

# Challenges and ‘obstacles’: reframing our perspective on the transition into adulthood for young people with life-limiting and life-threatening conditions

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## INTRODUCTION

Young people with life-limiting conditions (LLCs) and life-threatening conditions (LTCs), diagnosed in childhood and presenting with palliative and complex healthcare needs, often have diagnoses congenital in aetiology and with complex multi-system and neurological manifestation. Their care needs, both medically and socially, are largely unfamiliar to adult palliative care services, traditionally concerned with the care of an older population and often providing services for end of life and cancer. It is known that young people with LLCs and LTCs are now often living considerably longer and this is observed across a range of conditions.<sup>1,2,3</sup> The National Council for Palliative Care defines palliative care as:

the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.<sup>4</sup>

While this definition can be applied to both palliative care for children and adults, it is clear that children’s palliative care embraces a ‘wider’ definition (Table 1).

Increased life expectancy in young people with LLCs and LTCs from childhood is largely accounted for by advancements in medical technology and resuscitative interventions; of particular note is the impact of assisted ventilation.<sup>2</sup> In turn, this has presented healthcare services with a new challenge in meeting the complex and dynamic needs of young people requiring an equivalently personalised level of multidisciplinary and multi-agency specialist support beyond paediatrics services. It is known that transition to adulthood can be particularly difficult from the point of view of care-

**TABLE 1** Four categories of LLCs and LTCs affecting children and young people<sup>5</sup>

<p><b>Category 1</b>  <b>Life-threatening conditions for which curative treatment may be feasible but can fail</b>                  Access to palliative care services may be necessary when treatment fails or during an acute crisis, irrespective of the duration of threat to life. On reaching long-term remission or following successful curative treatment there is no longer a need for palliative care services.</p> <p><i>Examples: cancer, irreversible organ failures of heart, liver, kidney</i></p>
<p><b>Category 2</b>  <b>Conditions where premature death is inevitable</b>                  There may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities.</p> <p><i>Examples: cystic fibrosis, Duchenne muscular dystrophy</i></p>
<p><b>Category 3</b>  <b>Progressive conditions without curative treatment options</b>                  Treatment is exclusively palliative and may commonly extend over many years.</p> <p><i>Examples: Batten disease, mucopolysaccharidoses</i></p>
<p><b>Category 4</b>  <b>Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health complications and likelihood of premature death</b>                  Examples: severe cerebral palsy, multiple disabilities, such as following brain or spinal cord injury, complex healthcare needs, high risk of an unpredictable life-threatening event of episode</p>

coordination.<sup>6,7</sup> Many young people and their families experience a disjointed transition with limited models of delivery of transitional services being apparent<sup>8</sup> or best practice ways of providing transitional provision between paediatrics and adult healthcare.<sup>9,10</sup>

The differences between children and adult palliative care services are well reported<sup>10</sup> and it is known that,

within the context of adult palliative care, services have traditionally catered for the care of individuals with malignant, non-curable diagnoses. Adult palliative care is generally conceptualised within the framework of end of life care and elderly end of life care, with a lack of knowledge and awareness of the transition process.<sup>10</sup> While the focus on end of life care reflects the historical remit of palliative care for adults it does not communicate the diverse nature of children and young people's palliative care. There is a need for medical and supportive care for a wide range of conditions from diagnoses through life, death and beyond for the child or young person and their family, including provision of respite, social and sibling support as well as care at home, within a hospice setting and in school is typical. This differentiation between children and adult palliative care services is a key factor in impeding a joined-up transition. Though it is true that many of the issues discussed in this paper are not exclusive to those requiring palliative care (e.g. issues around wheelchair accessibility or continuing access to respite care), the unpredictable nature of many LTCs and likelihood of an end of life care situation arising add a layer of complexity for young people needing palliative care. Additionally, not all respite and day provision is accessible, not only in terms of environment, but specialist staff or staff who can perform those duties which would be typically associated with hospice input (e.g. suction).

With condition-specific palliative care needs for young people continuing into adulthood, it has been clearly asserted within a systematic review<sup>10</sup> that a need exists for planning models of a specialist nature for transitional palliative care services. For young people entering adult services with complex continuing health and social care needs, but not of a palliative trajectory, a bespoke and coordinated transition is equally required.

The organisation and coordination of services into adulthood continue to present health, social care and educational services with a challenge to which historically there has been considerable exposure<sup>11–15</sup> and to which all services should be committed. Despite this, many of the transitional difficulties encountered by young people and their families, with respect to accessing and organising continued care into adulthood, reflect a deep-rooted unpreparedness on the part of both adult and paediatric services to operate in a coordinated fashion during the transitional phase. The 'obstacles' resulting from this can be categorised as manifesting on three crucial levels; an organisational or systems level, an operational or practical level and on an interactional level.

### **Distinctive needs**

The needs of young people as a group distinguishable from children and adults is a conceptual 'gap' that has emerged from our analysis of policy and guidance

material relevant to transition from children's to adult services in complex and palliative care.<sup>16</sup> With a rising number of young people requiring non end of life palliative care, often for non-malignant conditions, the need to capture young people, families and practitioners' views on how to best support the process of transition in a bespoke way is underlined. Transition pathways within the context of children with disabilities have been explored,<sup>17–19</sup> but are not straightforward. For young people with palliative care and complex healthcare needs, there is a risk of losing the integrated continuity of medical, social and psychological support as they move into adult services and it is unsurprising that many young people have described the transition as analogous to standing on the edge of a cliff.

With regard to hospice care provision, measures have been taken by some UK children's hospices in response to the growing need for palliative care services beyond adolescence and in to young adulthood with a young person-focused care approach. The expanded provision of palliative care for young adults up to the age of 35 is one such example.<sup>20</sup> For young people with LLCs and LTCs surviving into adulthood, continuing specialist care and support is essential. Acquiring a solid grasp of the particular, self-identified ongoing care needs of young people and their families as they transition in to adult services is vital for future service development and has been the focus of recent research.<sup>16,21</sup>

## **CHALLENGES AND 'OBSTACLES' TO SEAMLESS TRANSITION**

Understanding the nature of some of the challenges to a seamless transition to adult services affords better awareness of those key areas where targeted intervention may benefit services and, in turn, the experiences of young people and their families. There is a body of literature in which some of the key stumbling blocks to transition are identified,<sup>12,13,15,19</sup> with a fragmented transition process experienced by young people<sup>10</sup> due to a lack of continuity between services.<sup>22</sup> Research with young people and families has revealed how transition planning and preparedness may be impeded on organisational, practical and interactional levels.

### **'OBSTACLES' TO TRANSITION ON AN ORGANISATIONAL LEVEL**

The obstacles to a successful transition on an organisational or systems level refer to bureaucratic challenges faced by young people and families as they attempt to access services which are appropriate for a young adult across health, social and educational needs. The complexities of funding and service-led systems may compound the natural stresses of growing in to adulthood and for the family unit, contributing to the often traumatic nature of coordinating their child's care

and anticipating a stable quality of life with the continuity of services provided for in children's services.

There is considerable anxiety around the decision-making processes for determining eligibility for continuing healthcare. Within the context of highly complex, progressive and palliative care needs this is deeply pertinent since by the very nature of such needs, health and social care requirements will inevitably continue, in real terms. Where this is not reflected in administrative processes there is potential for a catastrophic outcome for young people and parents, who, for reasons associated with process and criteria, may fail to 'qualify' for continuing healthcare. In reality their state of health may have stabilised, but this should not be confused with recovery. While issues about care coordination are not specific to young people with palliative care needs, this group are more likely to struggle to access replicable provision in adulthood, such as access to an appropriate adult hospice with the right skills and knowledge.

## A REACTIVE SYSTEM

A crisis reactive system (i.e. fast tracking into continuing healthcare or re continuing discontinued healthcare) is unhelpful during moments of acute deterioration in health. The additional stresses and frustrations of negotiating a bureaucratically complex system during such a time to reinstate a package of care that ultimately would have been more beneficial to have had maintained in place already is a compounding factor. This disjointed and avoidably traumatising nature of transition into adulthood represents an unfortunate iatrogenesis.

## 'OBSTACLES' TO TRANSITION ON A PRACTICAL LEVEL

On a physical and practical level, for young people who use wheelchairs and mobility aids, the current inaccessibility of public places and facilities presents a significant and yet avoidable challenge. Many facilities such as leisure or educational facilities otherwise successfully able to cater for the needs of a young person growing up with physical disability or a neurodegenerative illness trajectory are perceived by young people to be inadequately meeting their mobility needs by failing to provide consistently accessible spaces.<sup>16</sup> For young people seeking an independent identity as they approach adulthood, the attention of having to request assistance to access facilities where permanent accessibility features are absent, such as suitable wheelchair ramps, may be psychosocially detrimental.

An absolute lack in the diversity of and availability of young person and young adult oriented day care and respite facilities of an age and developmentally

appropriate nature poses a real and anxiety-causing challenge. It is a struggle to find local and accessible amenities post-children's services that are able to cater both for their complex physical healthcare needs in an environment which is psychologically and socially stimulating and an opportunity to meet and interact with others of a similar age and with similar interests.

## 'OBSTACLES' TO TRANSITION ON AN INTERACTIONAL LEVEL

Some young people perceive that they are often, in light of a physical disability, assumed to be lacking in mental capacity.<sup>16</sup> Given the Mental Capacity Act's<sup>23</sup> default leaning towards presumed capacity this is concerning. Young people feel they are inadequately involved in decisions surrounding their own care when they were more than able to do so. The consequences of this can be detrimental to a young person's care and sense of self-esteem, breeding avoidable frustration and potentially problematic and mistrusting relationships with healthcare providers. There is no financial cost to listening, with the exception of those costs which may be incurred by potentially failing to do so. The inference here is that the perception of a disabled young person with a LLC whose prior trajectory of care has been delivered within the paternalistic structure of paediatric services may continue to be one that is conceptualised within a children's care context. The staggered and often disjointed nature of transitional care across agencies is depicted as problematic not only with regard to the orchestration of multidisciplinary teams, but also to communication with family carers.

## A THEORETICAL SOLUTION: KEY WORKING AND THE CO-ORDINATION OF CARE

The presence of a single professional, with oversight of the range of services which are required by a young person and family as they prepare for and negotiate the transition to adult services is received positively. The notion of having a single point of contact where appropriate, as opposed to making repeated contact with multiple agencies and services when arranging care and attempting to access specialist support, is one which parents consider much needed.<sup>16,24-26</sup> Policy advocates this model.<sup>27-29</sup> Crucially, guidance on key working needs to specify how, in practice, working in an inter-professional way can be achieved<sup>30</sup> and in a sustainable way.

Within the context of young people with disabilities, primary qualitative research with parents has revealed:

...not all young people had access to a Transition Key Worker or a person identified as the main point of contact. The long-term sustainability and viability of key working provision, especially through transition into adulthood is indeterminate and was highlighted

within the wider key working literature. Positively, in England, through the SEND [Special Educational Need and Disability] agenda, funding provision has been made available to further develop key working training to instil key working functions into the role of professionals supporting disabled children and young people and their families from 0-25 years of age and to begin the process of achieving what needs to be effective, sustainable and young person-centred key working. Nonetheless, activity on the ground is less evident and the co-ordination role unclear.<sup>31</sup>

It is perhaps this precise lack of role clarity that presents one of the biggest problems in implementing transitional key working, alongside difficulties establishing who, within a multi-agency and multi-professional system, would take on this role. However, it has to be seen as positive step that engagement with debate about and exploration of this role and its function in supporting young people and families continues and that there is policy leverage for its implementation.

## CONCLUSION

For young people with LLCs or LTCs the future is uncertain. Layering this uncertainty is the presence of a milieu of needs which constitute a life affirming identity and one which is experienced uniquely by each young person for whom such physical care needs are a daily reality. The essence of every young person is distinct from any diagnostic label or symptom experience, and, as such the identities imposed upon them by society need to reflect who they are and not who we perceive them to be. This ethos needs to underpin, first and foremost, any approach to enhancing the support that is provided for young people with complex health and care needs and the support provided for those delivering their care. In turn, safe, well-directed, effective and person-centred care can be enabled for young people as they journey through life and grow in to adulthood within a culturally and infrastructurally enabled network of social, psychological and physical support; support which is sustained throughout the young person's life and responsive to their individual and evolving care needs.

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