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**PUBLIC
SERVICE
WORKS**

**EXECUTIVE SUMMARY
[‘LIFTING THE CLOUD OF
LIMITATIONS’
ACHIEVING A FULL
ADULT LIFE: FINAL
REPORT OF THE MARIE
CURIE YOUNG PEOPLE &
TRANSITION
PROGRAMME]**

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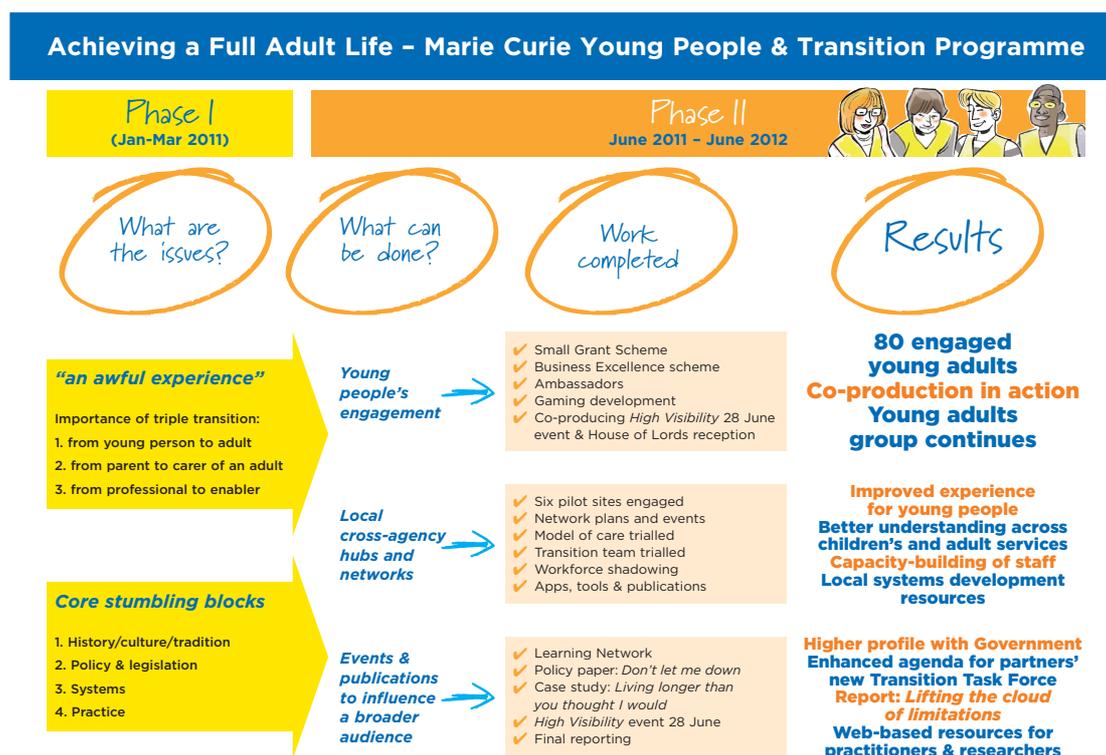
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Introduction

What is the report for?

The Marie Curie Cancer Care Young People and Transition Programme explored ways to improve the difficult and often unsatisfactory experience of a planned transition to adulthood for young people with life-limiting conditions.

As a core principle, the programme 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 wellⁱ. All elements of the programme were shaped by the belief that young people themselves, along with those who support them, can best co-produce ways of working towards their desired lives. By exploring with them creative ways to support their strengths and aspirations and therefore to challenge the traditional, needs-based focus of many services, the programme has complemented a range of other initiatives across the UK.



This report records plans, actions and developments during phase 2 of the Marie Curie Young People and Transition 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.

Who is it for?

The report 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
- 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.

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. These include family relationships and sexuality; and education, housing, work and transport. 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. The principles of co-design and co-production are outlined and described in action.

The section **concludes** that the aim of transition planning must be to ensure that all the 'enabling' dimensions are considered, and that there is effective coordination of broadly based support.

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

Section 1 showed the direction in which people want to travel. This section looks at what holds them back.

Over eighteen months, the programme uncovered a consistent picture of the major blocks to good transition, grouped here under the broad headings of 'history, culture and tradition', 'policy and legislation', 'systems', and 'practice'.

These blocks are described and analysed in the light of the ‘triple transitions’ that have to be negotiated successfully if young adults’ lives are to show a marked improvement. These are:

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

In practice, this means taking account of young people’s aspirations, the stress and anxiety of their parents, and the concerns of professionals.

The section **concludes** that the current fragmented systems militate against a holistic view of transition, and that 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.**

The section **concludes** that 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

Working from explicit co-production principles: Co-production requires a fundamental shift in mind-sets and cultures for both professionals and service users. 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.

Facilitation skills: The importance of support from staff with really excellent facilitation skills was highlighted throughout the programme.

How to plan work which is by nature 'emergent'

It was clear early on that, because of the complexity of the programme, the work needed to be seen as emergent rather than entirely susceptible to a linear project planning model. 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.

How to approach local systems development

The programme had 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 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. 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.

Importance of motivating both people and organisations

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 the necessary support to both professionals and organisations.

Good value for investment of even small sums

Learning from the programme suggests that investment of relatively small sums of money can make a substantial difference.

The section **concludes** that 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 as follows:

Better evidence

It is 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

Better commissioning

It is 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

Better practice

It is recommended to the Transition Task Force to:

- Follow up the evident commitment to the work made by Paul Burstow 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 work
- 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

Better policy

It is 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.

Partnership working and dissemination

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

Detailed material and outputs from the programme is stored online for public access at www.mariecurietransitionprogramme.wordpress.com

ⁱ 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.