The Transition Taskforce

Transforming transition for young people with life-limiting and life-threatening conditions 2016-18

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1. DEFINING THE PROBLEM

Transition is commonly described by those working with young people with long term health conditions as “…a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems.” (Blum RW et al, 1993)

There is a particular problem for young adults with life-limiting and life-threatening conditions, many of whom are now living in to adulthood due to advances in medical and therapeutic technologies, because services have not yet been developed to support this cohort of young people. There is also an urgency to address the issue of transition for these young people as their lives are likely to be short. They do not have the luxury of time.

We are concerned particularly with the cohort of young people who have been, or could have been, using children’s palliative care services. This cohort includes young people with a range of conditions. Some will have high cognitive functioning but complex health needs, others will have mild or profound and multiple learning disabilities as well as a high level of medical and nursing needs.

The fact that young people with life-limiting conditions have deteriorating physical health may make transition planning a challenging prospect and indeed is a reason why some young people and their families find that transition planning does not happen – because children’s services hold on to the young people in their care, either because they don’t feel there are appropriate adult services to support them or because they feel the young person is too unwell to consider moving on to adult care. It can get in the way of planning for a future in adult services and make it difficult for children’s services and families to “let go”.

There is a tendency within health services to focus on treating the young person’s condition so as to ensure their survival into adulthood, but this does not support them to plan for their futures in a more holistic way. These young people face multiple issues, not only with accessing the right level of health and palliative care services that can support their degenerative and unpredictable conditions, but also in achieving other life goals such as education, friends and relationships, meaningful occupation and living arrangements that are right for them. For some young people this will mean them living relatively independently, for others it will mean finding a suitable residential care provision that can meet their complex needs and support their inclusion in the community. We support the concept of person-centred care, whereby plans are made in partnership with young people (and/or with their parents/carers if appropriate) and are strengths based, looking to enable young people to reach their potential.

The Transition Taskforce wants to reduce these barriers to good transition for young adults with life-limiting conditions. With the right partnerships in place and the right training and support, young people with life-limiting conditions can be supported to be well cared for and achieve their aspirations in a wide variety of settings by a wide variety of agencies.
The challenges in health, social care, education, employment & housing

Health

We recognise that it is the complex health needs of young people with life-limiting conditions that makes their transition to adult services more difficult. Much of the focus of the Transition Taskforce is therefore on ensuring that children’s and adults’ health and palliative care services work together and are equipped to support young people with their transition to adulthood and settling in to adult health services.

Young people with life-limiting conditions will be using a range of health services. As children they will have had a paediatrician overseeing their care as well as condition-specific consultants (‘ologists) and are likely to have used the support of a community children’s nursing team as well the support of a local children’s hospice or palliative care provider. There is no direct equivalent for many of these children’s health professionals in adult services which means that health transitions are complex and require long-term planning and joint working between children’s and adults’ health professionals, as set out in our Stepping Up framework.

In children’s services, palliative care is an approach that is provided from the point of diagnosis and which can extend over many years. Adult palliative care tends to be provided only towards the end of a person’s life, normally the final twelve months. Because of this many young people currently find that they do not meet the criteria of adult palliative care.

On the other hand there are many young people who are diagnosed with a life-threatening condition in their late teenage years (in particular those with cancer), we know that these young people have less of a struggle to access adult services because their conditions are well recognised by adult services and provision is available through organisations such as the Teenage Cancer Trust.

Many young people with long term life-limiting conditions also find that they do not meet the threshold for adult continuing health care services and struggle to secure care packages that can fully meet their medical and nursing needs. The Transition Taskforce is specifically seeking to support this group of young people.

There are initiatives within the health sector to improve transition such as the NICE Transition Guidelines published in 2016 and the Ready Steady Go programme. We need to ensure that such initiatives meet the needs of young people with life-limiting and life-threatening conditions.

We see that in focusing on meeting the complex health needs of young people, we can enable and empower them to access the range of other agencies and services that can help them to achieve what is important to them in adult life, such as social care, education, employment and housing.

Social care

In England, responsibility for supporting children and young people with disabilities sits in social care, with local authorities. The Special Educational Needs and Disability (SEND) reforms have a transition programme called Preparing for Adulthood. We recognise that
most young people with life-limiting or life-threatening conditions will have the same needs as those classed as being disabled. The principal differences are the unpredictable and degenerative nature of life-limiting or life-threatening health conditions, which means that they have a higher need for support from health and palliative care services and means that adult health care and/or local hospice and other palliative care services need to be part of the planning and be available and equipped to provide 24/7 symptom control and end of life care as and when required.

We recognise that if we work with partners, such as Preparing for Adulthood, to improve the support available for disabled young people, we will improve much of the support that is needed for young people with life-limiting conditions too. The PfA programme is working towards achieving life outcomes for disabled young people relating to employment, independent living, community inclusion and health.

Education

Education providers have a statutory duty to provide education for disabled young people as part of their Education, Health and Care Plan. Specialist colleges for disabled young people are working towards expanding their provision to meet the needs of young people with more complex disability and learning difficulties.

Employment

Whilst full-time paid employment may be difficult to achieve for the majority of young people with life-limiting conditions or not be appropriate for those with profound and multiple learning disability, where possible young people should be enabled to contribute meaningfully to society. This might be through paid work, setting up a small business or cottage industry, doing an internship or volunteering with a charity. The PfA programme and organisations such as the British Association of Supported Employment are working to break down the barriers to employment for disabled young people and there is much to learn from their approach and how this could be adapted or extended for young people with life-limiting conditions who may need additional support to achieve their employment goals.

Housing

Some young people will want greater independence and may wish to live outside the family home. There are a variety of housing options they may wish to consider, such as buying or renting another property, sheltered housing schemes, supported housing in the community or through shared living schemes (formerly called adult placements). We want to work with a variety of partners to stimulate the development of a range of living arrangements which have the necessary health support underpinning the provision as well as access to community, social, education and employment opportunities.

Transitional care must involve young people, their families and/or carers as well as paediatric and adult care providers in health, education, social services and the voluntary sector. (McDonagh 2006)
2. TRANSITION TASKFORCE: PHASE 1 (2013-16)

The Transition Taskforce Approach

Together for Short Lives established a UK wide Transition Taskforce in 2013 to focus on the specific needs of young people with life-limiting or life-threatening conditions, including, but not limited to, their health-related and palliative care needs. The Transition Taskforce is a collective of professionals, services and organisations who have indicated that they wish to play a part in developing improvements to the transition process for young people with life-limiting conditions and/or in the support that they receive as adults to enable them to enjoy life and achieve what is important to them. It is inclusive, working with everyone who has an interest in resolving the question of transition for young adults with life-limiting or life-threatening conditions, in particular those from adult services. The Transition Taskforce includes within its membership expert individuals from across the spectrum of professional backgrounds, sectors and provider organisations across the UK.

The Taskforce is led by an executive team based at Together for Short Lives whose aim is to develop a coordinated approach to providing integrated planning and delivery of care and support for young people with life-limiting or life-threatening conditions as they make the transition from children’s to adult services.

Transition Taskforce Mission Statement

We redefined our mission statement at the end of the first phase of the Taskforce, to combine the former Vision and Mission into one overarching mission statement:

“All young people with life-limiting or life-threatening conditions should make the transition to adult services and live their lives according to their wishes, while receiving the care and support they and their families/carers need. We will overcome the barriers to good transition by building bridges between children’s and adult services.”

Stepping Up: our blueprint for a good transition

The Taskforce approach is based on the model set out in the Together for Short Lives ‘Stepping Up’ Guide, published in 2014, which provides a system-wide blueprint for planning transition for young people with life-limiting or life-threatening conditions across all agencies. In this guide, transition can be broken down in to three phases:

- Preparing for adulthood
- Early days in adult services
- Ongoing care and support in adult services (the Pentagon)
It sets out five key standards that should be achieved and breaks these down into a series of goals that will lead to the achievement of each standard. It also sets out some key outcome indicators for both young people and families.

It provides a generic template that can be adapted and applied to local service configuration and has an accompanying ‘self-audit’ tool that can be completed by both services and young people to assess where there are key gaps in services and where attention should be focussed.

The *Stepping Up* framework is a young-person centred approach which also takes account of the needs of families. The approach is about meeting the whole range of needs of a young person and their family, from recognition of the need to plan for transition, making the move to adult services and providing ongoing support within adult services. The approach advocates that planning for transition needs to start early, by age 14, and that parallel plans are in place both to maximise life opportunities and to ensure that the young person has the best possible end of life care, should this be needed.

The young person’s health care needs are an essential part of this support, however it is not just a ‘health’ problem and the guide describes a ‘Pentagon’ of support that should be planned for with all young people.

A key section of Stepping Up is about ensuring that young people are settled in adult services and this is a key element of the Transition Taskforce approach, seeking to match the balance from children’s service “push” to adult services “pull”.

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**Diagram**

[Diagram showing the 'Pentagon' of support with sections for Education, Work/life balance, Social care, Healthcare, and Housing.]
3. Review of Progress to Date

During its first three years of operation, the UK Transition Taskforce has delivered against all the milestones that were set out in our initial 3-year funding award from the Department of Health (England). An external evaluation of this activity, being carried out by Coventry University, is due for delivery at the end of April 2016.

As part of this DH funding, we have achieved the following:

- Established Regional Action Groups (RAGs) in all 8 regions of England and joined with National Forums in Scotland, Wales, and a formative group in Northern Ireland.
- Developed and published a new framework on transition for young people with life-limiting conditions called ‘Stepping Up’
- Published guidance for Clinical Commissioning Groups on commissioning transition services for young people with life-limiting conditions.
- Published new online resources for young people themselves on Personal Budgets, with a new online guide for young people on transition (reflecting the Stepping Up framework) due by the end of April 2016.
- Jointly published a new guide on sexuality and relationships for young people with life-limiting conditions, with the Open University.
- Set up a committed group of Young Avengers who have co-produced our materials for young people and represented the Taskforce at various parliamentary and media events.
- Inputted to a number of key policy initiatives including the CQC report ‘From the Pond into the Sea’ and the new NICE guidance on transition, both of which highlight the particular needs of young people with life-limiting and life-threatening conditions.
- Held four 2-day masterclasses on transition in London, Glasgow, Leeds and Belfast, aimed at adult hospice and palliative care professionals.

Overall the achievements of the first three years have been to raise awareness with a variety of stakeholders, to create an infrastructure and develop resources that will be needed to deliver the range of service developments and improvements that we wish to see in the next strategic period.
We now need to assess where there are gaps in awareness, turn awareness in to motivation and action, assess whether the infrastructure is fit for purpose and assess/pilot the utility of the resources.

**Review of the challenges**

There has been a lot of learning along the way and in developing our new strategy for 2016-18, we have considered how best to adapt our approach in the future to maximise the impact of the Taskforce within a shorter time frame, in effect going further, faster.

The Taskforce approach over the past three years has aimed to:

- Bring together within regions a range of providers from children’s and adult hospice and palliative care services and other agencies from the pentagon of support
  - Commissioners
  - Senior clinicians and academics
  - Key agencies in the statutory and voluntary sector
  - Representatives of housing associations, universities and colleges and vocational training establishments
- Support the development of new services.
- Support the ongoing dissemination of the evidence base that has been built up by Together for Short Lives.
- Involve young adults with life-shortening conditions and parents/carers through its Young Avengers Group and Parents Group, providing a platform for them to share their experiences at national level and regionally.
- Engage with a variety of different professionals in the regions, to ensure that links are made with key representatives from across the ‘Pentagon of support’ including:
  - develop partnerships at national level with organisations and bodies that have influence.

Taking each of the approaches set out above, a brief analysis is provided of some of the key challenges that we have encountered.

**Bringing together agencies within RAGs**

In the RAGs we have had mixed success in engaging with all the agencies within the pentagon that need to come together to provide support for young people. Whilst representation from hospices and education providers is relatively strong, it’s not been so easy to engage meaningfully with Local Authorities and broader agencies that support disabled people with employment, housing and leisure. In the next period we plan to reframe our thinking about representatives of the pentagon attending RAG meetings, focussing on ensuring that there is an appropriate named link person in each of these agencies so that contact can be made when needed.

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1 For example, the best practice prompts from the STEPP Project, the findings from the Bridging the Gap Study, the recommendations from the Guide to Sex, Sexuality and Relationships, the Guide to Personal Budgets
One element of our strategy for the next phase will be to establish a baseline of where all the elements of the pentagon are, at regional and national level, in terms of their partnerships between children’s and adults’ services. For example, at regional level we plan to map where the 60 adult hospices are that have engaged with the Taskforce so far and rate them (red, amber, green) on how well they are engaged with local children’s services. At national level we will work with Hospice UK to try to increase the number of adult hospices that are engaged with us and to ensure that they work with us to share learning from the programme across their membership.

**Supporting service developments**

We have not made as much progress as hoped in terms of service developments due in large part to the fact that we have not yet managed to secure the funds for an Awards Programme to pilot new service developments. This is a priority for the next strategic period. We will be seeking to establish an Awards Programme over the next strategic period to enable new developments to be tested and learning shared across regions.

It has also been difficult to sustain meaningful engagement with commissioners who will play a key role in ensuring the sustainability of any new service developments. The new multi-agency approach being tested in the North East is potentially one way to develop engagement with commissioners, with potential to roll out this model to other regions if it is successful.

**Supporting the dissemination of the evidence base**

We have worked hard to promote the key learning and findings from the research and resources that have been developed, for example through the series of masterclasses. However more needs to be done to really embed this learning in practice and to evaluate the usefulness and influence of these resources on practice.

**Involving young adults and parents**

There has been good involvement from young people and the Young Avenges had 15 active members at the end of March 2016. However, we have not been as successful in ensuring that the experience and views of young people with severe cognitive impairments are captured, either through engaging directly with them or through their parents/carers. We need to find effective ways to ensure that young people with cognitive impairments and their families are able to engage as fully as possible over the next strategic period.

**Developing national partnerships**

We have also been less successful at engaging with national partners than hoped, partly due to key people leaving some of the key organisations with whom we wanted to engage and partly due to the fact that the needs of young people with life-limiting conditions do not fit neatly in to the agendas of large national organisations who are concerned with transition for all disabled young people. We have found that the needs of young people with life-limiting and life-threatening conditions can be seen as niche and are therefore not prioritised by some of these large national organisations. It is hoped that with additional staff resource being brought in to the Taskforce in 2016-17
we can address this in the coming strategic period and build strong links with some key national partners with defined objectives for these partnerships.

For example, we plan to build on our partnership with the Preparing for Adulthood programme so that young people with life-limiting conditions can benefit from the SEND reforms and achieve in all the areas set out in their life outcomes pathways. To do this we will work with PfA to ensure that the support they provide to local areas as a government policy reform partner includes the needs of young people with life-limiting conditions. We acknowledge that our approach is different to that of PfA. Their focus is on supporting existing services to implement the SEND reforms for all disabled young people, while our focus is more on stimulating new practice and service development for a group of young people for whom services do not currently exist (as identified in the NICE Transition Guidance and the CQC Report ‘From the Pond into the Sea’) and enabling young people to have access to these.

We also built links with the NHS(E) Strategic Clinical Networks and developed particularly strong links with the SCN in the South West which developed a dashboard for CCGs to use to measure their readiness to support transition for young people. These SCNs no longer have a focus on children or young people, so we will need to consider whether this work can be picked up in another way.

In order to document the progress of the Transition Taskforce and capture and share the new ideas and innovative service developments that are beginning to take shape, we are planning to establish a record of achievement and learning during 2016-19. It is intended that this will be a live document that will set out the vision of each new development, together with details of its business model and outcomes achieved for young people. There will also be a more clearly defined monitoring and evaluation framework for all levels of our activity.
3. TRANSITION TASKFORCE: PHASE 2 (2016-18)

The Taskforce Approach for 2016-18

Over the next 2-year strategic period we aim to accelerate our activity to reach the outcomes and impact that are set out later in this section.

We will be seeking to use the levers in the system to help to achieve these outcomes, namely the NICE Guidelines on Transition which were published in March 2016, together with the tools that have been developed during phase one of the Transition Taskforce activity, in particular the Stepping Up transition framework, which provides guidance, standards and goals specific to the transition for young people with life-limiting conditions.

During the next strategic period, the Transition Taskforce will benefit from increased staff resource at Together for Short Lives, with the arrival of our new Director of Service Transformation and dedicated input from our Director of Service Development.

The work undertaken in phase 1, will be organised slightly differently to reflect the input of the new executive team at different levels.

Transition Taskforce Strategic Objectives for 2016-18

Over the next two-year strategic period we plan to work through five workstreams to implement this approach:

1. Develop a strategy and programme to influence change at a national level
2. Strengthen our working with and through networks (RAGs)
3. Support the development of new services and best practice
4. Extend and strengthen the voice of young people and their family/carers
5. Mobilise knowledge and showcase developments
## Transition Taskforce Strategy for 2016-18

<table>
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<tr>
<th>Objective</th>
<th>Outputs &amp; specific deliverables</th>
<th>Outcomes</th>
<th>Lead</th>
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| 1. Develop a strategy and programme to influence change at a national level. | a) Develop an effective lobbying approach with policy makers in all 4 UK countries, working with key national partners where appropriate.  

b) Identify national enablers, such as the potential alignment of adult and children’s continuing health care criteria, as appropriate across the four nations.  

c) Develop partnerships with national programmes, such as Preparing for Adulthood, so that they design their activities to meet the needs of young people with life-limiting conditions  

d) Develop partnerships with national organisations who can leverage change in each of the domains of the pentagon, for example, strengthening and building on partnerships with national charities that provide housing (such as Leonard Cheshire) and develop approaches with the British Association of Supported Employment.  

e) Establish stronger links with professional bodies and national charities, including condition-specific charities. Develop clear and measurable objectives for each of these partnerships to explore innovative approaches to achieving better outcomes for young people across the pentagon. For example, in the sphere of education, national organisations play a role in developing policy and services to support transition for YP with lli/lti. | National organisations play a role in developing policy and services to support transition for YP with lli/lti. | Adrian  
(working with Lizzie, David, Shaun & Pat) |
of employment, explore whether hospice and palliative care organisations can provide employment opportunities for young people who use their services.

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<tr>
<th>2. <strong>Strengthen our working with and through networks (RAGs)</strong></th>
<th>a) Support the RAGs to draw up a map of engagement, undertake an audit of progress, a diagnostic to identify barriers and opportunities, and a process to establish priorities.</th>
<th>Services across the pentagon of support develop appropriate and sustainable care and support for young people.</th>
<th>Katrina &amp; Richard</th>
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<td>b) Facilitate better working between children’s and adults’ health and palliative care networks.</td>
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<td>c) Support the development of specific networks, such as transition co-ordinators.</td>
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<td>d) Implement in at least one region a system-wide improvement process that brings together health, social care, education, housing and employment, provider organisations and commissioners to improve provision of services for young people. Develop a roll out programme for this work to other regions.</td>
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<th>3. <strong>Support the development of new services and best practice</strong></th>
<th>a) Establish an Awards Programme.</th>
<th>Children’s and adults palliative care services work together, adopting best practice, to prepare young people for transition.</th>
<th>Katrina &amp; Richard</th>
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<td>b) Stimulate new service developments to deliver the ambitions of <em>Stepping Up</em> and the NICE Guidelines, connecting through RAGs and other networks, to promote two-way learning and enable spread.</td>
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<td>c) Work with specialist colleges for disabled young people to expand provision to meet the needs of young</td>
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<td>people with more complex disability and learning difficulties</td>
<td>d) Pioneer the paid/voluntary employment of young people with life-shortening conditions within service providers</td>
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| 4. | Extend and strengthen the voice of young people and their family/carers | a) Support the active involvement of young people and parents at local/regional and national level  
  
b) Capture the needs of young people with severe cognitive impairment through their families/carers  
  
c) Provide and promote tools that can help young people and families to navigate the system, gain confidence in planning proactively for their futures. | Young people and their families are informed and empowered to pro-actively plan for their futures | Julia |

| 5. | Mobilise knowledge and showcase developments | a) Develop a case study approach to capture achievements and learning from service developments.  
  
b) Develop our means of sharing knowledge, both active (through events and networks) and passive (through the website and Transition Times).  
  
c) Develop a strategic research agenda and seek to ensure its implementation & dissemination of findings. | Young people, families, providers and commissioners have access to the latest news, case studies, developments and research. | Lizzie |
4. Defining and measuring success

Demonstrating impact will be crucial in the next phase of the Transition Taskforce. We have developed a set of impact chains for our strategic priority relating to transition. This is part of our overall impact measurement framework for our new Together for Short Lives Strategy for 2016-19.

The overarching impact and mid-level impacts for our transition work is captured in the following diagram:

In order to measure the extent to which we are achieving impact in transition, we plan to work with our Regional Action Groups to use a service self-audit tool that has been developed to accompany our Stepping Up guide to transition. The tool enables services to grade how well they are achieving against the sentinel standards of Stepping Up and the goals that lead to this standard.

There are also versions of this Stepping Up audit tool that can be used by young people and by parents, to measure how well informed and empowered they feel about accessing services locally, their experience of being involved in transition planning and the extent to which they have achieved these plans in adult services, across the range of agencies in the Pentagon.
The five sentinel standards of Stepping Up are set out below:

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<th>Standard 1</th>
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<td>Every young person from age 14 should be supported to be at the centre of preparing for approaching adulthood and for the move to adult services. Their families should be supported to prepare for their changing role.</td>
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<th>Standard 2</th>
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<td>Every young person is supported to plan proactively for their future. They are involved in ongoing assessments and developing a comprehensive holistic plan that reflects their wishes for the future.</td>
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<th>Standard 3</th>
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<td>Every young person has an end of life plan which is developed in parallel to planning for ongoing care and support in adult services. This standard applies to all stages of the transition journey.</td>
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<th>Standard 4</th>
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<td>Children’s and adult services are actively working together to enable a smooth transition.</td>
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<th>Standard 5</th>
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<td>Every young person is supported in adult services with a multi-agency team fully engaged in facilitating care and support. The young person and their family are equipped with realistic expectations and knowledge to ensure confidence in their care and support needs being met in the future.</td>
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In addition to measuring this overall impact of the Taskforce, we will also collect data to measure and monitor the performance of the various workstreams of our Taskforce activity. This will include

1. A mapping and analysis of our national partnerships, looking at the extent to which we achieved our objectives with each organisation.
2. A regional mapping and analysis of adult services we are engaged with & their level of engagement with children’s services (this will be compared to a baseline analysis carried out in early 2016).
3. A Record of Learning and Achievement to capture information about new services developed, together with more in-depth evaluation of new service developments that are funded through the Transition Awards Programme.
4. Evaluation of masterclasses to provide evidence of improved practice.
5. Narrative feedback from young people and from parents about their involvement with the Transition Taskforce and whether they feel more informed and engaged with services locally.
6. Feedback on the resources we have produced and their impact and monitoring of website hits and numbers of document downloads.
5. The Transition Taskforce Structure

Nationally

There is a core executive team at Together for Short Lives that supports and coordinates the Transition Taskforce, bringing overall leadership to the issue of transition for young people with life-limiting or life-threatening conditions.

The staff team is supported by David Strudley working in a voluntary capacity to bring additional leadership and senior peer-to-peer support to the leaders of the Regional Action Groups.

Regionally & Locally

In 2016-18 we will continue to support the establishment and ongoing strengthening of Regional Action Groups (RAGs) or National Forums in the devolved nations, with a view to them becoming self-sustaining during this strategy period. It is intended that these RAGs or National Forums will take forward the approach identified above and establish links with adult colleagues, developing new partnerships and services to support young adults with life-limiting conditions.

RAG Leads are appointed to lead and coordinate the activities of their region and to provide reports back to the Executive Team. The Executive Team will continue to provide support and share learning, but will allow regions to prioritise and drive forward their own areas for development.

It is intended that the RAGs will work in a non-prescriptive, flexible way and will support the development of Local Action Groups to provide a focus on service developments in the regions. Any Local Action Groups should have a clear mechanism for reporting back to the RAG.