it was noted that service provision varied widely across the UK.

A three-year study in Yorkshire and the Humber used a process mapping approach to consult with over 300 young people, parents and professionals to understand young people's experience from diagnosis with type 1 diabetes through to transition to adult services (Kime, 2013). The author identified inconsistencies between the paediatric and adult care provided in hospitals, and limited partnership with primary care and community services.

Given the growing emphasis on the need to manage long-term conditions in the community and empower young people to self-care, Kime found that community nurses need to take a more active role in the transition of young people to adult services. The author stated that the community nurse was well placed for this role because they would often see young people with long-term conditions in the home and were therefore in a position to provide continuity of care and supervise a holistic model of transition that included the young person's lifestyle and broader needs. In addition, the community nurse could act as the communication link between young people and their families, and the professionals in both primary and secondary care. The Royal

College of Physicians of Edinburgh (RCPE) Transition Steering Group also noted that community nurses could improve the relationship between the primary care team and the young person and their family, by taking part in transition clinics with other professionals involved in the young person's care, such as community paediatricians (RCPE, 2008).

### **The role of primary care**

Guidance from the Department of Health recommends that primary care staff should be invited to participate in the transition planning process and that it may be helpful for primary care services to lead the coordination of care for young people with several long-term conditions, or where no adult service has been identified as part of the transition plan (DH, 2006).

The study on the transition of young people with type 1 diabetes described above (Kime, 2013) found that young people usually attended 6 transition clinics over a two-year period at which both paediatric and adult diabetes teams were present. However, the author found that none of the transition clinics included a professional from the primary care team, despite the fact that the GP was often the first point of contact when young people experienced worsening symptoms.

A review by Brooks *et al* (2009) explored the transition process for young people with long-term conditions, focusing on the UK. The authors highlighted that a good transition places the young person at the centre of the decision-making process and that professionals, particularly in adult services, should ensure they use flexible and age appropriate communication methods to build relationships with young people. The transition process must be supported by effective interagency communication and joint working, coordinated by designated professionals.

However, Brooks *et al* also identified a lack of good quality primary research and significant gaps in the evidence base in relation the role of primary health care professionals and the relationship between general practice, secondary care and social care. One of the studies mentioned in this review found that primary health care could be completely absent from the strategic planning process for the transition of young people to adult mental health services (Singh *et al*, 2008). No comprehensive model for the effective involvement of primary care has been established and Brooks *et al* concluded that the role of primary healthcare services in monitoring transition for young people with long-term conditions merits further investigation.

Research by Gibson and Aldiss led to the development of a set of benchmarks for the transition process (Aldiss *et al*, 2015; LSBU and GOSH, 2014). The benchmarks focussed on eight factors: 1) moving to manage a health condition as an adult; 2) support for gradual transition; 3) co-ordinated child and adult teams; 4) young people friendly services; 5) written documentation; 6) parents; 7) assessment of readiness; and 8) involvement of the GP. The indicators of best practice for the eighth factor included that the GP was involved in the transition plan and acted as the link to further primary care services. However, there was no detail about the role of the wider primary care team, or more specifically the role of general practices nurses.

In February 2016, the National Institute for Health and Care Excellence (NICE) published the guideline *Transition from children's to adults' services for young people using health or social care services (2016a)*. Whilst the guideline did not make any specific references to community or primary care nursing, one of the areas the committee recommended for further research was the role of primary care in supporting young people discharged from children's services. NICE did not identify any studies investigating the role of primary care for groups including: those who no longer have access to the same services when they enter adult care; those who do not meet eligibility criteria for adult services; and those who are placed in care outside their local authority, who are more likely to change provider and GP during transition. NICE recommended that research should be conducted into the most effective ways for primary care services to be

involved in planning and implementing transition, and in the follow-up of young people after the move to adult services.

In December 2016, Nice further published guidelines *Transition from children's to adults' services Quality Standard QS140 (2016b)*. This covers the period before, during and after a young person moves from children's to adults' services and its aim is to help young people and their carers have a better experience of transition by describing high-quality care in priority areas for improvement.

## **Transition interventions**

A review by Crowley *et al* (2011) explored the impact of transitional care programmes on health outcomes in young people aged 11-25 with chronic illness or disability, and aimed to identify the successful components. Of the 10 studies that met the inclusion criteria, 8 involved patients with diabetes, and the authors identified that patient education programmes and joint clinics or specific young adult clinics could improve outcomes for those with diabetes. The authors could not conclude whether the successful interventions were generalisable to other chronic conditions and they found that much more needs to be done to improve the evaluation of current and developing programmes.

Whilst it was focused on the transition to adult hospital care, the qualitative metasynthesis by Fegran *et al* (2013) criticised the review by Crowley *et al* for its focus on health outcomes alone, without considering the wider experiences of young people. Fegran *et al* found that the transition experiences of young people with chronic conditions seem to be generic, and that nurses can support transition planning by assessing young people's resources, relationships, preparedness, and responsibility, thereby ensuring the young person feels that they are a significant part of their healthcare.

A Cochrane review investigating the effectiveness of interventions to improve young people's transition from paediatric to adult services found only four studies that met the selection criteria (Campbell *et al*, 2016). All of the studies were conducted outside the UK, and the authors noted that the extent to which the findings were relevant to other healthcare settings was uncertain. None of the identified studies targeted healthcare professionals, nor did they involve community nursing services or primary care. One study did include a specialist nurse-led educational intervention, which led to slight improvements in the young people's readiness for transition and chronic disease self-management; however, disease-specific outcomes were not reported. The authors concluded that the evidence was very limited, both in terms of the range of young people's health conditions and interventions studied, as well as the long-term effects of the interventions, given that follow-up lasted only 4 to 12 months. Campbell *et al* recommended that future research should be conducted in other settings and should examine interventions that target health professionals and the organisation of healthcare.

## **Policy and good practice guidance**

In addition to *Transition: getting it right for young people* (DH, 2006) and *Transition: moving on well* (DH, 2008), the Department of Health included a section entitled 'health issues and transition for young people' in the document *You're Welcome - Quality criteria for young people friendly health services* (DH, 2011). In this section, the Department of Health recommended that health services have a clear procedure to prepare young people for transition, with particular attention given to those with long-term conditions, and to provide transition materials that are attractive to young people. In addition, staff members should be trained to support young people, their families and carers with transition from age 12 onwards, and all young people with ongoing needs should have an individual transition plan, including a named key worker to provide continuity during the process. The *You're Welcome* criteria are currently being revised to order to produce an updated version that will provide examples of good practice from across the country.

An article by Baines (2009) criticised the 2006 Department of Health policy (DH, 2006) for not providing professional staff with practical guidance on how they can improve patient transition. It was highlighted that since the publication of national transition policies, no quality reviews have been carried out to determine whether the government's recommendations have improved transition management in practice. The author noted that factors such as lack of training and funding, poor awareness of nursing staff and lack of specialist nurse involvement could lessen adherence to policy standards and have a negative impact on young people's transition. Despite a lack of funding for training to raise awareness of transitional issues and implement policies, Baines recommended that nurses should be proactive in initiating and supervising transition, by encouraging joint working with other professionals, and in understanding policies so that they can be incorporated into practice.

Since Baines' article there have been several projects to produce guidance that supports best practice for transition. However, there is currently a lack of assessment relating to the implementation of this guidance, or evaluation of its outcomes, and there is an absence of guidance specific to health care professionals in community and primary care services.

One example is the STEPP Project (supporting health transitions for young people with life-limiting conditions: researching evidence positive practice), which focused on the way that adult health services can influence transition outcomes for young people and led to a resource to support practitioners (Beresford, 2013a; 2013b). Further tools to support health care professionals include the guide to developing a good transition from Together for Short Lives (Chambers, 2015), a toolkit produced by Helen and Douglas House (2014) and the Ready Steady Go resources developed by University Hospital Southampton NHS Foundation Trust (2012). Whilst use of the Ready Steady Go programme has not yet been assessed in community and primary care services, there has been some evaluation of its implementation in hospital settings (Nagra, 2015). The feedback from young people, carers and health care professionals indicated the materials were simple, easy to use, helped to address key transition issues and improved clinical practice, but that not all questions were relevant and use of the tool led to a marginal increase in consultation time.

In addition, South East Strategic Clinical Networks released a guide for professionals which includes best practice pathways for asthma, epilepsy and diabetes, as well as generic recommendations applicable to any long term condition (Pathan *et al*, 2015). Even more recently, the 'Stepping Stones' transition toolkits for providers and commissioners were published online, and include links to many other resources to support organisations to make transition a priority (Yorkshire & the Humber Strategic Clinical Network for Children Transition Task and Finish Group, 2016).

The Children and Young People's Mental Health and Wellbeing Taskforce (DH, 2015) proposed that transition to adult mental health services should take a flexible approach based on individual circumstances, including flexibility around age boundaries. The Taskforce cited as best practice: gradual preparation and handover with joint transition planning meetings, joint working and shared practice between services and periods of overlap to promote continuity of care. Transition should involve consistency in key workers, agreed responsibility arrangements between services and opportunities for the young person to meet members of the adult services prior to transfer.

Despite the availability of policies and emerging good practice guidance, a report published by the Care Quality Commission (CQC) in 2014 found that the transition process was variable and whilst good practice guidance and protocols were often in place, they were not always implemented and some professionals were not aware of their existence (CQC, 2014).

The CQC report highlights the vital role of primary care in transition, given that it is the only service that does not change once a person becomes an adult. However, whilst the CQC heard that

young people receiving care from children's services were unlikely to visit their GP, the GP was often the first point of contact after the move to adult services and would be expected to manage complex health needs with little prior knowledge about the young person and their family. The CQC recommended that community paediatricians should involve GPs more throughout childhood to ensure GPs are prepared and able to support the young person during the transition process. However, no mention was made in the report of the role of the wider primary care team, or more specifically of general practice nurses.

The CQC found that many health professionals, including community nursing staff, felt that there were gaps in their knowledge, understanding and skills in the management of transition to adult services. Despite the presence of written policies, there was a lack of practical guidance, pathways and training. In some areas that were found to provide training on transition, community children's nurses had started to arrange joint clinics and handover plans for young people with endocrinology, oncology and rheumatology needs.

The Royal College of Nursing (RCN) also highlighted a lack of specialist knowledge of transitional care in adult teams and lack of confidence in knowledge (2013a). In *Lost in transition* the RCN recommended that education and training programmes for both children's and adult services should include transition, and staff in adult services should receive training related to young people's developmental and wider social and emotional needs (RCN, 2013b).

The CQC recommends that all staff providing care to young people are trained in meeting the specific needs of young people and how the different health and care services should work together. A further recommendation was that health and care services for young people must be coordinated by a named lead professional. Despite previous good practice guidance to this effect (DH, 2006; DH, 2008), 50% of young people and families and 70% of health and care staff consulted by the CQC said the transition process was not managed by a lead professional.

Some community children's nurses lacked the training and resources required to assess the additional needs of carers. In addition, in areas without continuing care assessment teams, children's community nursing staff carried out continuing health care assessments, but reported that they had difficulties fitting this into their workload.

The CQC found that there was ambiguity around roles and responsibilities during transition and that children's community nurses struggled to engage adult health teams in the transition planning process, a finding confirmed by adult health professionals who said they were not routinely involved before young people reached adulthood. Some adult health staff reportedly claimed that they were not commissioned to take part in transition planning, or would not engage because they had little knowledge of the young person concerned.

Both community children's nursing teams and district nursing teams reported that they were overstretched and were concerned about managing rising demand. Some services provided by children's community nurses to young people with complex needs were not available from district nurses, partly due to a lack of capacity and resources in adult teams, but also the differences in skills and expert knowledge between the two services. In addition, the CQC saw multiple instances of district nursing services that were unable to accept young people who were not housebound or who did not meet the continuing care criteria for healthcare.

Whilst the CQC found that individual healthcare professionals often worked hard to support young people, there was insufficient coordination of local services to provide a seamless transition and little development or recording of plans for the transfer to adult services. In general there was no provision to assess the process following transition; however, families frequently had problems with lack of information, coordination, and access to equipment and supplies after the move to adult services. In contrast, accounts of the transition arrangements for some specialist services,

such as cystic fibrosis, epilepsy, and cardiac services, were much more positive. The CQC recommended that commissioners need to work together to continually evaluate and improve services.

The CQC inspection criteria will now explicitly include transition, such as the involvement of and support for young people in the planning process, in both children's and adult health services in hospital, community and primary care settings.

## Conclusion

Overall, the literature review undertaken by the QNI has reinforced the view that there is a lack of robust research available on transitional care (RCN, 2013a), in particular relating to effective practice in community and primary care settings. A gap remains in the evidence available to date of the role of community nurses, including the district nurse and the general practice nurse, in supporting young people's transition from children's to adult health services.

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