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**Planning for transition into adult services: Providing support and preparation
for young people with complex health needs and their families.**

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Abstract

In a modern healthcare system, the survivability of children and young people with complex health needs requires a robust system for transition into adult services that is carefully planned. Effective planning is essential to ensure the transition process happens smoothly, in the best interests of the young person and family. This paper discusses the needs and requirements for planned and purposeful transitional processes to support young people with complex health care needs and their families. in relation to the preparation of adult services, the wider multidisciplinary team, the young person themselves and their parents. Recommendations for practice include the necessity for an integrated approach to ensure optimum outcomes, ascertaining the potential value of a nurse led service in delivering the transition process. In conclusion, there is a need to create a carefully tailored planning strategy to optimally prepare and support young people with complex health needs through the transition process.

Introduction

Young people with complex health conditions require a move from children's to adult services at a certain age and point in their development into adulthood. This transition process can be stressful and confusing, especially if there are problems with communication, gaps in care delivery (Lepkowska, 2017) or inadequate preparation. Therefore, careful planning is essential for successful transition. This review article discusses the principles of planning transition for the preparation and support of young people with complex needs and their families. Preparation of adult services, the team, the young people themselves and the parents will be considered, in line with both an integrated approach and the nurse's role within this.

To define the terms used, according to the National Institute of Clinical Excellence (NICE, 2016), transition is the process of moving from children's to adults' services and refers to assessment, initial planning, actual transfer between services and support throughout. The term young person, also defined by NICE refers to ages 14 up to 25 years old; who are involved in health and/or social care (NICE 2016). While the typical age of attaining adulthood is 18, under the Children and Families Act, some young people with an Education, Health and Care Plan (EHCP) stay in formal education until the age of 25. These young people need more support than is available through special educational needs and disabilities (SEND) support (Gov.uk, 2018). There is no confirmed definition of a complex health need. In the context of this paper however, it is defined as a child or young person who has or are at increased risk of having chronic physical, developmental, behavioural, or emotional conditions who require health and related services of a type or amount beyond that required by young people generally.

Background

Public Health England (PHE) estimate the number of children currently living with disabilities and complex health needs in England is 14.1% (PHE 2017). A recent report estimates that numbers have increased dramatically by over 50% since 2004, from 49,300 to 73,000 children and young people (Pinney, 2017). With improvements in health care availability, technology and provision; young people with complex health care needs are increasingly surviving into adulthood (Wright *et al* 2016). However, despite this emerging prevalence of young people moving into adult services; provision of transitional support for them and their families, has up until recently been slow as has been the establishment of evidence based guidelines for healthcare providers (Begley 2013; Betz 2013). As a result, adult services are often unprepared to deliver the nature of care that is needed, which before has been primarily specialised to paediatric services (Racine *et al* 2014).

As well as health implications; chronic illness or life-limiting conditions in children can result in physical disabilities, delayed cognitive development and a reduction in social and educational accomplishments (Al-Yateem 2013). These effects can be more apparent during transition from paediatric to adult services, and can be exacerbated when transitional care goes wrong. Bloom *et al* (2012) suggest that some conditions put young people at higher risk of poor transition and Speller-Brown *et al* (2015) assert that disease severity also has an impact. However, the negative impact on health of an unsupported move to adult services is felt across the spectrum; for young people, their families and their healthcare providers. explained mainly by the change in provision from a paediatric to adult setting, either by a difference in the quality of care or disengagement of young people from services post transition (Bloom *et al* 2012). Healthcare services are then impacted, and costs incurred, due to missed clinic

appointments and an increase in emergency hospital presentations and acute admissions (Speller-Brown *et al* 2015).

The provision of transitional support is part of the 2014 Care Act (Social Care Institute for Excellence (SCIE), 2016). This dictates local authority has responsibility in assessing the needs of the young person, and working in cooperation to provide support for them or act in their best interest if required. Therefore, supplementary guidelines and resources have been developed by organisations such as NICE (2016); and in joint governmental publications by the Department for Children, Schools and Families (DCSF) and DH (2007, 2008, 2016). The latest guidelines in line with best practice published by the UK SCIE (2017) shall be addressed later in the paper.

Preparing Adult Services

Accepting the assertion that adult services have not kept pace with the survivability of young people with complex health needs (Betz *et al* 2013, Wright *et al* 2016), better preparation for adult services in providing care continuity is a priority. A large part of this is education and training in the management of conditions that have traditionally been confined to paediatric services, due to disease mortality (Larivière-Bastien *et al* 2013, Racine *et al* 2014). Indeed this is a concern that has been highlighted and reported by both health care professionals in adult care and young people with complex health needs and their families (Porter *et al* 2014). Providing psychosocial support for parents, and working inclusively with them, is also a skill largely found in the paediatric sector. Therefore, adult services likely to be involved in caring for these young people, will require development and support to cultivate this ability (Dupuis *et al* 2011).

Close collaboration between adult and paediatric services and co-operating early in the process makes transition easier (McInally and Cruickshank 2013) including the transfer and assimilation of patient records, condition summaries and treatment histories, without which care continuity would be more challenging (Disabato *et al* 2015). This would also prevent the young person having to repeatedly explain their condition to different health care professionals in adult services which can be frustrating and daunting.

In addition, it is important to ensure young people continue to use adults' services as there may be a risk that the young person might stop using them when they transfer over. It is vital that planning includes conversations about what might help them use the service on a continuing basis or look for a different way to provide support, acknowledging of course how adult services are reported to be very different from children's services (Kerr *et al*, 2017).

Preparing the Team

An essential part of preparing a service is to ensure it's team is working together and is adequately trained. Multi-disciplinary interventions are documented as an optimal way of working that combines the nursing role of emotional support (Al-Gamal 2013), while focussing on including the family as part of the team (MacCallam and Higgins 2014). Consequently, the use of multi-disciplinary teams (MDT) is the best approach when providing care packages for young people with complex health needs (Whiting 2012) particularly at vulnerable times such as during transition.

At times, there may be gaps in collaboration between primary and community services however (Negeswaran *et al* 2012), and a lack of MDT working has been identified

during transition (Wright *et al* 2016). This is especially concerning considering published guidance advocates strongly for the use of MDT; as a foundation for transition planning, implementation and follow up (DH 2008, 2016, NICE 2016). Families of young people with complex health needs often work with a multiplicity of professionals (Mafuba 2015), and so having an assertive coordinator such as the nurse, to build and maintain trust with them (Whiting 2012) while streamlining the move into adult services is essential. This highlights and emphasises a need for an integrated approach to transition.

Preparing the Young People

Adjusting to adult services also means preparing the young person for transition by delivering instruction in condition self-management; exploring options for education, employment and housing and teaching young people to self-advocate (Betz 2013, Porter *et al* 2014, NICE 2016). When developing self-management strategies for young people with complex health needs, a developmental approach is favoured to ensure interventions are engaging, relevant and brief (Disabato *et al* 2015). Becoming age appropriate for transition does not guarantee the capacity to effectively self-manage (Speller-Brown *et al* 2015). Therefore, individualised assessments are needed to gauge the level of intervention required, to enable a young person to reach their full potential (Porter *et al* 2014), and this includes how best to engage the young person in self-management programmes (NICE 2016).

Examples of good transition practice involving optimum assessment is highlighted by preparing for adulthood.org.uk (2016), an excellent organisation that provides clear and person-focused information. Ensuring the assessment process within the

Children and Families Act 2014 is aligned with that of the Care Act 2014. The DH (2008) and more recently the PfA (2016) outline key examples of successful transition for a range of different conditions such as learning disability, chronic illness and physical complex needs: Success was achieved by the following:

- Ensuring that the process for Adults' Needs Assessment and Care and Support plan for young people post-18 up to 25 if applicable, are aligned to the assessment and planning process for the care element of an EHC plan.
- Establishing which professional, with good knowledge of adult care and support services, is responsible for what is known as a Childs Needs Assessment (CNA) assessment ensuring they work with those designing the coordinated assessment and EHC planning process.
- From Year 9, ensuring young people and families receive information on how to request a CNA and ensuring adult social care are part of transition reviews. The local authority should work with schools to identify the best way to achieve this and to inform the preparing for adulthood planning process
- Working in partnership with families, young people and other professionals to ensure planning enhances and supports wider aspirations of the young person.

The SCIE (2017) also outlines key areas to consider when approaching the planning of transition with young people, in order to support the promotion of their independence: These include being fully involved and addressing what would help the young person have a full role in their transition planning. Within this, the following need to be assessed; their physical, psychological and social development, communication needs, mental capacity, extent of peer support, whether they require

any mentoring or advocacy and being open to the use of mobile technology. The young person and their family also need to have enough information to feel fully informed and make decisions. With regard to this, SCIE (2017) propose key questions to consider which are outlined in Box 1.

Box 1: Examples of questions to consider when assessing for transition

- What will happen before, during and after the transition process?
- What support will be available?
- Are there any other sources of support and advice; e.g. about their condition, how to access advocacy, and information and support services?
- What is the personal budget, if applicable and where would they get advice about benefits and financial support?
- What information and support do the young person and their family need to help them understand and manage any long-term conditions independently?
- Is the young person's transition plan part of their Education, Health and Care plan (EHCP), if applicable?

Literature proposes the use of e-health strategies to engage young people; including SMS communication, smartphone applications and online training material (Disabato *et al* 2015, NICE 2016). Peer support is also heavily encouraged for the young person with complex health needs, both having access to other young people with similar experiences (Porter *et al* 2014) and young adults who have first-hand knowledge of the process (Betz *et al* 2013). It can also be helpful for young person to have contact with the adult services they will be moving into prior to transition (Bloom *et al* 2012).

A lack of understanding of what adult provision is, and what care models they offer, can cause unrealistic expectations of the services available. When these expectations are not met, trust is lost which can hinder the development of relationships with

healthcare providers (Dupuis *et al* 2011), and negatively impact the health of the young person if they subsequently disengage in services (Chu *et al* 2015). Managing expectations is an important factor in transition, and a part of this is building confidence and capacity within young people to self-advocate (Gormley-Fleming and Campbell 2011). Using advocacy to support children in health decisions is usually the remit of the parent, guardian or healthcare professional (Devakumar *et al* 2016). As children move into adolescence they will strive for more independence in managing their chronic illness, which is an important part of development and should be encouraged (McInally and Cruickshank 2013).

It is also important to consider the cognitive development of the young person, taking into account any learning or physical disability that would necessitate ongoing familial involvement, once the young person has transitioned (Bloom *et al* 2012). For some chronic illness, the degree to which it is possible for a young person with complex health needs to self-manage is limited. Therefore, self-management development strategies should be condition specific and individualised (Betz 2013), depending on cognitive ability and capacity (Speller-Brown *et al* 2015). A formal diagnosis of learning difficulties should necessitate the provision of advocacy for a young person with complex health needs, and their family, as a whole (Whiting 2012); but also, outside of the family, as an individual.

It is vital that both the young person and their family get to know adults' services. This can be achieved by arranging visits to services, meeting a member of the adult team to which they will transfer to, attending joint appointments or clinics, talking to young people or adults with similar needs and inviting relevant professionals from

adults' services to the young person's planning meeting(s). These interventions promote a graduated approach to the ultimate development of the young adults' autonomy throughout the transition process.

Preparing the Parents

Providing advocacy for the young person as an individual is not to contradict the guidance that transitional plans should be family focused (DH 2016, NICE 2016); as families are often the expert in their child and their child's best interest. However, occasionally the rights of the young person conflict with the rights of their parents (Devakumar *et al* 2016); in which case it is the responsibility of the transition coordinator to work to the best interests of the young person in their care (NICE 2016).

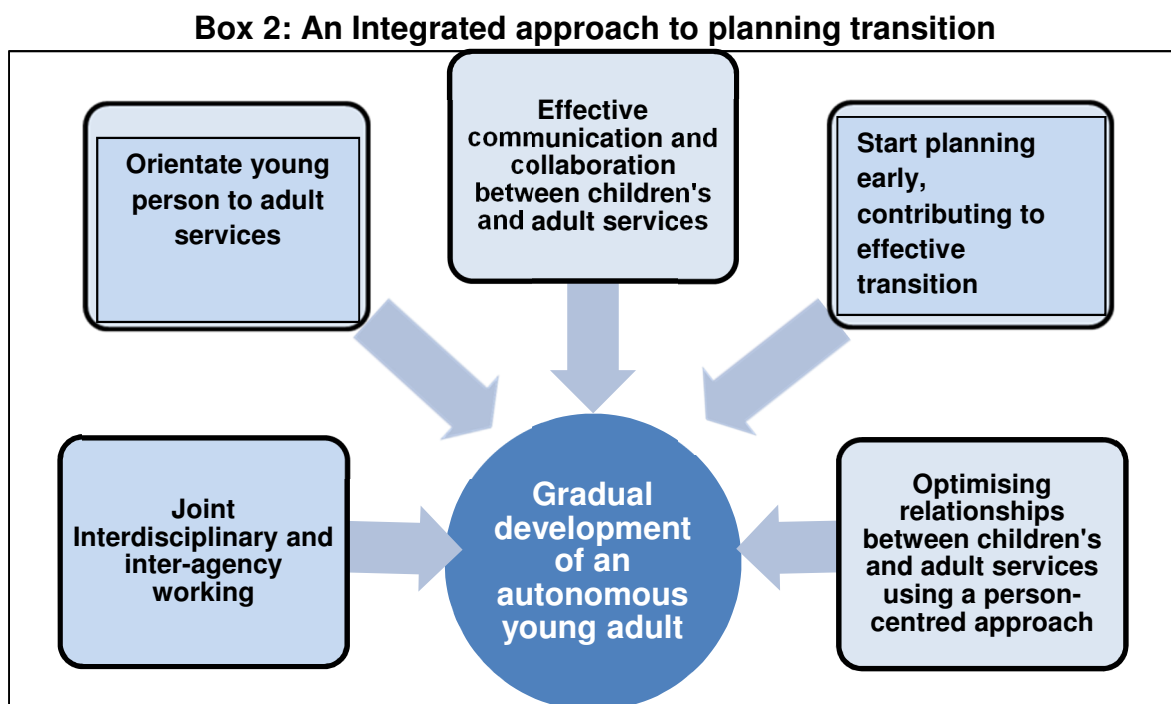
Although, parental overprotection could be a barrier to transition (Speller-Brown *et al* 2015); the preponderance of literature promotes family involvement (McInally and Cruickshank 2013, Porter *et al* 2014, DH 2016, Wright *et al* 2016), and suggests closer working between professionals and carers builds trust, eases familial concerns and prevents transitional barriers happening (Mafuba 2015). To empathise and communicate with the family it is essential to have an understanding of their situation, which is often fraught with emotional and financial difficulties both of which can impact the carer's own wellbeing (Whiting 2012).

The degree to which quality of life for carers is affected by their role is dependent on a multitude of factors; including the young person's disease severity and co-morbidities, the carer's mental health, the family's socio-economic status and home environment and their access to support services (Tseng *et al* 2016). As the young

person with complex health needs get older and move closer to transition, parent's burden of personal sacrifice increases (Al-Gamal 2013).

Recommendations for practice

Firstly, a key theme threaded through the discussion thus far is that of integration. Recent literature places integrated working at the centre of transition including during planning and is reported by a range of authors (Kerr et al, 2017; Wells and Manning, 2017; Lepkowska, 2017; Campbell et al, 2017). Kerr's comprehensive review of the literature summarises an integrated, best practice approach very competently, stating that*"Early planning, collaboration between children's and adult service providers, and a focus on increasing the young adults' confidence in decision-making and engaging with adult services, are vital to a successful transition"*. Box 2 below highlights the key elements of an integrated approach for good transition practice.



Following on from this, it is clear that the principles in Box 2 are inherent within the specific interventions recommended by SCIE (2017) in the latest UK guidance: See Table 1.

Table 1: Principles of good transition planning

<p>Working in partnership with young people and their families, start planning for transition early.</p> <p>It is suggested this should start from year 9 (age 13 or 14) at the latest.</p>	<p>Help the young person choose one practitioner (a named key worker) from those who support them to take on a coordinating role.</p> <p>The worker should act as a link to other professionals and provide advice and information.</p>	<p>Review and update transition plan at least annually.</p> <p>This meeting should include the young person, their family, and all those who support them. Consider if there is an existing EHCP</p>
<p>Consider each of the 'Preparing for Adulthood' outcomes when helping the young person to plan and set goals. These are:</p> <ul style="list-style-type: none"> • Education and Employment; • Being part of the community and having friends and relationships • Health and wellbeing • Independent living and housing 	<p>Work with the young person and their family to create a personal folder to share with adults' services. This and other examples of tools for sharing such as transition workbooks, communication passports and health profiles have been highlighted as good practice within the literature in conditions such as complex physical disability, learning disability and chronic illness ((Fegran et al 2014; Chu <i>et al</i> 2015).</p>	<p>KEY ELEMENTS</p> <ul style="list-style-type: none"> ❖ Partnership ❖ Key worker ❖ Review and update ❖ 'Prepare for adulthood' ❖ Personal folder

Transition is complex and requires preparation, with input from young people, families and pertinent agencies. It also needs to be a gradual and flexible process, not a fixed event which is constricted to institutional targets and the restriction of generalised strategies. In addition, challenges must be addressed. One example is when transition takes place. In reality, there is no set time. It can be when either the medical team or young person themselves requests it. However, there needs to be an appropriate seamless adult service that equates to children's services; i.e. adult congenital heart clinics or diabetes / cystic fibrosis clinics for adults. There may be difficulties when the young person has many complex needs that do not seem to fit into the existing adult services, hence why there is still no fixed age for transition from paediatric services. Therefore, a discretionary transition for some young people with complex needs may be required from specialist children's hospitals to adult services.

Providing individualised care planning is a standard of nursing and also a well-supported foundation of transitional care (Porter *et al* 2014, Speller-Brown *et al* 2015, DH 2016, NICE 2016). In transitioning a young person with complex health needs where there is neurodevelopmental delay or learning difficulties this is especially important; as any assessment should take this into account and produce a plan that is developmentally appropriate, and where transitional readiness is not solely based on age (Begley 2013, Racine *et al* 2014, DH 2016). Transitional readiness is universal, regardless of the chronic illness; and should consider the young person's maturity, ability to self-manage their condition and their overall independence as well as transfer timing (Bloom *et al* 2012).

The four-pronged approach discussed previously outlining the essential factors to consider in terms of preparing for transition can be seen in Table 2 which proposes the nursing role as central to the planning process. There is an argument for moving away from a medical model of transition towards adopting more compassionate and caring nursing philosophies into transitional care (Betz 2013). Guidance predominantly suggests a named worker is used to aide in streamlining the transition process and co-ordinating the support needed for young people and their families (McInally and Cruickshank 2013, Speller-Brown *et al* 2015, DH 2016, NICE 2016). Although nursing contribution to transitional care has been limited thus far, much of the literature advocates for nurses as the best possible candidates for transition co-ordinators. This spans service design to advocating for patients and families (Okumura *et al*, 2015), leadership of the multidisciplinary team (Wright *et al* 2016), setting benchmarks for good practice (Aldiss *et al*, 2015), running follow up clinics and evaluating program effectiveness (Hankins *et al* 2012).

Table 2: Four-pronged approach to preparing for transition.

Preparing Adult Services	Preparing the Young People
<p>Provides care continuity with:</p> <ol style="list-style-type: none"> 1. Education and training on conditions, management and psychosocial support for parents. 2. Increased collaboration with services for young people. 3. Transfer of patient records including histories and treatments. 4. Use tools to assist such as care plans, transition workbooks communication passports or health profiles that the young person can take into adult services. 	<p>Education in:</p> <ol style="list-style-type: none"> 1. Self-management 2. Self-advocacy 3. Adult services <p>Support in finding:</p> <ol style="list-style-type: none"> 1. Education 2. Housing 3. Employment <p>Strategies should include:</p> <ol style="list-style-type: none"> 1. E-Health 2. Peer support <p>Strategies should be:</p> <ol style="list-style-type: none"> 1. Engaging 2. Relevant 3. Brief 4. Developmentally appropriate

Preparing the Parents	Preparing the Team
<p>Good working relationships:</p> <ol style="list-style-type: none"> 1. Build trust with families. 2. Ease concerns and prevent transitional barriers <p>Monitoring factors with impact parental wellbeing:</p> <ol style="list-style-type: none"> 1. Emotional and financial difficulties. 2. Anticipatory grief. 3. Mental health. 	<p>Multi-disciplinary teams should:</p> <ol style="list-style-type: none"> 1. Be started early. 2. Create and follow up transition plans. 3. Be inclusive of families and professionals. 4. Be led by a nurse, as the key worker

It could also be said that traditionally, the values and priorities of the nursing role favour providing for behavioural, psychosocial and emotional needs (Betz 2013). This can be seen where family-centred care is an expectancy of the paediatric nursing role, and integral to good transitional care (Dupuis *et al* 2011, Porter *et al* 2014).

Having a dedicated nurse to provide transition coordination, through a designated service, is better at providing consistent and cost effective transitional care; in contrast with trying to incorporate it into an established nursing role. Literature has identified that nurse led transition has led to good engagement with adult services from young people with complex health needs (Hankins *et al* 2012). Also that nurses should act as leaders within the transition process (Porter *et al* 2014), as a link between professionals and between agencies and families and should guide future evidence based practice with transition models (Betz 2013). McInally and Cruickshank (2013) suggest there is an argument to establish a transitional nurse role from both paediatric and adult care, to support young people with complex health needs from planning through to follow up.

Conclusion

There are many key themes that are vital to address when planning, implementing and reviewing effective transitional care in which the nurse can have a key role in. From collaborating to prepare adult teams in caring for young people moving into their services; to utilising early MDT involvement in streamlining the transition process and building and maintaining trust with patients and carers. There must be a strong appreciation of the benefit of familial involvement, while being anticipatory in providing psychosocial support for carers at risk from a low quality of life. Programs must be proactive in delivering education and support in self-management and self-advocacy skills, while working to individualise transitional plans to accommodate for physical ability and cognitive development. Lastly, a transition service should be a standalone department which exploits inherent nursing values and philosophies of care; to provide co-ordination, professional collaboration, emotional support and family centred care. By providing a controlled and synchronised portal to move the young person and their family from paediatric to adult services, nurses can ensure better health outcomes for young adults with chronic illness and complex health needs in the future.

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