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**PUBLIC
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WORKS**

‘LIFTING THE CLOUD OF LIMITATIONS’

**ACHIEVING A FULL ADULT LIFE:
FINAL REPORT OF THE MARIE
CURIE YOUNG PEOPLE &
TRANSITION PROGRAMME**

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The Marie Curie Young People and Transition Programme: introduction

The Marie Curie Cancer Care Young People and Transition Programme has attempted to explore ways to improve the difficult and often unsatisfactory experience (as reported in [Phase 1 findings](#)) of a planned transition to adulthood for young people with life-limiting conditions. As a core principle, the programme has focused on the **aspirations** that these young people have for their adult lives rather than the **needs** that arise from frequently complex conditions: the report title 'lifting the cloud of limitations' sums this approach up well¹. By exploring with them creative ways to support their strengths and aspirations - and therefore to challenge the traditional, needs-based and professional-led focus of many services, the programme has complemented a range of other initiatives across the UK.

The programme was funded by the Department of Health as one element in a £30 million investment in improving children's palliative care, overseen by a coalition of agencies acting as the Transition Partnership (Together for Short Lives, Help the Hospices, National Council for Palliative Care).

The Marie Curie Young People and Transition Programme had two key phases, both designed and managed by PublicServiceWorks (PSW) on behalf of Marie Curie Cancer Care.

- **Phase 1** (January to March 2011) focused on gathering evidence on the experience of young people and their families at transition and generated a series of recommendations for action. See summaries [here](#) including 'Making the Most of Life' accessible publication.
- **Phase 2**, which took place between May 2011 and July 2012, built on the findings of this exercise by piloting a series of local and national initiatives designed to explore ways of tackling the complex challenges which get in the way of positive transitions for this group.

In developing the phase 2 work, an overall question was developed as a focus:

What stimulates and sustains satisfactory holistic support into adulthood for young people who have complex health needs?

Over the period of phase 2, there was a subtle but important shift in emphasis. It became clear that proposals to develop a positive transition and to enable young people to achieve their aspirations for adulthood must be rooted in the realities of difficult economic times and the rigours of setting real and achievable priorities for action. This shift is reflected in the core question posed at the final programme event in June 2012:

In these difficult times, what can and must be done so that young people can achieve a decent adult life?

The term, 'a decent life', was adopted to express the nuances involved in recognising the legitimacy of aspirations for these young people whilst also acknowledging that the ideal may be unachievable, as it usually is for the rest of the population. The boundaries imposed by these constraints, together with a

commitment to co-producing feasible and affordable solutions to transition dilemmas with young people themselves, have shaped the work of the programme during phase 2; they also underpin the information and analysis provided in this report.

Context

The very good news is that children with life-limiting conditions are living longer. This means, of course, that, increasingly, they require support into adulthood. There is growing evidence of unmet need as these young people make the transition from children's palliative care to adult services. Whilst the numbers involved are relatively small, they are growing (having doubled since 2000²), probably as a consequence of advances in medical and other technologies in prolonging life and optimising their functioning, together with changes in the health profile of the broader population. This trend means adult services are now working with young adults whose conditions are in many cases entirely novel to their practice.

Phase 1 of the programme, reinforced by many other studies and projects, made clear that for many young people and their families, the transition to adulthood is a very painful and unsatisfactory process. Losses typically include education, peer support, social engagement, meaningful activities, and specialist health and social care support. Many young adults find that their parents and families have to take on increased responsibility for their care – a development that reverses more normative processes in which adulthood involves decreasing dependence on parents. In some cases, parents and carers have had to give up paid employment to look after young people as children – a sacrifice that can come into acute conflict with a young adult's desire to take advantage of personal budgets to move into more independent living.

About this report

This report records what occurred during phase 2 of the programme and discusses what was learned from these activities. In the light of this analysis, suggestions are made for how the momentum achieved by the programme may be sustained to ensure that, in future, the arrangements for transition are more robust and produce better outcomes. The report is supplemented by the publication, *Don't Let Me Down* (available [here](#)), which stemmed from the Transition Partnership's work on future policy directions, and drew on some of the work of the programme.

The structure of the report reflects the varying activities and key findings of the programme. It is designed to be of value to people who are interested in understanding more about the systems, structures, cultures and practices that impede effective transition processes. Hopefully, amongst these audiences, it will be useful to young people themselves and to their parents, carers and families in legitimating high aspirations and in stimulating ideas about how these might be achieved. It will also be useful to those who wish to explore ways of doing things differently within their own organisations or across local systems and agencies, including the Department of Health, Transition Partnership agencies, clinicians and other professionals, service managers, and GPs and other commissioners in the NHS and in local authorities.

The report begins by focusing on young people themselves: [Section 1](#) outlines what is meant by ‘a decent life’ and how young people and those working with them view these elements, in order to foreground the aims and purposes of good transition from young people’s perspective. [Section 2](#) analyses the range of consistent blocks to good transition uncovered during the programme. [Section 3](#) charts the ways in which the programme attempted to tackle the blocks and explore the feasibility of enabling young people to work towards their aspirations. [Section 4](#) offers learning and insights from this practical work. [Section 5](#) contains a series of conclusions and recommendations for future action. The appendices offer detail on: the results of the evaluation survey ([appendix A](#)) and the priorities generated at the 28 June national event ([appendix B](#)).

This report is supplemented by a range of other literature and materials generated by the programme, which add significant detail to the analysis provided here and offer some tools for practice. Throughout the report there are links to the programme’s internet repository for these products and materials: www.mariecurietransitionprogramme.wordpress.com – the materials are also listed for reference in [Appendix C](#).

Section 1: A full adult life: what has been learnt about what young people want and what transition should be achieving?

This section explores the significance of the fact that young people with complex health needs want to live 'a normal life', getting to grips with the same aspects of adult life as their peers. A structured approach is offered to help identify key 'enabling' dimensions of life. How might aspirations and needs be met? The experience of the programme suggests that the answers lie in being guided by young people; developing trusting relationships with them; valuing their strengths; working with them to open up meaningful opportunities; and helping them develop their own networks.

'We want the same as the rest of you!'

The overwhelming message from the young people who contributed to the programme is that, irrespective of parental or professional judgements, they want to live a 'normal life' – getting to grips with the same aspects of adult life as their peers: going out, making friends, having relationships, getting work, looking good, completing their education. The public health model developed by Dahlgren and Whitehead (1993) is particularly helpful in summarising the range of enabling dimensions required by these young people (just as much as by the rest of the population) in achieving what have been called 'the social conditions of autonomy' (Smyth 2012). Figure 1 below adapts this well-known model to young people with complex health needs/life-limiting conditions, illustrating what transition planning needs to achieve.

'I found [the Programme] overall positive because I was being assessed and supported in a holistic way it made me feel empowered and that I have potential that will be utilized.' *Young person in evaluation survey*

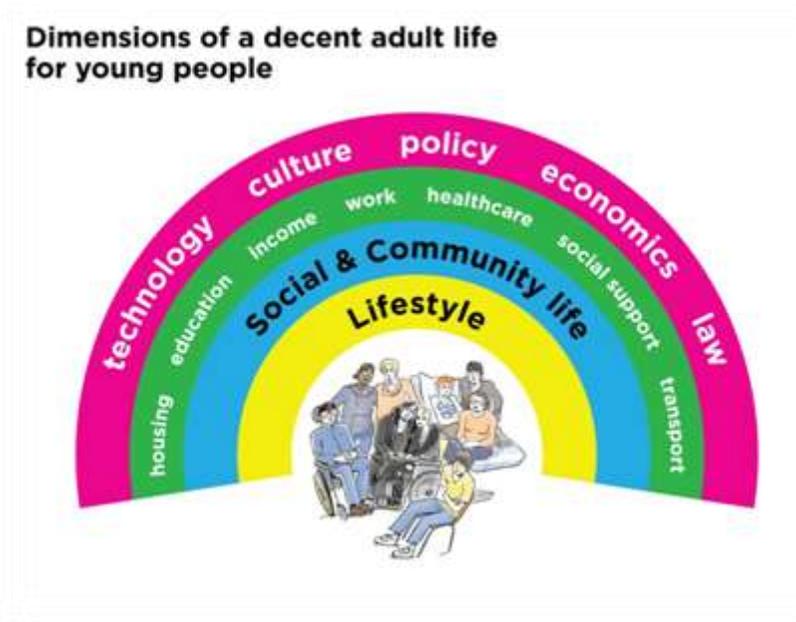


Figure 1 Dimensions of a decent life for young people

It is important to acknowledge that for some individuals, as shown in the box below, transition is a positive experience. Others may experience a less than smooth transition but still emerge into a young adulthood that offers excitement and promise. When transition is successful, it is largely achieved by a dedicated band of transition leads in different agencies committed to making the system work for 'their' young people – see box below.

'He has said that his transition went really well. He's an adult living in an adult world, socializing and doing things that he finds important. It is his choice. He has a girlfriend. He dabbles in college courses, he's not that fussed. For him the social element of his transition was important and the independence of being close to his parents but having a separate access to the house. And having his carers through direct payments has been a very positive step for him. It was quite easy to arrange. It took a long time to get to the planning and then all of a sudden it all fell into place over night. Once the agreement had been given, everything just fell into place really quickly. We supported him in interviewing the carers and they've been his original choices and they are still there. This is probably 3 to 4 years down the line now.' *Hospice manager*

Factors close to young people

Figure 1 shows the importance of social and community networks, including family and friends. These are important for all of us, individually and collectively, if we are to live productive and meaningful adult lives but are even more important for this group of young people who can be excluded and effectively further disabled by the absence of these networks or by gaps in their coordination.

Most people have three principal **social networks**³, linked to family, friends and work/education. From the programme's work, it is clear that many young people with life-limiting conditions are extremely isolated socially and have few friends or close relationships. It appears that, for complex structural and cultural reasons, even when they participate within normative social and collective experiences (such as student life) they remain isolated and excluded, so these experiences do not result in a significant expansion of their social networks.

The burgeoning **sexuality** of these young people can give rise to a range of challenges. Studies have shown significant levels of stigma in relation to the sexuality of people with physical and/or learning disabilities. Members of the community, personal carers and professional staff involved in care may all feel negative and/or anxious about this aspect of growing up; and these feelings may result in reluctance to engage in conversation on the subject. For their part, like their non-disabled peers, many young people are preoccupied with sex. However, it can be more difficult

'She (the young person) also had declared feelings for other women but couldn't talk to her parents about that, didn't think they would cope and couldn't explore that with other women. And she had no one she could speak to about it other than me.' *Care manager*

'I was asked to talk to a young man who had been inappropriate with a female member of staff. He could have been 7 or 8 from his knowledge and understanding and he did not have a learning disability.' *Family support practitioner*

'When you think these young people could die virgins, how normal is that?' *Support worker*

for them to get timely, accurate information about sexuality and sexual identity and begin to develop an understanding of their physical and emotional responses. This is largely because young adults with complex health conditions may miss out on some of the more stabilising factual sources of information. For example, they may miss teaching sessions at mainstream schools; they may experience different approaches at specialist schools; and they are likely to have reduced opportunities to socialise compared with those available to their peers. Many practitioners interviewed for the programme described the challenges of sexuality in this area and it was consistently raised by young people (see box on previous page).

The changing patterns of **social and family relationships** that characterise transition have a profound effect on parents, carers, family members and care staff just as they do on the young people themselves (see box below for workers' comments). And since anything that affects their family affects young people too, support for families during transition is key for achieving a decent adult life for young people. The workers' comments highlight some of the links between social and family relationships and the broader dimensions of life illustrated in Figure 1.

'She was keen on a residential home placement but the parents weren't so she ended up leaving the hospice and going back home again. She didn't feel strong enough to oppose their feelings'

'We need to take consideration of the young person's views but also of the family's views in this as well because they've been making the decisions for 16 - 17 years about what happens and all of a sudden someone's coming in and saying you need to start letting go now. It's a very difficult thing to do. That's part of the process of transition... the psychological perspective of where you are as a parent and when do you stop being a parent and which bit of being a parent do you let go of in order to move your child forward in life.'

'I feel it's imperative that the family and the young person have some control in the decisions that are being made about their care because they have very little else. They've got no control in other situations and I feel the same for transition.'

'Her needs have got worse, not better and she's an independent young woman, you shouldn't even be considering her parents as carers. I mean, yes, if they want to. But meanwhile her mum's sitting there steeling herself for another fight.'

Factors in the broader environment

The factors in the outer circles of the diagram describe the macro social, cultural and political landscape that bears down on and shapes individual experience. Because these factors are so significant for the lives of individual young people and their families, a major aim of the Programme has been to influence both national and local policy. There is increasing evidence of the negative impact on health and well-being of poverty, lack of work, cuts in services, poor or unsuitable housing, discrimination and barriers to participation (Marmot, 2010; Wilkinson and Pickett, 2009; OECD, 2011). The impact of these factors is intensified for this group of young people and others with long-standing and complex health and other needs. They and their families bear a disproportionate burden of socio-economic risks compared with the able-bodied population.

Housing and transport can be singled out as making particularly significant contributions to the ability of these young people to move towards adulthood and a measure of independence.

Lack of appropriate **housing** was continually raised by young people, parents and professionals as a major barrier to successful transition.

Homes are often unsuitable or too small and need substantial modification to meet young people's changing and often increasing needs. There is frequently no room for overnight carers. But it is no simple matter to find and move into alternative accommodation. Appropriate residential care is not easy to come by; and independent living flats/houses are in short supply. Furthermore, there is frequently a lack of clarity about which agencies pay for which aspects of the accommodation; hence decision-making is characteristically tortuous and prolonged. These difficulties can delay action until it is too late. The Programme uncovered many worrying stories of the impact of delayed decision-making and cost-shunting between agencies, including that of a young person who waited over a year for a suitably adapted flat but who died two weeks before she was to move in. It was notable that a limited exploration of the transition issues facing black and minority ethnic communities highlighted that in the Jewish community there is much greater emphasis on providing for independent living than in the mainstream. (see report [here](#))

'When the child is nearly a teenager and getting bigger they may ask can they manage in the house they live in? They might have to get a lift put in, which would take up a whole corner of the room and is very noisy, so they have to look at the house. Can they make the bedroom and bathroom downstairs? For some of our families it means they lose their living room. So some families' only sitting area is the kitchen because the living room has become the young person's bedroom and the bathroom has had to be extended as a wet room.' *Transition worker*

'They think I'm just going to die so they can't be bothered to move me on anywhere.' *Young man living inappropriately in an older people's home*

Young people involved with the programme provided powerful testimony about the importance of having accessible **transport** in order to live well, go to college, work and socialise. However, lack of easy access to many forms of transport, including buses and trains, was a problem for most young people. Difficulties in access were compounded in many cases by unpleasant social attitudes and discrimination on the part of the travelling public and/or public transport staff. It is of note that, independent of this work, a campaign to address anti-disability practices within public transport has recently been launched by a disabled adult (Bellisario, 2012). Evidence from this Programme suggests this campaign is very much needed.

Finally, the **technology** dimension of the outer circle of Figure 1 warrants comment. While technology can be an enabler of young people's independence, the programme found that young people do not perceive technologies as a substitute for relationships or direct social contact. Technologies, including social media, are as integral to their lives as they are for most young people. However, these are not seen as a panacea for the problems of profound isolation and lack of coordinated services, but rather as background tools. This insight emerged in phase 1 of the programme and influenced the design of phase

2, which had originally been envisaged as largely about creating new digital platforms to support young people.

‘You want to know what we want? Ask us!...’

Figure 1, then, illustrates some of the key dimensions of life that transition planning needs to cover. But how might the strengths be developed, aspirations and needs identified be met? The first lesson for the programme team was that, where possible, no assumptions should be made about what young people wanted; and that where assumptions had to be made, they should be checked out as soon as possible with young people. Real engagement was a core principle for the programme.

There was also no assumption that the only answer to meeting needs and aspirations lies in costly public services. Indeed, underpinning the programme was the contrary assumption that the young people themselves and those who support them can co-produce ways of working towards their desired lives. At some times, traditional ‘services’ will be a very important part of the solution; at other times, less so. In all circumstances, flexible and broad-based support will be essential.

The experience of the programme is that the activities that young people desired and valued came to fruition, whereas activities that adults/professionals favoured did not on the whole take off, or not in the form envisaged.

My main area of expertise is in Disability Rights and Sport Health + Fitness and with this knowledge I hope to help and get others involved in these topics too. The main skills I would say I have ... are that I am a great listener, willing to help anyone, always have something to say, always look for a positive and willing to do anything I can to benefit others.
grant panel member

I definitely recommend that if you don't feel you can even imagine driving, to go check it out. I felt I wouldn't be able to, to impress myself... that I was in a wheelchair and so wouldn't be able to... You have to fight for what you want and today I was so proud as my dad saw me driving *video blog by grant recipient*

Example: Developing Excellence

A strand of work called ‘Developing Excellence’ was originally envisaged as an arts-based programme offering a qualification to those interested in arts. Once young people had their say, it became clear that this approach did not resonate with them. Instead they were enthusiastic about developing a mentoring programme for young entrepreneurs engaged in starting their own arts-based businesses. Subsequently, significant progress was made in developing a group who are, variously: designing fashion accessories for wheelchair users; developing software games; pursuing successful graphics/animation and music production businesses; and launching their own craft business (read report [here](#))

‘...and then work with us to open up choices’

The programme sought throughout to gain the active engagement of young people in exploring and defining what ‘normal life’ might mean for them, and how they might be enabled to live as normally as possible. There was an accompanying commitment to integrate principles of co-design and co-production into the work. The characteristics of co-production are shown in the box below; and the role of co-production in the wider programme is discussed further in [section 4](#).

Characteristics of co-production

- **Recognising people as assets:** transforming the perception of people from passive recipients of services and burdens on the system into one where they are equal partners in designing and delivering services.
- **Building on people's existing capabilities:** altering the delivery model of public services from a deficit approach to one that provides opportunities to recognise and grow people's strengths and capabilities, and actively support them to put these to use with individuals and communities.
- **Mutuality and reciprocity:** offering people a range of incentives to engage, which enable them to work in reciprocal relationships with professionals and with each other, where there are mutual responsibilities and expectations.
- **Peer support networks:** engaging peer and personal networks alongside professionals as the best way of transferring knowledge and supporting change.
- **Blurring distinctions:** blurring the distinction between professionals and recipients, and between producers and consumers of services, by reconfiguring the way services are developed and delivered.
- **Facilitating rather than delivering:** enabling public service agencies to become catalysts and facilitators of change rather than central providers of services themselves.

(from Boyle *et al* 2010 page 9)

So, what did this approach mean in practice? In brief, funds were invested in developing the strengths, skills and capacities of young people so that they could develop their own support systems rather than being passive subjects of policy and practice. The engagement work aimed to find interests and strengths, and to put young people in touch with each other.

Example: Grants Scheme

Choices4U was the name young adults gave to a scheme awarding small grants designed to enhance opportunities in life. The scheme not only produced value for grant recipients but also brought key development gains for the young people, the Grants Panel, who ran the scheme, supported by members of the programme team. As elsewhere in the programme, young people took the time, and made great efforts, to do things that they felt contributed positively to their lives. The Grants Panel members insisted on monthly face-to-face meetings, despite the fact that they lived all over the country, necessitating long exhausting journeys. They very clearly valued social contact and peer support. As adults, they were also paid for their work and, in consequence, took it very seriously, initiating mentoring and evaluation and developing a [web presence](#), as well as attending Grants Panel meetings. They mentored successful applicants on extended travel, driving lessons, refining their applications, accessibility, and business development⁴ - as well as discussing their conditions and forming friendships. The group plans to continue its work and is actively seeking further funding to do so. (find out more [here](#))

The application of co-production principles and approaches produced a significant number of other interesting and unusual developments. These included:

- supporting a scheme in the West Midlands to train a cohort of young people to advocate for their group with the support of Acorns Children's Hospice. These *Acorns Ambassadors* have already input into the West Midlands Paediatric Palliative Care Network, the Preparation for Adulthood Steering Group and the Acorns Senior Management Group (on the Acorns Strategy)

and presented at the Acorns Annual General Meeting, as well as presenting at the Programme's 28 June event.

- The involvement of a large group of young people in the 27 June House of Lords event and 28 June event, both chairing sessions, performing a staged reading of young people's stories, exhibiting, presenting and preparing materials.

These activities all created vital spin-off benefits for the young people involved in terms of building their social networks, their confidence and their skills. They were able to share skills and ideas, be inspired by other young people and undertake new activities such as long distance travel, public speaking, mentoring others, influencing decision makers, and making decisions themselves about things that matter.



Young people taking part in the Ambassadors training

The aim of Transition Planning must be to ensure that all the elements illustrated in Figure 1 are considered, and that there is effective coordination of broadly based support.

Section 2: What's getting in the way: blocks to good transition

The previous section showed the direction in which people want to travel. This section looks at what holds them back.

Over the past eighteen months, the programme has uncovered a consistent picture of the major blocks to good transition. These are described and analysed here, in the light of young people's aspirations, the stress and anxiety of their parents, and the concerns of professionals.

Who stumbles over what?

The finding of the phase 1 report that transition is 'universally an awful experience' is reinforced by the information gathered during the second phase of work. It has become clear that the presence of committed professionals on the ground is not enough by itself to achieve the transformation required to improve young people's experience at and following transition. Systemic and organisational shifts have to go alongside changes in practice.

'I've heard it several times from different people. How bad must this system be that parents would rather their children died than stayed? How bloody awful must it be? These young people are small numbers needing huge resources. On paper, you're putting a huge amount of money into someone who's going to die anyway. No one's gonna write a blank cheque.'
Transition worker

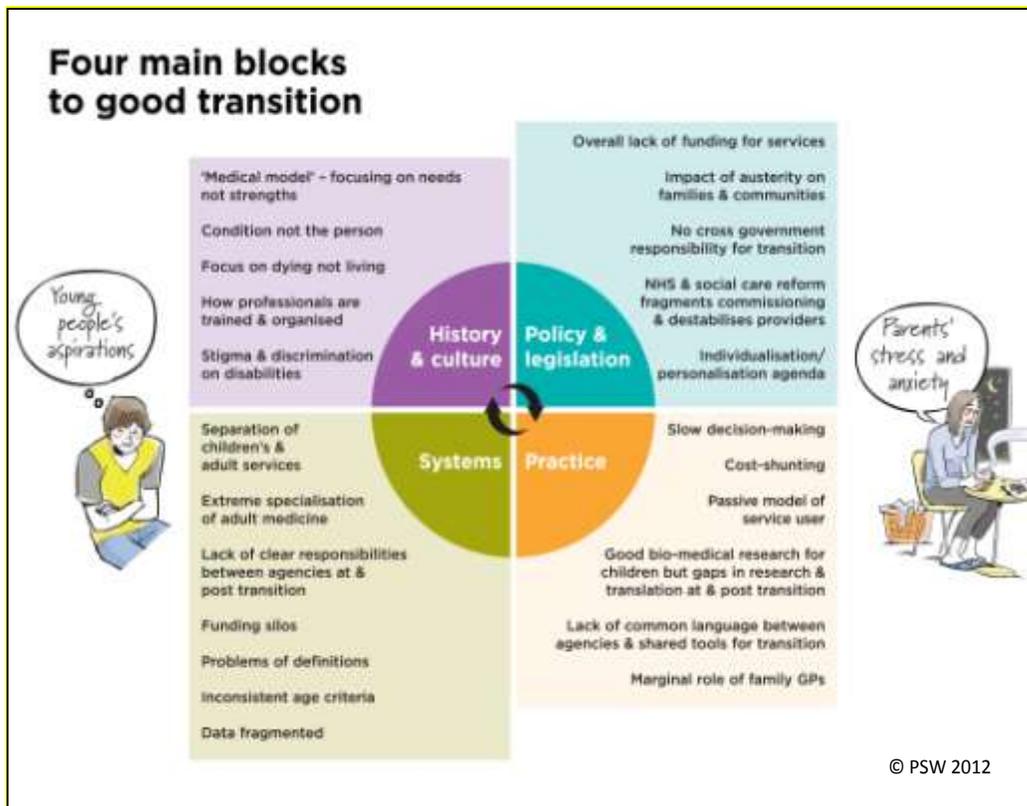


Figure 2 Stumbling blocks to good transition

As illustrated in Figure 2, the fundamental blocks to improvement at transition can be located in the following dimensions: history, culture and tradition; policy and legislation; systems; and practice. This

section discusses these and begins to offer an analysis of how these blocks can be overcome. Why is careful analysis particularly important here? The answer lies in the complex and wide-ranging nature of the transition process and the interconnected nature of these blocks.

In addition, Phase 1 of the programme identified the **'triple transition'** that has to be negotiated successfully if young adults' lives are to show a marked improvement. The three transitions are:

1. Transition from young person to adult – about growing up, independence and dignity
2. Transition from parent to carer of an adult – about complex emotions and anxieties
3. Transition for professionals managing a service transfer, either learning to let go or to enable young people and themselves take on the unknown

Accordingly, the stumbling blocks to effective transition need to be looked at in light of young people's aspirations, the stress and anxiety of their parents, and the anxieties and other concerns of professionals.

History, culture and tradition

The **'medical model'** has had much to offer society, and indeed has been the driving force behind improvements in medicine that have directly benefited the group of young people who are the focus of this report. However, real problems arise at transition if this model is unchallenged. Particularly in adult medicine and other adult services, the norm is to focus on conditions rather than people and on needs rather than strengths. Clinicians are still largely trained to 'do things to' people rather than 'work with' them. Assumptions arising from this model are deeply embedded in how services are designed and delivered. In adult palliative care, for example, the focus generally lies on supporting dying rather than living – a real shock for young people and their families when they transfer from children's services.

A further problem with the medical model is that it fails consistently to distinguish between *care* (often seen in clinical terms and settings) and *support* (dealing with the broader emotional and psychological, 'whole person' needs of the young person). These traditional perspectives have enormous influence over how professionals are trained and organised and therefore on their thinking and ways of working – and in turn on the expectations of those who plan and those who use the services. The extreme sub-specialisation of adult medicine is a major challenge here.

After transition there is no single clinical overview. The complexity of health and other needs and the frequent presence of extensive co-morbidities are rarely addressed holistically, further undermining efforts at services coordination. In addition, services and approaches that are not counted as 'medical' fail to be accorded the status, attention and care they deserve. For example, support with personal care and assistive technologies are both characterised by low status, patchy quality and increasingly rationed level of provision.

'You do need agreements with adult services for it to work well. With specific diseases like CF and diabetes they have transition clinics but the more complex conditions you could spend a year trying to find the right consultant to take a lead.' *Transition lead*

These then are some of the unintended consequences of the ‘medical model’ as they affect the lives of young people with complex health needs. Traditional attitudes of a different kind give rise to the enduring problems associated with **stigma and discrimination relating to people with disabilities** that also produce blocks of low expectations and marginalising of the strengths and capacities of the young people.

Policy and legislation

Policy and legislation both underlie and reinforce a range of problems. Transition for people with complex needs requires the coordinated efforts of a range of individuals and agencies on the ground. However, there is no single ministerial portfolio to address all of these issues. The communication and collaboration difficulties at local level are a reflection of the **lack of an effective cross-government responsibility for transition**. In this, transition from children’s to adult services is no different from other complex, multi-factorial social issues that are not obviously the responsibility of a single department of state or of a single stream of policy or funding.

The adequacy of funding for supportive services is a major challenge for this group and is likely to continue to be so, notwithstanding any benefits from co-production approaches. This is particularly the case in relation to funding for adult services suitable for this new cohort of younger people in a service that, up to now, has been skewed towards providing for much older people. The cross-cutting needs of many of these young adults add layers of complexity to inter-agency commissioning arrangements. Recent developments, including the fundamental reorganisations occurring as a result of the Health and Social Care Act, are likely further to fragment the picture. NHS and social care reform, including the individualisation/personalisation agenda, may offer benefits to some; but these changes are likely to fragment commissioning structures and destabilise existing providers, as well as add to the challenge of understanding the system for young people and families. They are also likely to expose gaps in provision that families will be unable to address. In addition, the impact of austerity measures on families and communities is of major concern, particularly when considered in the light of the proposed changes to welfare benefit, including disability allowance.

‘young man just turned 18, who has been paid for all along by children’s continuing health care, but he doesn’t meet the criteria for adults so they are going to stop paying. Do they knock on the door of social care to say ‘can you take it over?’ No! Somebody then has to approach social care to say can you come to do an assessment? They will then do an assessment; their managers will then say ‘are you sure he doesn’t meet the criteria for continuing health care, because that sounds like a health need to me?’ We’ve had trouble with this in several of our cases because they don’t talk to each other.’
Children’s hospice worker

‘Most 18 year olds with the best will in the world aren’t great at managing finances and employing someone. We seem to be expecting more of these young people than we would of the average 18 yr old. If you’ve got a family who can manage all that, fine, but a lot of our families struggle.’
Children’s hospice worker

Systems

Heavily influenced by history and by policy and legislation, the key systems operating at transition have several extremely unhelpful effects. For example, they arbitrarily separate children's and adult services; they create problems of definitions and inconsistent age criteria; and they reinforce extreme specialisation within adult medicine compared with paediatric care. **Funding silos operate with fragmented data; and clear responsibilities are not laid down between agencies at and post transition.** Young people may be 'missed' in the varying categories they come under within systems: learning disability, physical impairment, special educational need, complex needs, palliative care needs.

This fragmentation is further mirrored in the commissioning systems that have grown up around existing provision arrangements, creating massive complexity in funding sources and flows of funds. In one pilot area ([East Anglia](#)) the programme team identified over 30 people involved in commissioning for the care of this small group – and there are more people still unidentified... All this creates a complexity that defies understanding by the professionals working within it, let alone by young people and families.

Practice

All this produces practice that suffers also from **silos working, slow decision-making, cost-shunting between agencies and mostly assumes a passive, deficit model of the service user.** While there is good bio-medical research for children, there are gaps in research and its translation into practice at and post transition. In addition, there is a lack of common language between agencies and shared tools for transition, with key partners such as family GPs too often marginalised. In every participating area of the programme, different planning tools and approaches were in use. Even though people had researched good work elsewhere and were using it, no one pilot site was using the same tools and approaches.

People make the difference

Within these blocks are people: those who try to make systems work as well as those who don't; those who struggle to understand the issues in these young people's lives; those who battle against the odds; families under enormous pressure; and the young people themselves, often trying to protect their parents.

Within the cohort of young people, there are enormous differences. For example, for reasons of short timeframe and limited resources, the programme worked primarily with those without cognitive impairment or substantial communication disabilities; but these are the minority within the cohort. The parents of the young people who have cognitive impairments and communication disabilities are under the most stress and have the hardest time at transition. On the other hand, there was a view that *'if they've got learning disabilities, there's definitely more out there for them, there's some great work, it's just not available to the young people we deal with [with no cognitive impairment]'*. The programme's experience echoed both perspectives; the validity of one view did not make the other any less valid. This example serves to emphasise the complexity and individual nature of the disabilities and impairments the young people have, along with the patchy nature of local provision.

As things stand, there is no focus across systems to promote a holistic view, and it is a struggle to get people in education, housing and health and care agencies working in concert to build on the young person's strengths and meet their needs.

Section 3: Working with the grain of what people can do: the Marie Curie Young People and Transition Programme

This section describes how and why the programme took the form it did – ‘emergent’ rather than conforming to a pre-determined linear plan. The programme worked with what people wanted to do – and with what they could do. The key workstreams that made up the programme are described and discussed: young people’s engagement; local pilot sites; programme events and publications.

Shaping the programme: what will improve transition?

The evidence gathered in Phase 1 of the programme concluded that improving the transition experience required the following:

- **broader support system**, beyond the dominant subsystems of education, children’s services and adult services
- **defined clinical lead** role
- **cross system networks**
- **young person-centred** ethos
- **joint training and development**
- **constant flexibility at the frontline** so that professionals and agencies can negotiate on and broker pathways through funding silos, organisational and professional cultures and practices and across children’s and adult’s services, in order to further the aspirations and meet the assessed needs of young people and their families.
- **pooled or collaborative funding** for transition planning
- **good communication across partnerships**
- **working with young people and families to co-produce** transition plans and service responses.

These findings shaped the activities undertaken in Phase 2, summarised below:

1. Continued **engagement** work with young people with life-limiting conditions. Avoiding one-off processes, this work would foster the trust and relationships necessary for innovative work and which are a pre-requisite to co-production with young people.
2. The development of **multi-functional local networks** involving local agencies in participating pilot sites. These would test/prototype ways of co-creating a broadly-based support system with young people and families, over a 12 month period. The pilot sites all participated with other interested parties in a **learning network**
3. A limited exploration of the issues facing young people and families from **BME communities**, and in engagement of the **education sector**
4. Development of a limited **digital platform** offer aimed at young people and at parents

Over 80 per cent of programme resources were invested in 1 and 2 above. Figure 3 illustrates the approach:

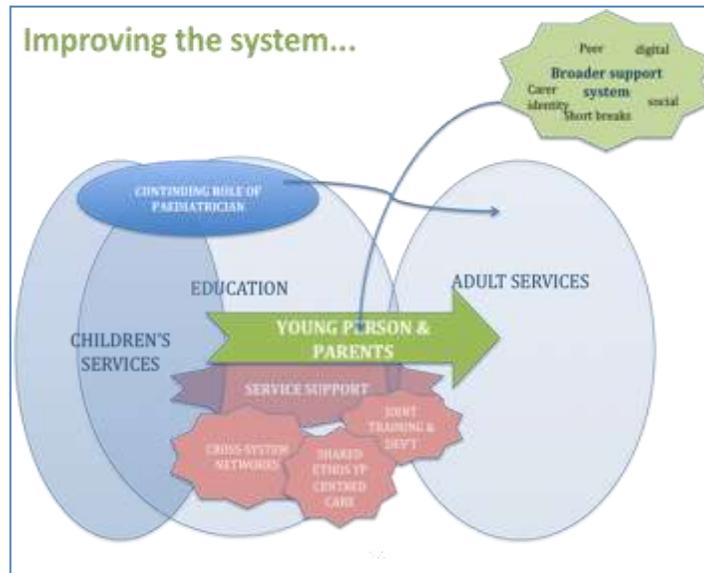


Figure 3 Phase 2 approach to improving the transition system

The wider influencing of policy, which was a key programme aim, is discussed separately in section 5. The Digital workstream was deleted in December 2011 in order to divert more resources into policy development and communication and supporting digital developments in other work streams⁵.

Working with the local grain – not imposing a model

The work programme was complex, developing multiple activities as the work progressed. It was not created as a pre-determined, linear plan but one which was deliberately ‘emergent’ (see discussion in [section 4](#)), judged to be the

only way forward given the variable local contexts within which activity was taking place.

The programme worked with what people wanted to do – and with what they could do – rather than impose an external model or intervention. Many people on the ground had been working on transition issues for some years and had formed their own views, developed their practice and established initiatives that the programme aimed to build upon, especially

in pilot sites. The approach in each site was therefore co-produced by local activists and facilitators from PSW. Work in all pilot sites was focused on the achievement of seven ‘statements of intent’ (see box):

Statements of intent for site work

1. The wellbeing of young people and their carers/families will be the focus of flexible responsive support and good information, irrespective of age, condition and stage of their personal journey
2. Young people will be enabled to make a contribution and develop their own voice
3. Young people will be enabled to have as far as possible a ‘normal life’, improving social life and combating isolation
4. Young people, their families, carers and those who work with them will act together for a positive transition
5. Parents will feel supported on their specific journey of transition with their child/children as they become adult(s)
6. Commissioners will understand the needs of this group of young people and their families and will be acting to improve what happens locally around transition
7. Partners across the whole system, including the public, will better understand the issues and opportunities for this group of young people and their families and make a contribution to their lives

*“These statements underpin all the work people are doing around transition. They capture the key elements... very accessible statements which young people can engage with.”
(clinical psychologist, children’s hospital)*

aspirational strategic aims or principles which underpinned local plans and guided activities. The statements provided a common language for the site work despite the adoption of very different approaches in each area. All sites were exploring different ways of achieving the statements of intent in order to learn about what had the potential to work, as well as what didn't. Cross programme learning from the local initiatives was shared in the [Learning Networks](#).

Overview of programme activities

What actually happened during the programme? Activities are grouped under the following workstreams:

1. **Young people's engagement;**
2. **The local pilot sites;**
3. **Programme events & publications.**

Work on black and minority ethnic communities and the engagement of education was threaded through all three workstreams – more on this work can be found [here](#).

Young People's Engagement (YPE)

The Engagement workstream was designed to stand alone, using co-production approaches to stimulate and support the development of a range of activities. However, it was clear from the beginning that engagement approaches would also be needed to support pilot sites and policy development. Planning and developing the work also involved: trialling the '[Choices' board game](#) from phase 1; collecting 'transition stories' from young people; encouraging the generation of many ideas for engagement.

What happened?

Young people have developed a range of creative initiatives to improve their lives at transition. A small grants scheme is run by a panel of young adults, with support from the programme team, to award small sums for young people to do something inspiring. The panel provides mentor support during the application process and continues after the grants have been awarded. Other aspects of work of the programme with young people include:

- 'Developing excellence' – a mentoring scheme to develop creativity and business ventures
- Game development – working with experienced games designers, young people are developing a new, 2D web-based game based on real life experiences

The PSW team worked with site staff and the young people's carers/parents to enable the maximum number of young people to take part in activities despite their periods of being unwell. Around 60 young people took part overall.

Hubs and Networks (HN)

This work began with developing criteria for site selection. Essentially, sites needed to have work going on that could be built on and taken to a next level faster through the investment of this programme. The decision was made to increase site-based work to include three network sites and three smaller 'hub'

sites. The former would pick up the overall aims to develop local systems and the latter would each contribute to one dimension of improving practice.

The sites agreed were:

- **Network development:** North and East London, Solihull and Somerset
- **Hubs (and their focus):** East Anglia (linking adult and children's services), Newcastle (creating specialist young adults provision), Penarth South Wales (workforce development)

The following summary of the pilot sites' work featured in the 'High Visibility' event brochure on June 28.

North and East London

For some time now, staff and managers at Richard House, a children's hospice, and St Joseph's, an adult hospice, have been working with young people to find ways of bridging the gap between children's and adult services. With backing from the Marie Curie Young People and Transition programme, major changes have been made to assessment procedures, to ensure they focus on what young adults really care about. Community-based [models of support](#) are also being developed, involving a range of partners.



At the heart of the project is a group of young adults who support each other through the hard times – and push the boat out when life is looking good.

Solihull, West Midlands

Like the young adults in London, young people in the West Midlands were keen to help others as well as get the support that they themselves need to live a decent life. With programme support, nine young people from the Acorns Children's Hospice took part in an 'ambassadors' training' weekend. On March 28 2012, the team was awarded a Tryangle Award by the Worcestershire Council for Voluntary Youth Services, under the Community and Citizenship Category.



Much creative thinking about transition emerged from a local stakeholder event in December 2011. 'Snakes and Ladders' was an image that resonated with many; and a Snakes and Ladders-themed conversational [tool](#) was developed to help people – young people, parents and professionals – to engage with the ups and downs of the current system.

Avon and Somerset

It can be quite a challenge for young people to create and manage their transition plan. User-friendly transition tools developed at this pilot site include a tool that enables young people and their parents to rate their priorities on scales they create that are meaningful to them (see www.my-quality.net – now available as an app as well as



on-line). Work to create an online planner that can help young people generate their priorities in is process. Designed to empower young people and their families, the tools supplement face-to-face contact.

In a further strand of work, commissioners of services in Somerset and Avon have shown real commitment to exploring the issues raised by young people with a life-limiting condition/complex health need as they become young adults, in order to improve their experience at and after transition.

East Anglia

For partners here – and in particular for EACH, the local children’s hospice – the focus has been on combating the invisibility of young adults in the eyes of most people and organisations. An important regional event focused on growing a relationship between adult and children’s services, both providers and commissioners of services. Preparation involved interviews with commissioners of services and local carers. On April 24, 2012 the ‘Hi Viz’ event saw 80+ people working on transition priorities across East Anglia. These have fed into regional plans in local government and health.



This event provided the overall theme for the June 28 event; and work with young people here generated ideas about creating a new computer game. Supported by the Marie Curie programme, young people from several regions have been working with professional designers on a game that will break new ground in illustrating their real experiences, stories, hopes and achievements.

Newcastle/Tyneside

With the support of the Marie Curie programme, St Oswald’s Hospice developed a publication telling the story of why and how the hospice has struggled to create a new service for young adults, and with what effect. Meanwhile, times have changed in the world of commissioning, with huge potential impact for vulnerable groups like life-limited young people and their families.



Complex challenges of this kind used to be addressed by service providers working with commissioners of services in an existing web of relationships. This approach is no longer possible. What collaboration now can ensure a decent quality of life for young adults and their families?



Penarth, South Wales

Transition throws up big challenges for professionals as well as for young people and their parents. Staff from adult services, for example, may experience quite acute anxiety about the prospect of working with young people – a state of mind unlikely to help the young person in any way. Shared learning seems essential, so a pilot project saw adult palliative care staff from the Marie Curie Hospice,

Penarth, shadowing children’s staff from: the Tŷ Hafan family support centre & children’s hospice; the local teenage cancer service; specialist palliative care; and condition-specific nurses. Support from the Marie Curie programme meant the shadowing activity was given educational heft through small group reflective sessions and specially written learning support materials.

It is intended to turn this work into a Diploma module at Cardiff University, where Marie Curie researchers are also working with the Penarth project group to explore adult staff’s learning needs through a series of focus groups and a Delphi study. Long term, the project group aims to create a major education package about transition.

A national **learning network** (Figure 4) offered regular opportunities to share learning across the sites and other innovators in the field. Meetings were held in October 2011, early February and late March 2012. More on the learning networks meetings and outputs can be found [here](#).

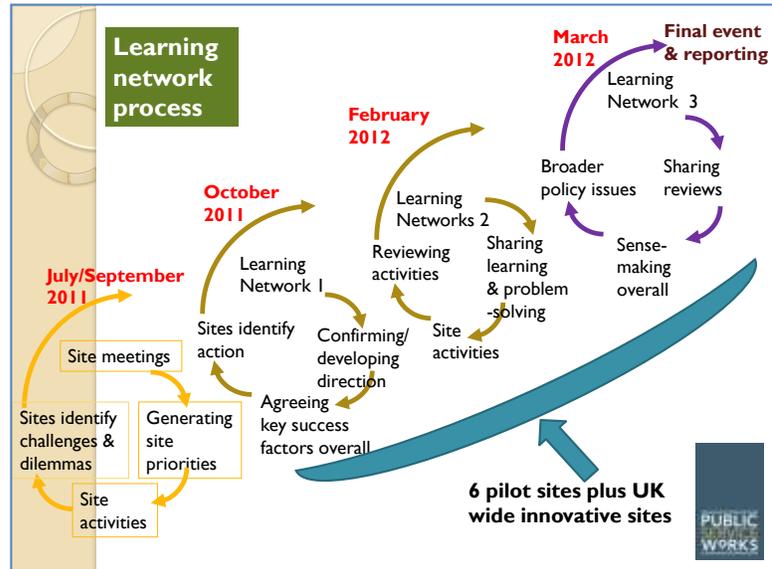


Figure 4 Learning Network process during phase 2

Programme events and publications

Events and publications have played an important part in:

- bringing the work of the programme to a wider audience
- stimulating the involvement of an increasing range of stakeholders directly in the workstreams
- galvanising support for stronger national policy on transition.

Consistent ‘branding’ on all publications, through the use of vivid illustrations and graphic strips, helped to ensure that there was a high-quality and distinctive visual identity for the programme. This quickly became recognisable in the field. The theme of invisibility, which the young people and practitioners identified as a major challenge to successful transition provided an organising focus for the programme as it evolved. The small numbers in the cohort, along with the frequently ill-understood conditions which are shoe-horned into the category of life-limiting conditions, conspire to marginalise the young people at transition to adulthood. The need to move from ‘In-Vis’ to High Vis’ provided a campaigning momentum over the months and, as noted above, provided the key focus for the East Anglia site and for the final event on June 28. The High Vis aim was

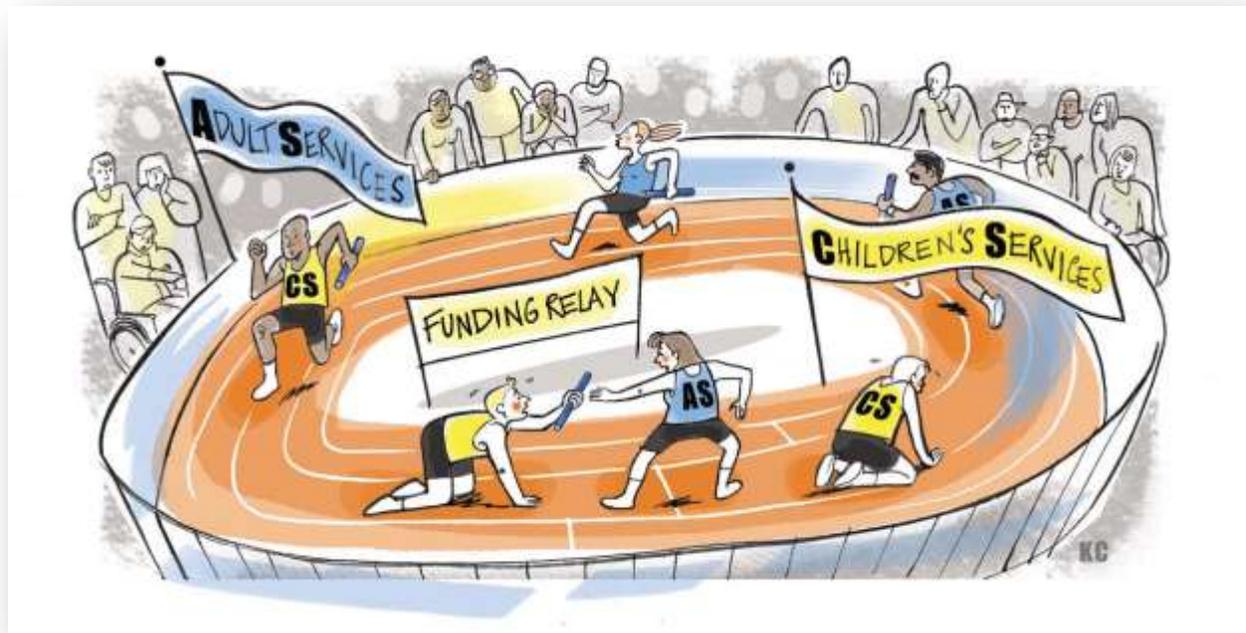


complemented by the use of illustrations as here, showing figures wearing yellow high-visibility jackets.

What happened

Programme events were held throughout phase 2. One or more stakeholder events were held in five out of six sites. Three learning networks were held – see Figure 4. Events were held at the House of Lords on June 27 to launch the policy document, with young people and the Transition partners, and at the Oval Cricket Ground on June 28, where over 200 people gathered at the High Visibility event to consider how to maintain the momentum of the Programme. All the programme’s site-based events were very well evaluated; and each event played a role in moving forward work at the site.

Innovative design and communications work, including the use of illustrations developed from the young people’s and site participants’ input, provided important images for the programme’s distinctive contribution and resonated with the whole range of stakeholders. For example, a relay race metaphor that emerged during site work gave rise to the illustration below – an image that participants in the programme described as crystallising the essence of their ‘handover’ problems at transition. However, it was hard for Marie Curie Cancer Care staff to work with this approach within their existing communications style. Nonetheless, by dint of much hard work and dedication, the programme team was able to publish three newsletters and put on a range of events as well as collaborate with sites on their communications work and events.



Results: what emerged in the workstreams – and what didn't?

In practice, how did the workstreams live up to their ‘statements of intent’? And what useful learning can be gleaned immediately from experiences during the programme? The discussion below offers a timely ‘de-brief’ on which aspects worked well, which less well. [Section 4](#) presents a deeper analysis of learning from the programme.

Overall, it seems that the emphasis that the programme placed on **building on existing developments** (especially on other initiatives funded from the DH £30 million programme) was well placed. The investment made through the programme enabled several projects to extend their lifespan, expand or come to fruition⁶. At times, it proved necessary to be willing to endure some discomfort as the work evolved in an organic rather than linear way. ‘Working with the grain’ meant focusing on what was feasible in a twelve-month timeframe, in a number of sites with different strengths and weaknesses, and adhering to co-production principles. The work seemed sometimes to be going in many unforeseen directions – and away from the plans!

‘the person centric approach has been consistent and engaging. Feedback from young people has felt to be genuine and inclusive. Equally, the team’s ability to engage service providers/ facilitators has been outstanding.’ *Comment in Programme evaluation survey*

The **learning network events enabled straightforward sharing** of learning across sites, including negative feelings and false starts.

An outstanding element of positive learning lay in the way in which the **young people involved were able to contribute to, and enhance, programme events and activities**. Despite some initial concern on the part of professionals, this involvement was a wholly positive feature of the programme.

Young People’s Engagement

Emergent work over 11 months with over 60 young people has produced pleasing levels of involvement and interesting and encouraging results. Supporting material and detail is [available](#) to support the summary that follows.

Small grants scheme

This was spectacularly successful; click [here](#) for detail and supporting material. The Grants Panel developed into a ‘core young people’s group’ for the programme, testing ideas, contributing to the policy paper, helping to devise the June 28 event, attending learning network events. They devised and undertook their own evaluation of the grants awarded, including travelling around the country to interview and photo/film successful mentees – known as ‘padwans’, trainee Jedi knights! They intend to continue after the programme ends, develop their ideas, and apply for funding from suitable Trusts. The success of the small grants scheme underlines the importance of small-scale funding for activities or initiatives that make engagement – and ‘normal life’ – possible. The [principles of co-production](#) were clearly demonstrated here through supporting paid roles for worthwhile work that produced something for others and developed a peer network. Roles were productively blurred between young people and PSW team members.

Developing a web based game

The working title of a [prototype web-based game](#) pioneered during the programme is the ‘strengths game’; and the strapline is ‘changing the world one player at a time’. This idea came from young people in the peer educators’ programme, linked to Demelza Hospice. There are virtually no computer games with disabled people in them, and the young people linked to the hospice wanted to change this. Early in phase 2 of the programme, over twenty young people expressed an interest in game development. A

half-day session with eight young people and professional game developers started the development of a game based on the life stories and experiences of young people with complex health needs. Real-life scenarios involve developing characters with strengths who can open up opportunities to acquire new skills – and thus enter a different level of the game.

A core of young people remain involved with the development; others are waiting to try the game. Intended audiences include adults who enjoy playing games and, through engaging with this one, will gain insight into the lives of disabled people. The East Anglia hub site's stakeholder event ran a successful workshop for people to test various web-based games to identify what they liked and didn't like. An exciting promotional [video](#) illustrating the concepts was produced for the June 28 event. As the development and early testing work will have been done through the programme's investment, seeking the substantial funding to develop the game proper should be possible. Consultation and input to the game development has continued through a blog site. <https://strengthsgame.wordpress.com/>

The Excellence programme

Five young adults took part in the excellence programme (more [here](#)) This programme put participants in touch with other young people and professionals in relevant creative industries, with the aim of gaining support and sharing and developing skills and strengths. The intention was to help young adults:

- Identify creative business ideas and goals
- Explore ways in which to reach those goals through building on strengths and skills
- Get in touch with people in their field who might inspire and support them, including professionals and mentors
- Access the grant scheme to support some of their ideas.

The Ambassador programme

Acorns Children's Hospice trained eleven young people to become Ambassadors for young people with a life-limiting condition. The original intention was to support the transition programme at the hospice; but ambitions have expanded beyond this, particularly after the award described on page xx and a successful [presentation](#) at the June 28 event. The creativity and focus of the youth worker at Acorns have been critical to the success of the scheme. This is a replicable model, if there is the appropriate support from workers of this calibre.

Contributing to the 27/28 June events

All of the above programmes participated in the 27/28 June activities in the market place, debate and showcase zones. Young people involved also worked on the [rehearsed reading of stories](#) that proved so powerful on both days, and the Grants Panel Chair chaired most of the plenary sessions, co-facilitating with the programme team and briefing speakers. Most of the excellence programme participants and the Grants Panel members attended the House of Lords event on June 27, enjoying the chance to advocate for their issues and experience the House of Lords.

Nuclear industry graduates: conversations

An opportunity arose for some members of the Grants Panel to discuss power and influence with young graduates from the nuclear industry. This led to an important link to able-bodied peers; and a short

[video](#) was made. Some of these graduates were enthusiastic enough to go on to volunteer at the 28 June event. Similar links could be sought elsewhere; and there may be opportunities for such graduate schemes to offer small pots of money. There is also potential learning from a volunteering scoping project in [Solihull](#).

Key learning from engagement workstream

The engagement work has:

- demonstrated how to enable/**allow emergence** in developing ideas with young people, and to nurture innovation with all its associated challenges, including the risk of failure
- shown how best to **express underpinning ideas**, such as co-production, in accessible ways, by sticking to the principles
- enabled a **richer view of young people** to emerge, based on their own sense of identity and how they view normal life – and issues of end of life
- demonstrated very clearly the **rewards of offering genuine work** with real roles and decisions and paying people for their time, reflected in the comment, ‘today was not a waste of time’ – meaning it was not some kind of occupational therapy, ‘fun’ or entertainment. Instead, the young adults felt heard and appreciated for carrying out worthwhile paid work.

The work was **not all about successes** since a considerable amount of time was spent ‘engaging’ people, making contacts, developing ideas that were explored and didn’t go anywhere. However, it is the case that every idea that came directly from young adults took off.

The challenge of working with young people with complex needs, who often have little or no use of hands, demanded **skilful facilitation** processes for group work, with the use of visual methods (such as participatory appraisal) and the support of personal assistants where necessary.

Relationships were key, with the workers and the young people. Entering into active engagement is a big leap for many; and a person who is trusted, even in a low key way, makes the leaps possible. PSW’s support, peer mentors, industry mentors and the involvement of able-bodied young people all helped to build up trust. High quality training and accommodation, interesting venues, nice food – these all helped too. The Grants Panel met in community venues, apart from one meeting, and the June central London hotel accommodation attracted considerably more young people to attend than the idea of staying in hospices. Nonetheless, it remains a challenge to reach the young people, even those not cognitively impaired; and **access to ‘gatekeepers’** who work with them was key. **Excellent support** to the programme from people who work with and understand the ‘life’ of young people with life-limiting conditions was invaluable and PSW could not have made such progress without them.

Hubs and Networks

The Programme invested £83,000 into activities in sites (one third more than planned) plus over 100 days of PSW and associates’ time in development and support. However, to develop networks in less than 12 months is a big ambition and the ‘*constant urgency was irritating*’ to some (see evaluation survey results in [Appendix A](#)). Nonetheless, over the year, seven stakeholder events were held across

sites and numerous partner meetings monthly or six-weekly in five sites, all supported by PSW. Results included:

- a **80+ person conference in East Anglia** that produced a clear agenda for regional work on transition, being sponsored by the East Regional Lead in local government
- an innovative **'shadowing' scheme for learning** across children's and adult palliative care in S Wales, together with specially written learning support materials that is now being turned into a module at Cardiff University
- the writing and publication of a **case study (*Living Longer Than You Thought I Would...*)** about young adults' specialist provision in Newcastle that raised many of the issues people across the programme grapple with and has been very well received
- the development and testing of a new, **young people-centred model of care** in London
- the scoping of **volunteering activities** and the production of a conversation tool **'Snakes and Ladders'** in Solihull
- the development of simple but effective **online tools for transition** in Somerset: My QuOL-T and MyFutureMyPlan
- a helpful stakeholder event worked on the complexities of commissioning in Somerset that informed the programme's wider work on policy for commissioners
- **stories of experience** from young people, workers and commissioners were also collected.
- a wide range of **new people were involved in transition** in the sites (except Newcastle) compared with those involved at the start, and each site will have a document recording this for circulation and further network building.
- Young people also benefited directly in London through the support to a new transition team testing a young person centred model of care at transition

(more detail on site developed [tools](#) and [events](#) is available online)

Because sites were already engaged in innovative work on transition, inevitably the work carried out under the banner of the programme was wedded to existing local or organisational agendas. This aspect had both positive and negative points. On the whole, people in the sites appreciated the programme's approach to supporting work done or in progress and the additional helping hand offered through programme investment. What was harder was to keep a 'pure' approach to network development as initially envisaged. Working with the grain meant allowing site work to progress according to local energy and trying to shape events rather than imposing a specific intervention or approach. This produced a rich set of experiences and material which, overall, adds a great deal to understandings of transition emerging from other work taking place nationally. It did not, however, produce a clear model or defined approach; rather it offers a glimpse of a number of the **elements that taken together add up to potentially helpful approaches to transforming local systems**. (See [section 4](#))

In addition, the **learning network across sites** provided forums for reflection, discussion and sharing ideas and good practice across the sites and also with other players who had something to contribute. Several participants in the networks worked at a national level and had a policy and lobbying role. Learning Network newsletters helped build a community of people, within and outside the networks, and this operated de facto as a coalition of interest, made visible at the final event in June.

Despite these achievements, there were, of course, limitations. Pressure of time meant a limit on the number of young people who could become involved in site system improvements. And, at a time of great change in both NHS and local government, it was often stressful for staff locally to even think of piloting new approaches. This all meant that fewer young people benefited directly from work in the sites than hoped. Parents were only involved effectively in Solihull and East Anglia. Commissioners or statutory sector staff were not consistently involved in sites except Somerset and East Anglia, and this was therefore a gap. Across all the sites, it was a struggle to involve adult services and commissioners. This included local Marie Curie staff who clearly found it hard to take time from 'normal business' to take part, mirroring the situation for adult services generally. However, willing and interested individuals from Marie Curie were consistently loyal to the programme in London, Solihull and Penarth, and this was of great benefit, since other partners were impressed at Marie Curie's involvement in this agenda as an adult provider.

Key learning across the pilot sites

- Working **transparently and sharing** across sites also started to create the trust needed for better networks. Programme team leads in the sites were able to win trust and worked with stakeholders in a facilitative way to create engagement.
- **Ownership** of site work and **leadership** were however problematic on occasion. Whose work was this? Who was in the lead? PSW attempted a catalysing, supporting role focusing on lateral links, not hierarchies, but in some cases was seen as the leader
- **The variable membership involved in partnership groups** in different sites led to very different conversations and action emerging everywhere (despite much the same goals and same problems). This, in turn, led to different results, making overall conclusions tricky. For example, in Solihull the decision was to build a very local network of support agencies rather than focus on commissioners, although these posed problems. In Somerset, on the other hand, commissioners were in the partner group and contributed a great deal to the programme's work on commissioning; however, there was less engagement from adult providers there.
- For some sites though, the focus lay on struggle between **operational and strategic levels** as partners came from both levels, especially in London and Somerset
- **Pragmatism** was the programme's friend – working with the grain (supporting what people could do or wanted to do rather than imposing an external model or template) was critical to moving forward e.g. in Penarth moving the shadowing work on when the research strand needed more time to clear ethical approval.
- **Dedicated worker time** undoubtedly helped site work. This was most clearly evident in London, with three transition workers co-funded by the programme. Development worker time on the ground paid for by the programme meant that important progress was achieved in Newcastle, East Anglia and Solihull, and a paid facilitator enabled reflective sessions to happen for participants in the Wales shadowing scheme.
- **Geography** is highly determining. It shapes agencies on the ground, the networks they form and the willingness of people to engage. People seemed often more willing to make cross-regional or national contacts than to stray across local boundaries. This raises real issues of what the concept of 'sensible geography' (identified in phase 1) really means for service or network

development. Even with a worker on the ground, it is hard to disrupt established ways of working or create cross-agency links.

- **Fragmentation** is the norm. Take transition planner tools, for example. Multiple versions of these and of person-centred planning tools are in use – but there is no coherence in what people select or how they use them, and there is no evidence of agencies linking up to share approaches. In this respect, the learning network meetings proved to be extremely popular and were well attended and evaluated.
- The **marginality** of this agenda for adult services is emphasised. It was hard to keep local Marie Curie people involved, hard to get other adult service providers involved and even harder to get adult services commissioners (from either the NHS or local government) involved – with a few notable exceptions in all categories.

Programme events and publications

The High Visibility event on June 28, and the House of Lords Reception for young people and their families on the preceding day, achieved their purposes very well, proving a genuine high point of the programme. The June 28 event was a cooperative effort between the programme team, Transition partners and the Marie Curie communications function, underscoring the importance of collaboration between a commissioning agency and external partners on an agenda such as this, where a nimble approach to communications is essential to the achievement of impact.

The establishment of a set of priorities at this event for future action by the new Transition Taskforce will be vital to carrying the programme's work forward - see [Appendix B](#).

The emphasis that the programme placed on building on existing developments was well placed. The investment made through the programme enabled several projects to extend their lifespan, expand or come to fruition. Another outstanding element of positive learning lay in the way in which the young people involved were able to contribute to, and enhance, programme events and activities.

Section 4: Programme learning: insights through practice

This section brings together key messages from the evaluation of the programme with the results of systematic review and reflection by the programme team in order to identify areas of ‘deep learning’ associated with the programme. The programme faced the challenge of delivering demonstration projects across England, within a year, in a fast-moving environment. Notwithstanding the constraints, a great deal was achieved. Key areas of learning included: how to get the best out of co-production; how to plan work which is by nature ‘emergent’; how to approach local systems development; the importance of motivating both people and organisations; recognition that, with this group of young adults, the investment of relatively small sums of money can make a substantial difference.

Evaluation of the programme

A final evaluation survey was provided to all stakeholders; and the findings from this are summarised in [Appendix A](#). Other evaluative work was undertaken throughout the programme, based on the ‘realistic evaluation’ approach pioneered by Pawson and Tilley (1997). The aim has been to describe what has happened within and between the pilot sites in order to distil (and accumulate) information about what seems to work across all contexts as well as what may be unique to each. The evaluation as a whole will be the subject of a separate, later paper. In this section, key messages from the evaluation are brought together with the results of systematic review and reflection by the programme team to identify areas of ‘deep learning’ associated with the programme.

The evaluation shows that people had an overwhelmingly positive view of the programme. Their concerns primarily focused on the importance of maintaining elements that showed promise. Singled out here are:

- the work on young people’s engagement
- building an alliance to press for the implementation of key recommendations, including continued pressure for policy change.

Key areas of learning from the programme are outlined below.

Co-production works

Section 1 described the [principles of co-production](#) and gave some examples of how the programme applied these in developing engagement with young people. Section 3 showed how these principles also informed work with participants in the pilot sites. Formal and informal evaluation suggests that co-production definitely brings about unusual and exciting results if the principles are grounded in supportive professional practice. The work which has taken place in the last year suggests that the following are the key components involved in an effective approach to co-production.

Working from explicit co-production principles

Co-production requires a fundamental shift in mind-sets and cultures for both professionals and service users. It is not the same as the consultation or discussions undertaken in line with current notions of good practice, where the frame for action is boundaried by what is – or is not - available. It is clear that if the aim is to work in an equal partnership to co-produce solutions in difficult circumstances, then it is

necessary to devote time to develop relationships with young people, to help build their confidence and capacity to express what they feel is required, and then to work on partnerships with others to find a way of bringing the desired arrangements about.

People leading work or developing initiatives on the ground need to have an understanding of, and a commitment to, integrating the principles in all their interactions. The experience of the programme suggests that if professionals are to recognise young people not as passive recipients of services but as equal partners in designing and delivering these services, there is a need for consistent support and dedicated human and financial resources. Support and resources need to be intensive initially and then sustained over a period of time.

The programme constantly struggled to reconcile the pressure to produce speedy results with the need to take the time required for genuine co-production. When the appropriate balance was kept and genuine engagement evolved, the creative results flowed. For example, one of the successes in the London site was the recognition by the transition team there of the enormous power of getting into a conversation with a young person about their aspirations and strengths compared with only focusing on needs: *'I learnt so much about them in that conversation and I had thought I knew them really well'* (transition worker).

The programme has also been able to demonstrate concretely how valuable it is to 'blur distinctions' between professionals and public. The Grants Scheme was run by young people, paid for their role; they were supported by programme staff but themselves led the Grants Panel and made decisions. As indicated earlier, this approach led to a number of benefits for them personally as well as for grant recipients.

Relationships of this kind were essential to the work in pilot sites too, which was also co-produced. It would have been easy for the programme team to have 'parachuted' into a site and imposed a pre-determined agenda. However, this was rejected in favour of an approach that set out deliberately to encourage mutuality and reciprocity. Partners in participating sites were offered a range of incentives to engage, bringing their interests, ideas and current activities with them. The incentives included programme funding to release key individuals from their substantive roles in order to work more intensively on transition; to support specific developments; and/or the provision of expert support from the programme team to strengthen or take forward existing activities.

The programme team understood their role as that of facilitating and enabling local effort rather than that of offering formulaic consultancy – or project management. Where the programme team were involved in supporting delivery of products or events, it was always in the spirit of co-producing these with local actors. For example, in Wales, support from the programme team was designed to complement local efforts to develop a transition learning resource that was already being planned. The programme's input (together with generous support *pro bono* from the Marie Curie Research Centre at Cardiff University) helped move the whole initiative forward more quickly than would otherwise have been possible. Similarly in Somerset, local SEN managers recognised the value of work being done in the pilot site to develop an internet-based tool for young people and professionals to manage transition.

emergent rather than entirely susceptible to a linear project planning model. The establishment of a national advisory group provided important support for this approach. The advisory group helped the programme through discussing issues that emerged over the year and providing important experience and insight, on, for example, matters of definition, language and presentation. As the programme evolved, the group advised too on issues of evaluation. Within most organisations, clear plans and monitoring are the expected mode of working; and Marie Curie Cancer Care is no exception to this. Accordingly, working in an emergent way was not always comfortable or easy for those involved with the programme. That said, the project sponsors recognised the risks of an emergent approach but understood the reasons for working in this way, and trusted the programme team to get it right. More generally, the experience of the programme shows that enabling work to evolve within a broad set of principles or criteria for success can be a deliberate strategy. The co-production principles guided the engagement work; the statements of intent guided the site-based work.

The insight that emergence *is* a plan, based on principles that can be expressed and then reviewed, is critical. This insight may be of value for all those engaged in complex partnership work.

What is a network...?

Phase 2 began with the aim of developing local networks in several sites to try out the idea of developing local systems to be more inclusive and more responsive to what young people and families want. The label 'network' was both positive and negative. Theoretically, a network supports change in three ways:

- It brings together '**the whole system in one room**'. This means that people used to working in and through their organisational silos have the opportunity to build connections across organisational boundaries within the framework of a common purpose. This creates a value that was not there before.
- Specific, focused and purposeful conversation helps network members to develop a **common language, share information and expose different mindsets**. Each of these is a pre-requisite for any change in behaviour.
- The network provides a new **legitimacy and support** to work across boundaries, especially any 'rule-bending' that might be needed on the ground and an element of emotional support in difficult work.

At the same time, 'network' means different things to different professionals depending on its usage in their sector. In health, for example, it has a wide range of meanings. The programme team was also aware from experience of how long it takes, typically, to develop a self-maintaining network (several years). Initial criteria for pilot site selection attempted to deal with this by choosing areas with developed relationships rather than ones where relationships seemed poorly developed. This meant that a range of established agendas and initiatives were already in play when the programme entered on the scene. This created the context for the unique combination of the co-productive and emergent approaches discussed previously.

Local system development

The fact that that multiple networks may already exist in a locality may or may not assist in creating an effective local system around transition. The programme uncovered that, typically, existing networks do not include both adult and children’s services, or both health and social care and education and voluntary sector representatives or both commissioners and providers – and do not generally include young people and families. Creating newer networks that can include this wide range of perspectives was extremely hard to do. Only in one site (Somerset) did any site meeting occur that included all of the professionals listed above – but this did not include young people or families. Much of the learning in this area focuses on the time required to build local systems and, in particular, to link local systems development to broader policy development goals, such as to address specialist commissioning. It is clear that it also takes a considerable amount of time to open up professionals to ideas of co-production with young people and families.

Figure 5 illustrates elements of local system development based on the findings of the programme from across all the sites. This is intended to offer clinicians, professionals and managers in local agencies ideas about a way of working together with young people and their families to improve everyone’s experience at transition – and to maintain improvements through engagement, mutual learning and ‘amplifying’ learning into local agencies through events and system members. (More details on the elements within this diagram [here](#))

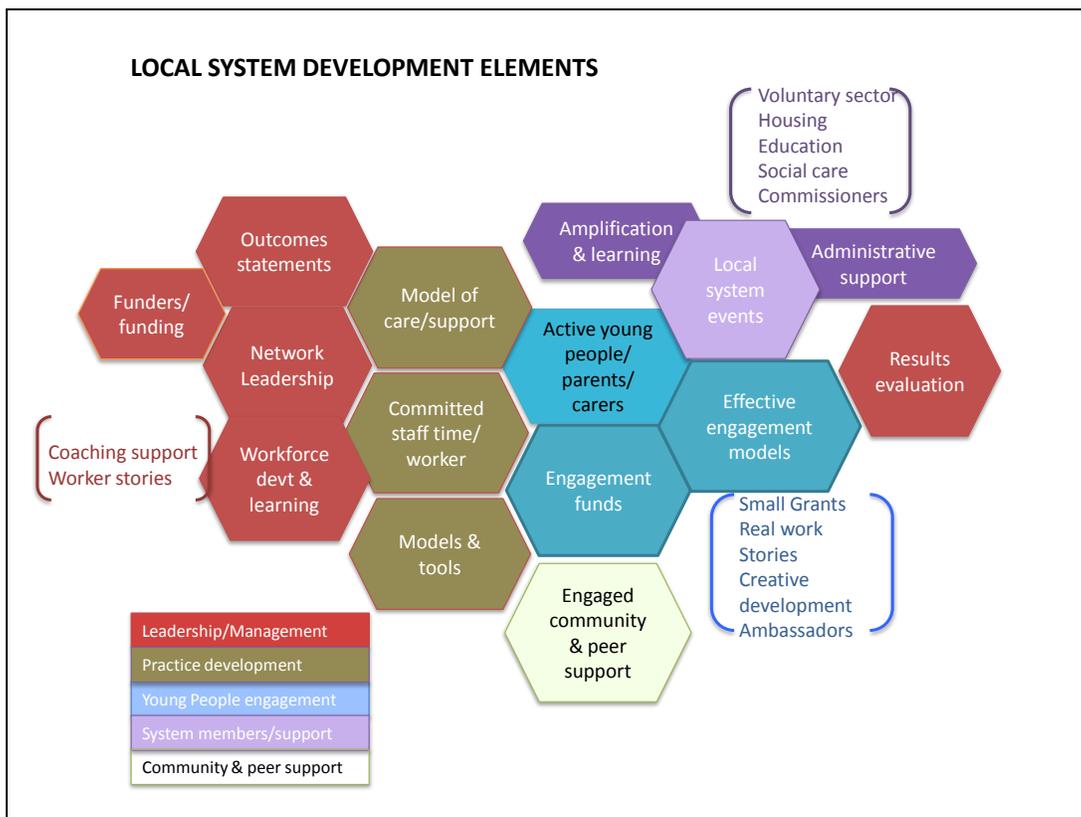


Figure 5 Local system development elements

The learning networks fulfilled this ‘amplifying’ role, enabling local sites to share their ideas and [news](#) on progress and receive support and challenge from others in a similar position. Participants very much valued the learning at these events as well as the networking opportunities – see box. This suggests that the maintenance of a national learning network would do much to strengthen transition practice, spread ideas and innovation and build a platform of support for policy development.

Glad to be involved in this work – increasing my understanding, opening up my mind (network participant October)

Usually at these kind of events people are busy defending what they do. There has been a real willingness to learn off each other today – it’s been really different. (network participant February)

Workforce and organisation development matters

The programme found that the active presence of committed transition professionals in local areas is not enough in itself to create the changes in the broader system required to achieve a good transition to adulthood. Typically, and because they had no other option, these staff ‘worked around’ unhelpful systems, cuts and delays in order to create individual solutions. Not infrequently, these led to inequity between young people and even potentially unlawful outcomes. As lone workers, transition professionals lack the power to bend the mainstream towards more effective and compassionate transition practices. Where agencies are responsive to the concerns and experiences of professionals, boundaries could be crossed and better transition managed. This requires: awareness of the issues surrounding transition so that they do not remain invisible; decisive and determined local leadership; and policy change.

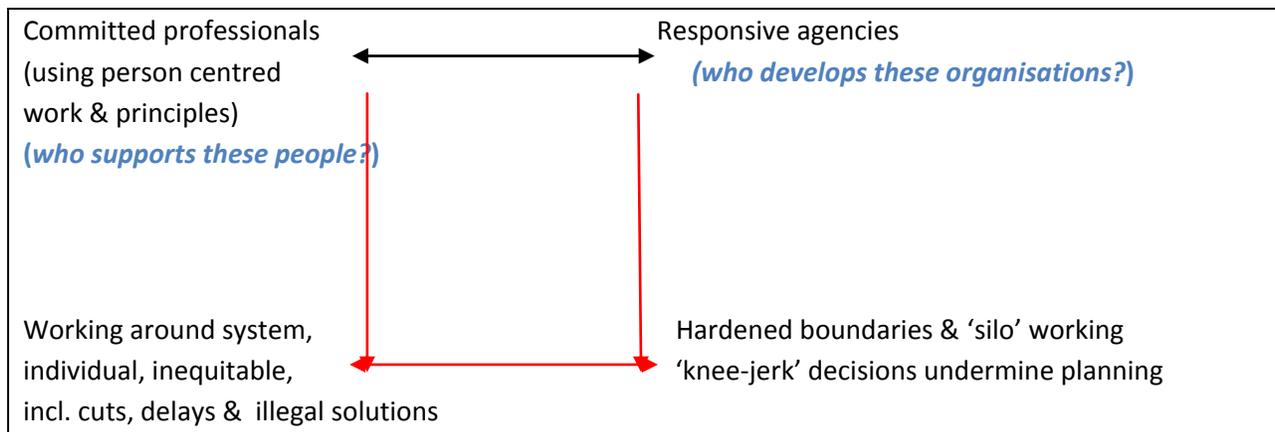


Figure 6 Achieving both committed professionals and responsive agencies

Figure 6 above outlines the need to achieve **both** elements on the top line without sinking into the ‘degenerate forms’ of those elements, indicated on the bottom line⁷. The degenerate forms are negatives or the fears of those involved. The danger is that once people are in this area of the square their work ‘flips’ between these negatives, which are the exact opposites of what people need to achieve: the question is **how to stay on the top line?** Mechanisms for motivating and supporting people and organisations are critical. Leaders and managers are responsible for both staff and organisation development, but programme experience suggests there are few people within systems who have the

position and knowledge, let alone the resources, to provide support to both professionals and organisations, to enable them to stay on the top line. Therefore the questions in blue in Figure 6 require focus in any local system development.

Investment and value for money

The programme invested the Department of Health grant in a variety of ways. At the outset of phase 2, the programme team proposed that the bulk of investment should go to young people's engagement and to local site development rather than to digital developments. The learning suggests that investment of relatively small sums of money can make a substantial difference. Two examples illustrate this:

N & E London pilot site – the programme invested £40,000 to fund a staff team (3.5 days per week shared between adult hospice social worker and children's hospice transition lead plus half time administrator) from November to June. Time was also invested in mentoring support of 8 half days, and project review meetings by the workers, their managers and programme staff. The project worked with 19 young people on transition planning and organisation of innovative support for them. The organisations involved were very pleased with the work and the learning they gained, and concluded that the transition team was a viable model for future work in partnership between them.

Young people's small grants scheme – the programme invested £40,000 to create a small grants scheme run by young people. Half the money went to small grants recipients, helping over 70 young people achieve their aspirations in amounts of £150 - £1500. Of the remaining money, 53 per cent provided payments to the young panel members and paid their travel for grant meetings, visiting applicants and evaluation. This funding also supported their work for the June 28 event and their presentations there. Programme staff support to the scheme, including its development and administration, totalled £9,600. This demonstrates the benefits leveraged by a small amount of professionals' time through co-producing with 'experts by experience' (as the young people termed themselves in presenting on June 28) and the value to young people of very small amounts of money.

The learning from the programme represents a clear call to the Transition Partners and to government that it is necessary to avoid the 'one-off project' syndrome that many feel has failed to challenge the 'invisibility' of this group of young people and impeded positive change to date.

Section 5: What can and must be done in difficult times so young people can achieve a full adult life?

This section argues that the current approach to transition represents a very poor use of scarce resources, and that alternatives need to be found as a matter of urgency. The Marie Curie programme can usefully be regarded as a testing ground for innovative policies and practices. Detailed recommendations aim to ensure that impact from the programme is sustained and extended by the Transition Partnership and new National Taskforce. Recommendations are grouped under: better evidence; better commissioning; better practice; better policy; and partnership.

Time for a better approach

The evidence gathered by the programme demonstrates that current arrangements are **failing** many young people, their families and the dedicated staff and organisations who work with them or on their behalf at transition, if not before. Current arrangements are not generating positive outcomes; worse, a number of contributors to the programme have suggested that these arrangements are harmful for considerable numbers of young people and their families. **The current approach therefore represents a very poor use of scarce resources.**

This is not the ‘fault’ of the system but a reflection of a lack of ‘fit’ between current practices and services and profoundly transformed social phenomena. In this specific case, the increasing numbers of young people with life limiting conditions have both intensified strains and pressures within and between organisations, increased pressures on funding and present unprecedented challenges to the ethos of services. Since beginning phase 2 of the programme, the global financial situation and the ‘austerity’ measures developed in response to this have intensified the crisis in the system overall. As a result, it is imperative that approaches are generated swiftly to bring about a sustainable transformation. Transformation of this kind may produce transferable learning for other groups with complex needs.

There are signals (both strong and weak) from this programme and elsewhere that give some clues as to the way the future might helpfully evolve. These include:

- interesting new evidence on the value of co-production and an emphasis on user and citizen participation
- the use of social networking and enabling technologies,
- better evidence and new technologies to support the management of chronic illness and disease enabling the prolonging of life
- a reconsideration of what ‘palliative care’ end-of-life may mean for individuals.

Some of these, but not all, are present, somewhat opaquely, in Coalition Government policies. Phase 2 of this programme has involved looking for such **emerging approaches, which may have the potential to be transformative.**

There is too an **emerging vision of a new approach** where young people with these conditions can benefit from the technological innovations that will occur – and who will also be enabled to manage their transition from childhood to adulthood more seamlessly and positively. In this vision, a broader

perspective will be taken on the lives of young people; no more will 'care needs' define the limits of support. What is needed for this vision to become reality? Structures and practices will need to embed and strengthen these emergent approaches; and agencies will need to consolidate them into how they do current business.

The programme should therefore be viewed as a laboratory for testing and strengthening innovative policies and practices, identifying and promoting those with real potential for others to take forward.

Components of a better approach to transition

Engaging young people

Policy or practices that continue to position young people as passive consumers of traditional services rather than active players will fail to exploit their energy and creativity or respond to their legitimate aspirations for their short lives to be meaningful. The key principles underpinning the programme and brought to bear on local developments were:

- co-production
- addressing the practical
- young people being tasked with real work
- using effective incentives to gain young people's commitment and persistence

Individual budgets may have the potential to achieve more creative and flexible care and support provided there is **creative facilitation and advocacy**. This is vital in achieving added value from financial investments or individual budgets. The required facilitation role is much more active, engaged and entrepreneurial than traditional support or 'brokerage', requiring the identification of opportunities beyond traditional 'welfare' systems. In addition, the facilitator needs support from all agencies in gaining access to these young people, which is particularly challenging given the current fragmentation of data across agencies. Additional challenges arise in winning the commitment of young people and their families to the co-design approach which may be very different to previous experiences. Advocates are important to help with these issues and especially where young people have cognitive impairment or communication disabilities. Advocacy was a key priority emerging from the June 28 event (see [Appendix B](#) Top Priorities).

Effective local systems

Learning from the programme suggests that **effective local systems need to have the following characteristics**. These include:

- **Engaged commissioners** who have some idea of the transition issues
- **Young people at the centre of what happens**
- **Providers working together** in focused way on transition
- Solid links to **education** and developing practice
- **Dedicated workers** on the ground focused on transition but with a vision of a model – not just firefighting
- **Networks** where people know each other and can share learning
- **Regional focus** to combat issues of small group

- **Workforce development** issues recognised
- Recognition of a continuing **research agenda**

These elements are all key to achieving the successful transformation of local systems and practices – a finding that exposes the enormous complexity of the task and, perhaps, goes some way towards explaining why change is so hard to achieve (though no less worth striving for). A comprehensive intervention with willing local partners, involving all of these elements and sustained over a number of years, would produce the desired result. Ideally, of course, intervention at local level would have central support and, critically, sustained funding. There is a clear role for Government here. The full range of desired changes cannot be produced by local efforts alone.

Much, though, can be achieved by concerted effort at local level. Figure 7 draws on experience across the programme to show what action was found to make a real difference locally (poster downloadable [here](#).)

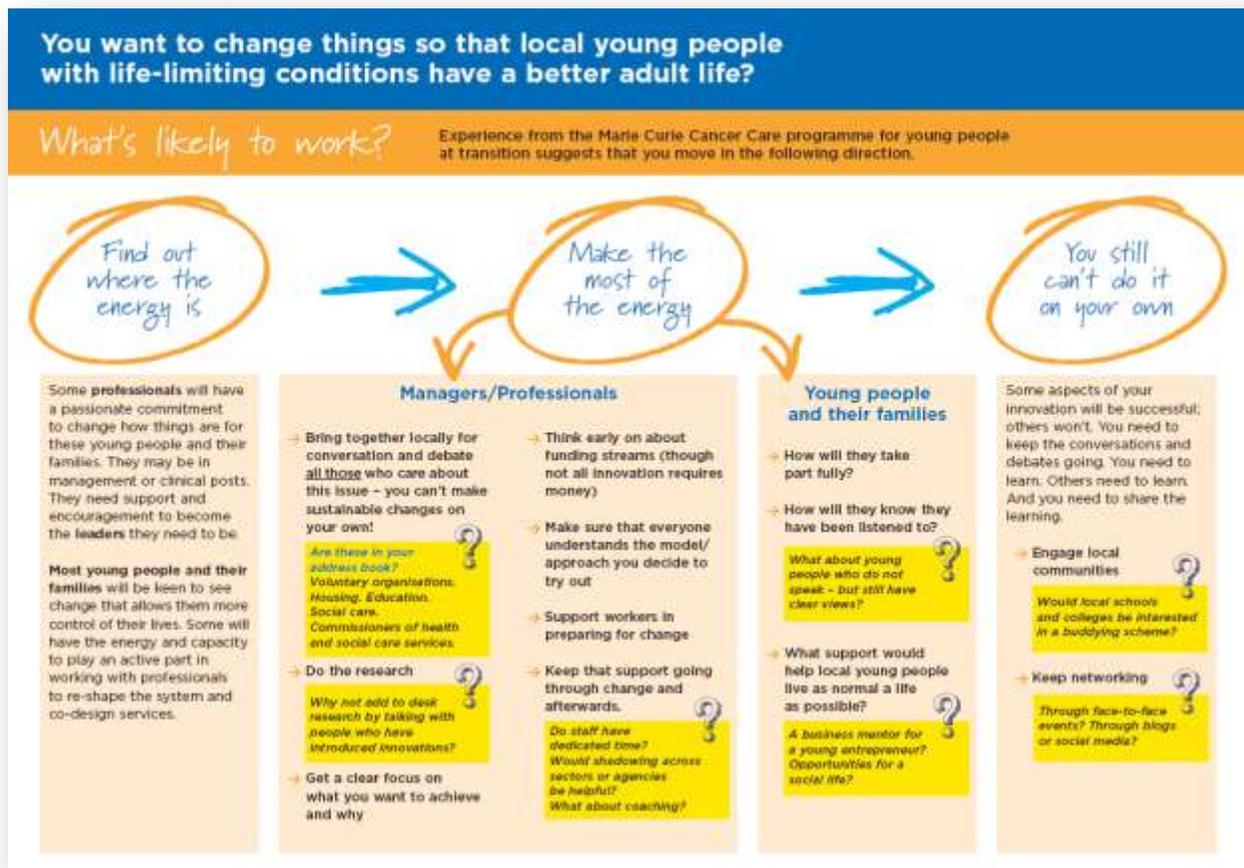


Figure 7 Effective local working: learning from the programme

Workforce and organisational development

A key casualty of constrained resources at all levels is a relative lack of workforce and organisational development. It is also harder to work in creative partnerships when each agency is fighting in its own funding corner. Why does this area present such a vital agenda for future action? The answer lies partly in the persistence of the historical and cultural blocks to transition; the complexities of the [‘triple transition’](#) as this affects professionals; and the challenges of co-production. Participants at the June 28 event recognised workforce development amongst their [top priorities](#). It is clear that in order to combat blocks and produce change on the ground, it is not only necessary to have **committed professionals** but also to have **responsive agencies** within and with which they work. There is an urgent need for resources and systems to support the development of professionals and organisations, both specialist such as those in palliative care and generalist such as primary care, so that all can play their part in supporting transition more effectively. National professional registration bodies, royal colleges and professional associations all need to take up this challenge.

Better policy

The determining importance of policy and legislation has informed the programme’s focus on wider influencing of policy and decision makers, and the aim and emphasis of the High Visibility event on June 28 2012, addressed by Paul Burstow MP, Minister of State for Care Services. The Minister responded to the summary of policy recommendations published by the Transition Partnership [Don’t Let Me Down](#), promising a favourable response by the Government. It is hoped that this promise is vigorously followed up by the Transition Partners and new Transition Task Force launched on that same day.

In addition, [‘Living Longer than you thought I would’](#), a publication by one of the programme’s participating sites, outlines from the perspective of agencies and practitioners involved in working directly with young people before, during and after transition, the range of both policy and practice challenges which bedevil the work, and makes a series of well-considered recommendations for change.

The publication of *Don’t Let Me Down* does not mean of course that the policy work has now been ‘done’. Whilst this initial work on policy by the transition partners is very welcome, it is clear that without sustained attention both to policy implementation and to further policy development, local practice innovation may not thrive and a number of the gains from the programme may be lost, particularly those which enabled the direct participation of young people. (see programme material on this [here](#))

The findings of the programme overall urge further policy attention in the following areas:

- **The limited scope and potential interpretations of definitions of palliative care needs also reflected in *Don’t Let Me Down*.** This has the potential to reinforce a narrow medical model which can be an inadvertent means of excluding these groups of young people from certain kinds of services, particularly in hospices. There is still considerable contestation about the use of the term ‘palliative care’ and varying definitions in use within services and this may add to confusion about what services/ interventions are involved. Furthermore, it is important to differentiate between ‘care’ and other support needs for young people and to find a formula

that attaches equal importance to support which enables independent living as well as care which addresses the alleviation of symptoms. It is important that the views of young people and their families are sought on this point.

- **The impact of individual budgets on the experience of young people and their families and, in particular, the kind of support required to make these work for all without the imposition of major administrative burden.** Additionally, further attention is needed regarding any differential impacts of personal budgets for those with cognitive impairments. This group are very deeply excluded; little is known about them and their needs and this programme did not address this in detail.
- **The stimulation of high- quality provider ‘markets’ capable of delivering good ‘wrap-around’ packages of care at the lowest possible costs.** The programme has information from some parents that the devolution of a personal budget is of no use to them or the young person if there are no services for them to purchase. One parent said publicly on June 28 that the personal budget which she manages for her ‘extremely disabled, cognitively-aware daughter’ felt like a ‘major burden and a con-trick’, given an almost total lack of services available in her area of North London.
- **The regulation and quality assurance of provision purchased with personal budgets** is a concern in an extremely cash-lean environment and in the context of recent concern over the emergence of two-tier social care for older people. This is likely to be a considerable concern to parents/carers and may intensify problems in ‘letting go’.
- **The impact of reforms to the NHS and social care on the transition experiences of this cohort.** The work of the programme details the range of current challenges faced by those attempting to work at local level, and there are concerns that the creation of Clinical Commissioning Groups and commissioning support arrangements may create further partnership stresses (see papers on commissioning in East Anglia [here](#) and overall messages from the programme [here](#) and final section in ‘[Living longer than you thought I would](#)’). It is vital that CCGs and new commissioning structures understand the context for this group, where small numbers and complexity of need has, up to now, ensured that they are invisible. It is particularly important that attention is focused on the need for creativity in commissioning and service co-design, involving young people and their families, in order to make the most of limited budgets and to lever maximum benefit from a wide range of existing community resources and assets, including those of the young people and families themselves.
- In this regard, it is important that **the role of local Health and Wellbeing Boards** is addressed by the Transition Partners for further action on policy. There may be much to be gained from ensuring that transition is built into local Joint Strategic Needs Assessments (JSNA) and the Health and Wellbeing Strategies required by the Health and Social Care Act 2012. These are part of the roadmap of getting to shared understanding of what local NHS and local authorities need to commission and may represent a key method to raise awareness locally about the needs of

this group. For example, current consultation on the draft Birmingham City Health and Wellbeing Strategy (see www.bhwbb.net) is structured around six priorities proposed by the influential Marmot Review into Health Equalities in England (2010) subsequently accepted by government. One of the Marmot priorities states that local agencies should ‘enable all children, young people and adults to maximise their capabilities and have control over their lives’ and has particular salience in the context of this programme.

Recommendations

These recommendations are designed to ensure that any impact from the programme is sustained and extended by the Transition Partnership and new National Taskforce. As with many government-funded, time-limited initiatives, the danger is that, without further action, gains will be lost and committed people will feel cynical about change and improvement. The recommendations are also intended to show how young people’s engagement must be part of every action, not seen as a separate ‘nice to have’ activity.

1: Better evidence

Further efforts are needed to develop evidence-based policy to support better transitions. The extreme volatility of the policy landscape currently interacts with a series of underlying gaps in the evidence about the numbers, aspirations, strengths and needs of young people with life limiting conditions at transition to adulthood. This is of concern if the intention is to develop robust policies to ensure better outcomes from transition.

It is therefore recommended to the Transition Task Force that the recommendations set out in *Don’t let me Down* are supplemented, within the next 12 months, by a further series of policy proposals reflecting further research with young people and their families, in the following areas:

- **The scope and definition of palliative care needs** and the development of specific guidance for providers reflecting this
- **The impact of individual budgets on the experience of young people and their families.** This should include a consideration of any differential impacts of personal budgets for those with cognitive impairments.

There is an urgent need for policy and practice guidance in this area, particularly addressing the vital issues of the kind of support required to make individual budgets work for all without the imposition of major administrative burdens on young people and parents, the regulation and quality assurance of services provided through personal budgets, including safeguarding arrangements, and the stimulation of new providers at local level

- **Take account of the Programme’s work on black and minority ethnic communities in developing their activities and stakeholder network and in particular in stimulating further research into needs and assets in BME communities in the context of transition**

- Explore **options for funding and hosting a permanent National Learning Network for Transition** to ensure continued knowledge sharing and research translation

2: Better commissioning

Better commissioning requires better intelligence. There are continuing gaps in the data about the prevalence of life-limiting conditions amongst children and young people and what happens to them at adulthood, especially at local level. It is not yet possible to calculate or describe any impact from reforms to the NHS and social care on the transition experiences of this cohort. There is considerable anxiety amongst young people, parents, commissioners and clinical staff about the destabilisation of current arrangements when Clinical Commissioning Groups begin formal operations in April 2013.

It is therefore recommended to the Transition Task Force that further attention needs to be paid to how to ensure effective commissioning arrangements for young people with life-limiting conditions and complex health needs at transition, including:

- Detailed examination of the potential benefits of **centralised, specialised commissioning compared with devolved arrangements.**
- **Creating guidance for commissioners** of health and social care that addresses the need for creativity in commissioning and service co-design with young people and their families, in order to make the most of limited budgets and to lever maximum benefit from a wide range of existing community resources and assets, including those of the young people and families themselves.
- **Linking to the on-going Palliative Care Funding Review implementation** to ensure transition features in its work and the complexities of young people's requirements are understood

3: Better practice

This area focuses on the twin issues of workforce development and supporting tools and processes for transition. It refers importantly to the agreed top priorities from the June 28 event, which had an especially solid input from practitioners at all levels.

It is therefore recommended to the Transition Task Force to:

- Follow up the evident commitment to the work made by Paul Burstow MP and explore arrangements to **secure funding for continuing local developments** in discussion with hub and network sites
- Take up the [Top Ten priorities from the 28 June event](#) as a forward agenda for its work
- Explore **options for funding and hosting a permanent National Learning Network for Transition** to ensure continued knowledge sharing and practice development

- Engage with the **Royal Colleges and professional and regulatory bodies** to consider the feasibility of setting standards for multi-professional training in this area
- Explore with DH and other national stakeholders **the feasibility of developing a skills escalator** for working in this area, reflecting tested national models in other areas. See for example: <http://www.institutemh.org.uk/-education-/the-knowledge-and-understanding-framework>
- Continue to **support local work developing online tools** to assist at transition
- Ensure that the **education sector is involved** in the national taskforce at strategic and operational levels

4: Better policy

This is a key component of a better approach and has begun with the publication of *Don't Let Me Down* and the involvement of the Minister on June 28. However, continued advocacy for policy change may be needed both to implement the recommendations of *Don't Let Me Down*. **It is therefore recommended that the Transition Task Force:**

- Puts in place an initiative to develop **further policy proposals**, as discussed above, to supplement *Don't Let Me Down*
- Maintain **contact with the Minister** and relevant Ministerial colleagues to keep the transition agenda alive for them
- Ensure **local Health and Wellbeing Boards** are addressed for further action on policy and that transition is built into local Joint Strategic Needs Assessments (JSNA) and the Health and Wellbeing Strategies required by the Health and Social Care Act 2012.

5: Partnership working and dissemination

The limited duration of the formal second phase of the programme has meant that much more is known about the blocks to transition than what can be done to overcome them. The findings of the Programme suggest some mechanisms which may be promising in bringing about positive change. This challenges Marie Curie, The Transition Task Force and funders to maintain a learning approach to implementation beyond phase 2. The main risk to the achievement of the desired transformation lies in the willingness of all in the current system to accept the required disruption that inevitably accompanies the attempt to create a better one. In other words, to 'redesign the plane whilst flying it' (with thanks for this concept to [International Futures Forum](#)).

It is recommended that Transition partners and Marie Curie Cancer Care should commit to working to:

- **Rapidly disseminate this report in appropriate ways to key stakeholder and policy bodies i.e. ADASS, ADCS, LGA, NHS Confederation, NHS Commissioning Board**
- **Sustain highly promising initiatives of value from the second phase of the programme and, in particular, support the cohort of young people who worked in the engagement stream to secure sustainable funding for their continuing work**

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Notes

¹ The source for this phrase is Emily, a Paralympics *Gamesmaker*, talking about the difference that playing wheelchair basketball has had on her life. She was quoted by Sebastian Coe in his speech at the closing ceremony of the London 2012 Paralympic Games.

² See the report from Leeds University with Together for Short Lives: Fraser, L. et al (2011) *Life-Limiting Conditions in Children in the UK*, Division of Epidemiology, University of Leeds

³ 'Social networks' here is used to signify sets of personal face-to-face relationships, explicitly excluding so-called internet-based social networks.

⁴ The panel of 5 young adults, 18-22 year olds all attended a ½ day training with a participatory appraisal specialist to develop them as a group and help them to think through how they would approach the work of a grants panel. The panel met 9 times since September 2011, and held skype, email, msn and facebook communications. The length of their meeting days doubled from 2.5 hours to 6 hours despite people travelling from Liverpool, Norwich, outer London, and Birmingham. Attendance was exceptionally consistent and reliable although all of them had a least one episode of illness. One able bodied young person brought his perspective and added to the continuity of the group. Over £15,000 was awarded to over 70 successful applicants. 2 non verbal applicants were successful. Awards have been for £200 to £1500 for groups. Every successful, or potentially successful applicant was given a mentor (a grants panel member) to explore, develop, and support them. The activities supported ranged from a day out in London on the London Eye and a river cruise to awarding travel and accommodation costs to enable a power wheelchair football team to move into the premier league – which they won! Adapted camping equipment, new weapons for a UK level wheelchair fencer and a radio workshop, were some other successful applications.

⁵ It had transpired that several digital offerings had developed more organically from work on engaging young people and in pilot sites and these seemed more valuable and relevant to support than a whole new stream of work

⁶ The MyQuOL-T tool in Somerset, the Bristol work on provider guidelines, the Ambassador scheme are examples

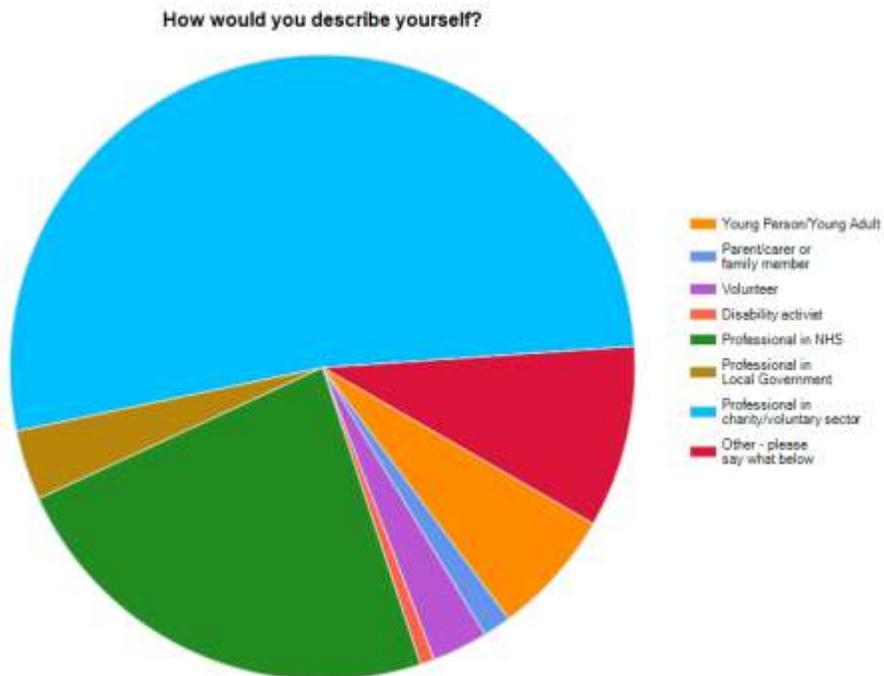
⁷ This diagram is an example of a 'Helvig Square' a thinking tool to help deal with paradox. See Marsh, S. and Macalpine, M. (1999) 'A 'really useful' tool for managing paradox', *Journal of Management Development* vol 18 no 8 - downloadable from <http://www.swampyground.org/papers.html>

Appendix A

This Appendix summarises the results of the programme's evaluation survey carried out online during June 2012 via 'survey monkey'.

About the people who completed the survey

Invitations to complete the survey were sent to everyone who had been in contact with the programme in any way. This included everyone involved in the pilot sites, in the engagement programme, the Learning Network, respondents in the evidence gathering, participants at the the High Visibility June 28th event as well as colleagues in Marie Curie and in the Advisory Group. The number of such invitations amounted to around 350 people.



139 people did the survey (around 40% response), of whom 83% completed all thirteen questions. The majority of those who did the survey were either professionals in the NHS (24%) or in the charitable sector (53%). 8% were young people or their parents.

The largest proportion of respondents lived in London (34%). 19% were from the Midlands or in the South East, 13% from Wales, 13% from the South East and 11% from the South West. There is a correlation between respondent home areas and the Marie Curie Programme pilot sites.

About two-thirds of these people had had direct contact with the Marie Curie Programme and a third had not. Of those with previous contact experience, a little over half had been involved in a local or regional event organised as part of the Programme. Many (42%) had participated in one or more of the three learning network events, had been interviewed as part of the evidence gathering work (22%), or had been part of the demonstration site activity (24%).

Of those who had not had previous contact with the Programme, almost half had found out through the 28th June event. A third found out about the Programme through a work colleague, a fifth through the Marie Curie website. Just under a tenth had found out through social networking (either Twitter or personal friendship).

How respondents felt about the Programme

Of those who had had prior contact with the Programme, 88% took a generally positive view of the Programme, 4% had a generally negative view and 8% had a neutral view. People liked the innovative, engaging and inclusive nature of the Programme events, which they found to be professional and well managed. They very much appreciated the way in which the Programme had been effective in foregrounding the role of the young people. Many felt that the programme had been successful in enhancing the national profile of Transition as an issue that required specific attention. Several commented on the way they valued the networking opportunities with others in the same business – perhaps a reflection of the perceived isolation of one [hospice?] from another. A residual anxiety is about longer-term impact and this was well put by a respondent who hoped, ruefully, that “this would not be another shooting star project”.

There were few negative views about the programme, so it is difficult to find clusters of opinion. Two comments were mentioned referred to two issues that at least another person had also mentioned; first that “the constant sense of urgency was irritating” and second that it seemed that “the Programme was too broad... lacked structure and leadership”. The second of these is particularly interesting when considered in relation to the appreciation of the inclusiveness and the “ability to shape the flow of the events” –perhaps for some, the benefit of the latter may come at the cost of the former.

Had respondents experienced any change as a result of the Programme?

Almost half of those who replied believed that the Programme had effected positive changes; another fifth thought that there might have been a positive impact. Thus, 66% of those answering this question believe that the Programme either has or might have effected a positive change.

What leads them to believe this? There seems to be consensus around three principal factors.

The young people who have been involved in the Programme report positive impact on themselves, for example, “I have been supported to start my own business selling my handmade crafts and photography. I've met wonderful people and I'm having great opportunities”. This is supported by the views of people who work closely with young people. Several report that those young people involved appear to have “grown in confidence and in their ability to challenge decisions that don't meet their needs” ... I have seen young people with disability become more confident through their involvement with MC and I've seen very positive co-working and combining of resources which ultimately leads to a better service.”

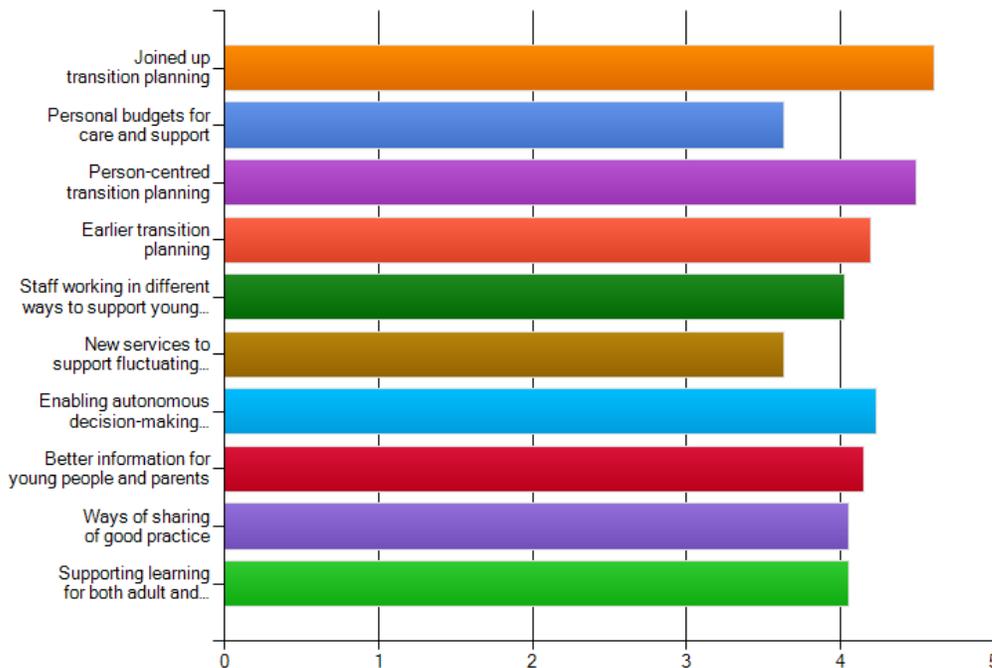
By far the most common observations of positive outcome come from the professionals who work in the care services. Here are some of the impacts they mention:

- *growth in awareness & interest ...* “more insight into young people...better understanding of transition locally, better links with adult services, young adults are receiving better care as a result of the project. The project has helped raise awareness of an emerging client group for which little services exist which are targeted and meet need...transition higher up the agenda of agencies”
- *compelling reason to work together better ...* “there is a lot more joined up working around young people with palliative care needs and transition... increased interest and drive to develop joint working... I chair a children's palliative care transition sub group and have now got adult palliative care nurses to join us on that group. From networking as an organisation we find it easier to phone and ask re queries we may have, they may not be able to take referrals but now they are willing to help us find a solution.”
- *more effective links between children's and adult's services...* “As I work in adult services I was made aware of the challenges young people face during the transition between services. This encouraged me to develop a network of people within my local area and arrange a meeting to look at what we can do to help the process.... It has influenced our work with young people and made us look at new ways to engage. It has also informed our discussions about upper age limits...We have begun to support a young person as part of their transition activities. This has developed our relationship with the locality children's hospice”.

Marie Curie staff (MCCC runs nine adult hospices nationally) report their view that the organisation is now much more sensitised to the needs of young adults and their potential future clients. The fear of inundation by demand has receded and there seems a willingness to think about the implications of young adult admission. Nevertheless some anxiety and uncertainty remains about the perceived absence of direction from MCCC national leadership.

Factors that make the biggest difference to young people's experience of transition

People are telling us that the following changes will make the most difference to young people's experiences at transition? Do you agree? Use the scale to show us how important you think these changes are. If there are other changes you think are more important add them in the Other box.



Clearly, the fact that respondents (112) see all ten factors are seen as important validates the factors identified through the work of the Programme. The five perceived to be most important are:

1. joined up transition planning
2. person-centred transition planning
3. enabling autonomous decision-making
4. earlier transition planning
5. better information for young people and their parents.

Nine people added other factors. While it is not possible to gauge the weight these should be given, it is worth identifying them:

fast-track funding allocation to avoid the lengthy process during which a young person may die... current practice is not good enough...need a can-do attitude!

Expedited care packages... for terminal care and periods of increased uncontrolled symptoms

without needing admission to hospital.

Health and Social Care working together better in relation to Personal Budgets... alignment of currently different rules about how Health/Social Care funding can be spent, which may impede person-centred support plans.

Issues independently raised by respondents

An aim of the June 28th event was to stimulate *personal commitment to action*. It was therefore warming to see statements such as the following: “I would like to know what I, personally, can do to help young people with palliative care needs to live a normal life. I don't have loads of time to offer and my work doesn't focus on this, but I would like to do something, even if it is really small. I would happily meet up a young person in my area and do something for/with them on an occasional basis, write to my MP, send a donation to the project - whatever might be helpful. It would be lovely if someone could get back to me about this [email address given].”

Another respondent was keen that the learning from this Programme should be fed into the “reforms to the SEND system. Soon to be published Children and Families bill will legislate for a 0-25 Education Health and Care plan, personal budgets and more choice and control”. As wider influencing was another aim of the June 28th event, this suggestion will be put to MCCC's Director of Policy.

A number of people were stimulated to urge themselves to *think and behave more laterally*. “Must think laterally/out of the box as money is short and that will not change. Look at different ways of offering respite/ holidays /breaks for YP and families by using Charities More For example, Jumbalance Trust for Accessible holidays. They use volunteer nurses, doctors and carers so costs are much lower and you get a real holiday not just a week in a Care Home/Hospice”. Another observed: “Move away from traditional models - e.g. hospice care, and start thinking outside the box. Don't try to fit round pegs into square holes! What can we do to encourage independence in young people with complex disability?” Others, in a variation on the joined-up theme, were struck by the opportunity to learn from each other: “I think training for both adult and pediatric services is a priority as there is a wealth of experience and knowledge out there but it needs to be shared.”

Similarly, there was a sense of *urgency about the need for change*: “Funding assessments should be a joint and straight forward process and bickering about who pays what should stop and the needs of young people and their families should be paramount. These young people need the funding there today to get the most of their shortened lives.”

Several respondents in the survey as a whole wonder how *Marie Curie* will be taking forward the

agenda that has emerged, in terms both of leadership and network management. “How does Marie curie intend to take things forward from here? You have gathered a lot of information on their behalf, and started some good things- how will Marie Curie ensure these projects are supported to continue? What will they do with all that valuable information? Where will it lead them? We would like information /feedback from them about this.”

Finally, many referred to PSW, admiring their approach to this work as *innovative, creative, inclusive and effective* as learning. “Really appreciate the opportunity to be part of the work and am sorry it is coming to an end. The shared sessions were incredibly valuable and helped to spark transferable ideas. Thank you for the opportunity”. Another said: “Participating in the Programme has been an educative and enjoyable experience. It has been timely for our service, as we are planning a new-build hospice and are committed to supporting those with palliative and end-of-care needs in our community.”

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Appendix B

Below are the Top Ten Priorities that emerged from the discussions and voting at the 28 June High Visibility event at the Oval, London.

Over 200 people took part in the event, drawn from across relevant sectors, principally health care, social care, the voluntary sector and research. Over 10% of attendees were young people and their carers/parents. A comparatively large number of participants were clinicians (from both the hospice movement and the NHS), with somewhat smaller numbers of managers and commissioners. There was a small group from the education sector.

The participants worked during the afternoon in small groups. They self-selected to work on one of the four high-level blocks-to-progress identified in the in figure 2 (page 14): history/culture; policy and legislation; systems; practice. Their goal was to identify ways of overcoming the blocks. This process resulted in a large number of proposals for action. All the proposals were displayed and participants took part in a voting process designed to identify the top priorities for moving transition work forward in the next year. It was expected that the top proposals would form a forward agenda for action by the new national Task Force on Transition.

Rank	Votes	Priority for Action
1	94	Include young adults and carers in training all professionals
2	84	That the adult social care white paper and the Children and Families Bill have the same policy on transition. Government depts leading by example on working together and listening to what each other are doing.
3	81	Statutory obligation for health and social care to be involved in 14 plus transition reviews that are already carried out by education.
4	71	For all young people to have an advocate during transition period
	71	Personalisation to be rolled out for all so they can take control of their life. - education not ignorance.
5	69	Cross over training between adult and children's services and both ways
6	64	Amplifying the voice of the young people in order to shape and promote the services available
7	61	Equality of funding between services and collaboration between adult and children services.
8	50	Allocated key worker / professional taking the lead to utilise resources that are already available e.g. hospice
9	49	To legislate for a common, shared transition tool to facilitate speedier decision making
10	48	GPs need to be included as someone that tracks child's support through their life. They shouldn't be afraid of being seen to provide specialist care.

Appendix C

This appendix is intended to help researchers and practitioners easily to locate material generated by the programme.

The listings below show in various ways the material available at www.mariecurietransitionprogramme.wordpress.com

- 1 listing according to webpages on the site
- 2 listing according to key programme activities
- 3 alphabetical listing

1 Website page listing:

Web page	Documents downloadable on the page	Brief details
Evidence gathering: what were our questions – and what were the answers?	phase 1 full report ; executive summary of phase 1 report ; Annexes to phase 1 report	Full findings and summaries of phase 1 evidence gathering work Jan – March 2011
	'Making the Most of Life' short report	An accessible more visual version of the Phase 1 work
Evidence gathering in Phase 2	BME and faith report completed through series of interviews June/July 2012	Short exploration of Muslim and Jewish experience in order to bring wider minority ethnic and faith issues into focus
	Transcript of a 'staged reading' using stories from young people	Perspectives from young people formed part of Programme events in June 2012, with this piece read by young people
	Perspectives from the Education sector – report completed through series of interviews June/July 2012	The report begins to fill a notable gap in Phase 1 work through distilling a range of experience from education professionals.

	Reflections on interviews with commissioners ; East Anglia Commissioner Quotes ; East Anglia Parent Quotes ; presentation on the material	Perspectives from commissioners and from carers/parents based on the East Anglia pilot site. This work was also presented on 28 June 2012
	Themes from workers' interviews	Perspectives from frontline staff working with the young people in transition
	Final volunteering report Solihull ; vol/befriending summary	A scoping study into befriending and volunteering between young people and their peers was carried out in Solihull

Engaging young people: how can young people be supported to live their lives as they wish?	The Excellence Programme: summary	Report on the development of a group of young entrepreneurs involved in fashion design for wheelchair users; software games; graphics/animation/ music/craft businesses
	Choices 4U Small grants scheme information ; choices4u grant scheme summary poster 1 ; choices4u summary poster 2. Also link to a short video young people made as part of their evaluation of the scheme.	Material produced around the programme's small grants scheme that not only produced value for grant recipients but also brought key development gains for the young people who ran the scheme that programme designers never foresaw and which were inspiring.

	Links to the blog and promotional video for The Strengths Game	A strand of work developed by young people to create a unique web based game using real stories of disability and aimed at a wide audience
Publications: how did we share our work and recommendations?	Programme newsletters - September 2011 ; December 2011 ; March 2012	These described programme work, especially writing up the experience of the learning network meetings
	<i>'Living longer than you thought I would'</i>	Report from St Oswald's Hospice with PSW on their experience developing a specialist Young Adults service, including issues of commissioning
	Workforce development – Shadowing Scheme Learning support materials units 1 & 2	<i>Developed for the Adult to Children's palliative care services shadowing scheme in Penarth, South Wales, March-May 2012</i>
	'Snakes & Ladders' Discussion tool	<i>Developed in Solihull to help create earlier conversations about transition with all those involved</i>
	Report of Hi Viz regional event in East Anglia	Regional event jointly with EACH April 2012
	Report of High Visibility event June 2012	Reporting on the national end-of-programme event
	Programme posters x 2	<i>These posters summarise the work and were prepared for High Visibility event June 2012</i>
	<i>'Don't Let Me Down'</i>	<i>Policy proposals document jointly produced with Transition Partnership organisations and launched at House of Lords 27 June 2012</i>

London's work	Model of care ; 6 case studies of young people's situations at transition	The model of care was trialled through the work of a dedicated transition team in the East London pilot site comprising nurse and social worker expertise. Case studies from this work can be used for staff development
Somerset/Avon's work	Transition planner for trialling; introduction to transition planner for professionals. Also link to MyQuOL-T web tool and app for user tracking of quality of life	A transition planner that young people hold and share with their professional support circle. Based on a successful format already in use for young people with cystic fibrosis & initially envisaged as a paper planner, now under development by SEN team at Somerset County Council to create an online planning tool more suited to young people with cognitive impairments.
Workforce development: how can staff be supported to meet the challenges transition poses them?	Shadowing scheme in S Wales: summary poster; report summing up the project; learning materials units 1 and 2	The shadowing scheme in March-May 2012 enabled staff in adult palliative care to learn from colleagues across relevant children's services. Learning materials supported both shadowers and those being shadowed
	Support sessions in London with transition workers: summary	<i>PSW offered staff in London a monthly mentor/support session with a skilled facilitator. This proved very valuable and yielded important learning.</i>

<p>Programme events: how and when did people get together during the Programme?</p>	<p>Learning network proceedings: 1st Learning Network London ; 2nd Learning Network Birmingham ; 3rd Learning Network Bristol</p>	<p>Learning Networks involving pilot sites took place in October 2011 in London, on 2nd February 2012 in Birmingham and 27th March 2012 in Bristol. They were viewed as a key part of the Phase 2 work.</p>
	<p>Documents relating to High Visibility event 28 June: plan of day; Hi Vis brochure ; diagrams focusing afternoon discussions ; transcript of Staged Reading by young people ; feedback summary ; High Visibility report of day</p>	<p>This final Programme event at the Kia Oval in London attracted 220 people. Material from the day beyond these documents is hosted at www.act.org.uk/highvisibility</p>
<p>Pilot Site events</p>	<p>Solihull events: 6 December 2011 programme ; report 6 December 2011 ; stakeholder event report 11 May</p>	<p>2 stakeholder events took place in Solihull to develop a local network and priorities for action, both attracted 20-30 people.</p>
	<p>Somerset/Avon commissioners' event notes:</p>	<p>Gaining the perspective of a range of commissioners was viewed as critical for progress & with both adult and children's commissioners involved in the network group here, a special meeting was convened in January 2012</p>

	<p>London stakeholder event 22 March 2012: Invitation; Follow up notes</p>	<p>The London site was keen to expand its local contacts and network in order to support a broader support system for young people as envisaged in the model of care being trialled; a well attended event was held in March 2012</p>
	<p>East Anglia Hi Viz event: High Viz invitation ; High Viz Event report:</p>	<p>The East Anglia pilot site held a large regional event focused on combating invisibility of this group of young people. Senior commissioners and regional leads were among the 90 people who attended the event in Bury St Edmunds on 24 April 2012</p>
<p>Putting it all together locally: what needs to happen on the ground for young people to achieve a decent life?</p>	<p>System development diagram ; accompanying notes on local system development approach ; local action poster</p>	<p>The programme's work with the 6 pilot sites helped to give a picture of what elements need to be in place in an area to support transition and help young people achieve a decent life in adulthood. The learning about the key elements is summed up in the diagram and accompanying notes. The programme's overall view of how best to put it all together locally is illustrated in the poster</p>

<p>Materials for local development work</p>	<p>Programme materials: criteria for pilot site choice; information sheet on local work with sites; framework of ‘statements of intent’ to focus longterm goals and ‘milestones’; example of site milestones and progress as at May 2012.</p> <p>Site developed material: model of care used in London & London transition team summary poster ; Solihull befriending and volunteering publicity poster & ‘Snakes and Ladders’ discussion tool</p>	<p>Materials the programme created to develop and support sites plus materials developed in sites helpful to people working locally in their own areas.</p>
<p>... and what needs to happen nationally for local work to thrive?</p>	<p><i>‘Don’t Let Me Down’</i></p>	<p>Policy document produced with the Transition Partnership (Together for Short Lives, Help the Hospices, National Council for Palliative Care) working with Marie Curie Cancer Care and drawing on the programme’s work.</p>
	<p>Programme summary of policy potential</p>	<p>A tabular guide to possibilities for policy change, based on key goals for change arising from the programme’s work: tackling system fragmentation, increasing visibility, mainstreaming individualised care and personalised services and equipping the broad workforce to work more effectively</p>

	Image of the dimensions needed for a decent life for young people after transition to adulthood; image of the core blocks to good transition.	These 2 key images informed discussions on 28 June at the programme's final event
	Summary of commissioning issues raised May 2012	The work on commissioning carried out in Somerset/Avon, in East Anglia, at learning network meetings, enabled the gathering of local and subnational policy issues on flows of funding.

Listing of materials by key programme activities

(brief details on each item are included in the listing above)

Activity	Materials	Link
Phase 1 evidence gathering	Full findings and summaries of phase 1 evidence gathering work Jan – March 2011 ;	Evidence gathering: what were our questions – and what were the answers?
	'Making the Most of Life' short accessible report	Evidence gathering: what were our questions – and what were the answers?
Phase 2 evidence gathering	Themes from workers' interviews	Evidence gathering in Phase 2
	<i>Programme summary of policy potential</i>	... and what needs to happen nationally for local work to thrive?

	<i>Image of the dimensions needed for a decent life for young people after transition to adulthood; image of the core blocks to good transition.</i>	... and what needs to happen nationally for local work to thrive?
	<i>Summary of commissioning issues raised May 2012</i>	... and what needs to happen nationally for local work to thrive?
	(see also 'programme publications' below)	
Young People's Engagement	The Excellence Programme : summary	Engaging young people: how can young people be supported to live their lives as they wish?
	Choices 4U Small grants scheme information ; choices4u grant scheme summary poster 1 ; choices4u summary poster 2. Also link to a short evaluation video by young people	Engaging young people: how can young people be supported to live their lives as they wish?
	Links to the blog and promotional video for The Strengths Game	Engaging young people: how can young people be supported to live their lives as they wish?
	Transcript of a 'staged reading' using stories from young people	Evidence gathering in Phase 2
Hubs and Networks	<i>Criteria for pilot site choice ; information sheet on local work with sites ; framework of 'statements of intent' to focus longterm goals and 'milestones' ; example of site milestones and progress as at May 2012</i>	Materials for local development work

Pilot sites	East Anglia: Reflections on interviews with commissioners ; Commissioner Quotes ; Parent Quotes ; Presentation ; Report of <i>Hi Viz</i> regional event in East Anglia April 2012 ; <i>High Viz invitation</i>	Evidence gathering in Phase 2 Publications: how did we share our work and recommendations? Pilot Site events
	London: <i>Model of care ; 6 case studies of young people's situations at transition ; Worker support sessions summary ; stakeholder event 22 March 2012 Invitation & Follow up notes</i>	London's work Workforce development: how can staff be supported to meet the challenges transition poses them? Pilot Site events
	Newcastle: <i>'Living longer than you thought I would'</i> Report on experience developing a specialist Young Adults service	Publications: how did we share our work and recommendations?
	Penarth South Wales: shadowing scheme <i>learning support materials units 1 and 2; summary poster; report summing up the project</i>	Publications: how did we share our work and recommendations? Workforce development: how can staff be supported to meet the challenges transition poses them?

	<p>Solihull : Final volunteering report; vol/befriending summary ; ‘Snakes & Ladders’ Discussion tool ; 6 December 2011 event programme ; report 6 December 2011 ; stakeholder event report 11 May</p>	<p>Evidence gathering in Phase 2</p> <p>Publications: how did we share our work and recommendations?</p> <p>Pilot Site events</p>
	<p>Somerset/Avon: Transition planner for trialling; introduction to transition planner for professionals. Also link to MyQuOL-T web tool and app for user tracking of quality of life ; commissioners’ event notes</p>	<p>Somerset/Avon’s work</p> <p>Pilot Site events</p>
	<p>Local system development diagram ; accompanying notes on local system development approach ; local action poster</p>	<p>Putting it all together locally: what needs to happen on the ground for young people to achieve a decent life?</p>
Programme publications	<p>BME and faith report completed through interviews June/July 2012</p>	<p>Evidence gathering in Phase 2</p>
	<p>Perspectives from the Education sector – report completed through interviews June/July 2012</p>	<p>Evidence gathering in Phase 2</p>
	<p>Programme newsletters - September 2011 ; December 2011 ; March 2012</p>	<p>Publications: how did we share our work and recommendations?</p>
	<p>‘Don’t Let Me Down’ policy document</p>	<p>Publications: how did we share our work and recommendations?</p>

Programme events	Report of High Visibility event June 2012 Documents relating to High Visibility event 28 June: plan of day; Hi Vis brochure ; diagrams focusing afternoon discussions ; transcript of Staged Reading by young people ; feedback summary	Publications: how did we share our work and recommendations? Programme events: how and when did people get together during the Programme?
	Learning network proceedings: 1st Learning Network London ; 2 nd Learning Network Birmingham ; 3 rd Learning Network Bristol	Programme events: how and when did people get together during the Programme?

Alphabetical listing

Item	Activity	Link
1st Learning Network London	Hubs & networks	Programme events: how and when did people get together during the Programme?
2 nd Learning Network Birmingham	Hubs & networks	Programme events: how and when did people get together during the Programme?
3 rd Learning Network Bristol	Hubs & networks	Programme events: how and when did people get together during the Programme?
BME and faith report	Publications	Evidence gathering in Phase 2
Case studies	Hubs & networks	London's work
Choices 4U Small grants scheme	Young People's Engagement	Engaging young people: how can young people be supported to live their lives as they wish?

Commissioning : commissioners' event notes; interviews; summary of issues	Hubs & networks	Pilot Site events Evidence gathering in Phase 2 ... and what needs to happen nationally for local work to thrive?
Core blocks to good transition	All programme	... and what needs to happen nationally for local work to thrive?
Dimensions of a decent life for young people after transition to adulthood	All programme	... and what needs to happen nationally for local work to thrive?
<i>Don't Let Me Down</i> policy document	Publications	Publications: how did we share our work and recommendations?
Education sector report	Publications	Evidence gathering in Phase 2
Excellence Programme	Young People's Engagement	Engaging young people: how can young people be supported to live their lives as they wish?
High Visibility event June 2012 report and associated documents	Events	Programme events: how and when did people get together during the Programme?
Learning & development: shadowing scheme report & learning support materials; staff support	Hubs & networks	Workforce development: how can staff be supported to meet the challenges transition poses them?
Local system development diagram, notes & poster	Hubs & networks	Putting it all together locally: what needs to happen on the ground for young people to achieve a decent life?

<i>Making the most of life</i> summary report	Phase 1	Evidence gathering: what were our questions – and what were the answers?
Model of Care	Hubs & networks	London's work
My QuOL-T web tool	Hubs & networks	Somerset/Avon's work
Parents: Parent Quotes; Presentation	Hubs & networks	Evidence gathering in Phase 2
Phase 1 report	Phase 1	Evidence gathering: what were our questions – and what were the answers?
Pilot site development & planning	Hubs & networks	Materials for local development work
Policy potential	All programme	... and what needs to happen nationally for local work to thrive?
Programme newsletters	Publications	Publications: how did we share our work and recommendations?
Snakes & Ladders tool	Hubs & networks	Publications: how did we share our work and recommendations?
Specialist Young Adults service: Newcastle report	Hubs & networks	Publications: how did we share our work and recommendations?
Stories from workers	Hubs & networks	Evidence gathering in Phase 2
Stories from young people	Young People's Engagement	Evidence gathering in Phase 2
Strengths Game	Young People's Engagement	Engaging young people: how can young people be supported to live their lives as they wish?
Transition planner & intro for professionals	Hubs & networks	Somerset/Avon's work
Volunteering & befriending:	Hubs & networks	Evidence gathering in Phase 2