Evaluation of the Together for Short Lives 'Improving Transition for Young People Programme'

FEBRUARY 2022

Foreword

For many years we have known that the transition from childhood to adult life can be a difficult time, socially and emotionally as well as for health care. Moving from the dependence of childhood into an adult world where independence is expected, brings special challenges for young people who have life threatening and life limiting conditions.

The Together for Short Lives Taskforce on Transition, led by David Strudley, spent 4 years identifying the areas of need and setting up regional systems of support. But it was clear that innovative solutions were needed and we were fortunate to be awarded funding from three very generous charities which enabled a call across the UK for innovative solutions to the challenges which we knew still existed. This enabled us to fund projects in many of the areas identified by the Taskforce, some locally based pilot projects which if successful could be rolled out across the UK and others looking at solutions from a national viewpoint.

The advent of the Covid epidemic added a huge new challenge to many of the projects, but we have valuable learning from each of them which can be accessed via the links from each project's summary at the back of this report.

We were very keen to understand what the challenges of these projects had been in order to guide future work in this and other areas of Together for Short Lives' work. Each of the project leaders were interviewed and this report is a summary of the feedback, with some analysis of themes which have emerged. This report includes a summary of the outcomes of each of the projects as well as lessons learned.

The work of the Transition Taskforce and the ten projects funded through the Improving Transition for Young People Programme have improved the situation for many young people and their families who are transitioning into adult life. There are an ever-increasing number of young people who need help with ever more complex problems. This work is not finished.

We are grateful to our three funders who had the vision and courage to support us in this very challenging area and they can be assured that progress is being made. The cliff edge which is the fear at transition, now at least has signposts to help young people and their families make the leap into adulthood and hopefully have a soft landing into an adult world, which allows young people to fulfil their dreams.

Professor Sir Alan Craft

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Aims of this evaluation

This evaluation report aims to share insights about the barriers and facilitators to delivering new approaches to transition for young people with life-limiting conditions. It identifies the elements of the projects that can have the greatest impact on young people's experience of transition and which have greatest potential for replication in other areas. We hope that this learning will help services working in children's and adults palliative care sector to improve their support for young adults and their families.

Sharing learning was central to the programme, with the funded projects coming together twice a year to reflect on and discuss successes and barriers they faced. As an innovation fund, the importance of capturing learning about what didn't work was just as insightful as the learning about what did.

The evaluation involved two interviews with the project leads at the mid-point and end-point of their projects (see appendix 1 for interview question matrix).
This report is structured around the questions that we asked in the interviews:

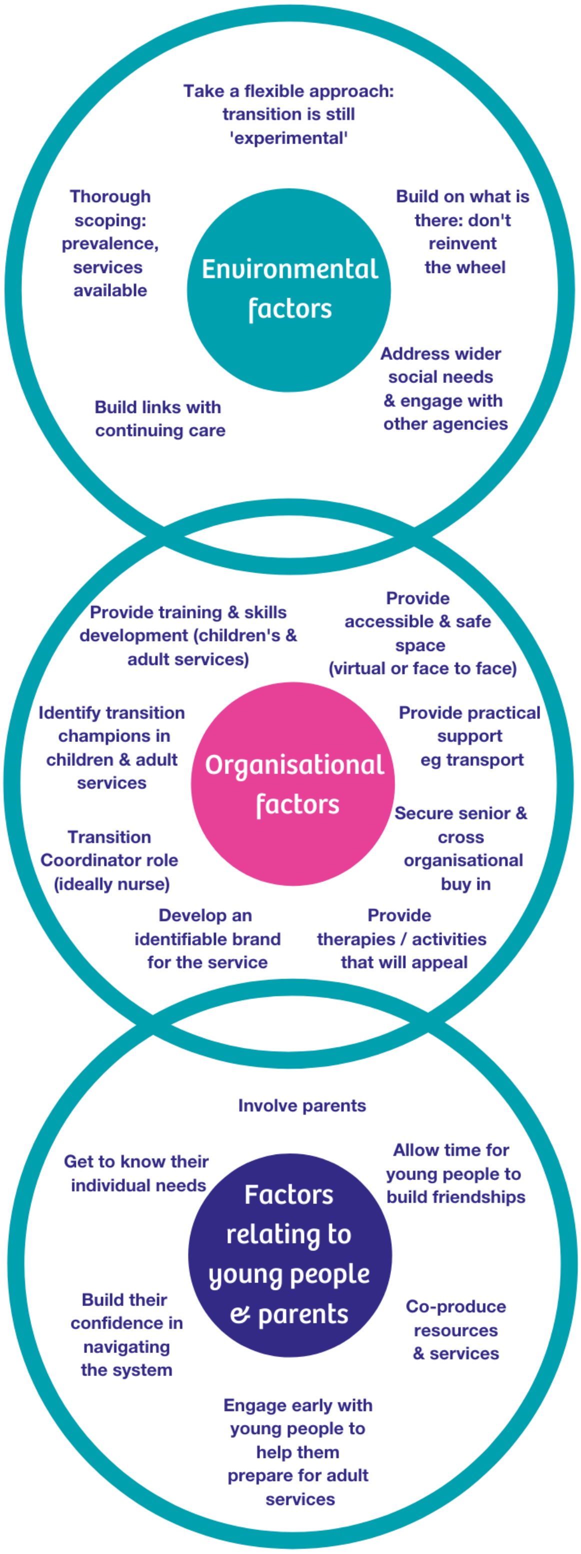
1. their hopes and expectations for their project and whether they felt these were met
2. the barriers and challenges that hindered the projects
3. the facilitators that helped delivery of the projects
4. what the projects would have done differently

We have also captured some of the themes that came out of the Shared Learning Events that we held with project leads during the course of the programme.

Alongside these interviews with project leads, an economic evaluation was commissioned and undertaken by the York Health Economics Consortium, who worked with the four of the direct service delivery projects to capture the economic case for adopting these approaches.

Findings at a glance

The programme has provided some invaluable practical learning about how the process of transition can be improved for young adults with life-limiting conditions. Some of the key areas of learning are summarised in the diagram below.



Background

Advances in medicine and technology mean that more and more young people with life-shortening conditions are now surviving into adulthood and planning for their futures as users of adult services.

Sadly, the services that are needed to provide care, support and life opportunities for these young people as they make the transition from children's to adult services, have not kept pace.

Funding from the programme was used to commission an updated research project to look at the prevalence of young people with life-limiting or life-threatening conditions[1]. This study showed the extent of the rise in prevalence:

1. the overall number of young people aged 14-25 with a life limiting condition (LLC) identified in this dataset from England rose from 27,316 in 2009/10 to 38,261 in 2017/18. This includes those diagnosed in childhood and young adulthood

2. the numbers of young people with an LLC who were diagnosed whilst still in childhood rose from 16,107 in 2009/10 to 24,773 in 2017/18

3. the prevalence of young people with an LLC who were diagnosed whilst still in childhood rose from 19.7 per 10,000 in 2009/10 to 30.2 per 10,000 in 2017/18

Poor planning and a lack of age-appropriate support has resulted in significant gaps in services, at a critical time in their lives. All too often, these young people find themselves falling through the gaps – caught between children's and adult services – and missing out on opportunities to achieve their full potential.

There are numerous publications and research studies that have identified these shortfalls in transition support and some references are included below[2]. [3]There are particular problems for young adults who use palliative care services. They are often used to being cared for by a team of specialist paediatricians and these roles simply don't exist in adult healthcare. There is no equivalent doctor that looks after the 'whole' of them, with GPs often not having the skills or resources to be able to support these young people.

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[1] Fraser L (January 2021). Making Every Young Person Counts: Estimating Current and Future Prevalence of Young People with Life-limiting and Life-threatening Conditions in England. https://www.togetherforshortlives.org.uk/resource/making-every-young-adult-count/

[2] Care Quality Commission (2014). From the Pond into the Sea: Children's Transition to Adult Services. https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report_Summary_lores.pdf

[3] Marie Curie (June 2012). Don't Let Me Down: Ensuring a good transition for young people with palliative care needs. https://www.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/past-initiatives/ypt/dont-let-me-down.pdf

In addition, the model of care in adult hospice and palliative care is very different. It's also very hard for parents who have often cared 24/7 for their seriously ill child to trust and 'let go' of their child to unfamiliar adult services.

> Young adults are too old for children's hospices, but we don't fit into adult hospices either. Quality of life is of the utmost importance when you have a life-limiting illness, as you want to be able to enjoy the time you have left.
>
> Young Expert, Together for Short Lives

Although these young people have life-shortening conditions, they should have the opportunity to live their lives to the full and do all the things that teenagers and young adults enjoy. Beyond their healthcare needs, they may have ambitions to study, train, to work, have relationships and to have more independence.

Time is so precious for this group of young people and it is vital that services are in place to ensure they have the best transition possible and the best opportunities in adult life. The Improving Transition for Young People Programme was developed to find ways to achieve this.

The Improving Transition for Young People Programme

The establishment of the Improving Transition for Young People Programme (IT4YPP) followed a 4-year Transition Taskforce project that was run by Together for Short Lives from 2014-1017[4]. This UK-wide programme established Regional Action Groups for transition across the country. These groups brought together a range of providers in children's and adult's services and built links with services and organisations working in other agencies (social care, education, housing, employment/leisure).

Although there was good engagement from a wide variety of services and a range of partnerships were established, it became apparent that something needed to be done to enable some of the innovations that were being discussed to be put into practice.

Funding was secured to run a grants programme in 2017 and so the Improving Transition for Young People Programme was born.

Timeline of the programme

January - April 2017
Funding secured (3 funders), criteria developed and call for applications

May 2017
Round 1 Interviews
34 applications
5 shortlisted and attended interview
2 projects were selected in Round 1

October 2017
Round 1 Projects commenced

October - December 2017
Scoping criteria for Round 2 of the programme

June 2018
Round 2 Interviews
42 applications
13 shortlisted
11 attended interview
8 projects selected in Round 2

December 2018
Round 2 Projects commenced

January 2019 - June 2021
Held 6 sharing & learning events with Projects during the delivery phase

September 2021
Project delivery phase concluded (originally delivery phase was due to end in June, but was extended for some projects due to Covid 19).

December 2021
Final evaluation reports published

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[4] The UK Transition Taskforce was chaired by David Strudley, former Chief Executive of Acorns Children's Hospices, who was instrumental in establishing the Improving Transition for Young People Programme.

The criteria of the Improving Transition for Young People Programme

The Transition Awards Programme was established to distribute a small number of awards for innovative projects that had the potential to transform the experience of young people with life-limiting conditions as they prepare for and move on to adult services. It aimed to support new approaches to help young people to achieve the best quality of life possible across the full spectrum of their needs.

We aimed to build a portfolio of examples of service developments that could be readily understood, replicated and adapted by other providers, commissioners and policy makers. Proposals were encouraged across the different phases of moving to adulthood that are described in our guide to transition 'Stepping Up'. We also encouraged applications and partnerships that reflected the breadth of services involved with these young people's lives.

A panel of experts from different backgrounds in the field of transition[5] were put together to assist with shortlisting and to be part of the interview panel. This included representation from young people, parents, service providers from health, social care, education and commissioning.
Two projects were funded in the first round and eight in the second round, following an additional scoping exercise to provide more clarity on the criteria for the programme.

There were two key conclusions from our scoping exercise:

1. that innovation in transition for the population that we are concerned with was likely to be relatively small scale and locally identified, rather than involving whole system transformation. We therefore felt it was important to continue to include locally driven needs-based projects within the scope of the programme
2. that there are three key areas where there seemed to be scope for major change to be brought about if small-scale pilots could be scaled up in the future
   - i. projects that focus specifically on young people with cognitive impairments & degenerative conditions
   - ii. projects that are about supporting/empowering professionals in the adult primary care sector (such as GPs) to support young people with life-limiting conditions
   - iii. projects that are about providing short breaks/respite for parents and supporting them emotionally

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[5] The two interview panels were chaired by Professor Sir Alan Craft and member of the two panels is provided in Appendix 2.

The ten projects

The Improving Transitions for Young People Programme funded ten projects to pilot new ways to address the cliff edge in care experienced by young adults with life-limiting conditions in their transition from children's to adult services. The funded projects were distinct and varied in nature and all presented something new to test.

The ten projects are listed below and further information about their activity, resources produced and their individual evaluation reports can be found by following the links.

Council for Disabled Children: The Expert Parent Programme
Adapted their series of co-produced 'Expert Parent' workshops so that they could be delivered by and to parents/carers of children with life-limiting conditions going through transition. The project also adapted and evaluated bespoke on-line learning modules.

Martin House & St Leonard's Hospice: Expanding Worlds
A collaborative project with young people to identify and help them address the areas of biggest challenge for them in their move into adulthood, across health, emotional well-being, social opportunities, housing, work and leisure.

Royal College of GPs: The Developing Positive Transitions into Primary Care project
This project developed online training modules to support GPs to make improvements to the service they are able to offer to seriously ill young people.

Royal Devon & Exeter Hospital Trust: The Pathways Clinic
Piloted a model for transferring young people with complex needs from a consultant paediatrician to a consultant adult physician to see if the 'umbrella of care' model, enjoyed in paediatrics, could continue into adulthood, including when admission to hospital was necessary.

Sexuality Alliance (Hospice UK): Talking about Sex and Relationships
This project co-produced short videos with young people and developed a resource for professionals to support conversations about sex and relationships.

St Elizabeth Hospice: Transforming transition experiences of young people in Suffolk
Piloted a transition coordination role within the adult hospice, working across the Clinical Commissioning Group, Continuing Healthcare team, childrens' and adult hospice, hospital, neuromuscular service and community teams.

St Oswald's Hospice: Engaging GPs – Improving Outcomes
A pilot to develop and test systems to enable collaborative working with GP's supporting young adults with palliative care needs.

Sunderland Royal Hospital NHS Trust: Teen matters: Transition: Each and Every Need Matters
Evaluated their current transition pathway for disabled young people and developed a series of tools to support its use for young adults with complex health needs.

Ty Hafan: Transition Hubs
Provided a holistic one-stop point of contact where young adults can receive support with transition from paediatric to adult palliative care. Young people with palliative care needs were able to access a 'Hub' hosted at their local adult hospice.

Volunteering Matters: The Futures Project

This project supported young people in their last year at school and aimed to match them with a trained volunteer to explore opportunities for them to sample life in the workplace through skills training and/or work placements.

Learning from the projects

This section of the report looks at the key themes that have emerged from interviews undertaken with the Project Leads and the reflections and discussions that took place at our Shared Learning Events over the course of the programme.

The section is structured to reflect the interview matrix (see Appendix 1), with a section for each of the following four questions:

1. hopes and expectations of the projects
2. the barriers and challenges that hindered delivery of the projects
3. the facilitators that helped delivery of the projects
4. what the projects learned

We grouped our findings from these interviews into three broad themes:

Three themes of findings:

Factors relating to the population of young people and their families.

For example, the particular demographics of this group of young people and their families and their individual characteristics.

Organisational factors

For example, factors relating to organisational change and service delivery.

Environmental factors

For example, societal factors or the wider health, social care and education system that impact on this group of young people and their families.

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1. Hopes and expectations of the projects

In our interviews with project leads we asked about what their hopes had been when they were initially developing their projects, in order to gain an understanding of what the programme as a whole might expect to learn about. We grouped these into the three themes described previously:

1. factors relating to the population of young people and parents
2. organisational factors
3. environmental factors

Factors relating to the population of young people and parents

Some projects worked directly with young people and parents to provide support and work with them to develop resources. Their hopes related to providing positive experiences for them as individuals.

To increase access for young people to a new service/way of working/information
Each initial project plan set out how many young people would benefit from contact with their activity.

> We wanted to expand their experiences, adjust to new models to interface with the adult world. I was keen to see if there was a way of bridging the gap between the very different models of child and adult services.
>
> Children's & Adult Hospice Partnership

To support young people to be more proactive
Several of the projects were aiming to encourage young people to play an active role in preparing themselves for becoming young adults and helping them to be more proactive in building relationships and social opportunities.

To co-produce resources with young people
One project hoped to explore what works best when co-producing a resource with young people.

> We wanted to produce something led principally by the ideas of young people, with all the challenges and unpredictability that brings.
>
> National Collaboration

To support parents
Projects also wanted to provide an opportunity for parents to learn about what is involved when their son or daughter needs to move from children's to adult services and how they can best support this process.

Relating to organisational issues

A number of projects focused on exploring ways to better engage with different parts of the health, social care and education system in their locality, others were hoping to build the capacity of their own organisations.

To build confidence and skills of staff

To support staff to understand the different needs of young adults and to build their confidence and skills in providing care and support to meet these needs.

To build cross-organisation support for transition

To embed transition services within the organisation, with strategic and operational buy-in.

To create a space and community for young people and parents

It was important for several projects to create an appropriate and accessible space for young people and for parents to come together, to feel safe and secure in sharing with each other.

> We wanted to enable families to talk about their child in a space they don't often have freedom to do so. We wanted to ensure the workshops went beyond the event – creating a community to have these conversations with.
>
> National Charity

Relating to environmental issues

One of the barriers to young people accessing the support that they need is that they are not identified and recognised as a group with needs in common. Several projects looked at how best to increase awareness of their needs and how to engage with the wider health and care system.

To identify young people and their needs

One project in particular was hoping to develop a system-wide tool to help to identify young people and enable them to access care pathways that are appropriate for them.

To engage adult hospices

To raise awareness of the needs of young people with life-limiting conditions with adult hospices and support them to increase the support that they can provide.

> Our hope was to provide an opportunity for young people and their families to come together in an adult hospice setting and to address psycho-social, practical and emotional support, through 3 joint hubs.
>
> Children's Hospice

To engage NHS clinicians

To pilot a successful model of handing over the clinical care of young people within NHS settings so that the transition of their health care needs can be as smooth as possible.

To engage primary care
To engage GPs in identifying and understanding how they can contribute to supporting young people with life-limiting conditions.

To develop multi-agency models of care
To pilot models of care that enable different agencies to come together to provide a ‘one stop shop’ for young people and their families.

> We wanted a pathways clinic, it was what families had asked for. We were trying to fix what parents describe as ‘falling off the edge of the cliff’ with there being no one in secondary care to look after young people. We wanted to create a continuum as the paediatrician finishes, someone to take over that role.
>
> NHS Service

2. The barriers and challenges that hindered delivery of the projects

We talked to the project leads about the barriers and challenges they encountered in delivering their projects. Again, we have grouped the findings into the three overarching themes previously described.

Some of the projects were being run during the Covid pandemic and we have highlighted separately some of the challenges that this caused.

Factors relating to the population of young people and parents

The low numbers of young people

The relatively low prevalence of young adults with life-limiting conditions made it difficult to prove the need to adapt or develop services specifically for them and to do this in a resource-effective way. One adult hospice described how the population of young adults in their hospice catchment area was very small and that a more regional approach was needed to bring them together for the kind of social opportunities that the young people wanted.

> There was push back as to why we're supporting adults from other areas who could be having support from their own hospice. We argued that the peer group factor was so crucial, as most young people wanted this social element rather than being one young adult in an adult hospice somewhere.
>
> Children's & Adult Hospice Partnership

GPs in particular, with their small footprints, had very few patients to refer. This was recognised by three of the projects which aimed to help GPs to identify young people who might need support from palliative care services.

A spectrum of complex health needs

The varied health conditions and needs of the young people involved in the projects meant that time needed to be taken to personalise and tailor the support that was offered to them. Some young people will be relatively independent and stable, whilst others may have profound and multiple learning disability or have a rapidly deteriorating health condition. Their health needs will change over time, which is one of the factors that makes their transition more complex than for disabled young people whose conditions are stable. It is important to recognise that it is time-intensive and can be costly to ensure this kind of tailored approach, but it is essential to delivering outcomes that are meaningful for young people and for their families.

> It's a mixed group of young people with different levels of cognitive ability. The more able young people have enjoyed coming together and socialising and have benefitted from the complementary therapies, but also discussing anxieties about symptom control or transferring to adult acute setting.
>
> Adult Hospice Service

The disempowerment of young people

Young people with life-limiting conditions have often been protected and cushioned in children's services. As they become young adults this means that they are often passive and have not developed a sense of self-agency. One project in particular had been aiming to try to address this lack of self-agency by encouraging young people to engage in social groups and organise activities themselves, but still found it more difficult than expected to maintain this level of engagement.

> They've always been special so it doesn't matter whether they get things done on time. You need to allow them to fail, but not in a disastrous way.
>
> Children's & Adult Hospice Partnership

Risks to safety of young people

This group of young people can have unstable conditions that place them at a high risk of a sudden health crisis. They may also be reticent about disclosing this information. It is vitally important when working with this client group to carry out a detailed risk assessment with each young person and ensure that they tell you about their personal health risks. Mitigating actions can then be put in place such as using a venue where clinical support is available.

Organisational / structural factors

Lack of physical space and facilities

The lack of appropriate and accessible physical spaces and facilities limited some of the opportunities to deliver services to young adults. In the adult hospice setting this impacted on opportunities for short breaks and carrying out group activities. In the hospital setting it made it difficult to find space to hold one-to-one health consultations. For employment settings it limited the opportunities that were available for work placements.

Staff turnover

One of the key pieces of learning from a project delivery perspective is the importance of staff continuity. Projects experienced lengthy delays when new staff needed to be recruited part-way through and this hadn't been built into a risk register or contingency planning for the project.

NHS bureaucracy

For projects working within a large infrastructure such as an NHS Trust, there can be layers of bureaucracy that slow progress and potentially have an adverse impact on the ability to be innovative. They found that considerable time needed to be factored in for various processes, such as gaining ethical approval for research-related activity, governance issues, recruiting project staff or signing off press releases. One NHS-based project had not included any administration support in their budget and this was difficult to secure, as job roles were very rigid within a hospital setting.

Importance of meeting social needs

One project described the fact that their hospice project was almost exclusively clinically focused and that this meant that young people missed out on the opportunity to have their broader social needs met. The clinical model involved infrequent visits for health assessments that didn't allow for this wider assessment of need.

Differences in the child and adult hospice model

One of the aims of the Transition Programme was to look at how the adult hospice care model could be adapted to meet the needs of young people. Traditionally adult hospices are more focussed on supporting people at the end of life and this difference was felt as a barrier in one of the projects. It led to young people engaging very differently with their service.

> It is interesting thinking about risk and adaptations because teenagers and young people's developmental job is to take risks, but the older adult world has become risk averse. One of the young people said [the children's hospice] is about living and [the adult hospice] was about dying. Not as a criticism but they wanted to feel like they were living their life rather than reviewing the life they'd had, sorting out unfinished business.
>
> Children's and Adult Hospice Partnership

Organisational gatekeeping

This was a real issue for one of the projects that was trying to recruit parents to attend workshops. However well meaning, some partner organisations were reluctant to spread the word about the events which meant that very few parents were recruited. To combat this, the project advertised the workshops more widely but found that they then attracted parents of young people who didn't have a life-limiting condition.

Environmental factors

Fear of and misunderstandings about palliative care

Two projects found it difficult to reach young people and families due to the focus of the programme being young people with life-limiting conditions. It was difficult to overcome the need to be explicit about the population that their projects were aimed at and at the same time to encourage participants to come forward and engage with a project that may be perceived as being about end of life care.

Insufficient evidence of the need

It was important to scope the needs of young people and families locally prior to project commencement. Projects where this hadn't been carried out in advance had to spend considerable time gathering this evidence in order to convince their own organisations and local partners of the need to develop services and define what their role should be. Time needs to be factored in to gather this together.

Engaging with continuing care

It was recognised that engaging with some of the adult statutory sector agencies was problematic, in particular with Continuing Healthcare as this is a recognised barrier to transition.

> Continuing Healthcare (CHC) have been a delicate relationship to manage. They've worked really well with us to get us contracts for short breaks, but we know the CHC team has been the hardest part of most young people's transition and the part of transition that we wanted to influence as best we could.
>
> Adult Hospice

A long, slow road to effective partnership working

Projects described the length of time it takes to engage partners and the effort it takes to maintain momentum. Several described initial enthusiasm from partners but then found that it waned over the course of the project, with strategic engagement dropping off. The projects that had already built relationships with partners prior to their projects starting, fared much better than those who were starting afresh with relationship building.

Engaging with some partners, especially GPs and other staff from primary care, was a real challenge, largely because of pressures on their time. With statutory services stretched to breaking point, it was important to try and 'sell' their involvement in transition as 'essential core business' rather than 'nice to do'. There was a concern about the drain on resources and lack of capacity to provide support for this additional patient group. A considerable amount of groundwork was needed to reassure staff that they can play a role in supporting these young people.

> Just having the project has opened doors and being able to approach people as a cold contact has led to an exciting network of professionals who are all interested in transition for these patients and making things work. I'm investing in these relationships in a long-term way, I want to look back in 10 years and think, now it's working!
>
> Adult Hospice

The impact of Covid

Part way through the programme, the Covid pandemic caused major disruption and we agreed with funders that we would provide a 3-month extension to those projects that were most impacted.

Unsurprisingly, Covid featured highly as a hindering factor for several of the projects:

"Sometimes the unexpected pulls the rug out from under you, eg a pandemic!"

Projects that were aiming to work with GPs were particularly impacted as were those whose project staff had been redeployed.

"Restarting the programme after Covid was quite a challenge – if we could have picked it up and got it back on the GPs agenda faster it would have been a bit easier."

Many of the projects providing direct service delivery had to cease face-to-face provision and adapt to virtual working. They found that there were some benefits in terms of reach, but that it did not suit all young people.

"There are numerous benefits offered through engaging with young people and families digitally. However, it is important to understand why some may be either unable or unwilling to do so"

Many projects found it difficult to engage with young people and families during this phase, as so many were shielding and had other priorities.

"The impact of the pandemic was in both availability of staff to deliver and appropriateness of asking families to engage in evaluation activity with such pressing priorities,"

"We've got the whole range - people who are still not leaving the house or letting a single person in the house, to people that have been wanting to come back and don't want us to wear masks. We've had all ends of the scale. The impact on the siblings is huge too, not being able to have any friends round. People have put the 'wartime' effort in during the pandemic, but people are now getting really exhausted. They're on their knees and desperate."

One of the projects described a positive impact as families were more open to being contacted:

"A positive impact of the pandemic was the ability/'permission' to proactively contact families rather than wait for their next visit or appointment. Project activity during Covid has also identified other young people who missed out on a good transition in their teens and now require support in their early 20's."

The pandemic impacted on the ability of many of the projects to carry out their evaluations as they had hoped, largely due to the fact that staff had heavy workloads and new priorities, but also because face-to-face events with young people and families had to be cancelled, which meant reliance on virtual means of seeking feedback. This led to lower response rates than anticipated.

3.The facilitators that helped delivery

We have used the three themes in this section to group factors that were identified as having enabled projects to be delivered effectively.

Factors relating to the population of young people and parents

Engaging early with young people

All the projects working directly with young people learned about the importance of engaging early with them to build their confidence and find their voice. Where young people lacked this self-agency, it took a long time to empower them to take on a more active role in new adult services, but once achieved it helped them to open doors to new experiences. It was important to work at a level that the young people were comfortable with.

> We have seen the young people grow in resilience. It's been interesting seeing them learning how to work as a group, rather than as individuals. They learnt how to be kinder, tolerant and more supportive.
>
> Children's & Adult Hospice Partnership

A co-production approach with young people

One interesting insight into co-production was the evidence of a shift in power in some cases where the voice of young people had grown louder than the adults. Although a challenge to manage, this true co-production approach gave real integrity and richness to the project.

> It wasn't the project that we designed originally, but we stayed true to the project's ethos and aims and got what we wanted and more. The young people were really a part of the project the whole way through and had autonomy.
>
> National Project

Engaging parents

When working with young adults with complex life-limiting conditions and often profound and multiple learning disability it was important to keep in close communication with parent carers and to try to get the balance right between empowerment of parents and safeguarding of the young person. Finding ways to build trust and confidence with and through parents was often the key to young people finding out about services and being able to access them. A trusted 'point of contact' within the organisation was really important to retain family involvement.

Organisational factors

Identifying transition champions

Many projects reflected on the vital importance of having people within their service and network of partners who were personally passionate about transition. It was essential that these champions existed in both adult and children's services in order to share the responsibility of transition. Identifying 'movers and shakers' at senior clinical level was particularly helpful as was having a person for other agencies to link with in order to form a team around the young person.

Supporting staff in adult services to build their confidence

Several projects talked about the need to skill up staff working in adult services who were not familiar with supporting young adults. Providing training and education opportunities for adult services was integral to several of the projects and it was important to build in time to do this well and to provide opportunities to introduce staff to young people in an informal setting. This helped to break down some of the barriers that were put up by staff from adult services, much of which was fear of the unknown.

Providing a safe space for parents to talk

Providing a space for parents to talk with other parents in the same situation enabled a community for peer support that helped them to be able to share their fears and in turn give them the confidence to 'let go' of their young person.

Virtual working

Working virtually with young people and parents was both a barrier and a facilitator. It enabled wider engagement and provided an accessible online space in which they could meet. On the flipside it hindered the kind of in-depth relationship building that was essential to some of the projects.

Providing transport

One very practical factor mentioned by several projects was the importance of providing transport for young people. Having the costs for this budgeted proved very helpful in removing the barrier to young people attending social events.

Having a clear identity and brand for the service

Having a funded tangible project helped to open the doors to engagement with partners. One project described the importance of having an identity for their service that was visible and that everyone could engage with and become proud of.

> It's brilliant and everything is branded now – even our name badges. So even if you work on reception or in the kitchen you know about Zest. It's the value that is being placed on it from the top level down.
>
> Adult Hospice Service

Environmental factors

Building on what is there – don’t reinvent the wheel

One of the success factors identified to developing a sustainable model of transition support was to build on the local services that already exist, empower their staff to take on responsibility for caring for these young people rather than setting up something new and taking over.

> We didn’t want to take over from the GPs, as that solution doesn’t scale. We needed to come up with something scalable and sustainable.
>
> Hospice Service

Taking a flexible approach

There was a recognition that transition was still ‘experimental’ and that a really flexible approach was needed. Some of the projects were trying something completely new. Several of the project leads commented on the importance of this kind of ‘innovation’ programme which enables experimentation and learning about what works and what doesn’t. It’s important to take an organic approach and be ready to adjust delivery in light of external factors and learning from service users and partners.

What the projects learned

We asked projects to tell us about what they had learned about transition for young adults with life-limiting conditions. We asked whether they would have done anything differently and also whether they felt that overall their projects had achieved what they set out to do. In this section we have set out some of these reflections and key learning points.

Factors relating to the population of young people and parents

Choice and independence

Projects that had not worked with this cohort of young people before were surprised to learn about the complexity of their personal care needs and reflected on their need to have carers with them. This impacted on the extent to which young people had choice and independence.

> Needing help with personal care meant there were quite a lot of hurdles to jump over.
>
> National Charity

Importance of addressing social issues for young people

Several projects identified that what mattered most to young people wasn't managing their complex health needs. Their paramount concerns were about meeting friends and having things to do with their time. One project lead mentioned that she would have included more social opportunities in their project to combat the sense of isolation that is experienced by many of these young people.

Allowing time for young people to get to know each other

There was an observation about the importance of allowing time for young people to get to know each other, so that they felt fully comfortable to engage with the project. It helped if they had developed friendships with people with whom they had interests in common.

Organisational factors

Providing an accessible and adaptable space for activities

It was a learning for some projects about the need to provide a welcoming and appealing space for young people, somewhere with enough space for large wheelchairs where they could be together and enjoy social activities that could cater for their range of disabilities and personal care needs, for example an environment with accessible facilities and hoists.

A blended approach to service delivery

Covid had forced projects to think differently about how services were provided and this was important learning to take into the future. Several mentioned that they would look to continue with a blended model of virtual and face-to-face working.

> We think we will look towards a blended model of virtual and face-to-face as there is still an element of convenience and reach that you get from virtual sessions.
>
> Children's Hospice

Some critical success factors for a transition coordinator role

Two of the projects employed a transition coordinator role to lead their projects and both learned about some critical success factors for this role:

- ✓ having a clinical/nursing background helped to build trust with adult health services
- ✓ having a single base for the postholder – so that young people/parents and professionals knew where to come
- ✓ allowing sufficient time initially to embed the transition coordinator role

> Lots of work wouldn't have happened if we didn't have an enthusiastic, skilled and experienced staff nurse with clinical knowledge.
>
> Children's Hospice

Project management and administration

One project within the NHS fed back about the importance of budgeting for administration support from the outset as this had significant impact on their ability to run their clinics. There was also learning about the need to allow for sufficient time for robust evaluation, in particular when feedback was being sought from young people and their families.

Training and skills development needs to be integral

It was identified that training is really critical to the successful introduction of transition services and that this needs time and resource. Adult practitioners and those not working in palliative care specific roles, needed considerable support to become confident at communicating with and providing clinical support for young people who often have conditions and complex care needs that they were not familiar with. Children's practitioners also needed training to enable them to help young people prepare to engage with adult services, moving out of their traditional paediatric roles. Also it was important to build in sufficient time for clinical supervision of staff in transition roles.

Environmental factors

Fear of engaging with palliative care

A fundamental issue for those working in hospice or palliative care settings was that young people, families and some professionals were reluctant to engage with their services, often due to a perception that the service is purely about end of life care. This misunderstanding led to gatekeeping by some professionals and challenges that needed to be overcome in order to engage young people with adult hospice settings.

The need for a robust scoping of needs & services available

It was very apparent that those projects that had carried out a full scoping exercise prior to the start of their projects were able to make better progress because they were able to demonstrate the need for their service to new partners and commissioners.

Summary of learning

From the programme's conception, Together for Short Lives sought to nurture a culture of sharing and learning amongst the projects so that innovative practice could be discussed and used to adapt approaches. The programme has provided some invaluable practical learning about how the process of transition can be improved for young adults with life-limiting conditions. This learning can be shared across the statutory and voluntary sectors, in hospitals, hospices and in the community, between children's and adults' services.

As in previous sections we have used the three categories to highlight some of the most important learning from the programme.

Factors relating to young people and parents

It was found to be vital to recognise the individual needs of young people, the complexity of their health condition and how this impacted on them, before services could be developed for them. This individual person-centred approach was time consuming but vital for a successful project.

Engaging young people and parents early on was important in order to build trust with them and enable them to develop relationships with staff and friendships with other young people. A co-production approach was a key element in building trust, ensuring that young people felt their voices were heard and that they had influence over the resource or service being developed.

It was also important to be clear from the outset that although the number of young people or parents being supported may be relatively small, the impact is huge. There need to be clear outcome measures that can demonstrate this value.

> You look at the numbers and think it's really small, but it's about the colossal value it has to that small number of people.
>
> National Charity

Organisational factors

Of particular importance was the need for skills development and training for staff. This was needed for staff in children's services to help them develop skills in supporting young people to develop independence and in adult services to help them build confidence in supporting young people with conditions and needs they may not be familiar with.

Another key learning was that services for young people were more successful where there was cross-organisational and strategic engagement, so that there was a high level of awareness and a real sense of ownership of the service. A clear brand for the service helped build this engagement.

Factors that helped to engage young people included; the provision of fun activities/outings, having access to facilities that can meet their care needs, together with providing practical support such as transport. Using peer support could help young people to engage in wider social opportunities such as volunteering or work experience.

Creating an environment in which young people and parents could feel comfortable and share experiences was vital in terms of building their confidence. These environments were successfully provided virtually or in face-to-face settings.

Environmental factors

Projects found a low level of awareness within local health and social care systems of how best to support young people who have life-limiting conditions and a lack of understanding about how palliative care services may offer them a lifeline to access social opportunities, therapies, care assessments and end of life care when this is needed. Scoping these needs locally can help to better fill the gaps in provision for this growing population of young people with life-limiting or life-threatening conditions.

The value of building and maintaining strong partnerships with other organisations and agencies could not be underestimated. Having a dedicated transition coordinator role was found to play a key part in facilitating these links to be made.

Plans for sustainability and spread of the learning

Sharing the learning from the programme is very important to us. We want to share the innovations that were tested, embed the approaches within the organisations that were part of the programme, and support the spread of the knowledge so that they can be adapted and adopted elsewhere.

The projects provide examples of good practice that can be shared by practitioners in different services across the statutory and voluntary sectors. We will be working with a range of stakeholders to share this learning, including individual professionals and organisations (children’s & adults) working in the palliative care and disability sectors, national charities, professional bodies and Royal Colleges. We will be capturing learning and case examples from the programme in the new edition of our Stepping Up Transition Pathway, information for families and in future education and quality improvement programmes.

We plan to engage with funders and policy makers in order to influence future funding and development of transition services across the UK.

Whilst the programme has produced new evidence about the need to plan for this growing number of young people and the potential health economic benefits of commissioning transition services, there remains a fundamental gap in our knowledge about how transition support and developmentally appropriate care for this growing population of young people is planned, commissioned and sustainably funded. We do not currently know the extent of the gap in services. Alongside supporting the spread of the learning from this programme, this will be a major focus of our future activity in transition.

The ten funded projects

1. Council for Disabled Children - Expert Parent Programme

Aim

To deliver a version of the Expert Parent Programme tailored to the needs of parents of young people with life-limiting and life-threatening conditions, who are preparing to transition to adulthood.

What they did

The Council for Disabled Children (CDC) developed a bespoke programme of face-to-face workshops led by parents of young people with palliative care needs, supplemented by accompanying e-learning modules. The model consists of a sustainable train the trainer programme. All content for the programme was coproduced with parent carers and they worked collaboratively across CDC's health and social care teams to use their expert knowledge of the health and care systems to develop accurate and engaging content. The team worked specifically with the parents of young people with profound and multiple learning disabilities. During Covid the delivery team translated the training materials into a format that was suitable to be delivered on-line.

What they learned

- create an environment where families can share difficult and personal issues with each other
- include content around legislation and legal rights, eg the Equality Act
- include information about how to prepare for meetings with professionals, eg language to use, the kind of evidence that is helpful to gather
- use a parent with lived experience as a trainer, to help build trust

The benefits/ impact of the project

- helped parents advocate on behalf of their children and navigate the confusing landscape of support that they often face
- improved the outcome of key meetings with professionals, such as the GP Annual Health Check
- improved parents' mental health as they felt less anxious about the future for their young person

An evaluation of the project is available here

2. Martin House & St Leonard's – expanding worlds

Aim

For the young adults:

- to develop their skills and confidence to actively participate in planning activities
- to increase their ability to function well in group activities with peers
- to provide an opportunity for one-to-one consultation with Martin House or St Leonard's staff

For Martin House Children's Hospice:

- to learn about 'what works' and 'what does not work' for young adults with LLC

For St Leonard's Adult Hospice:

- to better understand the needs of young adults who may benefit from using the adult hospice

What they did

This project was a partnership between Martin House Children's Hospice and St Leonard's Hospice for adults. It worked collaboratively with young people to identify their areas of biggest challenge in their move into adulthood, across physical health, emotional well-being, social, housing needs, work and leisure. The project comprised of 10 sessions taking place on an approximately monthly basis from 1:30pm – 6:30pm over the course of each year. Sixteen young adults took part in the sessions over the course of the two years. The sessions took place at the day centre within the adult hospice and began with having a meal together and then a combination of unstructured time together, whole group discussions and activities, individual and small group activities and a variety of 'mini-projects' that ran over more than one session. Young people could access a one-to-one consultation with Martin House staff and a complementary therapy appointment with a member of St Leonard's staff. The young people also arranged social activities in other venues.

What they learned

- children's hospices should consider integrating approaches that support self-determination and active agency of young people into routine practice within their short breaks provision
- compared to their peers, young adults with LLC may have more limited life experience and restricted opportunities for self-determination. This should be accounted for in the design, objectives and duration of projects/service development activities
- providing transport was very important to enable young people to access the sessions
- offering complementary therapy appointments – something not provided at the children's hospice – attracted young adults to services provided by adult hospices
- the aims and objectives of a new service need to be clearly articulated and shared among all involved. This necessarily requires the meaningful involvement of young people
- training and supervision of staff should be incorporated into the project specification

The benefits/impact of the project

This project demonstrated how young adults can be provided with a positive way to spend their time, enjoy new experiences, activities and time with peers. The project helped to increase understanding within children's and adult hospice staff about the different approaches needed when supporting young adults.

Learning from the project is captured in their Evaluation Report.

3. Royal College of General Practitioners - developing positive transitions into primary care development of e-learning modules for GPs

Aim

This project aimed to support GPs to make improvements to the service they are able to offer to seriously ill children and young adults, to ensure good communication between the primary care team, patients, carers and secondary care professionals.

What they did

- engaged with key stakeholders, including young people and their families, to design the right solutions for improving care within the primary care environment
- developed processes that will integrate the care between health professionals and the community and providing safe and supportive outcomes for the young person
- informed and supported GPs and the wider primary care team by providing them with the training and tools they require
- engaged and linked GPs and the wider primary care team with wider support services and programmes in their locality supporting young people with life-limiting conditions
- developed two new e-learning modules which were launched via webinar in late July 2021

What they learned

- recognition at CCG level of this work is essential to develop the engagement of GPs. Planned transition for young people in primary care is a new concept that will benefit from further funding for continuous professional development of general practitioners to highlight its benefits for both patients and clinical teams
- a mechanism needs to be developed to identify and support children with life-limiting conditions within GP practices
- the project identified areas which can be neglected if primary care is not involved, for example sexual health, dealing with common conditions seen in primary care, co-ordination and rationalisation of referrals and medication management

The benefits/impact of the project

The eLearning modules provide practical information for GPs which can be accessed free of charge. These modules can be accessed here: https://elearning.rcgp.org.uk/course/info.php?id=485
Some of the learning from the project will be beneficial for other GP practices to take forward, for example building relationships with services such as Children's' Hospices, Community Paediatrics and hospital-based Transitions Teams, with a view to ensuring that general practice is included in local transition planning meetings. The practices who worked on the project have been able to develop a register of high need patients and plan in 6 monthly reviews for these young people.

You can read their evaluation report here.

4. Royal Devon & Exeter Hospital Trust - pathways clinic

Aim

To improve continuity of care for young people with complex needs by transferring them from a consultant paediatrician to a consultant adult physician and establishing a ‘carousel clinic’ model.

What they did

Fourteen clinics took place for thirty young people over 39 appointments (thirty 1-hour new appointments and nine 30-minute follow-up appointments). The average age of the young people was 18.83 years. Clinics at different settings (for eg in schools) were attended by professionals and carers from more than 14 disciplines and agencies, including medical, nursing, education, social care, allied health professionals and residential care.

What they learned

The main success factors identified for the Pathways Clinic were:

- allowing a ‘robust’ handover with information sharing within the multidisciplinary team (MDT) - including safeguarding
- facilitating a patient and family-centred approach to care
- providing a clear route for ongoing support into adult services
- ensuring the environment is appropriate for the patient, in particular being large enough for the number of people
- extending the inclusion criteria for the clinic
- promoting greater representation from social care and streamlining the clinic for the professionals (eg grouping patients for a specialist)

The benefits/impact of the project

Parent and carer feedback highlighted that the clinic was efficiently organised and run. Carers felt the team listened to and understood their concerns and provided solutions and suggestions. Carers valued having the appointments within the school setting.

Professionals fed back that although their attendance at the clinic appointment took more time than a regular appointment, they still considered it was an effective use of their time. They felt that the clinic improved patient care and promoted multidisciplinary working.

The team are delighted to report that following submission of a successful business case to the Health Board, funding has been secured to ensure that the Pathways Clinics are ‘mainstreamed’ and stay in place as the preferred delivery model to support young adults through transition to adult care.

You can read their evaluation here.

5. Sexuality Alliance (Hospice UK) - talking about sex and relationships: young people speak out

Aim

Making friends, having relationships and exploring sexuality is an important part of the transition to adulthood for all young people. However, young people with life-limiting or life-threatening conditions have had limited opportunities to learn about relationships and sex. This project aimed to develop short videos by young people and an accompanying professional resource to support conversations about sex and relationships.

What they did

The project ran from November 2018 to October 2020 and supported young people and practitioners with this often neglected but important area of transition into adult life. The project was led by a group of young people called the 'AdversiTeam' which consists of approximately 18 young people who come together primarily through a Facebook Group.

The project developed a range of Open Educational Resources (OERs) to facilitate young people to have conversations about sex, intimacy and relationships with their family, carers or professional support staff. The project team also developed a booklet "Talking about Sex: A booklet for young people with life-limiting or life-threatening conditions and their carers" which is available to download here.

The project has also equipped health practitioners to provide better support to young people on this invisible topic through knowledge, resources and a better understanding of the views and experiences of young people themselves.

What they learned

The learning from this project was mainly about the importance of co-production with young people and some of the factors that supported this were:

- the value of building a community for young people
- the importance of confidentiality and privacy within this platform
- the knock-on value of this community in terms of providing other opportunities for young people to engage with

The project identified a demand for ongoing support and training for professionals regarding talking to young people about sex, intimacy and relationships.

The benefits/impact of the project

The online resources had been accessed almost 5,000 times by November 2020.
Following the completion of the project, the team delivered training based on the content of the resources at 20 different events, reaching almost 250 professionals.

The final evaluation report is available here.

6. St Elizabeth Hospice - transforming transition experiences of young people in Suffolk

Aim

To pilot a new transition nurse coordination role as part of the Zest young adult service, based at the adult hospice, to provide coordination across the Clinical Commissioning Group; Continuing Healthcare Team, children's and adult hospice, hospital, neuromuscular service and community teams. To upskill the adult hospice, paving the way for a developing young adult service.

What they did

This project provided a transition coordinator, (a 'key worker') to support young people aged 15-19 and their families to plan, coordinate and support seamless transition across multiple services. The transition coordinator actively led transition planning from children's to adult services, providing one point of contact for young people and their families. The project enabled the pilot of a new young adult residential short break service based in an adult hospice, which has subsequently been commissioned.

What they learned

The evaluation of the service was carried out by the University of Suffolk and aimed to develop a greater understanding of the numbers, referral patterns and reasons for referral to the Zest service, as well as evaluate impact of the coordinator role. The evaluation evidenced positive impact for service users, and explored views of partner organisations and wider stakeholders.

Findings from their qualitative interviews are themed into four areas:

- Engagement and the importance of the Zest service
- Transition
- General Support
- Future developments

Participants suggested that they key elements that made the service work were good communication and the staff behind the service. In particular, the Zest nurse/Transition Coordinator was vital in developing strong relationships through working with the families and young people and being identified as their key worker. The short breaks were also emphasised as being important for respite, carer/family support and for the autonomy of the young persons.

The benefits/impact of the project

During the period being evaluated, 1394 contacts were made with young people and the highest number of these contacts (65.4%) were with a registered nurse. The Zest service also provided specialist nurse-led short break care for young adults, which could be in the form of day care, or a short break weekend stay. Over the two-year period a total of 89 short stays were provided. The Zest nurse/transition coordinator provided the relevant knowledge and skills to expand the Zest service, enabling significant growth of a Zest care team. The project has led to commissioned short breaks and Zest days, alongside ongoing transition coordination and adult hospice support for an increasing number of families.

'Having our project funded by the IT4YPF has been a catalytic moment for Zest… before we were given this opportunity as an adult hospice we didn't have a dedicated transition post, or a paediatric trained nurse that we desperately needed. The Zest service has now gone from strength to strength with this funded key role enabling us to provide transition coordination and deliver a new short break service for young adults. The feedback from young people and their families in our project evaluation clearly evidences the positive benefit this funding provided - enabling services to be available where they previously didn't exist.'

Their evaluation report can be accessed here.

7. St Oswald's - engaging GPs: improving outcomes

Aim

To run a pilot to develop and test systems which will enable GPs to confidently provide support in their local communities for young people with life-limiting conditions.

What they did

The project piloted a multidisciplinary transition service for young people aged 16-25 years. The service primarily involved an outpatient assessment with the team, followed by ongoing support tailored to the needs of the patient and their family. The team approach prioritised supporting the GP to lead in the patient's care and working collaboratively with the other health and social care professionals caring for the patient.

To promote the new service and gain referrals, the team were active in networking and training, publicising not only the service, but the wider needs of the patient group during transition. This networking role has had reach beyond the region, with invitations to speak at several national events. The team worked closely with an independent evaluator to maximise learning from the clinical encounters, and the experience of developing the service. The feedback from patients and professional stakeholders demonstrated the potential value of an ongoing service.

What they learned

- the need for a retrospective approach – to provide support to young people who had already moved on to adult services after the age of 18
- the length of time it takes to establish partnerships, but also the huge value of having close collaboration, for example establishing a local MDT with hospital specialists and the hospice, to enable discussion of cases and two-way referrals
- there were five key issues that young people presented with: sleep problems, pain and symptoms, lack of relationship with GP/Consultant, lack of respite and absence of care planning
- the most common issue raised by parents was frustration with their GP. They also feared that active regular treatment of their child's symptoms (eg spasticity) would not take place as adult clinicians may not be aware of how such treatment could improve their young person's enjoyment of life
- the engagement of GPs can enable a preventive approach, for example dealing with more common symptoms before they escalate
- the project enabled difficult conversations about end of life and plans to be put in place

The benefits/impact of the project

This project has provided evidence of how effective partnership working can be established between the hospice, hospital specialists and GPs. It has shown how a hospice-led transition service can add value to services that are already in existence, play an effective central coordination role for young people & parents, as well as provide a point of contact, education & training for professionals.

The project's evaluation reports can be read here: Learning and Recommendations and Project Evaluation.

8. Sunderland Royal Hospitals NHS Trust - teen matters: transition of each and every need matters

Aim

This project hoped to enable all disabled young people and their families to receive appropriate care at every step throughout transition to adult services, and on an ongoing basis throughout their adult lives. The project aimed to ensure access to a team with the right expertise to address every need, every step of the way through the development of a suite of tools to support the implementation and evaluation of transition care pathways.

What they did

The paediatric, neurorehabilitation and palliative care teams at South Tyneside and Sunderland NHS Foundation Trust collaborated with the learning disability and mental health teams at Cumbria, Northumberland, Tyne and Wear NHS Trust and Sunderland Parent Carer Forum to review and improve care pathways for disabled young people as they transition to adulthood and adult services.

A suite of resources were produced to underpin the transition journey, including:

- web version of a traffic light tool to inform clinical consultations and data capture at the point of care
- disability complexity calculator

What they learned

The project team have reflected together on local pathways, recommendations for best practice and the detailed data which their online tool can capture at the point of care about the needs of young people accessing the various care pathways. You can read more about the project in this blog by Dr Ellie Bond, who worked on the project. They have set out 9 recommendations:

1. Identify a learning disability champion in all paediatric teams, to lead on the early identification, documentation and flagging of children and young people with learning disabilities. Consider using the learning disability screening tool within the multimedia resources for families available here https://learningdisabilitymatters.co.uk/

2. Proactively notify general practice teams about children and young people identified with learning disabilities, so that they can include them in their learning disability registers, offer reasonable adjustments when healthcare is needed and annual learning disability health checks from 14 years onwards.

3. Lead paediatrician to consider, for all young people approaching 14 years of age, which care pathway is most appropriate to their needs on transition to adulthood and adult services and communicate this with the young person, family and wider team who need to know. Consider using the Needs4Pathways tool https://needs4pathways.herokuapp.com/ to calculate and analyse needs to inform choice of three steps of care pathway:
    - all young people with a learning disability access step one
    - young people identified to need ongoing secondary healthcare as adults also access step two
    - young people with the most complex needs who are most medically frail also access step three

4. Lead paediatrician to identify a clinician in the adult medical team, to ‘receive’ disabled young people who require ongoing secondary healthcare and establish joint transition clinics to ensure robust hand over of secondary healthcare.

5. Establish a transition pathway with the adult medical lead, including joint clinics to hand on the baton for leadership of secondary medical healthcare and input from the learning disability nursing team as needed.

6. Lead paediatrician to establish links with the adult palliative care team, including setting up a care pathway for safe transition of the most medically frail young people with the most complex needs. These needs can be assessed using the Disability Complexity Scale supported by the Needs4Pathways tool

7. Establish a multidisciplinary, interagency transition pathway for the most medically frail young people, to involve input from the:
    - young person and their family
    - GP and primary healthcare team
    - learning disability nursing team where appropriate
    - adult secondary healthcare medical lead
    - adult palliative care team

   Transition on this pathway is more likely to be a process over months, or even a year or more, to ensure build-up of confidence in and relationships with the new teams in adult services and robust handing on of the baton for care for each and every need.

8. Identify a paediatric data champion in all paediatric teams, to lead on data capture at the point of care to make visible all of the multifaceted needs of children and young people, including those aged 14 years+ approaching transition to adulthood and adult services. This would allow real data to inform service commissioning and design. Reflect on data captured at the point of care to inform the commissioning and design of transition care pathways.

9. Support of all staff involved in the care of young people and their families to be able to have appropriate level communication skills to respond to difficult and sensitive conversations in real-time. This should include school and nursing staff. Offer staff training to enhance and develop communication skills to hold these conversations.

The benefits/impact of the project

This project has developed a suite of resources to improve the processes needed to identify, assess, document and share information about the needs of young people approaching transition. It can support referrals to the most appropriate professional teams, including palliative care for those who are the most medically frail. It can inform care pathway commissioning and design to continue to meet the needs of young people as they approach transition to adulthood and adult services.

You can read their full report here.

9. Ty Hafan - transition hubs

Aim

To evaluate and roll out a one-stop point of contact within an adult setting to support young adults and offer benefits and legal advice. The specific objectives of the project were to:

- increase service provision for young adults with palliative care needs
- ensure young people leaving paediatric palliative care services are known to the local adult palliative care team
- increase confidence and support to enable young adults to access appropriate adult palliative care at the point it is needed
- enable a single point of contact to access a range of support and advice
- share skills and information with adult palliative care services

What they did

The Transition Hubs project aimed to provide a holistic one-stop point of contact where young adults could receive support with transition from paediatric to adult palliative care. Young people with palliative care needs could access a 'Hub' hosted at their local adult hospice. The Hubs provided clinical advice alongside more holistic support around independence. They also encouraged social peer group support. The Hubs were facilitated by a transition nurse who also provided emotional support to families. There was a social media group to enable peer support and home visits when possible, to offer reassurance and help build confidence. Regular study sessions to encourage skill building for adult palliative care colleagues were built into the model.

What they learned

- the appointment of a suitably skilled and experienced co-ordinator was crucial to the success of this project. This post was held by an experienced palliative care nurse, which gave the project the clinical credibility to establish relationships with the adult palliative care teams and inreach to hospital wards. It was also of benefit that the postholder had a pre-existing relationship with the young people and families
- the social aspect of the Hubs was a key to their success and the team extended these opportunities to enable ongoing peer relationships to flourish. Even prior to the Covid restrictions it was evident that social media and the closed Facebook groups were instrumental in maintaining these relationships. The virtual events levelled out barriers around location, mitigating travel issues and also appealed more to those who found social situations difficult
- the involvement of the adult palliative care/ hospice consultant was very beneficial and if they are engaged early on they strengthened links with the wider adult palliative care team
- the main resource needed to ensure the Hubs ran smoothly was the role of the transition nurse.

The benefits/impact of the project

Those attending the Hubs felt the benefits of the holistic support and one stop shop approach. Another important benefit they derived from attending was the opportunity to have a clinic appointment with the adult consultant. Once the Transition Hubs had been established with each of the adult hospice teams, they quickly became embedded into practice. As the costs involved in running the hubs largely related to practitioner time, the teams worked this into their business as usual work schedule. As a result of this successful pilot, this model of working and the transition nurse post has secured funding to continue.

Their evaluation report can be read here.

10. Volunteering matters – futures midlands

Aim

This project aimed to support young people in their last year of school and match them with a trained volunteer to explore opportunities for them to sample life in the workplace through skills training and/or work placements.

What they did

The project began in November 2018 and ended in March 2019. The project was a partnership with the Acorns Hospices in the West Midlands, based in Birmingham, Walsall and Worcester. The project also worked with schools and colleges in the West Midlands. The target group was young people with life limiting conditions aged 17 to 19 in the key transition period.

It supported 12 young people living with complex and life-limiting illnesses and conditions to recognise their skills and positively shape their futures through volunteer mentor support. The mentors worked alongside the young people to engage them in skills development, volunteering and social action, and work placements. The project organised training workshops, volunteering opportunities, work experience placements and mentoring opportunities.

What they learned

There was learning from this project about the barriers in engaging young people to think about and take part in volunteering or work placement opportunities and the barriers in engaging with employers. One key finding was the relative passivity of young people with life-limiting conditions.

Volunteering Matters put together a checklist of factors for a successful volunteering or work experience placement:

- ✓ an accessible building
- ✓ an appropriate and accessible working environment, which should be risk assessed
- ✓ access to accessible toilets
- ✓ access to personal care where needed
- ✓ induction and training for the young person
- ✓ a contact person that the young person can go to at any time
- ✓ provision of a buddy
- ✓ a clear but simple role for the young person
- ✓ structured and achievable activities
- ✓ opportunities for the young person to suggest their own ideas and co-produce their own project, where possible
- ✓ flexibility in case a first option does not go to plan

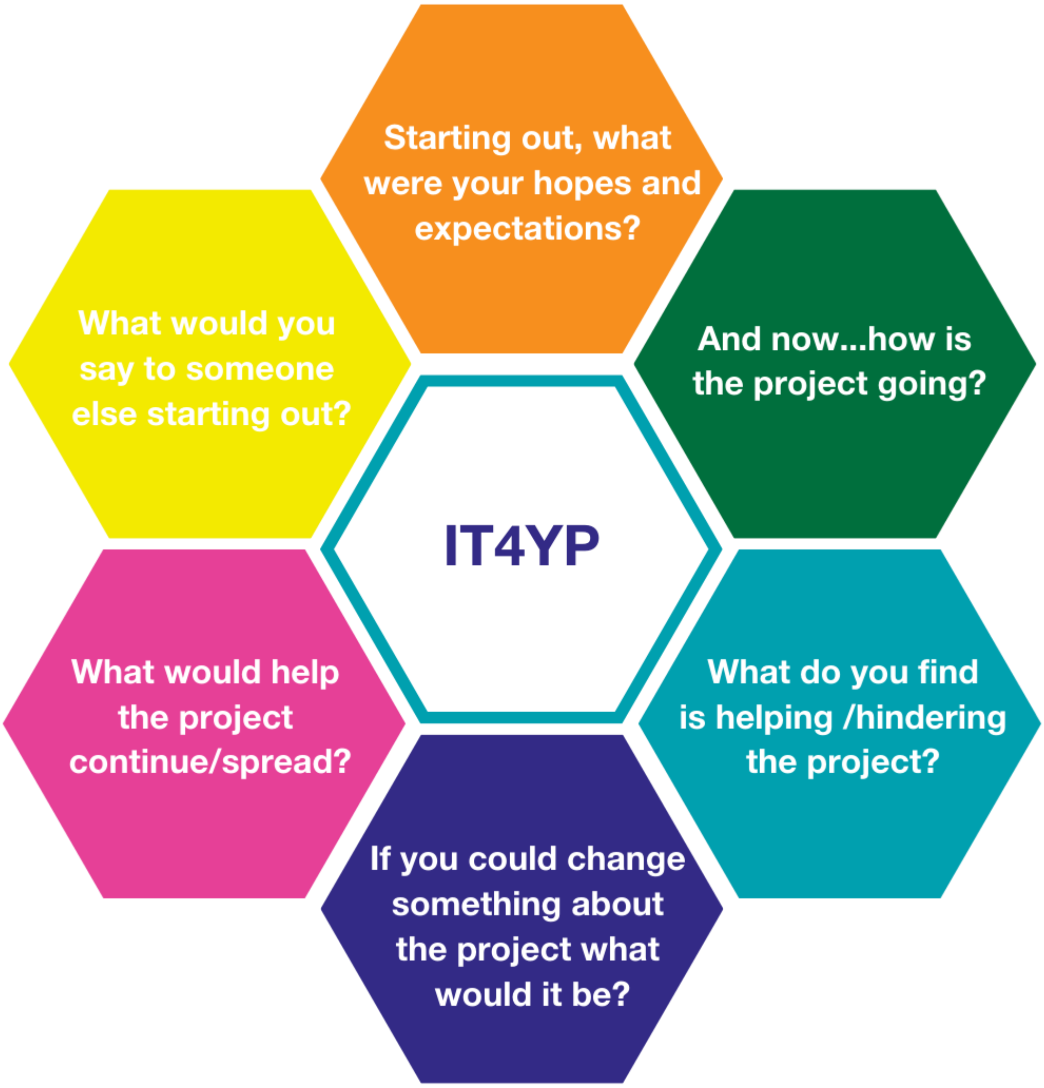
The benefits/impact of the project

The Futures Midlands project had many obstacles, but where volunteer mentors were matched successfully, the outcomes were very positive. The project demonstrates key success factors in enabling peer mentoring to help young people with very complex health needs access volunteering or work experience placements.

You can read the recommendations from the project here, and the full evaluation report.

Appendices

Appendix 1: Interview question matrix for transition project leads



Appendix 2: Acknowledgments

We are indebted to the three funders who have supported the Programme from its conception and throughout its delivery. We would like to thank them for their vision in supporting this Programme of innovation in this emergent field of transition for young people.

Quotes from Project Leads:

> The flexibility of the IT4YP Programme has enabled us to share our offer to better support young people and our local ways of working.

> It's been a real springboard. I do not know where we would have been without the funding.

> We were pleased that the funders had the vision to step out of their comfort zone and go with the project. It was not easy to commission but it's great that they had trust and faith in our pilot.

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We would also like to thank Dr Antonia Beringer, Senior Lecturer in Children's Nursing at the University of the West of England for her support in the evaluation of this Programme.

Advisory Group

Dr Hilary Cass, Chair of Together for Short Lives
Professor Sir Alan Craft, President of Together for Short Lives
David Strudley, Former CEO, Acorns Children's Hospices and Chair of the UK Transition Taskforce

Interview Panel Members

Sue Ben-Abrahams, Parent
Leah Booth, Young Adult
John Carswell, Director of Teaching, Learning and Assessment, Community College Initiative
Alison Cooke, former Director of Care, Rainbows Children's Hospice
Professor Sir Alan Craft (Chair), President of Together for Short Lives
Andy Fletcher, CEO, Together for Short Lives
Zoeta Manning, Commissioner, Birmingham and Solihull CCG
Dr Mike Miller, Former Medical Director, Martin House Children's Hospice and Trustee of Hospice UK
Doug Morris, Parent and lead for the Parent Carer Forum in Wiltshire
John Powell, Association of Directors of Adult Social Services
Emma Roberts, Young Adult
David Strudley, Former CEO, Acorns Children's Hospices and Chair of the UK Transition Taskforce

Interviewees for the scoping exercise

Professor Bryony Beresford, Co-Director, Social Policy Research Unit, University of York
Professor Allan Colver, Professor of Community Child Health, University of Newcastle
Dr Karen Horridge, Paediatrician in Sunderland & former Chair of the British Academy of Childhood Disability

Dr Katherine Knighting, Senior Research Fellow, Evidence-Based Practice Research Centre, Edge Hill University
Dr Janet McDonagh, Clinical Senior Lecturer in Paediatric and Adolescent Rheumatology, University of Manchester
Professor Jane Noyes, Professor of Health and Social Services Research and Child Health, Bangor University
Julie Pointer, Director, National Development Team for Inclusion and the Preparing for Adulthood Programme

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