Young people with life-limiting conditions: transition to adulthood

‘Small numbers, huge needs, cruel and arbitrary division of services’

Phase 1 report for Marie Curie Cancer Care

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CONTENTS

Acknowledgements 3

Executive Summary 4

What is it for? 4

Where did it come from? 4

What is it about? 4

Who is it for? 4

How was the evidence gathered? 5

What evidence was gathered? 5

What is the key learning? 7

Conclusions & Recommendations 8

Section 1: Framing the phase 1 work 10

The brief 10

The commission 11

The terrain 11

Framing the evidence gathering 14

Section 2: How we worked 16

Talking to young people 16

Engaging with practitioners across the system 22

Interviews with key stakeholders 23

Reviewing research and policy 24

Section 3: What evidence have we gathered? 25

Young people: 'It's your life. Only you know what's best for you' 25

Parents: 'You are off the radar after 19' 34

Practitioners: 'we don't work in a way that's joined up, we could be more brave and transparent' 35

Institutional stakeholders: 'a danger that 'transition' becomes another neat category, a box to be ticked' 43

Research & policy 51

Section 4: Discussion & key learning 60

Triple trouble... 60

Critical questions... 62

Improving the system... 63

Section 5: Conclusions & recommendations 67

Recommendations to take the work forward 67

List of Annexes 71

Notes & References 72

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"New ways of thinking and doing in difficult times."

Executive Summary

What is it for?

The report summarises an intensive three months of evidence gathering and analysis on the situation, needs and aspirations of young people with life-limiting conditions who are growing into adulthood (age range 13-25 years).

The aim is to enable Marie Curie Cancer Care better understand the end-of-life care needs of this group of young people and therefore be positioned to scope effective ways of providing support. The report will also inform MCCC's service development plans, including the possible development of a digital engagement strategy to help meet the identified needs of this group.

Where did it come from?

Children with life-limiting conditions are living longer and thus requiring support into adulthood. There is growing evidence of unmet needs as these young people make the transition from children's palliative care to adult services. Historically, Marie Curie Cancer Care has cared for comparatively low numbers of young people. Aware that it does not have enough experience in caring for this group of patients to understand their needs, the charity resolved to take active steps to better understand how it can develop services that will be effective.

Accordingly, supported by funding from the Department of Health, MCCC invited bids for the initial, evidence-gathering phase of a two-phase England-wide project to develop and enhance the charity's knowledge of the end of life care needs of young people with life limiting illnesses and their carers. The commission was awarded to PublicServiceWorks Ltd (PSW), who fielded a team of independent consultants with wide-ranging and complementary experience and expertise. Phase 1 of the project took place in the period from January to March 2011 and ends with this report, written by the PSW team. Phase 2, concerned with the design and implementation of strategies and action recommended in Phase 1, follows on immediately.

What is it about?

The questions at the heart of the inquiry are:

- **What are the issues and opportunities for young people with life limiting conditions, and for their families/carers, in managing their own best transition to becoming young adults?**
- **How can we together best tackle these challenges?**

Evidence was gathered from young people themselves, their families/carers and those responsible for their care and welfare at policy, commissioner and provider level. Recommendations are made for action to build on pioneering excellent practice and to remedy current failings and inadequacies (in many cases, widely recognised by those working in the field) in the level and type of care and support available to these young people and their families/carers.

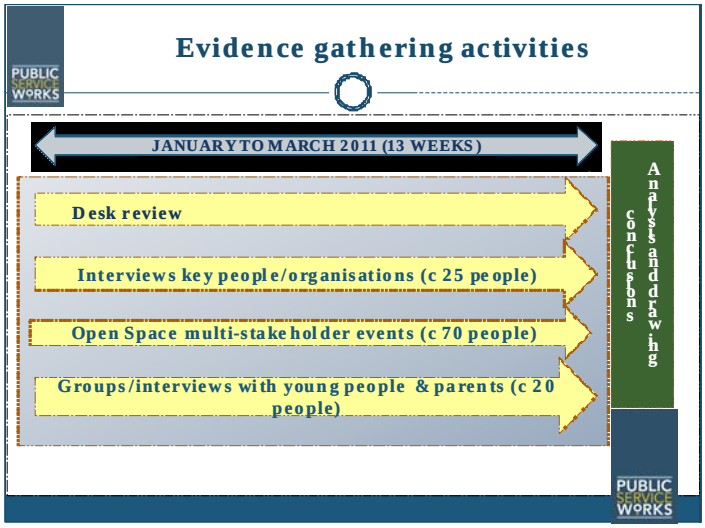
Who is it for?

The report was principally written to inform decision makers at Marie Curie, but its findings will be of interest to a wide range of organisations and people concerned with this field at policy, commissioning and provider level across sectors. The report

highlights overarching issues about processes of transition which are likely to be of help to others struggling with these in other settings.

How was the evidence gathered?

The work was constructed as a set of parallel tracks where multiple sources of evidence could be drawn on so as to create a rich picture that can be acted on in the real world of practice and inform decisions. We focused on gathering evidence in order to understand the people who create, interact and relate in this field of work. As illustrated left, evidence was sought from young people and their parents, from practitioners, researchers, and from stakeholders in other organisations. We aimed to explore what they do and what they think – i.e. their ideas and practice and the assumptions that underlie both.



The report outlines key learning associated with the work in each of these strands. Crucial to our ability to process much of the evidence gathered was the **learning we gained** from working with young people and their parents:

- young people with life-limiting conditions are as **creative and resourceful** as their peers without life-limiting conditions and they have a lot to say
- **language and communication style and skills**, flexible enough to accommodate the huge diversity of young people and their capacities, are critical
- engaging with the young people means **engaging with their parents and carers** who in most cases need to be involved directly
- talking to parents opens up the **whole family setting** to view and this is very important in understanding the issues.

What evidence was gathered?

Young people

Young people overwhelmingly have a **poor experience of transition**, both in terms of services and in terms of having the level of autonomy and control they desire

Young people share a common **aspiration for a 'normal life'** and hold largely reasonable ambitions for what they want to achieve in their lives, such as an active social life, education, work opportunities, and what concerns them as young adults such as friends, relationships, going out and looking good.

Young people are **concerned about their parents** and the strain of their care on parents

Some young people are **keen to engage with others** and to contribute their experiences to help others. Digital platforms are used by most young people as part of their daily

life, but digital platforms development for them should be **gradual** and focus on young people-led options and links to sites used by all young people

Innovative work is being developed within children's palliative care to engage young people in thinking about their move into adulthood, involving group-based social activities, and creative work such as drama, video, radio.

Parents

Parents overwhelmingly have a **poor experience of transition**, both in terms of its impact on the young person and in terms of the impact on themselves of fewer respite and short break services

Parents have **their own transition** to make as their child grows up: to acknowledge and support more autonomy for the young adult and to face the shift from parent to carer of an adult, alongside the painful and growing reality of early death of their child

Parents **appreciate peer support** but this is currently ad hoc and marginal in their lives especially after transition.

Practitioners

Transition is a shock for professionals too.

- They still **live in silos**, locked into separate and differing assumptions, structurally separated systems that are Children's and Adult services and that operate different protocols (for example, in pain relief)
- They **aspire to networks & better partnership**
- They have **few means of sharing insights into each other's work** and culture and find it difficult to identify and adopt good practice
- They **struggle to operate transition planning procedures** across agencies and try to **'work around' the dysfunctional systems** that confront young people and families
- They recognize the severity of problem – especially in current pressures – and **ALL said that the young people must be put at the centre of the transition process in a person-centred approach.**
- They also noted **a lack of skills** for practice and the communication approaches to do this and would appreciate **more innovative tools** to help with this
- They could offer **no clarity on the necessary cross-system strategic leadership**: neither for clinical responsibility and quality of care, nor for the organizational challenge of the 'key worker' approach, nor for the impetus to create the more flexible networks they felt were crucial to better care and better transition

Institutional stakeholders

The people we spoke to agreed that the fragmented patchwork of services offers no consistent support for these young people, nor the opportunity to have their voices heard and responded to. They also emphasised:

- There is **no clear model** of care underpinning services
- For there to be sustainable improvement in the situation of these young people, **three parallel transitions** have to take place – for the young people themselves, their family, and the professionals who care for them. Promising innovative

work is being undertaken with this end in view, and this needs to be evaluated and learned from.

We found a surprising **lack of capacity to comment** from senior people we would have expected to have a view.

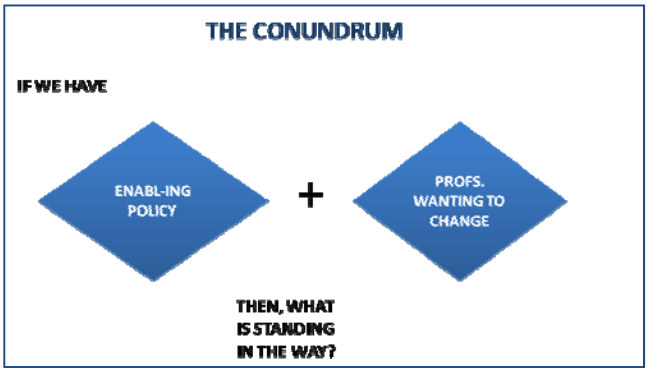
Research and policy

We found that notwithstanding the many instances of good practice taking place at local level and the positive policy context, **much more needs to be done to achieve a step-change** in transforming the outcomes for young people with life limiting conditions at and after transition.

There are **few clear models** for re-working services and transition processes to produce better results of young people's lives and commissioners are hampered by the **lack of detailed information about this group** as well as the inherent complexity of its needs.

Addressing the gaps identified above sets a **challenging action agenda** for governmental and non–governmental bodies and may provide a focus for Marie Curie in Phase 2 of this project.

What is the key learning?



A classic puzzle in public policy, the conundrum shown left, offered us a helpful starting point for understanding why young people and their families/carers continue to suffer from '*a universally awful experience*' in relation to services available to them as they enter young adulthood.

The report describes in some detail the analysis we developed in answer to the conundrum. **Three sets of triple challenges** seem to be involved, as illustrated below.

These sets of challenges raise a series of critical questions:

Critical questions to move forward.....

In the light of the challenges and critical questions, what could improve the system so that young people and families have a better experience and the system delivers equity as well as effectiveness? The following elements seem to be essential to any sustainable programme of change:

- a **broader support system**, taking on the social issues raised by young people
- a continuing **clear clinical lead** role
- **cross-system networks**
- **young person-centred** ethos
- **joint** training and development.

Conclusions & Recommendations

In beginning this section it is worth stating that for this group their **small numbers, huge (and diverse) needs, and experience of cruel and arbitrary divisions of services** makes meeting their needs extraordinarily complex and difficult, as everything in this lengthy report illustrates. Our conclusions are, however, paradoxically brief!

Our conclusion overall is that young people should have the choice to stay with the relationships they have, adapted to age and changing need, and their support needs require creative joint funding under their and their families' control, possibly from a new national 'pot'.

In addition, the consistent messages in the evidence require **flexibility at the frontline** for professionals to negotiate on aspirations and needs with young people and their families:

- To improve directly the experience of young people and parents
- This can only happen through children's and adult services (and their funding) collaborating closely on the question of transition

The messages and issues show **a good fit with *We put patients and families first,*** Marie Curie Cancer Care's 2011-2014 Strategy, for example:

- ***Better care***: hospices as hubs, understanding need, improving quality links to issues of new local networks
- ***Wider reach***: links to carer coordination, extending to young adults, supporting carers
- ***Stronger Foundations***: spreading risk through partnership & joint working

The messages from the report also underline that **working with partners is fundamental**

- To work with young people and families in co-producing changes
- To develop networks within health and social care across statutory and voluntary sectors and national, local and regional levels
- To work on digital media in partnership with organisations well placed to take this up in the longer term

Recommendations to take the work forward

That Marie Curie influence the wider context and other key stakeholders through:

1. Feeding the findings into National Funding Review, which includes both adults and children, but is not yet explicitly considering teenagers and young adults as a group
2. Highlighting with key stakeholder organisations the very different responses of statutory agencies in England, Wales, Scotland and Northern Ireland to the challenge of transition and the practical implications of these, especially in relation to the severe inequalities suffered by these young people and their families
3. Holding a national launch event to involve young people directly with policy, commissioning and practitioner stakeholders
4. Publishing key messages from the report in a range of media e.g. on website, in popular form; an academic paper
5. Helping shape the workforce development agenda in concert with the Transition Partnership especially
6. Disseminating broader learning about practice and innovation to other condition areas (e.g. dementia, long term conditions)
7. Using the database of people who want to be involved in the future and should be

That Marie Curie in Phase 2:

1. Continues to develop some elements started in Phase I
2. Fills key gaps that the Phase I activity has revealed
3. Follows new leads as indicated by what we have learned from Phase I
4. Develops a limited digital platform offer aimed at young people and at parents

Section 1: Framing the phase 1 work

The brief

Historically, Marie Curie Cancer Care (MCCC) has cared for comparatively few young people. In the year ending 31 March 2010, for example, MCCC was able to care for only 26 young people (aged 16 - 19) in their own homes, and only three young patients received hospice care.

Across the UK, young people with life-limiting conditions are living longer and thus requiring support into adulthood. The Association of Children's Palliative Care (ACT) estimate that there are between 6,000 to 10,000 young people living with a life limiting or threatening condition in the UK. There is growing evidence of the unmet needs of young people as they make the transition from children's palliative care to adult services[1].

While recognizing that teenagers and young adults have specific needs that are not well met by either children's hospices or adult care services, MCCC was also aware that it does not have enough experience with this group of patients to understand their care needs and therefore resolved to take active steps to better understand these and their impact on services offered.

Accordingly, in late 2010, supported by funding from the Department of Health, MCCC invited bids for the evidence-gathering phase of a England-wide project to develop and enhance the charity's knowledge of the end of life care needs of teenagers and young adults (aged 13-25) with life limiting conditions (LLCs) and their carers, particularly those young people who are likely to undergo transition from children's to adult services. The project would inform the charity's service development plans for 2011-2012, including the possible development of a digital engagement strategy to help meet the identified needs of this group.

Box 1 shows the two-phase design of the overall project.

Phase I – **Evidence Gathering –** early January till end March 2011 aims to:

- Gather insights from key stakeholders, including teenagers and young people, families, carers, stakeholder organisations
- Stratify the insights from teenagers and young people into at least two groups – 13 to 15 and 16+
- Gather insights related to the need for digital engagement
- Map current services
- Produce a report with recommendations on the needs of young people with life limiting illnesses who are in transition from children's to adult services and their carers
- Identify other potential service innovations and make recommendations to the Marie Curie Executive Board.

Phase II – **Design and Implement** - mid March onwards aims to:

- Produce a digital engagement strategy, if required
- Implement the digital engagement strategy, if required
- Implement any further service innovations approved by the Executive Board
- Consider other issues raised in phase I

The commission

The commission to carry out Phase 1 of the project was awarded to Public Service Works Associates Ltd (PSW), who fielded a team of independent consultants with wide-ranging and complementary experience and expertise, including a clinical advisor.

Critical issues for evidence gathering were identified by PSW as:

Complexity of needs: the thankfully longer lives of young people with LLCs have meant increasing complexity for care and more need for transition to adult services. Provision has not caught up with this shift:

> *'accordingly, few plans exist for their co-ordinated care as adults and there may be very few services suitable for young adults (e.g. a lack of age-appropriate short break facilities, few chances of meaningful employment, few residential places that can take young people with very complex health needs and few specialists with a holistic approach to a young person's care)'*[2]

Involvement of health and social care: the holistic and seamless approach called for by policy reviews requires coordination across agencies. The recent Green Paper on special education also emphasises work across education, health and social care[3].

Supportive and palliative care not only end-of-life care (EOLC): the range of requirements and the length of time they are needed is likely to be extensive, more so than in adult palliative and EOL care. Traditionally in adult palliative care, condition related treatments cease and palliative care takes over; or progressive conditions see a gradual increase in the proportion of palliative care compared to specific treatments as end-of life approaches. In children's palliative care the trajectory is less clear cut: patients 'dip in and out' in a series of hard-to-predict cycles of need, wellness and illness.

Respecting and listening to young people's views: it is of critical importance to find ways to ensure that young people can be involved, can be listened to and feel listened to. Their wishes for their lives must underpin the design of any support offered..

Focus on the care setting as a whole: families and **carers are fundamental for young peo**ple to thrive whatever their condition. No one person or agency can determine what happens, but nonetheless an overview/coordination is vital within a holistic approach.

Learning from existing good practice and research/evidence from both child specialist and adult-focused palliative care organisations.

Awareness of the parallel work of the ongoing review into funding of palliative care which has reported its interim findings[4] – and in which MCCC is involved through its Chief Executive, who chairs the review.

It was agreed that the timescale of three months was very short for a project that needed to involve and engage a large number of young people and other stakeholders. Creativity and energy would be required as well as task focus.

The terrain

Growing numbers attract new policy interest…

Published literature provides some evidence that the prevalence of life limiting conditions amongst children and young people is increasing. Currently, it is estimated that approximately 20,100 children and young people aged 0-19 are likely to require

palliative care services annually in England. This amounts to numbers of between 900 to 2, 600 per current strategic health authority area or 16 per 10, 000 of the 0-19 population[5] (DH 2007). Moreover, the rate of change is exponential. Advances in medical and other technologies mean that many more children are living into adulthood with conditions that would have meant early death as recently as ten years ago, and it is likely that, in the next decade, we will see more and more young adults living with these conditions. The critical question is: *can robust transition planning enable these young people to live well into adulthood, notwithstanding the challenges and limitations associated with their conditions?*

The needs of children and young people with life limiting conditions, prior to, during and after transition to the adult stage of life has received welcome attention and policy interest in recent years further to the publication of the *Craft/Killen Report* on children's palliative care in 2007[6], the Department of Health's *Better Care, Better Lives* Strategy focusing on children with life-limiting and life-threatening conditions and their families and the Department of Health's *End of Life Care Strategy* for adults, both in 2008. These documents provide a framework for the way adult and children's services are viewed in England[7] and are the key reference points for exploring and making sense of the evidence gathered in this project. Similarly, the ACT *Transition Care Pathway* (2007) provides important architecture for exploring a number of the issues which have arisen in evidence gathering for this project.

A growing focus on transition for teenagers with complex needs, including current research activity in this area, has been stimulated by significant investment in children's end-of-life care and transition issues – in particular by the Department of Health – in support of the new policy framework. The work of the Palliative Care Funding Review, whose recommendations will be published in the summer of 2011, is also likely to have considerable impact on what care is provided, how, to this group of young people.

…but small numbers still mean a struggle to be taken seriously

However, structural issues remain highly significant. The approximate number in England of young people with life-limiting conditions is small, about 20,000, when compared with all children and young people with disabilities (numbering approximately 750,000); the size of children's specialist palliative care within the palliative care system as a whole is also small, for example, children's hospices estimate they are in contact with 4-5000 families, whereas hospices care for 250,000 people a years. Of the 45 children's hospices in the UK, less than a quarter offer specific additional services designed for young adults.

The challenges are not confined to lack of critical mass. The young people who are the focus of this study also find themselves caught between cultures. As this report will make clear, the normal, challenging, human experience of growing up becomes something approaching a nightmare for many of these young people. They have to contend not just with their own unpredictable feelings and physical condition but with the only too practical consequences of the widely varying assumptions and understandings of their paid and unpaid carers. The families – where there are families – have an uphill struggle too. A specialist in the field, Professor Myra Bluebond-Langner, describes the demands of care and treatment for this group of young people as *'a major assault on the family'*[8]. Relationships may break down under the strain; family income may plummet when one or both parents stops paid work in order to care, and other siblings experience family stress and sometimes neglect.

At the age of 18 typically, young people in England move from the care of children's services to that of adult services. Despite the development of the policy frameworks

described, this transition remains hugely problematic for young people, their families and the workforce in both health and social care. As the report will show, young people and their families feel cast adrift when they are often at their most vulnerable; and staff in adult services often feel quite unprepared to identify, far less meet, the needs of these young people.

The contrast of cultures/practices between children's and adult services in health is summed up in the following Table.

Children's Services	Adult Services
Long term contact	Limited contact dependent on need assessment
Holistic family-centred approach	Clinical specialty is the focus
Wrap around, one stop care, lead paediatrician	Fragmented services that must be coordinated, sought out, several consultants involved
Not only about end of life care	Significantly about last year of life
Ends at 18, 19 or 25 years	Focused on over 60s primarily
Short breaks typical offer	No short breaks
Not just cancer but all specialist conditions	Often focus on cancer, little knowledge of life-limiting conditions in young people
Education involved	Education peripheral

Table 1: Contrast of cultures and practices between children's and adult health services

Children's hospices and adult hospices especially deal with very different conditions:

- **Children's Hospices deal with category 3 and 4 conditions** - complex neurological cases, brain injury, cerebral palsy, Duchenne Muscular Dystrophy, Batten's disease, metabolic disorders etc.
- **Adult Hospices deal mostly with category 1 and 2** - reversible organ failure, cancer, chronic heart and renal failure.

Some children and young people may need palliative care for their whole life, eg HIV, sickle cell, thalassemia – but they live much longer. Young people with cancer, HIV, cystic fibrosis, cardiac conditions etc. go to mainstream schools, they don't usually have the same level of disability or need for respite. Up to 80% of children and young people in touch with children's hospices have severe neurological damage, the other 20% have normal cognition. '*There is a big mismatch and a need for adult hospices to work with and care for category 3 and 4 young people who now live long enough to need adult hospice places.*' (children's hospice worker) A member of the evidence gathering team offered a concise summary of the situation of the young people at the heart of the investigation: *'Small numbers, huge needs, cruel and arbitrary division of services'*

Who should receive palliative care – and who should provide it?

In association with the coalition *Dying Matters*[9], the National Council for Palliative Care is currently hosting a series of consultations around England on how to involve people in end-of-life care. Discussions about who needs care, when, provided by whom are also taking place in Scotland and Wales.

There are core questions at issue – and there are few simple answers even for statutory services. The situation of the young people with LLCs highlight for voluntary organisations in particular some of the most difficult questions, where issues of equity may be involved as well as very practical considerations relating to pressure on services. MCCC, for example, has to be able to think about different groups of people who might be considered in need of palliative care, and be confident that the decisions that are made about far from endless resources are grounded in a clear understanding of the purpose and mission of the different services.

In the course of this gathering of evidence, for example, the medical director of a hospice raised the question of assumptions that need to be carefully explored and tested.

> *'We might assume that a person who develops a degenerative disease at age 10 should receive palliative care. But we don't assume that a person who develops a degenerative disease at age 23 will automatically be considered for that kind of care and nor a 60-year-old who has a stroke or heart disease or cancer: it is assumed that they will carry on living in as normal a way as possible.'*

There is an associated need, the interviewee pointed out, to review what is considered to be 'terminal illness'. There may be a diagnosis indicating that the illness will end in death; but does the fact that the patient is going to die influence immediate and short-term care and treatment? Does the need for palliative care emerge at diagnosis or at that point when someone sees death rising above the horizon?

The final NCPC report is likely to provide helpful agreed definitions of the key terms in the debate. But individual organisations will still need to make hard decisions about who is included and who excluded from their mission of care, and why. Perhaps one way forward is to develop more extended networks and closer partnerships. This project came across striking examples of constructive moves in this direction and hopes to stimulate more.

Framing the evidence gathering

From the outset, the team was determined to find inquiry questions that would give clear focus to the different elements of our evidence gathering. In beginning the work in the evidence gathering phase, the team focused first on clarifying goals and in framing core questions to guide the evidence-gathering. Inevitably this raised a wealth of issues and tensions, such as:

- How far should the work take up the issues both of transition to adulthood and of end-of-life care in talking with young people and their families in this short inquiry period?
- How far can the work specifically clarify the additional issues faced by this group of young people and their families/carers in transiting to adulthood, compared to their peers who do not have life-limiting conditions?
- How to balance the discussion of challenges, issues, needs and strengths in transition with the desire to develop innovatory support for transition

- How to create some mapping of and discuss existing support and services without pre-empting completely new approaches that may be very different. For example, peer-based and self help support rather than traditional 'services'.

We proposed three questions: an inquiry question that would prioritise the user voice, a follow-through question that would lead us towards innovative development and a synthesis question.

- **Inquiry question**: *what are the issues and opportunities for young people with life limiting conditions, and for their families/carers, in making the best transition to becoming young adults?* We thought it important to frame this question within a sense of what are the 'normal' or expected challenges of transition to adulthood in order to focus on what if anything is different for these young people and their families/carers.
- **Follow-through question** in the light of the responses to inquiry question: *how can we together best tackle these challenges?*
- **Synthesising question for project team and board** in light of responses to both above: *What should MCCC do to develop strategies for the transition process?*

In discussion, we came to realise that the key challenge was to set a core question that would enable us to explore more closely the 'normal' expectations for this particular group of young people with such complex and diverse needs. So our question became:

Inquiry question: ***what are the issues and opportunities for young people with life limiting conditions, and for their families/carers, in managing their own best transition to becoming young adults?***

The project team saw the questions as a focus for the numerous strands of work envisaged, in order to hold them and the findings together in a single robust inquiry.

Section 2: How we worked

Our proposals for this work identified the tight timeframe as the key risk and this meant constructing the work as a set of parallel tracks. We could bring in multiple sources of evidence despite the short timescale, in order to create a rich picture that can be acted on in the real world of practice and inform decisions. Our approach was gathering evidence **to understand the people who create, interact and relate in this field of work with young people with life-limiting conditions**. We focused on the questions explained in the last section to help us do this.

So evidence was sought from young people and their parents, from practitioners, researchers, and from stakeholders in other organisations. We aimed to explore what they do and what they think i.e. their ideas and practice and the assumptions that underlie both. We also made whatever links across the evidence gathering streams that we could in order for them to inform each other e.g. interviews informing work with young people, work with young people informing the regional events, desk research informing face-to-face work. The approach we took is summed up in Figure 1. This section briefly reviews each strand and what happened in practice. Annex A details who took part in what.

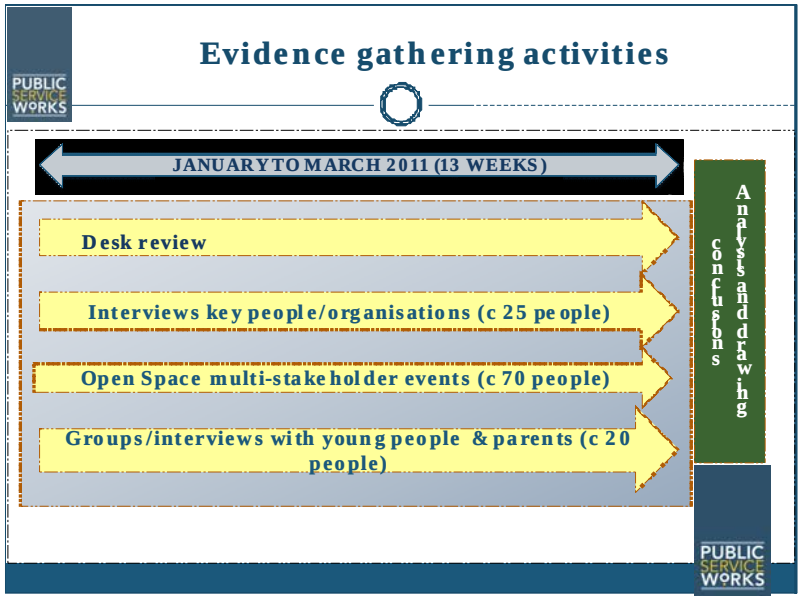


Figure 1: Summary of evidence-gathering activities

Talking to young people

Our approach aimed to engage young people in four main ways: in *groups* where creative activities would enable them to express their views and discuss issues that mattered to them; in *online discussions*; in *social network analysis*; and through a *gaming activity* to develop ideas about new support systems they would like to see.

Previous experience of working with young people showed that asking questions in a direct manner, especially of those in their early and mid teens, is often problematic. Individuals, before they address themselves to the question itself, think about why the question is being asked, how it should be answered and what the questioner might be expecting: what is the 'right' answer? The framing around the question seems to

become an important element of the response. More oblique approaches such as using visual material, story-telling or scenarios can help to get responses that are often more illuminating and have depth. For these reasons, the evidence gathering team planned a variety of interrogative styles and processes to get evidence. These included video-diary, collage, scenarios and case stories. It also informed our aim to involve young people in online discussions i.e. in a media environment in which they felt comfortable.

Our experience in practice was that this plan was very challenging. We had underestimated how much time would be needed to get these activities to happen, even through 'piggy-backing' on groups that other organisations were running in the timeframe. We spent considerable time in abortive negotiations to work with several organisations. The online plans were also slow to develop for reasons explained below. Both these issues impacted in turn on the social network analysis and gaming idea.

Groups

Setting up groups for this particular group of young people proved extremely difficult for the following reasons:

- Mobility is restricted for many of the young people and their degree of wellness/frailty fluctuates – this makes travel to a particular place difficult and the choice of venue very important, plus in most cases, their parent/carer also has to be free to come
- Parents and organisations that are involved in creating and running existing groups are understandably protective of the young people in relation to outsiders coming that they do not know or trust. These organisations are very sensitive, protective and busy.
- Many of the groups we hoped to link to are quite newly developed and not at a stage where visitors like ourselves were appropriate
- Some of the groups that take place are essentially social activities for the young people with full programmes or are planned meetings (e.g. of young people's councils or advisory groups) with pre-set agendas

In addition, once we gained access to young people with the help of two children's hospices, the complexity of the engagement process itself included:

- the different needs of each person: table heights are different for wheelchair and non wheelchair users; some cannot use their hands; some are visually impaired; some speak slowly or not at all. Many need help from carers/staff to engage in any activities whereas some don't. the wide cognitive range in any existing gathering of young people, and although those more cognitively able tend to help others who are less able the process becomes tricky to manage well
- a wide age range which makes it harder to discuss issues when the young people are at different stages
- some young people do not know they have a life-limiting condition and it is therefore not appropriate to make this explicit

All this meant we were entirely dependent on the goodwill and engagement of the staff in the organisations we contacted to achieve contact with young people: rather the opposite of accessing the un-mediated voices of young people that we had hoped for. However, we did work with two very interesting and very different groups of young people, one in Hampshire and one in East London, where we were able to observe and initiate creative work with the young people around transition that produced very interesting material. We took the decision also to pursue one-to-one interviews to

supplement the evidence from these groups. In all we spoke with 15 young people in the groups and 7 young people through interviews (two further young people helped us think through our online activity). Interviews then raised further issues:

- many young people are not keen to talk on the phone and cannot easily do so due to hearing impairment, or physical disabilities
- telephone conversations do not work well for those with speech or cognitive impairment and make it hard to understand what is being said on both sides
- a speakerphone or a parent holding the phone was needed for some and this compromises privacy to speak in the home where parents are present
- young people may not prioritise returning emails and calls promptly and it was inappropriate to harass them. Equally an arrangement made after various negotiations could be cancelled at the last minute due to sudden ill health.

See Annex B for the questions & activity framework that we used with young people

Following discussions at the project management board, the emphasis was on young people with a life-limiting condition that was not cancer, in order to maximise the voice of the hardest to reach young people – in the event we only spoke to two young people with a cancer diagnosis out of 24.

Online discussions

The aim was to try to get young people to join a conversation about life-limiting conditions in a media environment in which they felt comfortable. Initial contact with young people with LLC indicated that Facebook was widely used and therefore a similar platform might provide just such an environment. They would be discussing personal matters of an emotive nature, and this might be difficult for an initial period, and therefore the opening discussion would be posed in broad and relatively abstract terms. Levels of personal disclosure would be determined by contributors.

The on-line facility thus would have two principal goals: first, it would provide a site for young people with life-limiting conditions to discuss their experiences, and, second, it would provide researchers with information about their experiences that would supplement material derived from the group events and individual interviews.

For a number of reasons, principally security and control, the Ning platform was selected as the basis for developing the website. The target population was young people (aged between 13 and 24) who identify themselves as having a life-limiting condition. The site, *Normal Life*, went live two-thirds of the way through the Phase 1 timescale.

Three dilemmas had to be tackled:

1. Should the site be **open or closed**? An open site might have a better chance of attracting members but it would run the risk of harming a potentially vulnerable group of people by malicious surfers and 'trolls'. A moderated site would involve effort by the site administrator (initially not a young person, and not a person with LLC) and might get in the way of more natural community development.
2. How could the site be **promoted**, in particular, in time to generate membership and information for the project?

3. Should there be **community membership rules** or should the site community enable organic development without pre-established rules? On-line community management good practice suggested that a few simple rules were advisable.

Another area of difficulty was the use of the term 'life-limiting condition', whose ambiguity has been discussed elsewhere – does it limit life or opportunity? The first may be a medical fact or probability but the second is seen by some people as an issue of inequality that should be tackled head-on through taking a social model of disability. Our review of the research literature and our interviews with stakeholders showed that this is the appropriate term to use. However, some people with life-limiting conditions and their parents may not approve of it, and it may therefore exclude their involvement.

The project opted for

- a moderated site, with very low key moderator presence
- a set of 'groundrules' to establish the boundaries of acceptable behaviour
- the usual facilities to enable uploading of photos, videos, blogspot, and each member having their own *Normal Life* page.

The 'look and feel' factors are critical for young people to engage and highly skilled assistance would be needed, including from the target group of young people in order to make the site completely appropriate.. In the thirteen-week time span for the study (site launch was delayed by necessary consultation, including with 2 young people in the target group, and occurred in week 9) it was not possible to involve experts significantly.

Normal Life was set up as a social network group (see Annex K) mainly for and about young people with life-limiting conditions. The goal initially was to populate the site with the elements that young people recognise such as photos and videos as well as to have contributions from them on topics that they think are relevant. This might involve matters (sex, drugs, alcohol) that one might not expect on other sites but would clearly make *Normal Life* more 'real' and relevant.

It can grow only through invitations made by the moderator to individuals with whom the study comes into contact. New members though can invite their friends and are encouraged to do so. On this basis, and given the look-and-feel factors and the timing, growth will be slow. The site therefore did not provide the Stage I study with the information that it would have liked to see, but offers a potential platform for phase two development.

Social network[10] analysis

The aim of this workstream was to analyse the social networks that young people with life-limiting conditions possess and use and to assess whether and to what extent these may differ from each other and from what we understand to be the norm. These data would help to establish, together with other data collected from interviews with these young people and with their parents, the degree of social connection or isolation.

A further step would be to link these findings to other strands of work that aim to establish the degree to which on-line networks are accessed and used by these young people and, separately, by their parents.

Earlier work that we carried out [11] found that:

1. most people have three principal networks: family, work/school and friends. For adults, the members of these three networks tend not to overlap much. For younger people, there is usually overlap between friends and school/university
2. most people have between three and four networks, but a few unusual people – perhaps one in six- have both a large number of networks and a large number of people in some of these. These people have up to seven or eight separate networks, often independent of each other. They also often present a number of differing identities or personas that are reflected in their various and separate networks. These highly networked people therefore seem to be nodal points in other people's networks in that they have a larger number of connections than other people.

The question frame that was to be used included, in addition to the number of social networks, an approximation of the number of people in each network and the extent to which these numbers may have changed during 'transition'. These questions would help to illuminate some early findings in this study that indicated some young people's social networks (viz. peer/friendship networks) reduced significantly after leaving children's services/education.

The question frame included the following:

- what social networks do young people with life-limiting conditions take part in?
- do these teenagers and young adults have more or fewer than the number of networks common among young people?
- if so, what is the character of these additional networks (purpose/functionality, numbers)?
- are there any specific features of this networking that is related to their LLC status?
- what are the approximate numbers of people in each network?
- are these (or some of these) networks entirely private from their families/carers?
- If so, is there any significance?

Finally, the study aimed to ask a small sample of young people whether they would select three people from their peers in any of the networks. Researchers would then carry out a brief telephone conference designed to identify what support needs they would suggest for the young person with life-limiting conditions. The aim was to establish (a) what selection peers would make and (b) whether these selections were different from those made by adults (parents and professionals).

Game: wider support system and service design priorities

A further planned means of engaging young people directly was to get a group of 15 to 20 young people into a workshop session, in which two or three teams would compete to create the 'best' support service or system for young people with life-limiting conditions. Each team would be able to use a number of support components, each carrying a value (usually this would be an estimate of the unit cost of delivering such a service or activity), but would have to do so within a given budget. The young people would work in teams, among who non-playing other young people would observe and ask questions. Study team members would observe and record reasoning process and tacit selection criteria. The latter would be the panel of three peer judges on whose decision 'winning' would turn. The judging panel would be moderated by an adult to ensure that assessment criteria were consistently applied during the presentation that

each team would have to put together. There would be prizes for the winners (and consolation prizes for the runners up).

As the project progressed and the study approached the last quarter, it became clear that assumptions that had been made during the planning phase about the accessibility of the young people for this activity could not be delivered: the only group work that could be delivered took place 'piggy-backing' on events already scheduled by children's hospices active in this area. During these, the study was only able to explore the study questions but could not undertake any more extensive activity, such as a game.

The study aim had been to find out (a) what service components were most important to young people (b) what priorities and trade-off choices would be decided under budget pressures (c) what reasoning factors were involved in the decision that were made.

In order not to lose these objectives, the team decided to re-frame the game so that it could be used on a one-to-one basis and designed a board game cut in coloured acrylic (see Annex J). The aim was to use the board game with young people attending the regional Open Space events. The wider support system and service components were identified from the evidence already gathered through the interviews. These components were represented by nineteen tokens (three blanks were added to enable the player to make a choice that had not been included in the nineteen). They were organised into three domains (medical care, freedom and normal life) reflecting the key elements we were hearing about young people's lives and aspirations. The board game was supported by a glossary explaining the token labels, a set of three vignettes describing three young people with three separate life-limiting conditions and guidance for a game moderator.

The rules stipulated that the player could only choose twelve of the nineteen tokens. The idea here was to put the player under a pressure that would force trade-off decisions, thus revealing through dialogue with the moderator the decision criteria.

Initially, the player would make choices for a character in one of the vignettes. When that was completed, a photograph was taken as a record of the choices, supported by moderator notes about the decision rationale. Then, they were asked if these choices would be the same if they were making the selection for themselves; a second photograph was taken and stored with the moderator notes. Finally (without the young person being present) the parent(s) would be asked to play the game and a third photograph taken and stored.

Following a reasonable number (the aim was for about 25) of players, the study team would analyse the results, which would take the form of three types of findings:

- whether the choices made by young people clustered or diverged
- whether the choices made by parents clustered or diverged
- what these clusters and differences revealed about preference and priority
- what was the preferred pattern of wider support system components
- and what was the rationale and decision criteria that underpinned these.

At the regional events there were no young people who attended (for all the reasons enumerated above) so practitioners were offered the chance to explore this proposed 'game'. Two iterations of the game prototype were developed building on feedback received over the 3 events. Overall practitioners felt this was a helpful and novel way to get into some difficult discussions with young people and with parents. Everyone who looked at the game was keen to see it developed into a tool they could use, quite apart from its intended use to research support needs with young people in phase 2. Their

suggestions for a more visual version and perhaps animated digital versions using audio and online presentation as well as images were very exciting to hear.

As the study was unable to deploy the social networking analysis and the board game methods as planned, it is hoped these can be carried over to Phase II of this project.

Talking to parents

This element was not emphasised in the original workplan and came to the fore as a result of the engagement work with young people described above. Essentially we carried out interviews with parents when we encountered them in the course of talking to young people, when they wanted to contribute views to our work. This gave us a different perspective on the systemic issues that proved important and helped us recognise the social and contextual dimensions of the issues. We spoke to six parents during our work (see Annex A).

Learning

The process of engaging with the young people and parents taught us that:

- young people are as creative and resourceful as their peers without life-limiting conditions and they have a lot to say
- talking to parents opens up the whole family setting to view and this is very important in understanding the issues
- language and communication style and skills, flexible enough to accommodate the diversity of young people and their capacities, are critical
- the engagement process for young people involves their parents and carers who in most cases need to take part directly
- creating online resources for engagement requires specialist input and takes longer to build a community than one might anticipate, especially with this severely socially isolated cohort

Engaging with practitioners across the system

We chose Open Space as the method for regional events that aimed to draw in people from across the system in relation to young people with life-limiting conditions. See Annex C for a summary of this approach (and photographs of the events held). Open Space allowed us to have a very flexible event where those who came could propose topics for discussion but also set priorities for action. The style and ethos of this approach enables an open and trusting process where, for example, people are given the space to own up to the complexity of what they face without criticism. It is a process that encourages ownership of discussions, is about participation rather than consultation and sets a base for ongoing connections between people. Three events were held (in London, Manchester and Birmingham) that involved a total of 61 people who came from England, Wales and Northern Ireland and from a range of professional groups across children's and adult services, from local authorities, health and the voluntary sector. These included social work, learning disability, nursing, specialist palliative care, condition-specific teams, both locally based and with regional or national responsibilities. The lack of medical and education colleagues was a limitation. See Annex A for a breakdown of attendees.

The Open Space events focused explicitly on the key question the team had identified and invited participants to respond to this in suggesting topics for discussion:

How can we best work together for a positive transition to adulthood for young people living with a life limiting condition?

At two events we also offered participants the chance to talk to camera in a 'video diary room' and this material has been developed into the DVD (Annex L). Feedback from the events was very positive, with people appreciating the freedom of the conversations and the chance to meet people they would not normally meet from other services/areas:

'I appreciated the diversity of people who were here, their everyday jobs. I learnt lots and made lots of connections' (London participant)

*'It's been good to get out of the office and meet real people. I am very pleased Marie Curie are involved and interested to see what they get from this' (*Birmingham participant*)*

*'Some very interesting people from different areas, good to see we have similar scenarios and battles and we can learn from each other' (*Birmingham participant*)*

*'It's amazing what's come out of today and things that won't necessarily cost more money. Getting the children's services perspective has been good especially coming from an adult services perspective' (*Manchester participant*)*

'Surprised by what I have learnt, it's been really, really positive. Talking to each other there's lots that is alike, I thought it would be difficult but there are some very, very straight forward things that can be done, practical and that feels good.' (Manchester participant*)*

Learning

Events such as this work best in a locality where networks can be drawn on to ensure the widest circle of people get involved, including service users and carers. In this project we were dependent on national networks reaching local practitioners and this within a very short timescale. Despite the positive responses, our experience here backs up our knowledge that:

- a lead time of 6 weeks is desirable for such events and more time is needed to make complex arrangements to get young people and families to events
- weekday events are good for practitioners but not families
- local planning groups are best to achieve the right people in the room who can continue the work in action together afterwards

Interviews with key stakeholders

We targeted the key organisations and policy developers in the field of palliative care that link to young people. It was important to talk to them given the recent rapid developments and initiatives ongoing resulting from the DH investment. People were extremely accommodating in setting time to see us within the short timeframe. They also suggested others we could contact in a second wave of interview/discussions. In the event we talked to 40 people and could have spoken to many more. There remain organisations that we did not speak with who should be brought into the conversations in phase two e.g. Teenage Cancer Trust, Cystic Fibrosis Society. We developed a question schedule – see Annex D – and adapted this to focus on more specific issues as the interviewing proceeded into a second phase. Interviewees are listed in Annex A.

Learning

It proved impossible to secure interviews with people with an education background – frustrating as education is assigned a pivotal role for these young people. We asked for advice from directors of children's services and from officials at the Department for Education. Would we have had more success with a different entry point?

Nearly every interviewee talked of the importance of engaging young people – but comparatively few offered examples of how they had done so themselves.

One interviewee commented, *'Everybody recognises that this is a serious problem, but no one has the answer'*. The challenges for care of this small group of people seems to open up very big questions for future relationships between statutory and voluntary/ community sectors in relation to the care of other, much bigger groups, such as those with dementia. Different kinds of partnerships are being tried out, and the learning needs to be captured (e.g. 'a menu of options' when it comes to support for both young people and families).

Reviewing research and policy

Desk research was viewed as essential to inform the work as a whole but the timeframe meant that this work continued throughout the study. In particular, interviewees suggested papers and sources as we met them, to add to the desk review work. At the same time we were aware of other research work ongoing, in particular, the STEPP project being led by Children's Hospice UK with the University of York.

The aim was to provide a high level summary of the themes arising from policy/ research in this area. We did not carry out a systematic review of the literature as there are already a number of comprehensive analyses in existence including the extensive evidence base informing current national policy. Our task involved scanning the terrain for information and highlighting dilemmas which might guide our interviewing and engagement with stakeholders and assist us in producing workable proposals for phase 2 of the project.

Learning

The desk research enlarged the scope for our enquiries and encouraged us to make use of contacts in the UK other than in England (the focus for this work) including in Scotland, Wales and Northern Ireland and these featured in the interviews and contact with young people and parents.

It confirmed the extreme difficulty in enumerating this group of young people as completely as planning and commissioning stakeholders would like. It also confirmed the complexity of considering these young people as a group and the tricky questions of definition, diagnosis and prognosis that everyone involved in this field struggles with.

Section 3: What evidence have we gathered?

By working in a parallel process over January to March 2011, we have made significant strides in drawing on a wealth of sources. The limitation has been in enabling each source to inform and influence how we develop the others. However, the evidence gathering team kept in close contact throughout to try to cross-fertilise ideas and share emerging issues as much as possible. In this way the desk research produced a stream of ideas and issues that influenced all the face-to-face work and the experience of talking to young people and their families and care workers influenced the interviewing and the running of the regional events. The interviewing influenced the desk research and how the events were organised, as well as how we could reach groups of young people.

Nonetheless, our parallel process means we have essentially looked at all these sources of evidence side by side and then looked for clusters/commonalities and differences. This is important especially to ensure the views of young people and their families are genuinely heard in their own right and not mediated through the voices of professionals. This section presents the sources of evidence each in turn. The Discussion & Learning section will then consider overall issues and differences.

Young people: 'It's your life. Only you know what's best for you'

This section sets out what we learned from the young people that we spoke to directly, what we learnt from trialling a social networking site to involve them, what we learnt about how others are engaging young people in issues of their lives and the transition to adulthood.

As explained earlier, the plan to create or work with existing groups of young people proved extremely difficult, leading to a series of one-to-one interviews. However, the two groups with which we did engage provided a great deal of insight: both in terms of individual young people's experiences and in terms of the provision of group activities for them. Similarly the telephone interviews raised key issues beyond the content of the conversations: such as the lack of privacy for young people at home and the degree of their dependence on the help of parents.

What young people told us

The clearest message from young people was that transition is **universally an awful experience** for them. They describe it in graphic terms:

> *'The main thing I would change is making it so that when you move on from children's services it doesn't feel as though you have disappeared off the face of the earth'* (young person in 20s)
>
> *'when we become an adult… if the adult services were already in place we could smoothly be transferred onto them, removing all the uncertainty.'* (young person in 20s)
>
> *'you shouldn't have to go till 25 [from paediatrics] because it's very cruel, especially with a complicated condition. All of a sudden you hit it [transition] you get shoved over to other doctors and then again when you're 25'* (young person aged 16).
>
> *'A lot of people are involved when you go through the transition from children to adult services. They must have been through the transition [from child to adult] themselves but they didn't have the same experience or difficulties as someone in a*

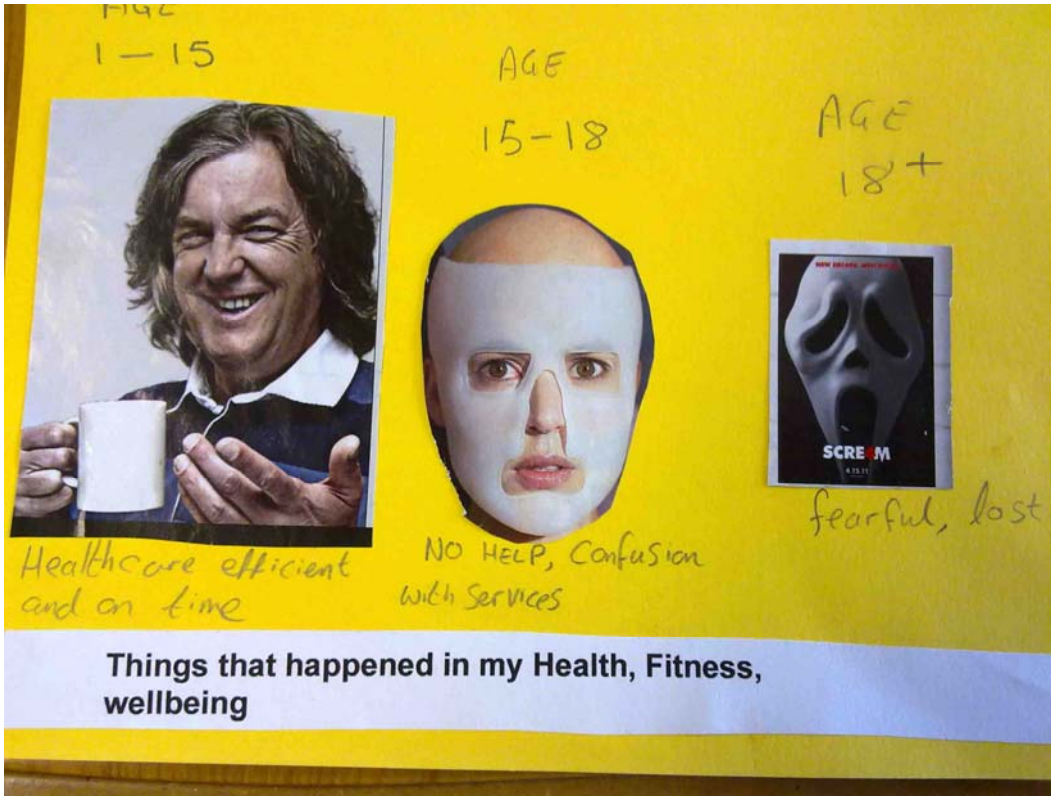
*wheelchair. They will tell you what they think you would like.' (*young person over 18)

The contrast is dramatic between adult services that they find unresponsive & hard to navigate and children's services that are widely experienced as effective:

'The place where I got [physio] closed down. Nowhere provides ongoing physio. If you want it, have to go private. Most of my friends don't get it.' (young person in 20s)

'I stopped children's services at 16 and there wasn't anything until 18. I was in a children's home. I came out and there was nothing out there after. I didn't feel safe or wanted' (young person in 20s)

A postcard compiled by one young person shows this shift extremely vividly:



It is also implicit in these quotations that, as might be expected, a young person's living situation and their parents' (if they have parents) ability to pay for services may have a further major effect on what happens to their care and consequent health inequalities.

More than this, it is clear that young people feel adult services do not understand their conditions nor their needs, unlike paediatric services which specialise in understanding rare conditions affecting children and young people and provide a holistic service for families to cope with the illness journey over many years.

While young people have concerns about their care and health, **they prioritise wanting a 'normal life':**

'I'd like a job. I've been out of college for 6 years, been on 20 courses but no job.' (young person in their 20s)

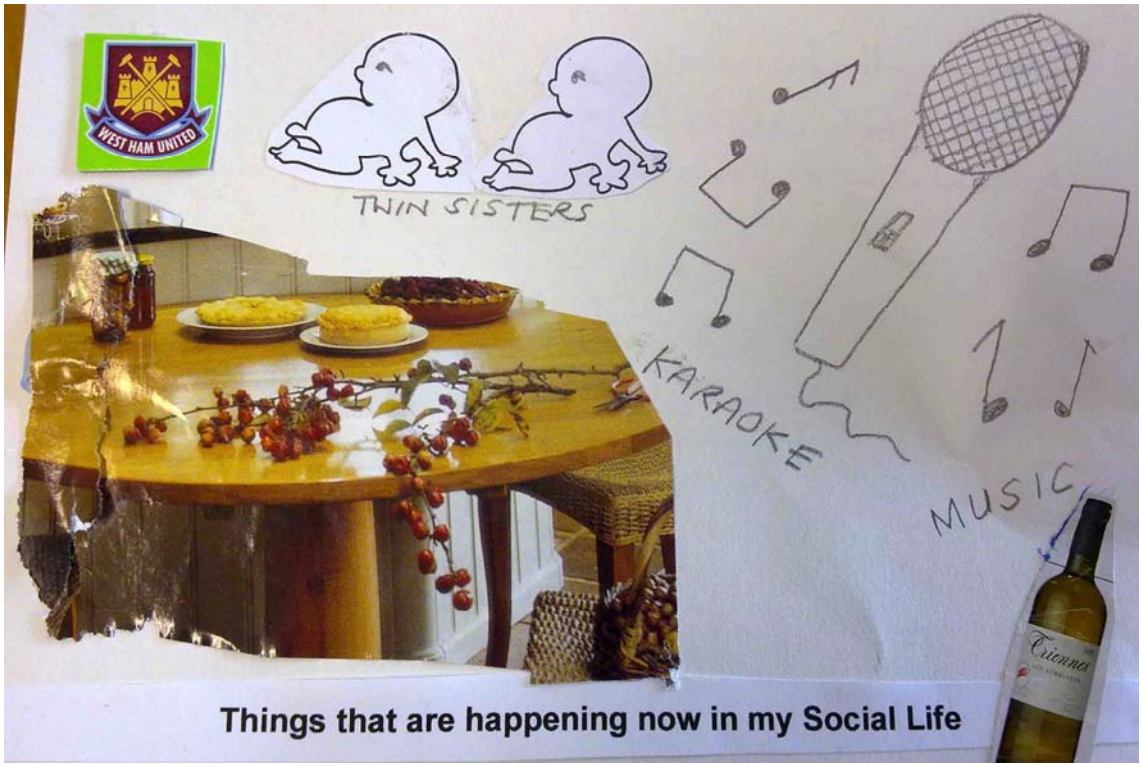
'I'd like to live in a flat with a flat mate, pay for my own carer, be independent and look after myself and have a job'

(young person under 16)

They want to experience what others in their peer group do: going out and developing their social life, taking risks, exploring society, expanding their development through education, work and leisure activities, feeling a sense of autonomy and freedom to make choices, try things, make mistakes, decide where, how and with whom to live and so on.

> *'I would like a bit of adult-free time because I have one following me around 24/7…'* (young person under 18)
>
> *'They [professional staff] will tell you what they think you would like.' (*young person over 18*)*
>
> *'Friends say, 'can I come over ?' and I say ' I'm not up to it.' I arrange things and then have to cancel. They didn't use to understand but now it's better. My friends are great. We go out on a Saturday to town. And they come round once a week and we have a movie night. All my friends have had training so if I'm out with them, they know what to do.'* (Young person aged 16)
>
> *'It's a good uni but they don't do what I would like them to do. They insist I have a carer all the time because I'm epileptic. I don't always need someone there and when I'm with a carer it can scare other people off. Other people think I don't need any one or I can't be friends with them.' (*young person over 18*)*

One of the groups we worked with offered a 'cocktail bar' for the over 18s and having a drink while doing activities/discussions in this monthly group was very important to the young people involved. One postcard from this group illustrates the importance of food, drink music and family:



Annexe E shows all the postcards this group created.

In short, these young people have **aspirations, legitimate and reasonable** aspirations in most cases, for living a full life while they can, and as full a life as they can, given their condition.

> *'I want to see Man United play and meet them. I've only seen one game live'*
>
> (young person under 18)
>
> *'I want to be a criminal psychologist. I'm doing psychology and law at uni now'*
>
> (young person 18+)
>
> *'I've got a 'bucket list' – 240 things to do before I kick the bucket – some are ordinary e.g. pass my GCSEs and watch a sunset and some are more dream stuff – get married and go to a ball. Well, last year I did go to London to a ball.'* (Young person aged 16)

It is especially difficult that the age of transition often sees a deterioration or beginning of deterioration for many in their condition and consequently the approach of death. The urgency to live their life at this time is therefore all the more.

Some of the young people we spoke to are active in campaigning and working with other young people on these issues. They want to contribute and to share their experience with others. Others feel support is more complex:

> *'I need support but would like it in a secret way, not in my face.'* (young person under 18)

Young people welcome peer support and for many this is the highlight of their social life, if they can access a group for young people with life-limiting conditions or an occasional weekend workshop.

> *'Mainly I can pass on my experiences, having gone through the transition period a few years ago now and having since been left to the mercy of adult services! A lot of my experiences haven't been particularly positive, but hopefully by letting others know exactly what is lacking they can be prepared for it and try to push for the services that we should rightfully be receiving.'* (young person in 20s)

However, they acknowledge their **dependence on their parents** for any and all of the above:

> *'My dad has to come out with me to places, which is not an ideal situation for either of us if I want to go out to nightclubs or concerts. I just want to have a normal social life like any able bodied 25 year old....'* (young person in 20s)

They are **concerned about their parents** and the impact of their condition on them, rather than resenting their dependence. They show realism in this respect and wonder what would happen if their parents were not there for them:

> *'If 24 hour care was provided I could live independently without my parents - they have to do the vast majority of my care. I don't like to think about what would happen if they couldn't'* (young person in 20s)

At the same time they are aware that parents need to hold them close as their condition advances and they often both collude to protect the other, for example in parents not

discussing the issue of death, in young people not talking about the burdens they feel they place on the family.

The co-dependence that a life limiting condition can create, including financially, makes the desire for autonomy and more freedom harder to express and achieve: one young man felt he would need to take more responsibility for chores now he was nearly 18, such as taking the rubbish out. He hoped he would have the chance to develop his social life, *'with my mother's permission'*. For some that permission is easy, but the sum of benefits that the family may receive due to the young person's situation can make the thought of independent living impossible, as the family would lose such a huge chunk of income, or even their accommodation, if the young person lived separately. This is especially a challenge if one or both parents have had to give up work some years prior, and/or where the extended family is also involved. In some cases the entire extended family economy may be de-stabilised if the young person moves out.

So their stories also show **a pattern of young people ending up isolated**, with restricted social networks, mediated by the constraints not only of their health but by the family and its means, and by practical issues such as lack of transport. Care staff are appreciated, but young people are aware of what gets cut off at transition and how funding schemes are limited in terms of how much support time they can get:

> *'You need respite; you need a PA to help go out to decrease the isolation. I had a PA to take notes and help with things [at university]. It ended when I left.'* (young person in 20s)

> *'I like to go out to concerts and so on. It's hard to meet up with friends. There is no support to help me go out so there is a lot of isolation.'* (young person in 20s)

In addition, while there is excellent work going on to create social opportunities for these young people, usually based on children's hospices with a specific young adult offering, this is inevitably limited to occasional weekends, or a monthly gathering, which does not equate to a normal social life. For others, their world is very medicalised, with their home an extension of hospital and the 'holding close' instincts of their parents mirrored in the approach of health professionals whose training privileges care and cure over enablement and promoting independence.

Other engagement of young people with life-limiting conditions

In starting out on our work, it seemed, especially from the desk research, that the voices of young people were not audible and that much of the perspective of 'need' for them was largely being mediated through parents' and professionals' views. In the interviews this perspective was further underlined. However, as the work continued to try to engage directly with young people, it became clear that pioneering work *is* being done to gather and amplify the voices of young people regarding their care, their transition and their aspirations as teenagers and young adults. For example, the young people's group at Richard House created an atmosphere where it was 'ok' to raise issues about death and dying, to have a drink, to plan going on holiday to Tenerife as a group. The staff ratio was very high and the warmth between staff carers and young people was palpable. Jack's Place, a custom built unit attached to Naomi House children's hospice in Hampshire, offers young people's weekends, special sessions for young women and sensory weekends for those cognitively impaired plus sessions and activities for siblings. The Demelza Hospice has developed a self management programme with young people to develop skills, communication and self advocacy for social independence called *'Taking Control'* and has trained young people with LLCs to

facilitate it over four weekends for their peers. CHAS and CLIC Sargent operate active young people's groups that contribute to policy and governance for their organisations. Barnardo's has a well thought-of transition booklet. Berkshire has a dedicated transition social worker. There are many more examples at children's hospices and in voluntary organisations that we were told of, but were unable to contact in the project period.

The internet has also enabled the posting up of stories in text, audio and video form on the sites of a number of organisations relevant to this field e.g. ACT, CHAS, Teenage Cancer Trust. Also specialist websites such as www.youthhealthtalk.org and individuals' blogs are adding to the richness of an online conversation. It is notable that this conversation is dominated by the experience of young people with cancer rather than those with other conditions, underlining the importance of our focus on young people with conditions other than cancer.

This section aims to give a flavour of that existing conversation/those voices alongside the views of the young people we spoke with in our work.

> *'I suppose the crux of this essay, my desire for university, and transition itself is this notion of independence. And this seems to be the buzzword of the day for those concerned with disability at the moment given this climate of equality. So what does independence mean to me? Absolutely nothing! I couldn't give a shit to be honest. 'Independence' is almost a negative in my opinion given the way it's been used so much - it's…lost all meaning... See my parents are the type to let their son loose with a bunch of mates full well knowing they're going to bring him back near comatose state at around two-three o'clock in the morning only to spend another hour dumping him into bed. That is devotion and that is why in the same breath I must leave them. I'm no fool, my parents are both over fifty now and I know that the care for me is taking a toll on them; this is why after university I will most likely not be returning home. I'll have tasted a more ardent concept of life, as they will find theirs will return. They'll struggle to let me go, but I don't think they'll see me as a man until they do!'* from Greg's story (in 2007 aged 18) accessed 18 March 2011 at http://act.org.uk/page.asp?section=200&sectionTitle=Your+stories

> *"Being around people my age going through the same thing as me helped me to remain strong, and no matter what was going on I never felt scared about my situation."* young people on TCT website

> Voice from the CHAS video on their website*: 'your parents give you that passion for life'* vs. getting sad about the situation

> Voices from youthhealthtalk site*:*
>
> *'I'm not brave, I just want to live a normal life really'*
>
> *'you feel you know more than they do, they're not really listening' referring to talking to clinicians*
>
> *'I haven't worn socks for 5 years! Because I can't put them on and so I just don't wear them'* a young people explaining his independence

> From Wish 143 an Oscar-nominated BBC film produced by a young man who recovered from cancer, featuring a young man with cancer who wants to have sex before he dies. He is met with resistance and attempts to deflect him into football or other activities... He comments *'no, no one tells me I am good-looking, I don't get touched except for tubes and medicine taking..'*

> Young people quoted directly in Sawyer et al 2007[12]:

*'My management is probably medium right now. Not the best it could be, but not the lowest either. I get sick of doing all the things I have to do' (*15-year-old boy*)*

'I really only have one friend that I can talk to as he has the same thing as me' (17-year-old girl)

'I'm managing well, but I feel that I don't have a social life at all' (17-year-old girl)

'I feel confident I can do what I want' (15-year-old girl)

It is clear that these voices strongly echo what young people told us directly.

Social networking & digital approaches to engagement with young people

On-line/internet issues were not spontaneously raised by any respondents in any of three respondent groups. This is not surprising nor unduly worrying since many of our respondents were older than the target group and perhaps less focused on the issue and younger users may see internet as routine, and so not remarkable. In addition, technology users are good at identifying issues regarding existing applications, but less effective in knowing what technology might make possible: the 'unknown unknowns'.

Therefore it is more important to concentrate on what people want/use and then see what digital approaches can contribute to delivering that need i.e. start small, test live, grow naturally. But essentially we found **no clear evidence of unmet demand** at this stage.

On probing, however, there was widespread agreement that on-line facilities are

- very much used by young people with no cognitive impairment
- and by those mildly cognitively impaired
- but very little by those who are severely impaired

Currently young people use the internet and mobile phones to get information, take part in social networks, and for entertainment, such as gaming. One young person we met used her phone as the key means to communicate through text replacing her voice. It is not clear whether there is a lower prevalence of broadband/computer access among young people with life-limiting conditions; the diversity of physical abilities and the strain on family income of coping with the LLC may create lower prevalence.

Our discussions with parents suggested that they should be seen as one key potential user audience for digital platforms, given their isolation, needs for information and appreciation of peer support.

Numerous organisations have already of course recognised the potential of the internet as a space for young people to engage, link up and share experiences. A number of specific offerings exist for young people with cancer, who are characterised as more able both physically and cognitively and, given the nature of their diagnosis and treatment, keen to get information and link to their peers. Digital offerings currently include:

- Young NCB space – a social network site for young people that is closed – you have to apply to be member through National Children's Bureau website. They also have an e-newsletter for members 'loudspeaker'. A general site for young people

- www.Thesite.org aimed at all young people and a possible model for open discussion
- http://www.youthhealthtalk.org/Young_people_with_long_term_health_conditions/Topic/1867 dealing with a range of health issues including mentioning life limiting conditions – uses video diaries and interviews by young people
- http://www.teenagecancertrust.org/get-clued-up/young-peoples-stories/ most of the videos feature young people who have experienced the specialist units that TCT sets up in hospitals
- http://www.jimmyteens.tv/ a special video channel set up by TCT that includes videos of young people and their experience – 'sharing experiences of cancer creatively' . They also do live podcasts of music and talks. The search for 'transition' here drew a blank – moving on here means after the cancer...
- http://belleofthebald.blogspot.com/ an example of the blog of an individual young woman, Maya, who charts her journey currently with Hodgkins disease – there are probably many more like this out there
- also www.stayingpositive.co.uk site which is part of the expert patient programme especially for young people. Unclear if life-limiting conditions are explicitly included.
- http://www.nhs.uk/youngcancercare - newly launched in March 2011

Comments on the digital approach from young people and others:

> *the net's quite a useful thing, and you can talk to people, you don't have speak to people face to face, you can talk to them about it, and you can hear different stories from people so, that really helped us, that's probably what got us, got us through that sort of thing, people who understood what you were going through... didn't really let a lot of people know, like around us, I didn't let a lot of people know that it was bothering us, but through, just the phone on the internet and forums as well were really helpful, you just post like a message, and like say your concerns, and then you go back maybe a day later, and they'll be five or six people who, who've like says you know I've been through this, and you've just got to realise that you know, take each day as it comes, and, like you used to just get like letters of support coming back and it's a lot more helpful, because if you feel like you can't talk to people around you, it's just that, a little bit more than like a resource that you didn't have...*
>
> young woman with Cystic Fibrosis 21 years old – at http://www.youthhealthtalk.org/Young_people_with_long_term_health_conditions/Topic/1873/Interview/1555/Clip/8716/

'this concept you have of an online community is extremely useful for disabled young people. It could easily be a tool for empowering disabled youngsters, as well as giving them a platform to discuss issues affecting lives, possibly become activists and campaign, or just have the opportunity to meet new people-an issue which shouldn't be overlooked, considering that disabled people are amongst the majority to be isolated... I feel the online community should follow the same principles outlined within the social model. You could even use the social model or similar principles as the opening message in order to explain why this online community can be a useful aid for disabled young people.

While I think the members of the group should have complete control over its direction and what discussions take place, I also feel it is vital that the online

community has a bit of structure. For many disabled people, especially young disabled people, they do not want to associate with the term disability or impairment. That is why you need to create an online community which "feels" like it's in a mainstream initiative. It also needs to be worthwhile and appeal to disabled young people in order for them to spend their time participating; that is why you can use the online community to not only provide a platform to voice opinion, but also teach and provide information which can empower disabled people.

Regards to whether the online community should be open or private, I think people should be allowed to apply for an account that gives privileges such as posting comments. Nevertheless I think blogs etc should be open to the public. You could set up so when people post comments they can publicise their comments to everyone who has an account or just individual members. For newcomers you could use the same initiative that the BBC sport 606 Forum has, were the first three messages posted by the new person is reviewed by a moderator in order to identify whether they are legitimate person or a spammer.' Excerpt from Miro Griffiths' note to us

'I would like to contribute my 'bucket list' [to an internet site for young people with life-limiting conditions] to show you don't have to give up on life. I'd like to support someone who's going through similar things through the Internet. The Internet keeps you busy and reading. When I was unwell I couldn't read. My best present at Christmas was a Kindle. When I'm well I read on it and when I'm unwell I turn it to audio and listen.' Young woman aged 16 interviewed who was keen to use the internet for information for self and to link to others in a similar situation

'it does seem to be an incredibly important way for young people to communicate and it's a very supportive community in a sense because it's so instant; there's always somebody to contact' Institutional stakeholder working in learning disability

Summary points

Young people overwhelmingly have a poor experience of transition, both in terms of services and in terms of having the level of autonomy and control they desire

Young people share a common aspiration for a 'normal life' and hold largely reasonable ambitions for what they want to achieve in their lives, such as an active social life, education, work opportunities, and what concerns them as young adults such as friends, relationships, going out and looking good.

Young people are concerned about their parents and the strain of their care on parents

Some young people are keen to engage with others and to contribute their experiences to help others.

Digital platforms are used by most young people as part of their daily life, notably Facebook or similar sites and 'google' searching on the internet. Current offerings for young people with LLC focus on those with cancer.

Innovative work is being developed within children's palliative care to engage young people in thinking about their move into adulthood, involving group-based social activities, and creative work such as drama, video, radio.

Digital platforms development should be gradual and focus on young people-led options, links to sites used by all young people and on parent support

Parents: 'You are off the radar after 19'

We had assumed that parents would be involved in the groups we held with young people and that we would be able to talk to them informally. Formal interviews were not planned. As we learnt more about the situation of parents, we recognised that brief conversations with them as the opportunity arose would be very valuable; hearing what was most immediately on their minds would be potentially very enlightening. The possibility of some telephone conversations also arose which we took up.

From our conversations with parents it was clear they absolutely **shared the universally negative experience of transition** that the young people recounted – and held a strong affinity with the children's services that had up till that point offered them and their families a much valued support structure. Typical comments about transition included:

'*You are off the radar after 19.'* (parent*)*

*'Nothing has gone right with the transition – it is rubbish and all wrong.' (*parent*)*

'*Key worker? Don't make me laugh.' (*parent*)*

They experience transition as the end of support just when they are aging/getting ill themselves and the young person's condition may be deteriorating. Critically they have **short breaks withdrawn or greatly reduced just at the point where they may be more needed** for them and the young person (for whom these breaks may be the bulk of their social life). This is especially the case in families where there may be multiple occurrences of children with LLC due to genetic conditions. All the parents speak in terms of fighting' and 'battles' to enhance the care they can access. They learn the intricacies of the health and social care budget systems, if they are able to. They turn their home into a care setting and worry about its impact on well siblings.

In short they too are **isolated, and like carers in general are exhausted**, with little 'respite' for their own 'normal life'. They are seen as parents first and carers second – they themselves may feel this way. However, transition brings challenges to both roles – increased caring demands and a complex transition from parent of a child to carer of an adult, who happens to be their child. This is complex, privatised pain. It can be exacerbated by **financial pressures** whereby the family can be locked into economic dependence on the life-limiting condition, as a result of benefits, the impossibility of working and caring, the involvement of the wider family network:

*'I go to sleep every night thinking about him and I wake up every morning thinking about him. We are only without him once a month when he goes to the group' (*parent*)*

*'Everything can be ticking along and then bang one or other, or both, is poorly. I had one year when they were both in different hospitals. My parents stepped in… Grand-parents never get enough credit. (*parent*)*

*'I don't have agency carers. The home is a private place. I don't want strangers tramping through the house. I don't want to pay them to sit on their bums and talk on their phones.' (*parent*)*

*'I do the majority of the care on my own. I'm a single parent. I do employ my parents and my sister at times'(*parent*)*

In this pressured situation it may be hard to acknowledge support needs, but our conversations showed that parents **welcome psychological support**: from peers, from known professionals. Often this happened as a by-product of the care and activities for young people: parents met when bringing young people to a special weekend, sometimes this grew into special input for them, or into informal socializing. Aware professionals took the chance to offer information and support when they met parents in the course of work with young people.

Parents also find it **hard to think of the future** and may reject the label of life limiting condition and the reality of an early death for their child. When the child/young person is well, this is especially the case. They too want 'normal life' for as long as possible:

*"Life limiting?" Who's to say that? Do the doctors know? No, I don't tell [my children] We take each day as it comes. I can't plan for the future' (*parent*)*

Summary points

Parents overwhelmingly have a poor experience of transition, both in terms of its impact on the young person and in terms of the impact on themselves of fewer respite and short break services

Parents have their own transition to make as their child grows up: to acknowledge and support more autonomy for the young adult and to face the shift from parent to carer of an adult, alongside the painful and growing reality of early death of their child

Parents appreciate peer support but this is currently ad hoc and marginal in their lives especially after transition.

Practitioners: 'we don't work in a way that's joined up, we could be more brave and transparent'

The three regional Open Space events drew in a range of practitioners from across the UK (see Annex A). Participants created their own agenda on each day and ensured reports of their conversations and recommendations were recorded on the day. They used a 'dot democracy' process to review their recommendations and create clear priority areas for action. The full reports produced by participants at each event are included as Annexes F-H. This section pulls together the outputs from the three events: the areas discussed and the top priorities from the voting, as together these reflect the core issues of concern to practitioners. The points are also illustrated by quotations from the 'video diary room' offered to participants at two of the events.

Overall issues of concern

Table 2 below summarises the key priorities that emerged from the three events together. While different proposals for action were made at each event, clear clusters of

priorities emerged and, taken together, form a remarkably coherent picture of areas that practitioners want to act on. These seven areas are then explored in turn.

Rank	Priority for action	Votes
1	young person centred work	43
2	key worker needed	38
3	coherent networks on the ground across adult and children's services	33
4	joint working	30
5	systems for quality & individualised care e.g. clear clinical responsibility	29
6	improved transition process	17
7	training/education	12

Table 2: Overall priorities from Open Space events

1 young person-centred work

> *'young people's views are not captured well enough, it is their life after all, it's easy for professionals at times to impose professional views and we may miss some of the very simple but fundamentally important things they want to do' (*transition social worker for young people with disabilities)

This cluster of ideas focused on the importance of ability, not disability, and choice for young people. At its heart was the view that practitioners wanted to understand better what young people are saying and make sure '*hopes, wishes and aspirations are not lost'*. Professionals could see that young people have a different view of their condition compared to adults' view: to adults the illness comes first and lifestyle concerns second; for young people their condition is simply part of their whole life.

> '*how is your health going to stop you doing those things you want to do is probably the best way to talk about maintaining their health.' (*ACT coordinator*)*

> '*The important thing here is teenagers have as normal a life as possible' (*parent & professional)

People recognised 'normal' development choices/behaviour may be denied because of illness/lack of mobility/limited ability to communicate or due to cognitive impairment especially; that in these cases parents/carers are making choices for them that professionals are not challenging perhaps as much as they could. Stories were told of infantilising young people and not letting go as a parent – as parents are often 'fighters ' by necessity and it is hard to let young people be independent. This is against a context of growing independence yet autonomy may be diminished by illness. Equally there are tensions for staff: the children's service handing over and *'not being precious about letting go - you can't do it all yourself'* but recognition that professionals have to step up to the challenge:

> *'if I don't support young people, or even challenge my peers to make sure young people have equal representation as adults on any commissioning or*

*decommissioning, I have failed in my duty of care. And potentially so has an organisation.' (*Children's joint commissioner*)*

These suggestions draw on the wealth of approaches and tools that exist to support professionals in person-centred working, with particular expertise in learning disability practice. They want tools '*that help open up the discussion and create a support system (it's not all about ' services')*'. These ranged from advance care planning ideas, to advocacy, from specific communication tools to young person led initiatives. While there was huge energy around these ideas, there was also a sense that people felt a lack of skills and confidence in enacting them fully, especially given the resistance to young people's autonomy that often came from their parents. The discussion picked up on the risk averse approach of parents and professionals whereas young people want the chance to take decisions, risk and have the opportunity to learn about failure just like any teenager.

To support the young person centred approach several discussion groups focused on advocacy, concerned about how far they had appropriate knowledge to support individuals with learning disability or particular conditions. Young people should have choice about who they want to advocate for them and part of this may involve advocating and mediating between young adults and their parents. People felt independent advocates were important and could be helpful at transition, although it may be a challenge to introduce this to families 'so they don't fight it'. Stories were told about how residential care can be very empowering for young people as it can give them independence and they can grow up – 'one young man who is now able to drive and take his mother about, before he just sat on the sofa'. It was felt the SEN green paper may start to undermine this in terms of funding for special colleges, plus general budgetary pressure to keep funding local and not out of area.

Essentially people wanted to work with the young person/child/family as the experts, part of the team, both in the centre of the psycho-social model of 'normal life' and of the medical model (person centred care). Discussion also suggested self managed programmes - peer facilitated – and mentoring with young people being 'buddies' for younger peers would help keep young people's views at the centre.

2 the key worker concept

*'Having a key worker from children's or adult services to coordinate all aspects of the care package whether its health, social or hospice care, or care at home, that's what's good about a key worker. ... They explain what's going on, it's in the ACT pathway, we recommend a designated key worker in adult services as well that would start to have links with the paediatric key worker from 14 or so and really start to build up a care package for the young person as they start to leave school and move on.' (*ACT Chief Executive)

This was about the coherence of the process of transition and the need to ensure a single person holds responsibility for coordinating the care elements as a total support system – as people experience the children's services. Responsibility for planning/supporting transition needs to lie with an identified individual, who works on behalf of the young person to help them negotiate these processes, and work with other clinical teams and other service providers to help them deliver age appropriate care. The current Green Paper on special educational needs supports the key worker role and cross service planning till age 25, which people felt is an opportunity to clarify issues nationally.

There was no agreement on who should take this role. Numbers of people felt the GP should be the person but others equally strongly felt the GP was not the right person – having been effectively disengaged from the young person's care early on. Others felt the paediatrician should retain responsibility, others felt social care taking a holistic view are better placed. It seems in reality the role falls to parents currently: one parent commented to us: *'key worker? Don't make me laugh!'*.

There was some support for the concept of the dedicated transition worker, already working in some settings. While this would provide one point of contact for families, continuity, develop expert skills and hopefully bring services together, there are risks. It could exclude and deskill other professionals and overload the transition worker who may not have the authority to ensure all relevant services come to the table: *'transition should be case managed and not case held'* i.e. the gap is in taking responsibility/ leadership across the children's and adult services divide.

3 coherent networks on the ground

> *'It's about how we move from independence to interdependence and let some of it go about our own organisations for the benefit of the people using our services, then I think we will have achieved something' (*Hospice Chief Executive*)*

This set of ideas embraced two key elements: the need for locality based networks *across child and adult services* to bring them together to help young people in transition; and the need for networks that are *multi-faceted* and draw in people and organisations that can operate not only across the children/adult divide, but the health/social care boundary, and integrate the social and clinical wants and needs of young people and their parents: *'right place, right expertise, at the right time to meet needs and priorities of young people and families/carers'*. The aspiration is for a multi-functional support system for young people and their families and one which can *'develop a strategic dialogue across organisations within a sensible geography'*.

The discussions ranged over the network models that might be feasible to practical short term suggestions for closer working:

- 'children's hospices could be at the core of a local network of services - a hub and signpost - to focus care but also the rest of life'
- 'joint working practices, policies and guidelines - which can be put into practice - not just have a policy for a policy's sake'
- 'need to join up adult and children's EOL/palliative care networks - they can link as a whole to the GP commissioning structure, health and wellbeing boards, healthwatch and user groups, education people... a whole sector approach not one lone provider voice'
- 'share scarce resources across the network e.g. hydrotherapy pool available to young people with complex needs, not only those with life limiting conditions'
- 'it needs to offer a coherent network of independent providers - to young people and commissioners (to make the complexity more manageable for them) This needs to span the locality and reach into the community base.'
- 'we must think more laterally about daycare perhaps offering specific days for young people'

This area of concern offered many ideas for a more creative approach on the ground that could make a great deal of difference to the transition experience. It also highlighted the on-the-ground challenges of the current context:

> *'The local transition networks have started to do work locally, little bits of work, but sadly lots of transition roles go this month (march 2011) I think 90% of transition workers across Leicestershire in health and social care and the ACT transition coordinators are all going at the same time.' (*ACT coordinator)

4 joint working

> *'Transition is really important because it's becoming evident that the services are not joined up – so a young person reaches the age of 18 and services suddenly change dramatically.' (*Paediatric palliative care, specialist nurse)

This cluster of proposals echoed much in the previous section on networks. However practitioners recognised the difference between creating new structural networks and the daily requirement for working across boundaries and prioritised both.

This was not only about needing children and adult services to work together but joined up working across all services/boundaries, including the voluntary sector and private sector. The concept of developing a common language was popular as were more joint appointments. Specific suggestions included:

- close work with special schools
- joint clinics and regular scoping meetings between children's and adult services
- meetings from both children's and adults teams to reconcile different philosophies and ways of working
- liaison with transition coordinators in hospitals
- common system for record keeping and records to be held by young people/family

5 systems for quality & individualised care

> *…how and when do you stop transitioning and move to End Of Life care? And deal with the things they need you to deal with at that point… we have just been talking about five young people who died recently, unexpectedly, just before their 18th birthday. The worker said she was so busy focusing on their transition that they missed the EOL needs. It was very traumatic, as they hadn't really got their head around EOL care as they were still in full transition.' (*ACT coordinator)

This concerned the highly specialised knowledge and skills involved in providing the right care to young people with complex conditions that are particular to childhood and only recently persisting into adulthood. This means that clinical responsibility and quality may inevitably accrue to the paediatrician or other medical lead who is the specialist. Not only do many of these doctors want to retain involvement post transition, they may be the only quality choice to take clinical responsibility. Where they can hand over, people stressed there should be a clear protocol for handover to another named specialist consultant. It was clear that retaining paediatric clinical lead was not necessarily seen as 'no transition' but that this lead clinician should be able to coordinate across the children's/adult services boundary (see also key worker discussion above).

However others advised: *'don't look at the condition, this frightens adult services! Break down the care elements of the condition. It's the same care that's required'*. Opinion also acknowledged that paediatricians 'holding on' was not always a recipe for

autonomy for the young person and what was needed was statutory responsibility for every young person to have a named adult consultant by the age of 18. This could mitigate the frustration of adult services being '*chopped up into different specialisms'* that confuses and distresses young people and families. Practitioners were adamant that clear procedures and action must be sorted out:

> *'There has always been a lot of talk but very little action, the time has come to start making changes in structures and the way we work and practice and not to keep talking about it, but to see some change' (*ACT coordinator)

6 improved transition process

> *'my own transition was really bad for me…. It was before personalisation … I had a really good advocate, my mum, who was able to fight for me all the way, but it's become the norm ... that families have to fight for their young people. It should be a simple transition. I don't want other young people to go through what I had to go through' (*professional facilitator aged 29 and a wheel chair user)

This priority concerned the actual process of undertaking transition, especially the planning and reviews from 14 years onwards. The key role of education was noted and the importance of health professionals especially engaging with this (statutory) process fully. People emphasised the importance of parallel planning with both children, young people and adult services where young people may, over time, move between age-defined services and where needs may change. The conversation needs to happen at several points e.g. along the elements of the ACT pathway, at the year 9 review in education. The sequence must recognise this is a dynamic process and priorities will shift and change over time. Equally transition plans must be developed by/with each young person and to be owned by them, and agreed by services, so young people know what to expect as much as possible, and families be better prepared. This is a challange for staff:

> *'I have learnt not to raise expectations, in the beginning I used to say transition is seamless, it's going to be lovely and I will guide you through it and hold your hand, but I have stopped saying that now. Transition is obviously not seamless and it's rocky and it's really stressful – and I say that now at the very beginning, and I wish it wasn't like that but to raise expectations has caused more distress that starting with the realities.' (*Continuing Care manager***)**

Many felt that getting the process right would take account of the variety of individual needs but recognised too that transition is an ongoing process not an event - although it should have specific aims: autonomy, decision making, sorting out funding and making choices, not just transferring between services. People felt this involved having a realistic view of what adult services can provide: '*don't set the families and YP up to fail'*. Equally *'a good transition doesn't have to cost extra, it can often cost less - the key is planning preparation and good communication'*. Practitioners also noted here that many young people are not in the system - especially those not in education who will not appear on people's lists - plus those cared for out of area and coming back as adults are unknown to professionals. Information gaps are critical.

Till now the transition agenda seemed to be a children's services one: *'we need more adult services to get on board'* – especially as more young people are reaching adulthood with a life-limiting condition. The top priority in London was to *'challenge adult services to think/ work differently to support young people'*. Essentially, there was recognition that transition is an issue for staff too!

7 training/education

*'We have a lot to learn and do in paediatrics, we realise we have a lot to do to empower the young person, help parents to let go before going over to adult services.' (*ACT coordinator)

Workforce capacity, workforce development and skills sharing, including joint training/education for health/social care and paediatric/adults, was a topic within many of the discussions on other aspects. In Birmingham it was the top priority overall. The issues for concern here included:

- training to work with an ethnically diverse population and provide ethnically sensitive services. People were at pains to point out this was not just about spiritual issues, though they are included.
- diseases of children are now diseases of adulthood and the need for more adult clinicians to get up to speed with the existence and complexity of conditions e.g. genetic cancer, many types of atrophies, neuro degenerative disorders ~~etc~~.
- promoting the attitude and skills for the culture change needed in children's services to help YP move towards adult roles and responsibilities; and for culture change needed in adult services to achieve smoother transition and meet the needs of young people and families
- helping people see and deal with their assumptions and professional 'blinkers' of medical or social models of the world: '*it's hard to get people in health to engage in long term living processes - not like Learning Disability teams'*
- the need to have knowledge of each others' roles to signpost successfully

Beyond these seven areas other issues that provoked robust discussion included:

- **the exclusion of primary care** from the lives of these children from a young age storing up issues later, when GPs and district nurses simply are not, and may not want to be, involved.
- The overriding **importance of short breaks provision** for both young people and families to provide rest and care for both and a slice of 'normal' life, socialising with peers in both cases. Issues for parents in general loomed large across the discussions with staff recognising their stresses and support needs.
- The importance of the **systems for funding and commissioning services and support,** both for improving the support system for young people but also to improve communication and the speed of decisions about funding. Discussions explored joint funding options including national and local dedicated funding e.g. for transition workers, joint panels ensuring quality and equity, social care commissioning health and voluntary sector inputs, the **contrast of flexible direct (social care) payments with inflexible continuing healthcare payments**. **Personalised budgets were favoured** largely and practitioners shared their strategies for 'working around' the system to keep the most flexible budget options for families, who value having **control** over resources available to them .
- The current context of **cuts and budget pressures** were felt to be likely to have a bad effect, not only on services directly (such as short breaks and transport) and on the voluntary sector, but on staff's capacity for spending time with clients, training and for

proper joint working. A retreat into one's silo was feared... This context is also producing mergers/mutuals In Westminster, for example, adults and children's services are going further in different directions making it harder for transition as well as creating loss of skills, knowledge and history, relationships and information/websites

- The need to **avoid reinventing the wheel as we work with evolving policy changes** such as health and wellbeing boards, GP commissioning, new planning process in the SEN Green paper, as well as holding onto existing policy such as *Better health, better lives*.
- The **vexed question of age groups** and the age for the transition process to adulthood. People began to voice the desire to do away with transition for young people close to end of life and perhaps to consider no transition till age 25 in any case, especially where there are cognitive capacity issues. On the other hand some felt it should start at 14 as now in education. Others felt that 18 years is logical as other adult rights come at 18. Some units have to work now with more than one age limit depending on the illness and some providers are lowering from 25 to 18 due to increased demand (Acorns) and others increasing to 35 years (Martin House). Special education looks at 19 years currently for transition although the new Green paper proposes 25 years – so much confusion! Layered on this is that individuals vary widely - some 18 yr olds want to be in the adult world , others don't or have much lower cognitive age or communication disabilities. '*19-21 years feels like a key stage for growing up for all young people. A lot can happen in those years, things fall into place, hormones settle down!'*
- **Inequalities in the system**: a range of important inequalities were discussed: for example inconsistencies between requirement to pay for respite care in child, young person's and adult hospices in 3rd sector; higher prevalence/low hospice use of BME people and young people with LLC from BME communities may be more excluded socially. '*We need ethnically diverse services, seen as a white service*.' Commissioners and service planners have a duty to assess the needs of their populations and this will mean pushing them on this group that has low volume, high cost problems and needs closer scrutiny. Cognitive ability was also viewed as a huge barrier to equity, as were postcode differences: *'a mother was moving from the NE and I felt like saying don't do it, you will get much less here'*.
- Issues of **'what is palliative care/when is end of life care required for young people?** This discussion recurred in the events and people learnt a lot about the very different approaches in children's and adult services. Palliative means symptom control to some, but to some it means end of life. Hospices mean dying to some people and staff cannot make assumptions about what the young person/family understands about death/hospices etc. This discussion was full of questions:
    - how do we address talking about death, given the frequent resistance and the lack of preparation for death?
    - who knows about the death/dying? - parents, the young person, siblings….?
    - what do adult specialist palliative care teams (with tons of specialist palliative care expertise) who work predominantly with older adults, need to work confidently with young people facing death? Who is best placed to offer this?
    - what does 'palliative care' mean today? Services have a different understanding/interpretation

- What psychological support is being offered for young people to think about their condition and the outcome?
- How can advanced directives/advance care planning be part of this work? Could long term plans, updated as the young person grows up, life circumstances change, focus on shorter term goals/plans as EOL draws nearer? Could this be used to avoid the need for adult services assessment when young person reaches 18?
- How are staff supported? They get involved with the young person as they develop and 'this makes death a hard thing, a shock even for paediatric staff, hospice staff, let alone the adult staff'.

The wealth of material from practitioners is immense and the DVD attached to the report adds the immediacy of their comments to camera. A further annex 'stories from the frontline' is included (Annex M) that contains illuminating stories from practitioners that the PSW team feels deserve a wider audience.

Summary points

Transition is a shock for professionals too.

- They still **live in silos**, locked into separate and differing assumptions, structurally separated systems that are Children's and Adult services and that operate different protocols (for example, in pain relief)
- They **aspire to networks & better partnership**
- They have **few means of sharing insights into each other's work** and culture and find it difficult to identify and adopt good practice
- They **struggle to operate transition planning procedures** across agencies and try to **'work around' the dysfunctional systems** that confront young people and families
- They recognize the severity of problem – especially in current pressures – and **ALL said that the young people must be put at the centre of the transition process in a person-centred approach.**
- They also noted **a lack of skills** for practice and the communication approaches to do this and would appreciate **more innovative tools** to help with this
- They could offer **no clarity on the necessary cross-system strategic leadership**: neither for clinical responsibility and quality of care, nor for the organizational challenge of the 'key worker' approach, nor for the impetus to create the more flexible networks they felt were crucial to better care and better transition

Institutional stakeholders: 'a danger that 'transition' becomes another neat category, a box to be ticked'

Two rounds of interviews were carried out. In the first round, key stakeholders at national level were contacted to discuss in broad terms the issues raised by the project. All those spoken to had significant experience in the field either in children's or adult palliative care or in related policy areas. Interviewees had backgrounds in the statutory

and voluntary sectors as well as in research. A second round of interviews followed up on contacts suggested by people in the first round, especially those who could add specific knowledge or information about good practice. A list of all interviewees is included as Annex A.

In our constrained timescale, it proved difficult to get any sort of input from education. We spoke to two directors of children's services, neither of whom were able to point us in the direction of education people who could help with the evidence gathering. We also spoke to a senior official at the DfE, who provided us with a contact but have had no response from that person to our invitation to speak. This gap in the interview schedule is frustrating for us, as education has a key role in how things are currently organised. The received wisdom is that working towards 'transition' should start at age 14, and that the school should take the lead in identifying what should happen, with an annual review for each child summarising how things are and indicating future milestones to work towards. In practice, one interviewee told us, the focus is on educational needs to the exclusion of other aspects. But we have been unable to pursue this or other issues further.

Interviews aimed to cover not only the experience of that person/organisation in this field and their thoughts on involving young people but also:

- Their view of the **(policy) landscape** for this group of young people and related policy areas
- Their understanding of **strengths/needs in this group** currently
- Their sense of the '**map' of current services**, what's working and any clear gaps from their perspective. Any knowledge of digital media use?
- Their view of the **worst aspects of the status quo** – for young people, carers/families, and other stakeholders (including providers of services).
- Their view of the feasibility and use of developing a **'user taxonomy'**; how do they group users and carers/families in relation to the target young people?
- Their thoughts on developing **ways to help support** young people in managing their transition.
- Their thoughts on **MCCC's position** in the field and potential to offer resources to this group.

Findings from interview topics

The landscape

All were clear that the policy landscape had shifted to put the transition issue within children's palliative care at the top of current agendas. The DH project and related investment money had raised its profile and was ensuring that needs analysis and research into mapping and developing services had got a boost. However, both policy people and those speaking from provider organisations agreed that the not uncommon split between policy and practice is particularly acute when it comes to the situation facing this group of young people as they move into adulthood. A children's hospice worker expressed frustration at a rather scattergun, top-down approach that means *'people on the ground have to try to link it all up'*; while an experienced policy person commented:

> *'There is a disconnect between health and social care, a disconnect on acute and community [*which leads to*] multiple assessments, multiple providers and poor coordination.'*

The complexities of linking the issues of this project to broader policy on young people with disabilities and on learning disability were also raised. This group occupies a crowded space on the margins of many interests and professions.

A senior figure in the world of children's hospices commented:

> *'There's a danger that 'transition' becomes another neat category – a box to be ticked, rather than what it is – a huge challenge to a wide range of care providers. Young people in transition represent a small (though growing) number of people but the impact is huge as are the resource implications.*
>
> *Looking over the policy landscape, there's a real danger of duplication of effort. For example, at the national level, there's action on transition for disabled children, then there's the work being done by the Transition Partnership – and there are a whole swathe of local initiatives that don't necessarily touch the national developments at any point. Not only that, but the transition coordinators in local authorities don't necessarily play the key role that's presumably intended. And it's our experience that what work is done at the local authority level is limited to support for young people with learning difficulties. There's nothing on offer for those without cognitive impairment. So, is there really a joined-up approach?'*

Interviewees recognised a convergence between young people with complex needs and disabilities and their needs at transition into adulthood, with this smaller group of young people with life-limiting conditions. This convergence stems from the trend to a longer life and for more conditions being able to be better managed as a result of clinical advances for life-limiting conditions. Still the view tended to be that more information is needed about this cohort of young people, the breakdown between different conditions, particularly between those with cancer and those with other conditions, and how those different conditions present challenges to 'normal' transition to adulthood for young people and their families.

The desire for more information surfaced in other ways too. At least two interviewees raised what is, for some commissioners and providers at least, a perplexing question with no easy answers: who are the children and young people who might have needs in transition, where are they, and how many of them are there? A clinical lead at an adult hospice commented:

> *'There seem to be a whole group of people who are just unknown – it seems very difficult to get this kind of information from records. […] Adult hospices know a tiny proportion of people, children's hospices know a tiny proportion, schools seem to know another lot, organisations that work with disabled young people seem to know another group, and there doesn't seem to be anything that has brought those numbers together. Even within the criteria for children that have a life-limiting condition there's this huge grey area, so some hospices seem to know them, other hospices don't –where are they and what's going to happen to them in adult life? Where are their transition needs being met?'*

Because so many different agencies are involved in the care of these young people (or not involved in their care), and because they can be grouped in several different ways, there is no single point or agency where information is pooled. This makes collecting information relating to transition frustrating and time-consuming. Even when an extensive, formal needs assessment exercise was carried out[13], the commissioners were still left with questions relating to quantitative data. They were looking for an answer as to how many young people with life-limiting conditions the local hospices should be

looking after; but the research could only offer an estimate of between 40 and 400, which is therefore of limited help in planning for the future.

Strengths and needs

People recognised enormous strengths within the group of young people and their families. Young people were seen to be often highly resilient, clearly demanding more independence as they become teenagers and many with high aspirations for their lives in terms of education, friends and work, as well as to live away from home. Families were viewed as providing the bulk of care in a highly self-sacrificing way that often put huge strain on family relationships and income. A parent who leads a charity talked of:

> *'The need to combat the 'abnormality' or surreality of treatment or illness with the 'normality' or reality of everyday matters and life. Otherwise home itself can become an 'abnormal' place like a hospital.'*

Needs were viewed as highly individualised and so hard to plan for in a coherent way across agencies. There was a sense that there are few models of care to draw on for transition and in early adulthood. In different ways, both children's and adult services can stifle young people's desire for more autonomy:

> *'In children's hospices, the young people don't get to make choices, they don't get allowed to make mistakes like other kids.' (*children's hospice worker*)*

> '*With adult services, we are setting them up to fail, it's a poor quality package, we meet their health care needs but not much else. They are totally managed as a clinical case, not as a person.' (*ACT coordinator*)*

Concerns included the increasing needs of young people just at the point when services would be fewer i.e. at 18+ and this period also coinciding with the increasing strain on their parents who themselves are ageing.

Much of the concern about needs focused on clinical issues despite the importance of social issues for teenagers: '*the medical needs are immense – but it's the social aspects that give these young people most distress'* (children's hospice manager). The desire for a 'normal life' outweighs for the young people the fact of the life-limiting condition. They simply want to do what their friends do. This is arguably a strength for them.

There was considerable agreement that there is a need to develop a model of care that plays to the young people's strengths rather than just their vulnerabilities – that enables them, if possible, to fulfil their desire to live independent adult lives.

Families were seen as both a lifeline and a burden for young people moving towards adulthood. The degree of dependence on family often associated with their physical condition (even when there is other support too) can grate with the aspiration to strike it out alone or with like-minded friends. Families can be judged to be over-protective of young people, unable to bear to see them take risks. But young people too can be seen as being over-protective of their families, feeling unable to make a bid for independence where family may have sacrificed a great deal for them. One interviewee spoke of a common desire of young people to protect their family from thinking about what it's going to be like after they've gone.

> *'You'll often find young people not wanting to initiate painful conversations within their families because they're coming to terms with it in quite lonely, isolated ways because they're doing a lot of protecting other people.' (*psychotherapist*)*

In social terms, several interviewees reported that in groups of young people with life-limiting conditions, it was quite usual to find that those with no cognitive impairment would be very facilitative of those with such impairment – a huge strength to build on.

Communication was seen by interviewees as both strength and need. Many young people, who have had good support, have developed effective individual systems of communication. But, of course, even good systems depend on other people being willing to learn them; and while this happens every day in children's hospices, the staff in adult hospices are not usually geared up to the challenge.

*'We do quite a lot of communication development with people who start to lose their communication abilities later in life – for example, people who have advancing progressive degenerative neurological conditions. But they're a very different client group with a very different set of needs and also their communication needs are very short-term in relative terms and you're really trying to help people continue to communicate their main needs – whereas actually for these young people they want to communicate properly, don't they?' (*clinical lead, adult hospice*)*

*'From the staff point of view, the challenge is learning a system of communication that we're not familiar with. For example, there's one young girl who spells out every single word on a board and she's quite good with it, but she's worked up quite a complex system. If you're not familiar with it, it takes you a while to get your head round it.' (*nurse consultant*)*

There was considerable agreement that, across a wide range of physical and cognitive ability, many young people shared interest/expertise in social and digital media, and were keen to get involved or experiment further.

Sexuality was also identified as both strength and need. Several interviewees mentioned the challenge (for everyone!) of young people's emerging sexuality.

> *'A lot of these young people as they're reaching adolescence – and certainly for the people with learning disabilities, they'll be reaching that slightly later – sexuality will be coming into play as well and that's a whole new difficult challenging thing that the hospices won't necessarily be ready for and experienced at managing; all that hormonal stuff.' (*psychotherapist*)*
>
> *'When a 15 year-old boy was first diagnosed with cancer and prescribed a programme of chemo, no health care professional discussed with him the potential implications for his fertility. Staff often reported that they felt uncomfortable discussing issues of sexuality/fertility with young people.' (*social worker*)*

Sexuality, of course, includes such important issues as body image – which may lead to rejection of important pieces of equipment. A nurse described the case of an 18-year-old whose choices were not accommodated – to very distressing effect.

> *'When she was with paediatrics, she used to have morphine by infusion but as soon as she went to the adult side they said they didn't do that and their protocol was to use a syringe driver or injection. She refused, they refused to budge and she lay in pain for eight hours. They just stopped listening to her and said she was being obnoxious. Complete breakdown in the relationship. It's in part about quality of life. A lot of teenagers want a good quality of life. They see the syringe driver as* 'a machine attached to me…it's not cool…I don't look good'. *They're very conscious of their body image. Even the instructions for its use are just not appropriate for teenagers. Yet it is such an important piece of kit that could really have helped her. It*

might have helped her have more autonomy; she used to say 'if you take it away [control], I lose everything'.

Current services

Interviewees were clear that no coherent system of services exists. There is much good work in specific localities, especially where a children's hospice has joined with other agencies to work on the transition issue, or where adult and children's hospices are co-located, co-run or have developed good relationships. The manager of a children's hospice described how they had appointed a lead person on social support and were actively building on existing good relationships with an adult hospice.

'We've been exploring ways in which the palliative care element can be threaded through other activities and offers for young people in transition. What we're piloting at the moment is a phased transition where young people get to know the adult hospice and gradually become more involved with life there. After all, like all children, they have to grow up, and returning all the time to a place that is part of your childhood may not be the best thing for you. So we now have three groups, depending on age, where the youngest meet at the children's hospice, the older meet alternately at the adult and children's hospice, and the oldest meet all the time at the adult hospice. We're just at the beginning of this programme. We've had two meetings of young people at the adult hospice. We built up to the first visit carefully, as the young people weren't initially keen to go, and the staff were nervous and anxious about what seemed like very new challenges. But all went well… We've now also held a 'summer camp' at the adult hospice, where, in the summer of 2010, young people went there once a week for 4 weeks. They had fun doing things together (the hospice has very attractive community space) and also really appreciated the opportunity to get independent welfare and other practical advice.'

The key problems with the current fragmented state of services were cited as: the shock of much less provision for adults than people are used to for children; the contrast of the one-stop children's approach vs. the multiple services that adults have to grapple with; the general lack of suitable respite care for young adults; the lack of experience of adult services staff of young people and their needs; the lack of age specific services or activities within anything that is offered.

People clearly described a huge difference in culture between children's and adult services in palliative care. Although this is evolving and converging to some extent with the growth in adult services taking on non-cancer referrals, this cultural difference was seen as a barrier to the transition process on both sides of the divide.

*'Adult palliative care is so different from the children's palliative care scene as adult palliative care is focused on the last weeks of life only'. (*manager of hospice*)*

*'We're not equipped or resourced to engage with young people who may have very high expectations of extended support to make the most of their lives, physically, psychologically and socially.' (*medical director, adult hospice*)*

As more begins to be understood about what make a good transition for different young people, there needs to be a parallel process of thinking about how to help parents and families make their own transition.

'It's fascinating when you meet the parents when the young people come here or we see them at the children's hospice that sometimes they haven't met each other before so haven't had a chance to talk. At our first event here, a group of parents went to the pub in the evening when their young people were here and had a good time. In

*some ways, you're not just helping those young people grow up and socialise, you're helping those parents separate and socialise too.' (*clinical lead, adult hospice*)*

*'Circumstances within the family can change drastically, there are so many different factors involved, and that's why the transition process should be for both of them, for both parties.' (*nurse consultant, adult hospice*)*

One interviewee, a psychotherapist, raised the difficult and complex issue of attitudes towards learning disability within mainstream adult services.

'I think there's also still a kind of disdain actually, which is unspoken, about learning disability and whether we should be prolonging these lives; I think that's hidden in there probably and it's very painful for people to recognise that feeling in themselves and therefore to express it. I think that's really difficult stuff to talk about and to bring out into the open but the 'Death by Indifference' campaign' helps us to bring it out in the open, so I think that's worth thinking about. It gives a starting point for raising the issues.'

Arguably, this particular group of young people are grappling with multiple taboos in trying to live their lives: taboos of death, of untimely death in the young and of learning disability.

Worst aspects

All the issues mentioned above were seen as the worst aspect by someone! In addition, problems of transport, family breakdown and of multiple affected young people within one family were raised. The complexities of commissioning and finding relevant care in the absence of clear models of care was also a concern as *'resources are wasted on arguing where people should go'* (children's hospice worker). The overall lack of multi-agency or multi-professional working around transition for these young people was also cited as a huge gap at all levels, but especially in localities.

User taxonomy

Various approaches to this were uncovered. These range from the complex 4 part distinction used by ACT (currently under review) to the simple 'cancer and not cancer' distinction that some people found most helpful. Others felt that age groupings were more meaningful e.g. under 16, 16-18 18+. Others felt that life and decision points were more meaningful e.g. leaving full time education: '*big problems come when young people leave education. They lose all their social networks as well as so much else'* (children's hospice worker). This is the point where if college or university are not options there is no regular activity outside the home. Other life changing points would be; leaving home; making their own decisions about care/self management; forming a partnership. Coupled with definitional problems and the important issue of a commonality of needs that will be discussed in the desk research section, it is not clear whether developing a taxonomy for this group is required and how best to do it, if it is felt necessary.

Ways to help support young people in transition

People focused on the importance of enabling young people's voice and choices in transition. However, this was often about influencing existing services and traditional models such as respite care – increasingly unsustainable and not feasible within adult services. The interviews reflect the overriding gap in the material we identified in the desk research too i.e. that ideas for change are mediated through adults' eyes and filters. For example, innovative ideas for online support by some organisations have fallen down at the first hurdle since adults have felt it important to moderate and control the

content of sites for the protection of vulnerable young people. Young people themselves in any case have preferred to set up their own social media options like their well peers do, and for those over 18 enabling this self-led support may be what is required to combat the sense gained from several interviewees of a paternalistic approach: '*in children's hospices they don't get to make choices, they don't get allowed to make mistakes like other kids'* (children's hospice worker).

Many interviewees were strongly motivated to try to identify/shape a model of care that focused on empowering young people as they grow into adulthood. The point was made by the clinical lead of an adult hospice that innovation needs to be based on careful investigation and testing of ideas; that it is only too easy to be carried away by enthusiasm and untested assumptions:

> *'If our work in this area only keeps asking hospices, for example, to keep thinking about transition all we do is keep recycling what we've always done and there are enough examples of where it has gone wrong or never taken off that we should really look hard at. For instance, in some hospices, real money's been invested, facilities have been amended and it just wasn't right. I'm really pleased about this piece of research because it sounds like it's starting with a much broader perspective. And the truth is that hospices may have only a tiny role to play.'*

From a variety of backgrounds, including social work, interviewees identified the need to enable young people, where possible, to grow up and live independently of their parents, having access to specialist care when they need it but not living as 'full-time patients'.

> *'There's a very subtle shift from what we have traditionally provided. We're really a whole variety of services that the young people can pick and mix from and engage with as they wish and stay connected with – but live their lives quite separately. I think we, as a hospice, are discovering that there's a whole group of people who need to live like that alongside us, not become our patients and have to be sick and be cared for. This may go on for maybe many years; then, as they deteriorate or as they come to the end of their lives, they may need to become our patients in the way that we've known people historically. But for a length of time, maybe for a decade, they could live quite independently just accessing us in terms of information, advice, practical help.' (*clinical lead, adult hospice*)*

There was considerable agreement among interviewees that if young people in transition are to be supported in an appropriate way, measures need to be taken to tackle the gap between the ethos of children's and adult services, including hospices. Structural change was suggested – such as the introduction of properly resourced key workers. Cultural change was seen as equally important – in the cross-professional development of staff from different services, for example, where learning disability professionals get insights into the nature of generic palliative care and palliative care specialists develop their skills in communicating with a wide range of people.

Marie Curie Cancer Care's position

Overall people welcomed Marie Curie's involvement in this work '*as a clearly adult focused organisation'* (national organisation). This was seen as helpful in crossing the adult/child divide.

External parties' enthusiasm for the involvement of MCCC in this area of work has to be balanced against at least some internal reservations.

*'We need to be sure that we're scoping things correctly – asking the right questions. There are issues of equity to consider and also very practical considerations relating to pressure on Marie Curie services. There is a risk that we may be carried along on a tide of assumptions about what is 'the right thing to do'. In particular, we have to be able to think about different groups of people who might be considered in need of palliative care, and be confident that the decisions we make about far from endless resources are grounded in a clear understanding of the purpose and mission of our different services. […] At Marie Curie, our role is to address complex needs associated with a terminal diagnosis and to support people at the end of life. We're not equipped or resourced to engage with young people who may have very high expectations of extended support to make the most of their lives, physically, psychologically and socially. Providing respite care for this group of people, for example, could have significant implications for our ability to look after other people who have more clearly defined needs for palliative care' (*medical director, Marie Curie hospice*)*

Summary points

A fragmented patchwork of services offers no consistent support for these young people, nor the opportunity to have their voices heard and responded to.

There is no clear model of care underpinning services and a range of statutory requirements that obstruct the provision of seamless care

For there to be sustainable improvement in the situation of these young people, three parallel transitions have to take place – for the young people themselves, their family, and the professionals who care for them. Promising innovative work is being undertaken with this end in view, and this needs to be evaluated and learned from.

There is a surprising lack of capacity to comment from senior people we would have expected to have a view.

Research & policy

The needs of children and young people with life limiting conditions, prior to, during and after transition to the adult stage of life course has received welcome attention and policy interest in recent years further to the publication of the *Craft/Killen Report* on children's palliative care in 2007[14], the Department of Health's *Better Care, Better Lives* Strategy[15] focusing on children with life-limiting and life-threatening conditions and their families and the Department of Health's *End of Life Care Strategy* [16] for adults, both in 2008. These documents provide a framework for the way adult and children's services are viewed in England[17] and are the key reference points for exploring and making sense of the evidence gathered in this project. Similarly the ACT *Transition Care Pathway* (2007) [18] provides important architecture for exploring a number of the issues which have arisen in the evidence gathering phase of this project. In the context provided by these key documents, we have attempted to take account of the growing evidence base on transition for teenagers with complex needs, including current research activity in this area which has been stimulated by the significant investment in children's end-of-life care and transition issues in particular by the Department of Health in support of the new policy framework.

This section of the report provides a high level summary of the six themes arising from our selective desk research (as described in section 2) and how we made use of these in our work.

Six identified themes

1 Engagement and voice of young people

Overall, the material reviewed is very clinical in its focus and approach with some important exceptions. The literature consistently identifies a lack of awareness of the needs and difficulties of young people with life-limiting conditions as seriously lacking in all sectors and within and between organisations and sectors. Whilst the need for communication with and empowerment of young people with life limiting conditions is heavily emphasised in all the literature and supported by policy and is clearly seen as key component of good practice, the voices of children and young people with life-limiting conditions are seldom directly represented in the literature. By and large, others speak for them, including staff, parents and carers and the clinical and academic communities. This finding emphasises the importance of this project which aims to address this gap and suggests that different kinds of evidence gathering is required including further, more detailed searches of the 'blogosphere', social networking sites and NGO websites, where initial explorations suggest there may be a rich pool of material to be unearthed (see also earlier section on young people).

Work by CHAS[19] to give voice to young people emphasises the importance of age appropriate activities (one 18 year old was unable to watch a 15 rated movie) for this group and how many young people made important relationships with staff (trust, flexibility and more comfortable to talk to) yet at the same time, a range of research suggests that staff (and families) struggle to accommodate the wishes and preferences of the young people themselves. This may be reflected in the plethora of tools and approaches to person centred-planning that have been and are being developed.[20]

Young people's involvement in the transition process however emerges as marginal (as at times, does that of parents). Heslop et al.'s survey (2002) [21] for example found that in 250 families, only four out of ten young people had any involvement in the transition planning process with a quarter having no involvement. Dee and Byers (2003)[22] have highlighted the ways in which young people without speech are particularly vulnerable to exclusion from the planning process. In addition, in planning for a young person's future, transition services do not pay attention to the things that are most important to young people such as friendship, social and emotional independence and leisure. (Heslop et al. 2002[23]; Morris 1999 [24]).

Overall, both staff and families appear to struggle with the issue of autonomy in a context in which 'normal' developmental tasks may not be achieved chronologically or where they may not be achievable. This is perhaps understandable given the extreme vulnerabilities presented, yet other evidence suggests that there is, nonetheless, a developmental trajectory for these young people, which needs to be accommodated in transition planning. Risk–taking behaviours, for example, are just as or more likely with young people with chronic conditions as with others (Sawyer et al 2007) [25] with potential adverse health outcomes. The CHAS work and other work cited in the earlier section on young people's views highlights the unique needs of life limited young adults as they struggle with the natural desires and aspirations of adolescence and young adulthood and the impact of their conditions. Both general and localised studies find that many young people have a desire to live independently whilst some are becoming more dependent as their condition deteriorates. Sawyer et al comment on the differing views of the same young person offered by doctors, parents and the young people themselves, for example young people tend to report differently from their parents in relation to mental health or behavioural issues, and from doctors in relation to physical

issues. Clearly an appropriate balance between protection and empowerment is a difficult one to achieve and maintain in the transition process.

The social aspects of growing up are a key area for further research for young people with life-limiting conditions and crucial for understanding the timing and nature of any support offered. Tackling inequities is a key theme of the government policy paper *Better Care, Better Lives* which it links to the need for local areas to have autonomy on local funding priorities, for example, how services are configured and delivered. The York Centre reports families often take on the burden of the care, suffer economic hardship, and cannot seek financial advice. Craft and Killen found families have become pressured, as they are often unsupported which leads to more costs being picked up by the state. Work reported by CHAS shows the importance of respite care (relieving family) as many young people saw themselves as burdening their family. Heslop et al and others paint a depressing picture of the experience of leaving school as a time of loneliness, disorientation, minimal contact with peers and critically, with limited opportunities to enjoy meaningful activities or to develop further skills and abilities, pre-determining future exclusion and economic and emotional dependence on family and services. Beresford comments 'that the process of transition … is more complex, extremely problematic and in many cases highly unsatisfactory'. (Beresford 2004). [26]

At the same time a growing evidence base (summarised in Sawyer, 2007) is emerging about the value of a range of support systems in promoting the development of robust identities promoting self management and modifying the impacts of poor health behaviours in this group. These supports include peer to peer support; community based support and technologically mediated methods which, it is suggested, 'seem especially promising for adolescents without the constraints of geography'. (Sawyer et al, p1487)

Young people need to know their rights and their desire for independence should be supported. Good practice guidance from ACT and CHAS focuses on communication: the young person needs to be listened to and his/her needs and wishes need to be taken into account at the planning process. The ACT transition pathway encapsulates this approach. This is especially important for young people with challenges to verbal communication who are particularly vulnerable at times of transition.

2 Complexity of cohort

There is a shortage of age-specific epidemiological data in this area, limiting more focused policy and planning considerations for adolescents with chronic diseases. As Sawyer et al (2007. pp 1481) point out, many surveys and reports of chronic diseases fail to recognise adolescence as a developmental stage by grouping adolescents with children (0-14) or with adults (15-34) and when adolescence is recognised, the choice of upper and lower age limits is variable.

The range of conditions in this group of young people, their complex incidence and challenges to diagnosis and prognosis make assessing the cohort and identifying needs in the traditional way a major challenge for any service. This is especially so for adult services for whom this cohort, however measured/identified, will always be a tiny fraction of demand for their services, whether palliative care or ongoing clinical care or family respite. The York Centre reports wide variation in the definitions of children with disabilities, with complex needs, and requiring palliative care and so major problems identifying these children, assessing needs and calculating the numbers needing services (there is a paucity of databases/consistent sources of data). The Craft and Killen report found there is an overlap between those with disabilities and complex

health needs and those requiring palliative care. Conversations with clinicians reveal very wide variations in data collection, coding and sharing practices at local level, with responsibilities split between community and hospital paediatricians, schools and education authorities, children's services more generally, adult social care and primary care. A small sample of Joint Strategic Needs Assessments examined for this project failed to mention this group giving rise to concerns that the needs of this group are not being addressed by JSNA processes, possibly because the numbers involved are relatively small at local level but also, arguably, because the complexity of the task of data extraction combined with lack of awareness more generally means that the issue does not 'compete' successfully with other priorities, suggesting a national focus may be more fruitful.

This may, also be influenced by the fact that, little work has been done to 'bring attention to what is common in young people's journey through adolescence with different chronic conditions, by contrast with the many disease-driven divisions that characterise much current practice, policy, and research' [27]. This failure to search for common ground means a lack of understanding of the common challenges for adolescents, parents, and clinicians—and a failure to find efficiencies of scale in systems and supports beyond traditional clinical groupings. Sawyer et al comment that 'experience from peer support groups emphasises the extent to which many problems and issues are shared by young people with different chronic diseases'.[28] Important ethnographic work by Professor Bluebond-Langner on cancer and cystic fibrosis comparing the USA and the UK has also concluded there are common trajectories and psychodynamics in the illness journey for young people and their families which point to the need for integrated service approaches and an understanding of the complexity of the lived experience of these families[29]. She comments:

> *'no parent [*in her studies*] ever initiated the discontinuing of any care or treatment directed at symptoms or at the disease, nor to stop contact with the [*consultant*] and they continued with any suggested investigative process ... because at bottom they wanted only one thing – more time with their child. They will always keep trying and asking for more... so we need to integrate disease-directed, symptom-directed and supportive care throughout [*the disease process*]'*[30]

Other research points to the limits of disease or condition based definitions in recognising co-morbidities including mental illness (Public Heath Group: Victoria Aus. 2001 & Australian Inst. Health & Welfare 2003)[31]. More recently attention has shifted to the development of generic or non categorical approaches to defining the cohort. These approaches recognise the commonalties of the lived experiences of young people with different conditions, with many of the consequences being independent of the condition or disorder. Stein and colleagues (1992) [32] proposed a framework based on the three concepts, all of which must co-exist - see Box 2 below. However, given the fragmentation of current systems and mechanisms for collecting and sharing data in the UK, it is clear that embedding such an approach would be challenging .

Comprehensive, system-based models of service provision, capable of addressing this complexity, have shown value in improving outcomes (Wagner 2001).[33] The NCCSDO study[34] stresses a need to acknowledge the individual specific needs of child and parents when thinking about service provision. Continuity of care at transition needs to acknowledge the unique needs of young people within the context of their psychosocial development.

Box 2 Definition of generic or non-categorical chronic health conditions

Chronic health conditions are defined as disorders that:

- **have a biological, psychological or cognitive basis**
- **have lasted or are expected to last at least 1 year**
- **produce one or more of the following sequelae**

a) Limitation of function, activities or social role in comparison with healthy peers in the general area of physical, cognitive, emotional and social growth and development

b) Dependency on one of the following to compensate for or to minimise limitation of function, activities or social role

- ✓ **Medications**
- ✓ **Special diet**
- ✓ **Medical technology**
- ✓ **Assistive device**
- ✓ **Personal assistance**

c) Need for medical care or related services, psychological services or educational services over and above the usual for the child's age, or for special, ongoing treatment interventions or accommodations at home or school

At the same time, young people are surviving into adulthood in increasing numbers with conditions that would have brought an early death even a few years ago; such is the advance in managing their conditions. This raises key problems of the lack of experience of staff in adult services in working with these clinical conditions, and the challenge for YP and families of their clinical needs tending to increase as they get older, yet the offer from adult services is less than from children's services. Additionally, the ethos of adult's services is completely different to that of children's services. Simply put; children's services in recent policy (*Every Child Matters*, now archived from government websites) aimed to address the needs of children holistically, locating individuals in their familial, social and economic contexts. The extent to which this is effective is clearly open to debate. However, adult services focus on the individual alone – or in users' experience often on their conditions or separate bodily systems. Whilst the Coalition Government will shortly issue new children's policy which may or may not introduce a radical break with the past, it is likely that in adults' services, the individualised approach will be sustained as the personalisation agenda and direct payments become the norm increasingly.

3 Policy and Practice Gap

There is overall a dearth of analysis in relation to the gaps between evidence, policy and practice in this area (the translational gap), very little exploration of the visible and invisible barriers and resistances which undermine transition policy in this and other areas or therefore there may be learning from considering what, if anything, may be generalisable to this area from other areas, where there has been strategic effort to improve the dissemination of evidence resulting in sustained innovations in practice and service delivery, for example in earlier pioneering work in relation to HIV/AIDS and personality disorder. For HIV/AIDS, the clinical challenge was to deal with complexity and a dynamic health condition affecting a series of fragmented patient groups and the organizational challenge was to create workable local networks of support. This work also took on multiple taboo areas successfully and arguably presaged what is now termed co-design with patients and users. Personality disorder, on the other hand, was a

national programme that involved service users in framing and deciding on a series of funding projects to change their experience as socially excluded individuals.

4 Fragmented Good Practice

Whilst it is clear that there is significant good practice is taking place at local and organisational levels, overall the picture that emerges suggests that this is taking place in a fragmented and piecemeal way, frequently driven by the passion and commitment of individual professionals or groups of parents, some of whom are creating possibilities for young people themselves to take a leading role. It is clear that the process of transition for young people in this group is still extremely problematic in spite of the enabling policy context. This raises the interesting dilemma of how possible and feasible it may be to 'scale up' good practice in a context such as this, where so much depends on personal experiences and commitment and where needs and resources are so very varied. The current climate of severe retrenchment in public services across the board will undoubtedly have an impact on how policy is implemented in the future. The concept of 'Big Society' may well provide both threats and opportunities, but there is, as yet, no evidence either way.

5 Challenges of coherent provision

Many of the challenges of creating integrated service provision to support the whole pathway of children and young people with life limiting condition arise from the advances in medical and other technologies that enable longer lives. The burden of chronic conditions in adolescents is growing and improvements in survival typify many conditions previously thought fatal.

Under-provision and concerns about large unmet need underpinned much work reviewed. For example a study in NE London[35] found differential impact and outcomes for young people according to what services they were able to access. Children who have grown up being looked after by community nurses have a bleak future. This is due to nurse visits becoming less common and procedures being needed that that the district nurse is unfamiliar with. Young people with conditions allied to adult services did better (for example, patients with muscular dystrophy can be seen at the local Neurology department), while young people with neurodegenerative disorders can less easily be classified. Young people who were socialised at school found themselves often on their own (no respite care). This work also found that young people who were doing better had moved to adult services; those doing worse had stayed with younger groups, suggesting that a developmental approach is important in raising outcomes.

The government's *Better Care, Better Lives* paper emphasises the importance of more integration across services and agencies, for example improving data sources, building stronger joint working relationships and developing better needs assessment and support regimes. At the same it argues for encouraging delivery of care in the best setting for the patient. The York Centre reports that many studies have shown failures of services for families and that services are inequitable in distribution and variable in quality. Levels of funding from PCTs have up to 10 fold variability. All this was further endorsed in 2010 by the Palliative Care Funding Review's interim report which calls for more explicit planning and cross agency work, as did the Craft and Killen independent report in 2007

Forbes et al.'s (2002) [36] multi method review looked systematically at evidence relating to promoting continuity in transition from child to adult care for young people with one of five tracer conditions (diabetes, learning disability, cystic fibrosis, congenital heart disease and muscular dystrophy) and also sought to identify good practice by means of

surveys and interviews with key stakeholders. Certain aspects of service structure and the process of service delivery were found to support continuity in the transition from child to adult services. The need for specialist services and skilled staff was identified, as was the need for multi disciplinary and multi agency working. In relation to service delivery, a range of factors was found to promote continuity including adequate preparation, active case management shared across agencies, strong therapeutic relationships between practitioners, the young person and their family and independent advocates. Further research reinforces these conclusions with specialist multi-disciplinary provision achieving better outcomes than mainstream health service provision (and no less costly) (Bent et al, 2002, Norah Fry Research Centre [37] ; Heslop et al, 2002 [38]; Ward et al. 2003 [39]) The DH review of statistics comments that for inpatient care costs of children and young people with life-limiting conditions amounts to one third of total costs for the group[40].

The question of specialism raises important definitional questions that are not resolved by current literature and may be interpreted differently in practice. This requires further investigation, if, as discussed above, good practice is still not happening at scale. There may be a need to support commissioners in coming to a firmer view about what various components of a pathway approach might be, including the specialist input required.

One of the difficulties stems from the broad scope of paediatric services, including palliative care services where early referral in the course of a life limiting or life threatening condition is the norm. Consequently those in transition to adult services 'have a diversity of diagnoses, disease groups and disease trajectories' (Craig, F et al 2011) [41]. Whilst some individuals graduating from children's services may experience a more seamless pathway, many do not. There is a lack of fit between specialist paediatric services and adult care services in many instances, including in palliative care which are generally focused on adults with more advanced progressive illness. In 2003, the Task force on the Management of Grown up Congenital Heart Disease identified that 'the new population of patients with CHD no longer fits within traditional divisions of training and practice' (cited in Craig, F 2011) and emphasised the need to integrate adult's and children's cardiac services in order to provide smooth transition. While there is some evidence of models for integrating some disease specific services, this does not exist for all conditions and such attempts may perpetuate current problems by failing to address commonalties!

6 Workforce Capability

Since there is a lack of clarity about the service models which may be required locally and regionally to address the range of needs amongst this diverse group of young people there is as a consequence a lack of precision in specifying the workforce capability issues, including values and behaviour as well as skills and knowledge, which are central to good practice. Professor Bluebond-Langner comments: '*The need for services has outpaced workforce capacity'* [42].

The literature is also clear that there is a skills and awareness deficit about the needs of children and young people with life-limiting conditions and that this impacts on the whole pathway, including at transition. Asprey and Nash (2006) [43] for example describe how poor communication between school and home and between heath and education is a central concern and indicate that there is a tendency on the part of mainstream services to underestimate the needs of the young people, particularly if their condition is less 'visible'. This, it is suggested undermines transition planning as well as day to day support.

The End of Life Care Strategy identifies a range of key competencies for specialist and mainstream staff working with people approaching the ends of their lives. It would be useful to develop an understanding of the ways in which the workforce dimensions of the EOLC Strategy have been implemented, to gain a better understanding of what has worked and to consider the application to work with children and young people.

It is evident however that irrespective of the model of service, there is a very challenging workforce development agenda in this area. The following material from a paediatric palliative care consultant received during this work identifies the range of capabilities that may be required in a comprehensive palliative care system

- **Generic**: skills and competencies essential for good palliative care in children that are expected from anyone trained in the care of children.
- **Specialist**: those skills that are expected from professionals who make palliative care in children their main area of training.
- **Semi specialist skills**: skills that are more than would be expected from most professionals trained in the care of children, but are not restricted to paediatric palliative care.[44]

These ideas may helpfully be generalised to all services for children and young people with life-limiting conditions.

How we used what emerged

The themes above produced three main pointers for our work on phase 1:

1. they **confirmed some assumptions** that had been made in framing our work: for example, the importance of aiming to amplify the voices of young people themselves, the complexity of identifying the cohort of young people and the very different landscapes of adult services and children's services
2. they helped **focus our conversations** with key stakeholders in testing how far they thought the cultural and planning divides between agencies and services could be bridged, and in thinking about what support might be welcomed by young people
3. they gave us a **framework for analysing material** both from interviews and from engagement events with young people and with professionals and families

However they also pointed to **gaps** in robust information in a number of areas including:

- The direct voices of young people with life limiting conditions in defining their own needs and preferences and in evaluating the impact of interventions
- Robust definitions to support integrated service planning
- Epidemiological data about incidence of conditions, presented in a usable format to local service commissioners and providers, possibly through the JSNA
- Commonalities in the need for support across conditions and how these may vary across the pathway

- The components of a comprehensive system to support these pathways including definitions of specialist and non-specialist services for teenagers and young adults

- The capabilities and competencies required in the multi disciplinary, specialist and non specialist workforce required to develop and deliver a comprehensive service.

Summary points

Notwithstanding the many instances of good practice taking place at local level and the positive policy context, much more needs to be done to achieve a step-change in transforming the outcomes for young people with life limiting conditions at and after transition.

There are few clear models for re-working services and transition processes to produce better results of young people's lives and commissioners are hampered by the lack of detailed information about this group as well as the inherent complexity of its needs.

Addressing the gaps identified above set a challenging action agenda for governmental and non–governmental bodies and may provide a focus for Marie Curie in Phase 2 of this project.

Section 4: Discussion & key learning

Section 3 and the related annexes demonstrate the breadth and richness of the evidence gathered, even in such a short project period. While much more could be done in terms of further research, in particular on the numbers and costs involved in supporting this group of young people, nonetheless there are very clear messages and learning in this work as it stands. This section summarises these and discusses their implications.

We started from a conundrum that is a classic puzzle in public policy (shown in Figure 2): why do desired changes not happen, even in a supportive policy context. This section attempts to explain this for this particular situation and so to help shape the recommendations for action in the final section.

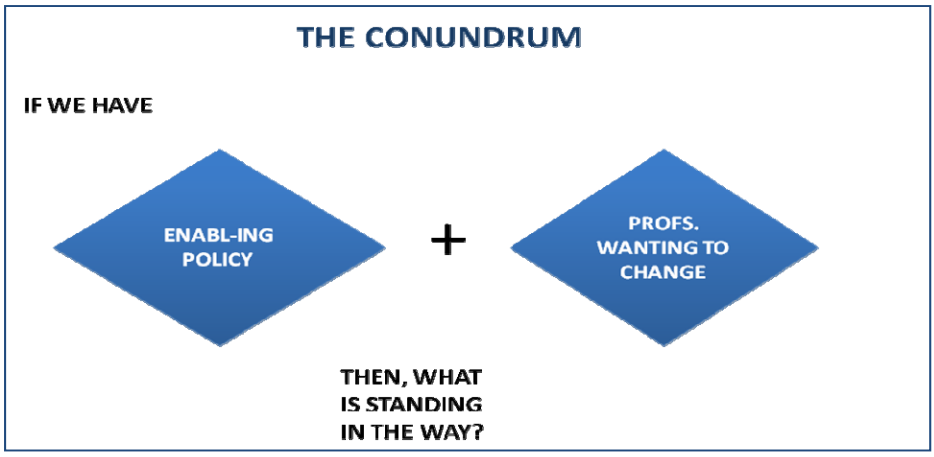


Figure 2: A conundrum of policy and practice...

Triple trouble...

We can sum up much of what we found as contained in *three sets of triple challenges* described below.

1 Three transitions

Transition is invariably discussed in the singular, whereas it is clear that (at least) three transitions are involved

- Young person to adult
- Parent/carer to carer of an adult...
- Service transition where professionals either must 'let go' or take on the unknown

There are probably more e.g. the shift for siblings in the family at this time which we are not addressing. The emphasis and indeed the term 'transition', compared to say 'reaching adulthood' or 'growing up' privileges the shift between children's and adult services for the young person over their own transition at this time. They themselves are undergoing a completely different kind of transition i.e. the psychosocial, identity and physical changes that are part of moving into adulthood. This is complex and challenging for those around them for teenagers in general, but for these teenagers there are special additional issues: they may be increasingly unwell and find they cannot keep up activities they value; they may be cognitively impaired and have a marginal voice in any decisions; they may have communication disabilities which contribute to their

marginalisation despite their mental capacities. They may be surrounded by adult carers and have little contact with peers.

Significantly too, this is a very painful transition for many parents: not only are they struggling to cope when services 'just stop' after 18 years, but they are having to come to terms with shifting roles as parent from the focused caring and nurturing of their ill child to supporting, enabling and caring for an adult, whose parent they happen to be. The tensions and stress in this shift are evident and of course heightened by the diagnosis and prognosis of their young person. Since '*parents have a pivotal role in setting the interactional context*'[45], their successful transition in turn hugely affects the young person's transition.

2 Three challenges for families

For many families the transition experience comes at the worst possible moment. This presents them with a 'perfect storm' of the most painful challenges:

- Many young people die at or just after transition i.e. in their early 20s – we heard many stories of this in the evidence gathering. This may mean that the transition difficulties presented in the evidence get in the way of proper attention to their condition deteriorating and the required palliative care input. Equally this is absolutely the worst time in terms of quality of care for such major changes in service offer and clinical responsibility to be made. It is hardly surprising that practitioners in children's services resist the shift and that many children's providers have begun to create specific young people's services within their organisations.
- So services 'just stop' exactly when they are needed most and add pressure to parents especially, who currently are the only system integrators. The struggle to keep needed services and to meet increased needs occurs often therefore at a time of crisis in terms of the young person's wellness.
- In addition, when young people are turning 18 and beyond, is a time when parents are themselves getting older ... The cumulative strain of their years of caring for the child and now young person is substantial. What is more, the pain of seeing approaching death for their child just at the stage when they are growing up into an adult can be overwhelming.

3 Triple challenge in the current context

Both of the above triple challenges are now taking place against a backdrop of a third set of challenges which are likely to make the whole problematic of transition very much worse for everyone involved.

- *Increased demand*: although figures are hard to come by, it is clear that the demand from this group is increasing i.e. more young people are living longer with a whole range of previously childhood conditions; medical advances are increasing the number of recognised conditions, diagnoses and treatments; conditions are becoming 'managed' and more like long term conditions in character. All of this produces more demand for care, facilities, treatment and carer support.
- *Cuts to services/budgets:* practitioners agree that the current climate in the public finances will mean not only fewer services – especially critical elements often

provided by the voluntary sector such as short breaks, daycare and transport. Local government is already reducing such services dramatically as well as raising thresholds for access to adult social care. In addition across health and social care the pressures will create a negative impact on workforce capacity through holding vacancies, reductions in staffing and severe cuts to training. Lower workforce capacity will especially affect joint working and genuine partnership, since people will be pressed for time, covering more work and tempted to remain in their 'silos'...

- *Major NHS changes:* through the move to GP commissioning and the resulting changes to the provider world, not only will there be disruption for staff making it hard to create smooth transition, but the organisational changes are likely to drive adult and children's service further apart as like services merge to achieve economies of scale.

Critical questions...

These sets of challenges raise a series of critical questions, summed up in Figure 3. The overriding concern is to respond to the question: ***what in this context could make things demonstrably better for young people and their families?***

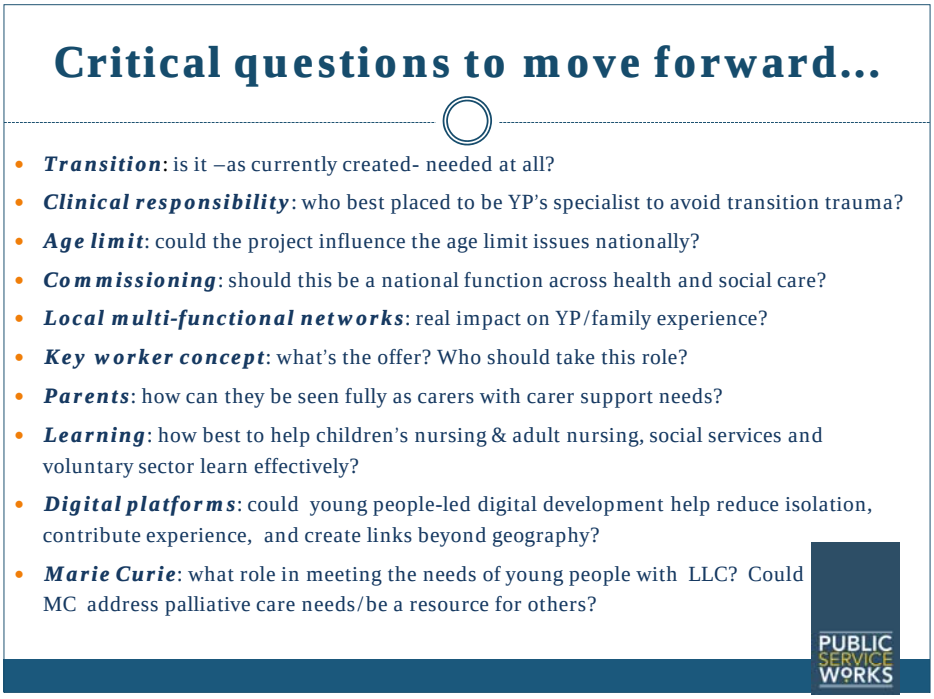


Figure 3: Critical questions to move forward

The most fundamental question we arrived at asks: ***is transition as currently created needed at all?*** With specialist units moving towards caring for people till the age of 25 or even 35 years, with the universally awful experience of young people and families of the transition process, how can it be justified? Is there any evidence that it produces better quality of life? In whose interests is 'transition' as it is currently carried out in relation to health and care services? What would a humane society do?

Linked to this is the potent ***concern with clinical responsibility and quality of care***. Who is best placed to be young people's clinical lead or specialist? What are the clinical governance issues in disrupting established specialist care and handing this to a series of

non-specialists? How can a lead paediatrician for example continue to lead but to bring in adult specialities too? What protocols might enable this?

Age limits and the age for transition are vexed issues: most argue that education-linked transition should start early, typically at 14 years, and focus on aspirations and life-path. What does this mean for young people not at school due to health issues? How can education transition co-exist with healthcare continuing within children's services? Could the age limit issues be resolved nationally to encompass those up to 25years as proposed in the Green Paper on special education?

How can a ***more creative approach to commissioning*** both influence services and enable continuing care of the right quality for this small but high-cost group? Should this be a national function within the new national commissioning board? How could it achieve a joint budget across health and social care to avoid the trade-offs and inflexibilities in current arrangements? How can the direct payments and personalised budgets that many value be extended to health care without losing flexibility?

Local support systems are vital for young people and families, so could ***multi-functional networks*** based on sensible areas make a real impact on their experience? Could such networks bring together support across the medical and social model divide to help young people (and their parents) achieve more of a 'normal life'? How might ideas for a key worker fit with these? Who should take this role?

While the focus on the needs of young people is vital, the evidence makes clear the pivotal role of parents and the stresses on them. Without them, young people would be lost and services totally overwhelmed. How can they be ***seen fully as carers*** with carer support needs? How can their unique perspective as parents be enabled to grow into supporting the young adult's autonomy?

Learning and staff development have been prioritised strongly throughout the evidence: so how best to help children's nursing & adult nursing, social services and voluntary sector learn effectively and together across the professional divides? How can this be tackled creatively in the current context where funds for training have all but disappeared for many?

Digital platforms: throughout the project there has been an assumption that digital platforms might offer something creative and genuinely positive for young people. From the evidence we must ask: could young people-led digital development help reduce isolation, contribute their experience to others like them, and create links beyond geography?

Improving the system...

In the light of the challenges and critical questions, what could improve the system so that young people and families had a better experience and the system delivered equity as well as effectiveness?

Simply put sustainable change requires **both cultural and structural aspects to be addressed** i.e. how things are organised and how people think ... [46] The forming of this view of system improvement draws on systems theory that encourages an analysis that takes action and intervention to a deeper level than simply trying to change events at a more superficial level. Figure 4 shows a simple schema for systems thinking that suggests that action for a sustainable change must not only try to change what happens in practice ('events'), but change the patterns of behaviour that produce those events. It

must also question the systemic drivers that reinforce the patterns of behaviour and at the deepest level could challenge the mental models or assumptions that underpin the systems themselves.

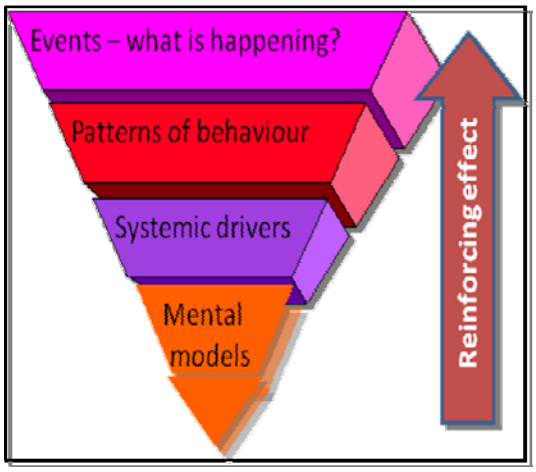


Figure 4: A schema for systemic analysis (from Senge et al 1994[47])

If a reasonably enabling policy environment is combined with practitioners who want to make change yet old patterns of behaviour and outcome persist, then there is clearly a system in place that is reproducing the latter. Trying to change practitioner behaviours by itself is unlikely to be successful because the way the system works is producing and reproducing those behaviours. What light might this analysis shed on the situation of this group of young people? Box 3 offers an illustration.

Box 3 Illustrating the conundrum using systems thinking

Mental models: two elements of the current mindset may be driving the unintended adverse effects of transition. These are

a) the precedence placed on the medical model rather than balancing or integrating this with the psychosocial model.

(b) the notion that adults and children should be separated at age 18 and that at a productive adult is defined at this age. While this may be fundamentally correct for the wider system of care, it is having an unintended effect on transition, causing a rupture in the continuity of care at possibly the most critical conjuncture for young people with life-limiting conditions and their families

Systemic drivers: these include the structural separation of children's and adult health services in ways that develop different cultures and practices (including basic procedures such as pain relief administration); professional specialisms and divides; the lack of agreed definitions and practices; the different age limits. Crucially all these are reinforced by funding arrangements that separate health and care.

It is clear that Marie Curie cannot **control** any changes at these levels but it, and its partners (potential and actual), and the wider audience for this report, can **influence** moderating or fundamental changes here.

Patterns of behaviour: Together the mental models and systemic drivers produce and reinforce practitioner behaviours that reflect a lack of skills, support and confidence to put young people at centre (unless they circumvent existing systems) or to work with parents as carers with needs. All this produces the awful **events** people told us stories about...

In this project we can see the poor experiences of young people and families in transition as the events we want to change: the question is what will change those events? In practical terms, what might this mean? Figure 5 shows a schematic view of the system and offers a menu of options for what might, in the light of the evidence, make a difference for young people and their families.

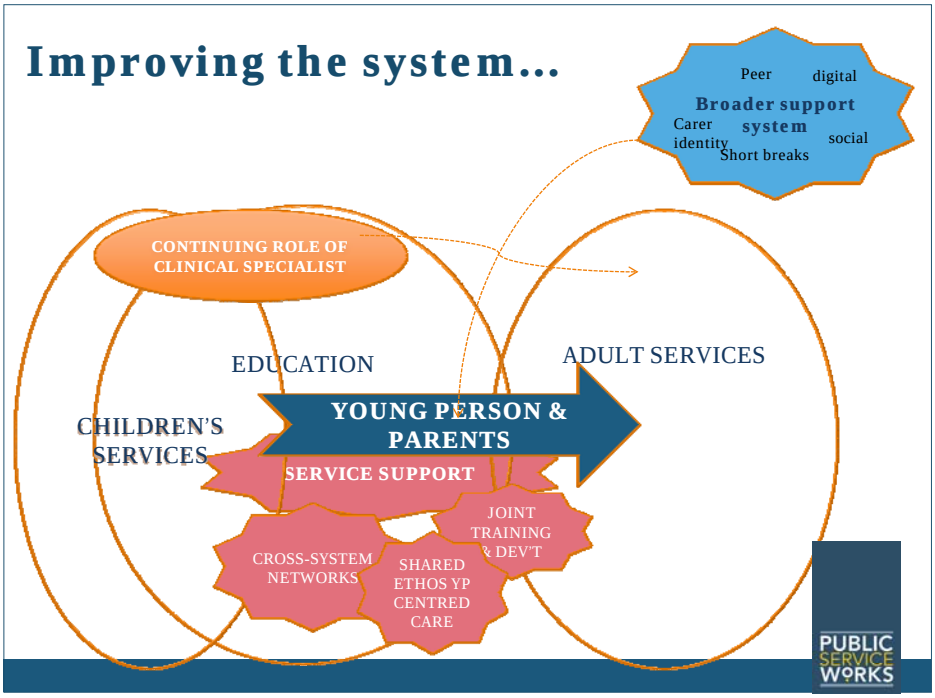


Figure 4: What might improve the system?

Firstly policy and practice must conceptualise a *broader support system* that is greater in scope than that of current services, namely, outside of the dominant subsystems of education, children's services and adult health services (the blue shape in figure 5).

This means that the under-pinning ideas that shape practice (including clinical training) need to include both a psycho-social model for transition as well as the dominant medical model. This would enable practitioners to take on the issues raised by young people, the importance of peer support for them and for their parents, their aspirations for independence and at least some elements of a normal life. It needs to recognise the underpinning place of short breaks in the lives of the whole family. Arguably this support system must include clearer focus on parents as carers and might include digital offers.

Next the importance of a *continuing clear clinical lead role* is emphasised. This role must be framed in such a way that it is capable of working across and linking the system components. The evidence from the study is that there is no clear consensus about who should play this role ('key worker', GP, paediatrician, lay person) although there may be some good arguments for basing a new role around a more broadly skilled and resourced paediatrician.

Finally, three elements are envisaged that extend and develop current transition work (the pink shapes at the bottom in the figure):

- *young person-centred ethos*: the development of policy and practice cultures that build processes that are young-person centred and that legitimise the young person's perception of need in much the same way as a child-centred ethos invests social care

- *cross system networks*: the development of formal and informal, and closer connections between children's and adult health services. The latter may, for example, include transition planning from an early (teen) age
- *joint training and development*: while this is probably a subset of the preceding point, the strength of feeling from practitioners about this merits its separate mention. There are good arguments for training programmes specifically for transition that includes practitioners from both domains (the study identifies that there is a workforce skills deficit). Similarly, organisation development initiatives might usefully be mounted to embed and to improve cross-domain processes.

In framing conclusions and recommendations we have considered this analysis especially and aimed to propose work that will challenge behaviours, systems and mental models to counterbalance a tendency to focus on events and trying to change them alone e.g. through changing the process for transition discussions, changing who is involved in discussions, changing when they happen etc.

Section 5: Conclusions & recommendations

In beginning this section it is worth stating that for this group their **small numbers, huge needs, and experience of cruel and arbitrary divisions of services** makes meeting their needs extraordinarily complex and difficult, as everything in this lengthy report illustrates. Our conclusions are, however, paradoxically brief!

Our conclusion overall is that young people should have the choice to stay with the relationships they have, adapted to age and changing need, and their support needs require creative joint funding under their and their families' control, possibly from a new national 'pot'.

We also conclude that:

- The consistent messages in the evidence require **flexibility at the frontline** for professionals to negotiate on aspirations and needs with young people and their families
    - To improve directly the experience of young people and parents
    - This can only happen through children's and adult services (and their funding) collaborating closely on the question of transition
- The messages and issues show **a good fit with *We put patients and families first,*** Marie Curie Cancer Care's 2011-2014 Strategy, for example:
    - ***Better care***: hospices as hubs, understanding need, improving quality links to issues of new local networks
    - ***Wider reach***: links to carer coordination, extending to young adults, supporting carers
    - ***Stronger Foundations***: spreading risk through partnership & joint working
- **Working with partners** is fundamental
    - To work with young people and families in co-producing changes
    - To work with digital media in partnership with organisations well placed to take this up in the longer term
    - To develop networks within health and social care across statutory and voluntary sectors and national, local and regional levels

Recommendations to take the work forward

Marie Curie should influence the wider context and other key stakeholders through:

8. Feeding the findings into National Funding Review, which includes both adults and children, but is not yet explicitly considering teenagers and young adults as a group

9. Highlighting with key stakeholder organisations the very different responses of statutory agencies in England, Wales, Scotland and Northern Ireland to the challenge of transition and the practical implications of these, especially in relation to the severe inequalities suffered by these young people and their families

10. Holding a national launch event to involve young people directly with policy, commissioning and practitioner stakeholders

11. Publishing key messages from the report in a range of media e.g. on website, in popular form; an academic paper

12. Helping shape the workforce development agenda in concert with the Transition Partnership especially

13. Disseminating broader learning about practice and innovation to other condition areas (e.g. dementia, long term conditions)

14. Using the database of people who want to be involved in the future and should be

For Marie Curie in Phase 2 to:

1. Continue elements started in Phase I
2. Fill key gaps that the Phase I activity has revealed
3. Follow new leads as indicated by what we have learned from Phase I
4. Develop a limited digital platform offer aimed at young people and at parents

Continue elements started in Phase I

1 We recommend that in Phase 2 Marie Curie should continue engagement work with young people with life-limiting conditions & parents. This should be a core element underpinning all the work in Phase 2.

- This reflects good practice in engagement i.e. that one-off processes do not foster the trust and relationships that are desirable for innovative work and moving to co-production of a support system. This is also key for this vulnerable group
- Continuing engagement will be vital to develop any work using digital platforms
- The prototype board game can contribute in helping to establish priorities of young people for a support system
- It will enable a development of social network analysis of the young people which was not feasible in Phase 1

2 We recommend Phase 2 includes work to clarify issues for BME communities, which was not included in Phase 1 due to the difficulties reaching any of the young people in the cohort

- the high prevalence of conditions and apparently low usage of services for particular ethnic minority communities indicates a potential problem of unmet need
- it should include focus on communities with consanguinity practice that leads to a prevalence of genetic conditions

Fill key gaps that the Phase I activity has revealed

1 We recommend tackling the engagement of the education sector and involving them in further development. This would include:

- interviews at senior level

- interviews at school level
- mapping pathways
- statutory aspect of transition
- Interviews with young people in a variety of educational settings

2 We recommend the development of a high level system map for young people with life-limiting conditions, focusing primarily on the 13-25 years age group

- this would analyse whole system journeys
- create a system map (illustrate and identify ± reinforcing loops)
- define leadership & change management processes & goals
- engage partners and young people/parents in this work

Follow new leads as indicated by what we have learned from Phase 1

1 We recommend the development of multi-functional local networks to create a coherent, broadly-based support system with young people and families

- The development of exemplary projects could explore the extent to which hospices, whether for adults or children, can become the centre of an expanded support system for these young people & their parents, especially after they leave education
- Such examples could be tested/prototyped via 3 Marie Curie hospices & their areas over a 12 month period, building on existing positive work
- This work should include a learning network process across the projects

2 We recommend Marie Curie further scope the implications of the report for their future service development

- To explore and design service options with partners e.g. carer support, care coordination, palliative care for young people in their homes, volunteer schemes

Develop a limited digital platform offer aimed at young people and at parents

We recommend that Marie Curie in Phase 2 considers the following strategy for digital platforms:

1. continue user research
2. co-produce digital solutions with young people willing to collaborate
3. include radio as part of menu of possibilities including internet and SMS text applications
4. adopt a Stage 1 social network site approach
5. follow a natural growth path
6. agree key review/decision points for further development

Figure 6 below illustrates some key functionality that could be offered in the light of this report.

Figure 6: Functionality of a new digital platform

If Marie Curie takes up the recommendations above, we estimate an investment profile for phase 2 approximating to the segments in Figure 7 below:

Figure 7: Suggested investment profile Phase 2

Our suggestion of this rough allocation of investment reflects our conclusions that:

- Substantial resources for young people's and families' engagement are critical to support all the areas of work and to build on the phase 1 work.
- Network development allied to this engagement has the best chance of improving the experience of young people and families in practice, creating exemplary work to promote more broadly.
- Digital development could offer a great deal to help young people and parents with this level of investment and at this level will effectively test what is helpful.
- Influencing more widely and specific further evidence gathering completes the picture of what investing the Phase 2 resources can achieve.

List of Annexes

Annex A Who was involved in what?
Young people and families
Regional events
Interviewees
Annex B Questions to young people
Annex C What is Open Space?
Annex D Stakeholder interview questions
Annex E Images created by young people
Annex F Open Space report – London
Annex G Open Space report – Manchester
Annex H Open Space report – Birmingham
Annex J Prototype of support system game
Annex K 'normal life' social media site
Annex L DVD –practitioners' 'video box' excerpts – to follow
Annex M 'Stories from the frontline'

Notes & References

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