st oswald's hospice

quality time for everyone

Living longer than you thought I would...

Working with young people with complex health needs and life-limiting conditions to meet the challenges facing them as they grow into adulthood

Lynne Young
with Marsaili Cameron

St Oswald's Hospice
St Oswald's provides hospice care for adults, children and young adults with life-limiting conditions from across the North East of England. Situated in Gosforth, Newcastle upon Tyne, St Oswald's purpose-built facilities offer a range of flexible services to North East families.
St Oswald's is a registered charity.

Marie Curie Cancer Care Young People and Transition programme
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Foreword

One of the greatest fears expressed by young people with serious disabilities, and even more so by their parents, is what happens to their care when they are no longer a child.

The last decade or so has seen a large increase in the number of such children surviving childhood and hence requiring transition from the rather protective world of paediatrics into the rather harsh world of adult care.

"Mind the Gap" and "Don't fall down the cracks" are two phrases often used to describe this phase of life which is very predictable but in the past has been very badly managed. The process of growing up is a natural evolution from dependency on others to eventual independence. Young people with long term illness and disability are no different in their need for such development yet many are physically unable to progress in the way that their peers do and remain dependent on others for many of their care needs. So there is a clear need to recognise that children are living longer with illness and disability and there are the two needs of having someone to care for them through and after transition and equally importantly to have somewhere to transit to.

I recall the graphic story told by parents of how their child had been wonderfully cared for by a paediatrician with multiple admissions to the children's ward for emergency and respite care. Three days after his 18th birthday there was another emergency and he was taken to his usual safe haven of the children's ward. A nurse met them at the door to the ward and told them he was too old for a paediatric ward and redirected him to the A&E Department. Several hours later the family found themselves in the strange and somewhat alien environment of an adult medical ward where his immediate medical problems were dealt with. Over the next few months he had several admissions to different wards with new doctors and nurses and before long he succumbed to the inevitable and died.

Cicely Saunders told us that the way a person dies lives on in those left behind. This particular family have fond and cherished memories of their son's life up to his 18th birthday but only nightmares thereafter. This need not and should not happen. Transition needs can be anticipated and can be planned for. There can be a smooth handover between those responsible for care at different ages and increasingly there are facilities and staff geared towards the special needs of this very vulnerable group of young people.

The story of how St Oswald's Hospice recognised the problem and did something about it is one which has lessons for all involved in this very demanding but also very rewarding area of care.

Above all we must listen to what young people and their parents want. Fundamentally they want to be as normal and independent as their condition allows. And only they can tell us what that is.

Cover up the cracks, fill in the gaps and offer all a seamless service to make the best of living.

Professor Sir Alan Craft
Emeritus Professor of Child Health
Newcastle University

Preface

This publication came about under the auspices of the Marie Curie Cancer Care Young People and Transition Programme. This aimed 'to better understand the situation, needs and aspirations of young people with life-limiting conditions who are growing into adulthood.' As a potential contributor to the national programme, colleagues here at St Oswald's Hospice were keen to be involved, but were wary of just what magnificent and insightful "truths" we might have to offer up! In the end, we proposed to simply tell our story of engaging in the transition agenda. We hoped that the best bits might inspire others contemplating moving their own services forward, and that the difficult bits might give fair warning of the challenges ahead for those that did.

Like many new initiatives, the impetus for our own service came from various different experiences and prompts. We were obviously aware of other hospices around the country that had already started to address these issues. Much closer to home, as our own Children's Hospice service matured, we discharged more young adults at 18 years old ourselves. Some discharges were entirely successful. However, feedback from staff, families and the young adults themselves was telling us that there was often no appropriate ongoing short break facility available in their locality. Worse still, they said that end-of-life care could unravel very badly, as inexperienced services did their best, but were totally unprepared for the care needs suddenly thrust upon them.

This then, is our story. Like all the hospices I know, our chosen path was not a desire to empire build, or attempt one-upmanship over other services already available. We carefully researched the potential need for such a service; talking to commissioners, other service providers, and the families and young people themselves. We also facilitated a Square Table event in February 2011 on behalf of our Strategic Health Authority, dedicated to the transition agenda. That had proved enlightening as to the continued challenges for any family with a life-limited child crossing the boundary of their 18th birthday. We believed that there was a genuine gap to fill, and garnered support from a variety of stakeholders. This gave us the courage to move forward, but of course, did not mean that anything was going to be easy.

It is a moot point, but 2011 may have been one of the worst years to choose to try and create and fund a new charitable service. (Although 2012 may be the obvious next contender). National economic factors have seen charities, by necessity, rein in their plans, as fundraising and statutory income becomes an ever greater challenge. The NHS and local social services departments, with whom we are inextricably bound in delivering co-ordinated care, were suffering great organisational and financial upheaval as well. In particular, NHS commissioning was hugely challenged by national and local changes. With such a niche issue, and in such challenging times, one can only be grateful for the progress that has been made so far.

Finally, at the time of going to press, June 2012, the future of our service still hangs in the balance. Having been started by significant grants, we are attempting to mainstream our funding from the statutory sector. We are engaged in constructive dialogue with our key commissioners, but as yet have no outcome to report. We believe that we have demonstrated that we can meet this small scale but incredibly important area of need with a good quality service. We hope that others agree, and that the service can carry on providing an essential bridge for all families in the North-East who are seeking the support and care that their grown-up children deserve.

James Ellam
Chief Executive
St Oswald's Hospice

Publication at a glance

What is it for?

All young people face challenges during the transition from childhood to adulthood. But young people who are disabled, with complex health needs and using a range of services, face additional, quite specific, challenges. For them and for their parents, 'transition' is not just between childhood and adulthood but between children's services and adult services. Research shows consistently that this latter transition is stressful and unsatisfactory for the majority of young people with complex health needs and their families – and also, in many cases, for those commissioning and providing services.

This publication aims to make a constructive contribution to the debate about how to change the current fragmented and ineffective system. It tells the story of why and how St Oswald's Hospice has created a new service for young adults, and with what effect. Meanwhile, times have changed in the world of commissioning, with huge potential impact for life-limited young people and their families. What collaboration now can ensure a decent quality of life for young adults and their families?

Where did it come from?

In the spring of 2011, St Oswald's Hospice launched a pilot service offering short breaks to young adults. This complemented the palliative care services that the hospice already offered to adults and to children. A few months later, St Oswald's became involved with the Marie Curie Cancer Care Young People and Transition programme, funded by the Department of Health and designed and managed by PublicServiceWorks on behalf of Marie Curie. The hospice became a pilot site for exploring best practice in support of young adults and their families; and staff took part in a UK-wide learning network. (For more information, see www.mariecurie.org.uk/youngpeople)

It soon became clear that the learning emerging from the St Oswald's experience could be usefully shared with other hospices – and with commissioners of services. It also became evident that learning from other pilot sites across the Marie Curie programme was likely to complement and supplement the findings at St Oswald's. Accordingly, the Marie Curie programme supported the Transition Project Lead at St Oswald's, Lynne Young, in developing a publication in close collaboration with members of the programme team – in particular, Marsaili Cameron, Director of PublicServiceWorks and experienced writer and editor.

Author

Lynne Young, Transition Project Lead at St Oswald's, has a background in social care, and spent over ten years working with the elderly before moving to children's services. Since then she has worked in a remand unit, as placements officer, fostering social worker, training officer and reviewing officer. She also managed a short break unit and short break fostering service for disabled children. Her interest in Transition began during that time when she saw at first hand the distress of parents and young people at the lack of services they would receive as adults.

She qualified as a social worker in 1985, and has two master's degrees – one in Social Welfare and Social Work and one in Autism. She also has a Postgraduate Certificate in Education.

Who is it for?

- Providers of services for adults and children in health, social care, education and housing
- Commissioners of services for children and adults in health, social care, education and housing
- Young people and their families.

How can you use it?

The publication offers insights and reflections from the hospice's experience of working with young adults – and invites you to contribute to active discussion of how to work together to shape a better future for this highly vulnerable group and their families.

The material is suitable for use by:

- Individuals – for example, as a briefing guide and to find out sources of further information
- Individuals and teams within departments – for example, for briefings, agenda setting, planning and review
- Individuals, teams and groups from different organisations, partnerships and networks – for example, to help identify areas of common purpose and work out the practicalities of shared approaches.

The publication is designed to support face-to-face work and also to encourage feedback and debate through St Oswald's website, facebook and twitter social media channels.

Acknowledgements

Thank you to everyone who has given their time to help us on this journey. I hope that I have done justice in the telling.

At St Oswald's, we are very grateful for the help, support and advice so freely given by our colleagues across the hospice movement. I would especially like to thank the following colleagues inside and outside the hospice:

Jackie Bolam	Children and Young Adults Service Manager, St Oswald's Hospice
Adam Copeland	Young Adults Champion
Professor Sir Alan Craft	Emeritus Professor of Child Health, Newcastle University
Debra Daglish	Communications Manager, St Oswald's Hospice
Angela Egdell	Director of Care Services, St Oswald's Hospice
James Ellam	Chief Executive, St Oswald's Hospice
Mathew Millar	Young Adults Champion

PublicServiceWorks and all others involved in the Marie Curie Cancer Care Young People and Transition programme

Pat Turner	Transition Lead, Acorns Hospice
Isabel Warren	Lead Nurse for Young People, Rainbows Hospice
Nikki Wilkinson	Campaign Manager, St Oswald's Hospice
Neil Williamson	Transition Service Coordinator, Richard House Hospice

Lynne Young

Transition – not just a minority concern

This section outlines key features and 'fault lines' of the territory entered into by young people with complex health needs who are approaching adulthood. We draw on findings from studies, research and our own experience to highlight what seem to be key issues and dilemmas for young people, their families, and the commissioners and providers of the wide-ranging support needed to ensure quality of life for young people and their families.

What is meant by transition?

* Dictionary definition of **transition**: 'the period of time during which something changes from one state or stage to another' (Collins 2009)

All young people face challenges during the transition from childhood to adulthood. But young people who are disabled, with complex health needs and using a range of services, face additional, quite specific, challenges. For them and for their parents, 'transition' is not just between childhood and adulthood but between children's services and adult services. Research shows consistently that this latter transition is stressful and unsatisfactory for the majority of young people with complex health needs and their families – and also, in many cases, for those commissioning and providing services.

Young people with profound learning disabilities, autism, severe physical disabilities, and/or life-limiting illness/disability have particular difficulties in making a successful transition (Getzel & deFur 1997).

In short, the system that is supposed to support young people with complex health needs/life-limiting conditions and their families is far too often, in reality, fragmented and ineffective.

Of course, the young people involved do not themselves usually talk about 'transition'. Like other young people, they are more likely to talk about 'growing up' or 'becoming more independent'. What they want is a normal life, as far as that's possible – opportunities for education and work, and an active social life. They are quite aware that they need services to support them in their aspirations; but, like everyone else, they want to feel that they are in the centre of their own lives, not cogs in a machine. As one young man commented, 'I want support; but I want it in secret, not in my face.'

For their part, many parents dread transition. The categories, 'complex health needs' and 'life-limiting condition', encompass a very wide range of capacity and ability, physical and mental. Transition between children's and adult services presents huge challenges at whatever point the young person appears on the spectrum of capacity. The mother of a child with no speech or cognitive skills commented:

> *'Transition is a worrying prospect for us. In the case of children who will never lead independent or semi-independent lives, we have to ask if transition (or what we understand of the term) is relevant for them? They are unlikely to develop any further skills and will always require the same degree of one-on-one full time 24/7 care.'*
>
> *'What concerns us is that whilst [her] needs won't change, the level of service and respite on offer will once she reaches transition age. It is not clear where we can go for the level of support and assistance we have benefited from and appreciated to date. Furthermore, it is a little alarming to think that [she] will be transferred to 'adult' services at a later stage as an 'adult' environment is not suitable for someone as vulnerable as her, regardless of age.'*

What kind of numbers are involved?

The numbers of young people affected by 'transition' issues are growing, partly reflecting advances in medicine. Children who in previous generations would have been expected to die in childhood are now becoming young adults, with associated needs and aspirations.

Studies in the mid- and late-1990s reported that more children with complex needs were reaching adulthood and transition had become a high priority for all services.

A report published by the University of Leeds (Fraser et al 2011) has shown that the prevalence of life limited children and young people aged 0-19 years has increased during the last 10 years:

Year	Total children and young people with LL conditions	Prevalence per 10,000 population	Prevalence young people aged 11-15 years	Prevalence young people aged 16-19 years
2000/01	**30,643**	24.9	17.4	16.3
2005/06	**34,066**	27.6	20.4	19.5
2009/10	**40,042**	32.2	24.0	23.6
Increase 2000-2010	**+30%**	+29%	+38%	+44.8%

[Adapted from table 1 Fraser et al *Life-Limiting Conditions in Children in the UK*, Division of Epidemiology, University of Leeds 2011]

The report found that congenital anomalies are the most common cause of life-limiting conditions; and that the number of young people surviving into adulthood has been underestimated. This number will continue to grow and challenge adult services to cater for this younger age group.

The challenges for young people and families

Research (Cameron et al 2009; Davies & Beamish 2009) shows that successful transitions to adulthood are achieved due to the support of parents and the young person's wider family. However, professionals and services do not always recognise the importance of family involvement and hence may not prioritise identifying and providing the right kind of support for individual families. In particular adult services have tended to focus on the independent adult whereas children's services have focused on the family as a whole.

Shared perceptions?

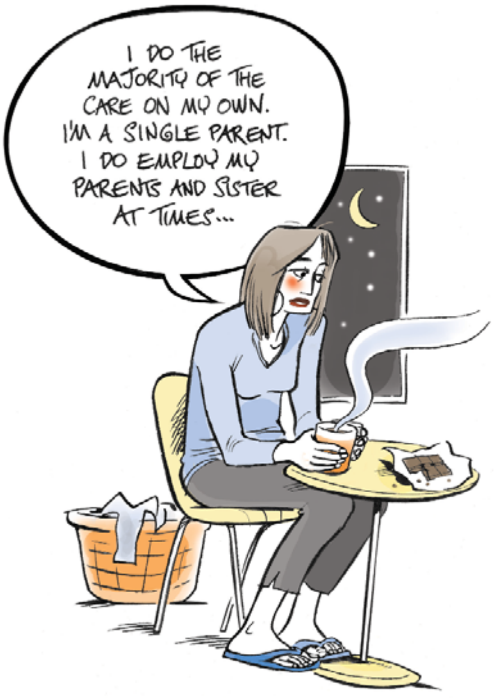
Do young people and their parents share perceptions of the main challenges facing them?

To some extent they do. On behalf of their young people, parents identify as priorities education, where the young person will live, social networks, hobbies, recreational activities, achieving the best quality of life possible, and having the right kind of assistance available. For their part, young people agree that what they want is a normal life as far as this is possible, with opportunities for education and work, and an active social life, which involves looking good and forming relationships.

Parents and young people agree too that it's very hard to move from children's services to adult services. Suddenly, the young person can't get care or support that they need, and they no longer feel in control. The move from children's to adult services also usually means a sharp reduction in the number of short breaks available to parents. Both young people and parents find it very hard to have to give up 'me' time, when each can have some time apart in which to re-charge their energies.

Of course, there are areas where there are real differences in perception – and indeed of experience – between young people and their parents. On one level, what could be more natural than this? After all, any growing up involves a separation between the generations. But there are specific challenges facing young people with complex health conditions and their parents. For example, each runs the risk of being over-protective of the other. The young person may have specific concerns about their condition but fear to distress their parents by asking questions or discussing it. For their part, parents may treat disabled young people as children for longer than non-disabled siblings and fail to give them the space they need as they get older to take their own risks and explore a more independent life.

Addressing causes of stress and distress at transition



Parents, particularly mothers, of young people with disabilities generally suffer higher stress levels than those with non-disabled children (Glidden & Jobe 2007). The time of transition can be particularly stressful (Cameron et al. 2009) since many young people will not receive the same level of support once they are adults, and parents see their caring responsibilities increasing not decreasing (Hallam 2007), at the same time as they themselves are growing older. There has been little research into parental wellbeing at the time of transition.

Planning for the future

Professionals carrying out assessments to help plan a young person's future all too often emphasise what the young person is unable to do instead of identifying any barriers that could and should be tackled to build on and develop their abilities and strengths.

The barriers, of course, are real enough. With education, for example, it is common for colleges that can meet the needs of individual young people to be too distant from the family home to allow daily travelling. On the other hand, young people who remain at home can become very isolated. If they attend day centres, then most other attendees are a lot older than the young people and their social interests are not met. Parents express worries at this time in the young person's life about what the future holds and what will happen to the young person when they are unable through illness or old age to continue to provide day-to day-care.

So, how can these barriers be overcome?
And what factors contribute to successful planning during transition?

First of all, a reminder. In many cases, parents and carers have not made plans for their children because they were told at the time of diagnosis that their disability would see them die in childhood. It is not necessarily easy to move from that point to active engagement with agencies and to contemplating a transition to adulthood.

Successful planning depends principally on the early involvement of services combined with constructive and flexible partnership working between the family, the young person, social care, health and education. Planning for those with special needs is supposed to start at the first school review after the young person's fourteenth birthday and then be continued through the transition to adult services (Abbott et al 2001). If planning is to be in the best interests of the young person, then all options need to be carefully explored. For this to happen, up-to-date relevant information must be available to the young person, their parents or carers and professionals.

There is an awkward disparity between the times that young people transfer to adult services – for example, often at age 16 for health care and at age 18 or 19 in education or social care. As a result, there can be confusion about what will happen and when. There are pathways for professionals to follow during this time but the same pathway will not meet everyone's needs and whilst some young people and their families will want to explore opportunities, others will choose to remain at home with the support of local services. Legally, all young people with a Statement of Special Educational Need must have a transition plan.

In some cases, young people and their families can experience shock and loss rather than simply confusion on transition. For example, when young people transfer from children's health services to adult health services, they can find that services stop without warning (DARE Foundation 2006) and trusted professionals are no longer available. In one case, a young man who had recently passed the age of 16, in acute respiratory distress, was turned away from the children's ward that he had attended all his life. 'You're an adult now', he was told by the nurse barring his way, 'and you can't come in here.' 'Where can we go?' asked his desperate parents, who were given the reply, 'To A&E, I suppose.' A six-hour wait followed in unfamiliar and at times disturbing surroundings.

Policy responses to the challenges of transition

During the past decade or so, central government has recognised that the population of disabled children reaching adulthood is increasing year on year. As these young people reach adulthood, policy makers have acknowledged that this group has been neglected at transition, one of the most important times in the life of all young people.

The policy initiatives and legislation shown in the box provide clear guidance on equality and inclusion for disabled people. Taken together, they make up a context in which it should be possible to take action to improve the experience of these young people and their families. However, despite the good intentions, the system that is supposed to support these young people and their families remains in reality fragmented and ineffective.

Policy initiatives and legislation

2001

The Department of Health published *Valuing People*, 'a new strategy for learning disability for the 21st century'.

→ highlighted the challenge of poor transition planning for young disabled people reaching adulthood

→ key principles of the report: Independence, Rights, Choice and Inclusion of people with learning disabilities

2003

The Department for Education published *Every Child Matters*, a comprehensive programme of reform for children's services. Key underpinning principles:

→ more closely integrated frontline delivery of educational, health, social and specialist services

→ earlier intervention to provide support before problems become serious

→ closer working between professionals who might be involved with the same child or young person

→ more coherent planning and commissioning of services

→ greater involvement of children, parents and carers in the development of services

2004

The amended Children Act 2004 provided for the legal implementation of *Every Child Matters*.

The National Service Framework for Children, Young People and Maternity Services set standards to modernise services and improve partnership working throughout childhood.

→ particularly important to young people whose disability is managed through the Health Authority as it ensures that all service providers are equal partners with equal responsibility to ensure that young people's transition to adulthood is the responsibility of the whole care team around the young person

→ states that palliative care could include short breaks, pain management and symptom control.

2005

The Disability Discrimination Act ensured that public sector authorities must build disability equality into service delivery.

2007

Jointly delivered by the Department for Education and the Department of Health, *Aiming High for Disabled Children: Better support for families* is the transformation programme for disabled children's services.

- the *Aiming High* agenda has ensured that transition has been given the high priority it both needs and deserves if disabled young people are to go on to lead fulfilling lives in a manner of their own choosing

Under the *Aiming High* agenda councils were given £19 million to develop transition support programmes. The core purpose of these programmes was:

- supporting disabled young people with the support and services that enable them to work towards living as they want
- ensuring that agencies in local areas work together in a coordinated way to provide better support for disabled young people and their families
- changing organisational culture to improve local service delivery
- providing targeted support to ensure that every local area is able to share learning and improve service delivery

2007 -2010

In support of *Aiming High*, Government announced the *Transition Support Programme*, designed to raise the standards of transition in all local areas. Consisted of two main elements:

- **The National Transition Support Team**, to coordinate the work with local authorities, primary care trusts, named advisers and existing experts; and
- **Support for change at local level** through a combination of direct grants and named advisers activity.

2011

The Department for Education funds *Preparing for Adulthood*, a two year programme to support delivery of the Green Paper, 'Support and aspiration: a new approach to special educational needs and disability'. See www.preparingforadulthood.org.uk

- brings together a wide range of expertise and experience of working with young people and families at a local and national level and across government, to support young people into adulthood with paid employment, good health, independent living, community inclusion.
- The *Preparing for Adulthood* team previously worked on key transition programmes, including the Transition Support Programme.
- The government response to the Green Paper consultation is leading to the provisions in the proposed Children and Families Bill announced in the Queen's Speech May 2012

The challenge for commissioners and providers

The situation is far from straightforward. As adulthood approaches, young people and their families need as much, if not more, support than was available when they were younger. The policy and legislative framework offers impetus for support and engagement of this kind. And yet research shows consistent failure on the part of 'the system' to deliver what is needed. To many, including providers of services to young people, like St Oswald's, this presents a real and distressing conundrum.

If they are to make the most of life as adulthood beckons, **young people with life-limiting conditions**, and **their families**, need access to wide-ranging support – and to be fully engaged in identifying the right kind of support for them.

If **providers of services** are to be able to develop and offer the right kind of support, they need to know that they can attract the backing of commissioners who can both recognise quality of service and access the money needed to fund it. Confidence of this kind is currently lacking. One provider of services to young adults commented:

> *'The NHS children's services commissioners are right behind the new young adults service and, I'm glad to say, already sing its praises. However, they are not in a position to fund it – it is outside their children's remit. Meanwhile, when we talk to adult services commissioners in the NHS, their eyes widen because they never expected to cover this expense, and are unsure as to whose responsibility this is.'*

If **commissioners** are to be confident that they are spending money wisely, they need to have clear insight into the range of needs and aspirations of young people and their families – and also a discriminating knowledge of the different services available locally. Many commissioners are indeed extremely passionate about the needs of this group, and are genuinely interested in trying to do their best in a time of uncertainty, budget cuts and organisational change. But the complexity of commissioning arrangements means that there is a split between front-line, operational commissioners and those with a more strategic role, as well as between children's and adults and between health and other service sectors. With huge responsibilities over often very wide geographical areas, it is hard for strategic commissioners especially to gain practical insight into the complex and multi-layered challenges associated with transition.

So, what exactly is going wrong, and why? And, crucially, what changes are needed to ensure joined-up commissioning and provision of the right services to the right people at the right time?

In Section 3 of this publication, 'Learning together for the future', we explore in some detail the urgent, real-life pressures imposed by the kind of commissioner/ provider splits described above; and we offer some questions and ideas that we hope may engage others in constructive dialogue with us and each other.

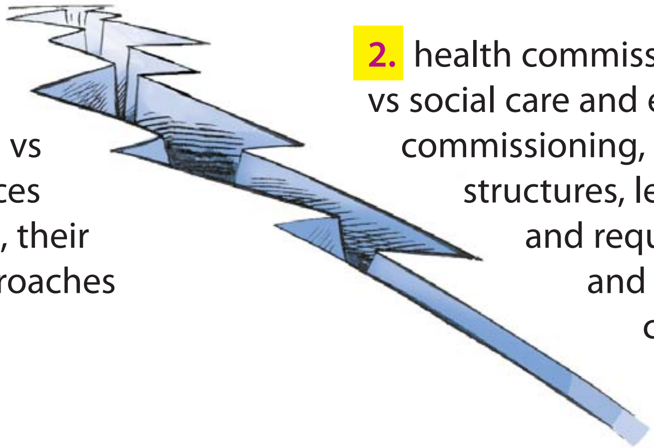
Here, drawing on studies from a number of quarters, we describe some of the key features of the landscape in which commissioners and providers are working.

Identifying the fault lines

During the Marie Curie Cancer Care Young People and Transition programme, some metaphors emerged that seemed to help describe and explain the complex territory surrounding transition. 'Fault lines' was one of these terms.

Key 'fault lines' cut across the territory of joint working on transition:

1. adult services commissioning vs children's services commissioning, their structures, approaches and priorities



2. health commissioning vs social care and education commissioning, their structures, legal duties and requirements and cultures of commissioning

What stems from these is system fragmentation and unclear (or passing back and forth) of responsibilities between agencies/sectors. The assumptions are 'it is either your responsibility or mine' rather than thinking about shared or cross-commissioning/providing.

In addition the tendency to focus on either family as a whole (children's commissioning) or the individual adult's needs (adult commissioning) can be unhelpful to the emerging young adult and adds to the problems of the fault lines. The individual/family split is layered over these and may add to a sense that this is not a human focused system.

These fault lines seem to be getting worse as a result of the current changes in NHS commissioning. New arrangements are emerging whereby elements of commissioning are divided further between subnational boards/national commissioning board, local clinical commissioning groups and local authorities. There is urgent and continuing need to spell out the impact on young people of these developments – higher visibility for this group is vital.

Nationally, the lack of a duty across all agencies to provide services specifically related to transition means that resources – such as staff to do this work – are not prioritised.

When young people with complex health needs reach the age of 18, there are few if any professionals in adult services, particularly health, who have expertise in their care. There is no adult equivalent to *Every Child Matters* or the *Aiming High for Disabled Children* programmes so there is little policy driven commitment to see plans through.

The source of funding directly influences the nature and sustainability of the support package. Where young people have had an assessment and are in receipt of 100 per cent health funding when they have their 18th birthday, then plans already in place are likely to continue. For those with social care funding or funding split between health and social care, then there is a real risk that services will be cut because of funding shortages. As this report is being written, a challenge is being progressed through the courts by an individual assessed as needing a high cost package and being allocated much less as a budget. The outcome of this case will impact on the care packages identified in the future both in terms of assessed need and the funding to cover this.

To be effective, it would seem obvious that transition planning should start early and include both children's and adult services. In practice, however, this is rarely the case. In children's services, transition planning must start when the young person is 14; so from this time, children's social care, health and education should be actively working together. (Each young person with a Statement of Special Educational Need is allocated a Connexions worker. However, the Connexions Service has had its funding cut and it is unclear whether this service will remain for all in this group.) Unfortunately, adult counterparts rarely get involved when the young person turns 14 and it is not unusual for individuals with complex needs to reach 18 before adult services know they are there. Even when professionals from adult services are aware of the existence and needs of young people with complex life-limiting conditions, there may be no age-appropriate services available. Where there are short break facilities locally, there is a real risk that, unless careful planning takes place, young adults will be placed with very much older people and their care and health potentially compromised as a result.

What has been learned about what works?

In October 2011 the Council for Disabled Children published information and learning from the *Aiming High for Disabled Children* programme. Key learning points included:

- Young people with the most complex learning difficulties or support needs require specialist information, advice and guidance that is beyond the scope of universal services
- Where employment, education or training are not appropriate aspirations for young people, the link between transition planning and short break services is critical to making leisure services more accessible
- Multi-agency protocols and pathways are critical stepping stones to progress, but not ends in themselves
- The importance of young people and parents participating in year 9 reviews
- Person-centred planning is key to success
- Better data shared by children's and adult services is essential to forward planning, quality assurance and efficient commissioning.

(National Transition Support Team 2011)

In recent years, in response to the needs of young people known to them, some hospices have started providing short breaks to young people aged 18-25 years. St Oswald's is one of these, and the story of how we researched and set up our young adults' service is told in Section 2.

Bringing it home

1. Which of the issues and dilemmas outlined in this section are familiar to you, and which unfamiliar?

2. Are there any gaps in knowledge or understanding that you would particularly like to fill?

3. Are there experiences or insights that you think it would be useful to share with others?

Section 2

Young adults at St Oswald's – the story so far

This section tells the story of why St Oswald's decided to set up a pilot young adults' service and how we went about developing our offer. We describe the wide range of experience and expertise that we drew on – from inside and outside the hospice – and reflect on the key learning for us during the first year of operation of the service.

Providing palliative care for adults and children in the North-East

St Oswald's Hospice has operated in Gosforth since 1986, providing palliative care for adults with life threatening/limiting illness. In 2003 a short break service for children and young people aged up to 18 years opened, adjacent to the adult's hospice, providing eight beds.

The service is provided across the region to Northumberland, Newcastle, North Tyneside, South Tyneside, Sunderland, Gateshead and Durham.

Why make separate provision for young adults?

Some of the young adults who left the service at 18 are now in their early twenties and there is evidence that, for many of them, the move to adult services has not been a happy one. There are reports of services breaking down or not being provided at all and young adults' physical and mental health declining for this reason.

This information emerged largely through feedback from parents. Parents of young people aged 16 and 17 expressed their concern about the lack of adequate provision for their children reaching adulthood. Parents of young adults reported gaps in support after they had left the service at 18.

As this feedback reached them, professionals across the region shared their concern and frustration about the lack of appropriate services and planning for young people during transition to adulthood. A care manager commented, for example:

> *'We have looked for a suitable place for [young man] to have short breaks for the three years since he was 18 and had to leave the children's service. Unfortunately, this has meant that he has had no break in that time and neither have his parents.'*

Two years after the children's service opened at St Oswald's, an evaluation was undertaken by the then Head of Children's Service at the hospice and a research team from Northumbria University. Recommendations for the future of the service included transitional care 'increasing the age to over 18 years, an outreach service and/or day care service.'

The following factors contributed to a recommendation for special provision for young adults.

Recognition that the numbers affected are growing

In May 2007, Palliative Care Statistics for Children and Young Adults (DH 2007) concluded that 'there is some evidence from recent mortality trends and from published research that life expectancy for people with some conditions that require palliative care is increasing.'

Recognition of a mismatch between budgets and care

Hospices across the UK were pointing out that young adults were being left without appropriate short break facilities at the very time when they were dealing with changes in their medical team and with major decisions about their future. For example, they had to think in a focused way about where they would live, who they would live with, and how they would spend their time in terms of further education, employment and socially. A young man described the service he received as an adult before returning to St Oswald's:

> *'The staff are lovely where I go now but there are three staff for twelve residents. If one of us needs personal care or hoisting, then there is one staff member for eleven of us. They don't have time to talk to me so I spend my six-night stay in my room on my laptop.'*

Budget holders had not been encouraged to think this situation through in terms of providing services, like supported short breaks, that could help young adults navigate this challenging territory. The changes in medical team were also often problematic. For example, clinicians specialising in muscular dystrophy and cystic fibrosis had no adult counterpart to refer the young people on to at 18. A community paediatrician commented:

> *'Preparation for transition to adult services for young adults with complex needs has become a significant issue for young adults, their families and carers and the health professionals they work with. Child health services have evolved over the years in response to the health and social needs of this group of children and young people. However, adult services seem now to be only beginning to see the needs of this group and develop the experience of managing their care.*
>
> *With the changing nature of healthcare provision in primary care and the role of the GP, along with the sub-specialisation of adult medical services, there is often no clear medical practitioner in primary or secondary care who is able to take on the holistic care of young adults with complex physical disability – and this at a time of significant changes to a young adult's educational and social care creates significant anxieties for the young adult and the family. We need to recognise the health needs of this group of young adults, and ensure we fully commission a service that facilitates the smooth transition to health services where the objective is to comprehensively provide the care needs of young adults with complex disability and life-limiting conditions.'*

These kinds of mismatch were in fact proving very expensive. With the needs of individuals and families going unmet, crises would arise, including family breakdown leading to the provision of very costly packages of often inappropriate care.

Shaping the pilot service – drawing on everyone's experience

In August 2009 the Head of Children's Service at St Oswald's left her post to take up a new challenge. Before her departure, she sent a letter to parents of young adults who had left the service at 18 informing them of her impending move and asking for feedback on their experiences of transition. Included in the feedback she received was a letter from a parent telling in graphic terms exactly what transition had meant to them. The letter included the following extract:

> *'St Oswald's is being taken away from us and there is absolutely nothing to replace it. We went overnight from having the perfect support system to absolutely nothing … The top and bottom of it is that there is* ***nowhere*** *that can care for terminally ill young people with disabilities. If [our son] had cancer, it would be a totally different story but because he was born this way then it doesn't pull at people's heart strings. He can't voice how he feels and show people what a special chap he is. The time in our lives when we need help and support – there is nothing available.'*

When this letter was circulated to managers in the hospice, it proved a tipping point in confirming their concerns. A visit to another hospice with a young adults' wing enthused them further.

Once it was clear that the regulator, the Care Quality Commission, would not object to children's and young adults' services running, with some restrictions, within the same building, the plans began to take shape. These were agreed by the hospice trustees and the search for funding began.

During the autumn of 2010, the Department of Health established a pool of £30 million in funding to support children and young people's palliative care services, including 'better transition from children's to adult services'. This was an opportunity to seek the funding to make accommodation changes to the Children's Hospice and employ staff to run the Young Adults Service as a pilot.

The Department of Health Grant provided more than half the cost of the two year pilot scheme. The remainder was made up by donations from other external funding streams, such as bids to charitable trusts. Increased staffing costs were included in the overall running costs but the first role that was advertised was that of Transition Project Lead.

Who shaped the service, and how?

Two people, both new in post, worked closely together to explore options and to go on to shape the proposal for the new service. These were the **Transition Project Lead** (TPL) and the **Children's Service Manager** (CSM). The latter post soon became known as the Children and Young Adults Service Manager (CYASM), to reflect the changes in provision taking place.

The job description for the Transition Project Lead was devised with the knowledge of what had worked whilst developing the children's service and information shared with managers by hospices that were already developing a transition service.

The TPL took up her post in September 2010. She had a social care background – something that, it soon became clear, transition workers in other hospices considered an advantage in planning the new service. The TPL was not so sure at this point since, having come from a social care background, she found 'health speak' was a whole new and bewildering experience! Where and how it all fitted together remained a mystery for several months. Reflecting later on the importance of bridging gaps between professional cultures, the St Oswald's Children and Young Adults Service Manager commented:

> *'It's a healthcare facility and although I have a background in community working and in working with social care colleagues, I did not have in-depth knowledge of the systems and processes within the social care system. It's a jigsaw and between us we had all of the pieces.'*

It soon became clear that the social care background did provide at least one clear-cut advantage. The TPL came into post just at the time that the Care Quality Commission (CQC) took over the inspection of services, using an evidence-based methodology that was unfamiliar to most health professionals. The TPL had extensive experience of an inspection regime that required thorough documentation and where visits were made without warning; and therefore was able to proceed with some confidence in negotiating parameters for the new service with the regulatory authorities.

The Children's Service Manager took up her contract at the hospice in the same week as the TPL. She had most recently managed community nursing services and had been the pathway coordinator linked to St Oswald's in that area since the children's hospice opened. She brought knowledge of the existing service provided at the hospice and community focus to her new role and she encouraged and supported the TPL in thinking outside the box in a way that a hospital-based manager might not have done. During the first few months of joint working, many avenues were explored and nothing was ruled out.

Management at the hospice had no fixed ideas about how the service would be developed and this gave the TPL the opportunity to research widely. The one assumption that had been made was that a pathway that had been developed with health and social care in the seven local authority areas covered by the children's hospice would be replicated for young adults. This assumption, as will be seen shortly, was modified in light of research carried out in preparation for the new service.

The development of the service was to be in three phases:

1. Ensure that those reaching 18 who were accessing the children's service could stay – if they wanted to do so.
2. Enable ex service users to return if they wished.
3. Find out who was out there who had not used the children's service, but who might benefit from using the young adults' service.

Researching widely…

On taking up her post, the TPL was provided with a list of hospices up and down the country that were providing a service to young adults. From the autumn of 2010 until early summer of 2011, the TPL and CSM visited all local hospices and several of those further afield that were known to have a transition service. They asked and were freely told of things that had gone well and things that had not worked at all. A significant positive comment was:

> *'Having a dedicated living space and staffing for young adults made the development of the service very easy.'*

Equally significant were the warnings contained in the following statements:

> *'Having got agreement from CQC that we could keep young adults when we did not have any specific plan in place other than we did not want them to leave us has meant that young adults are being cared for alongside children.'*

and

> *'Our new building is fabulous but we should have had much more storage space.'*

These conversations enabled several blind alleys to be avoided – though both the TPL and CSM would agree that they made a few mistakes of their own despite all the advice given.

It became clear that there were some good examples of young adults' services across the country. It was striking, however, that many providers had not developed a dedicated service for this group. Instead, they had, in effect, kept young adults by default when there were no other suitable services they could access post-18. For example, services reported 'keeping' young adults up to the age of 35, having asked for exemptions to their registration since there was still no suitable service available for these young adults. This meant that young adults were sharing accommodation and facilities with children, a situation that was far from satisfactory.

There was no consensus on how to define or identify those growing into adulthood. Many services talked about 'young people'; but, in practice, this term was confusing to both professionals and families. Blanket use of the term had other adverse consequences. For example, carers could, with relative ease, continue to consult parents rather than the person who, as a young adult, was entitled to be treated as a service user with full decision-making rights.

… but also listening to the people close at hand

From the beginning, the 'research team' composed of the TPL and CSM recognised that they needed to listen carefully to voices inside St Oswald's as well as those far from home. Two key groups were, of course, young adults and staff.

The Care Quality Commission agreed at an early stage that as long as young adults' sleeping arrangements were separate, and some dedicated daytime living area was provided, then there would be support for the single-site development of the service. The bedrooms in the unit are on two separate corridors so no changes were needed and a room that housed a moth-balled 'splash pool' was identified as being an area that could be developed as a young adults' room.

The TPL began a consultation exercise with the **young adults** about what this area might look like. She also collected information from the families of young adults who had left the service. Some were happy with the current services they were accessing externally, some clearly were not. The TPL arranged to visit families and young adults who showed an interest in the new service. Young adults across both groups were very keen to tell the TPL what their ideal would be.

The TPL became concerned at this point that the group of ex-children's service users were becoming very excited about a service that they might not be able to access for some time if the three-phase plan for the service was followed. Senior management at the hospice agreed that phases one and two should be consolidated so that ex-children's service users could return when the service was launched. It was further discussed and agreed that the TPL would attend all reviews for those aged 14 and above so that young people and families would be familiar with the TPL and her role. The TPL explained that it would be very difficult to work with these young people and their families without knowing them, so spending time on the unit when they were resident would be beneficial.

The existing children's service staff were also involved in active discussions at a very early stage. These discussions were stimulated by the continued presence in the hospice of a young adult known to the staff since childhood. Although the launch of the service was some months away, an agreement had been made with the CQC that the young adult who was 18 in September 2010 could remain until everything was in place. It was important from that early stage that staff began to think about things differently. It also helped them to prepare for the changes to come; many had expressed concern that as children's nurses they had no experience of nursing adults. At that time, some were very wary of the idea, whilst at the same time not wanting the young people to leave knowing that there was no appropriate service in the wider community. Reflecting later on their feelings at that time, staff commented:

> *'I'm not even sure what I was worried about.'*

and

> *'I was worried about working with cognitively able young adults. At that time I did not feel up to the challenge – not the physical care but the psychological care and wellbeing. Those worries have not been realised.'*

In the following months, while the service was being developed, these issues and concerns were talked about openly and in supervision sessions.

Identifying core priorities – and translating them into action

In November 2010, the TPL provided a report to the Hospice's Children's Commissioning Group. This report was supported by reference to the Health and Social Care Act 2008 (Regulated Activities) and the Care Quality Commission (CQC) (Registration) Regulations 2009.

At that early stage, the challenges identified were:

- Personal budgets – at different stages in health and social care.
- The cost of providing a high quality responsive service at St Oswald's being unfavourable if directly compared to short break services locally/regionally.
- Changes to commissioning in the health service might mean negotiating with unfamiliar departments and individuals.
- An increased focus on eligibility for services due to reduction in budgets held by health and social care.
- Understanding how many young adults aged 18-25 might want to access short breaks at St Oswald's.
- If commissioners want to commission set amount of nights, can the service respond?
- Involving staff from adult and children's services in providing the new service.
- Clinical Commissioning Consortiums will take over the health budgets for young adults, potentially changing new agreements reached.

The research phase of the project, outlined earlier, was a process of inquiry, looking both backwards into what had been done elsewhere in the past and forwards into the hopes and aspirations of young people and staff associated with St Oswald's. What worked, for whom, in what circumstances? For each approach that had something to offer, what were the upsides and downsides? And, crucially, how did what had been achieved elsewhere relate to what young adults in the North-East, and their families, would like from St Oswald's? The following priorities emerged from reflection on the process of inquiry and discussion of the implications.

Clarifying who the service is for

The research associated with the project indicated that it was very important to make it clear who the service was for, along with its underlying purposes and values. The St Oswald's team was fully signed up to the concept that transition was a stage, not an age (ACT 2007) and that transition should be seen as a process and not as a single event (DH 2006). However, as noted earlier, they had observed that where children's services 'kept' people well into adulthood, this situation met the needs of few of the people involved. Accordingly, the team decided that they would set the age of 25 as the upper limit for users of the new service. They also agreed that those aged 18 and over would always be referred to as young adults. This would help staff at the hospice to get used to the idea that they would be providing a service to young adults.

Ensuring continuous engagement with young adults

Young people and young adults have been at the heart of work to shape and develop the new service.

Getting the space right

From the very beginning, young people took part in discussions on what the young adults' living space should look like and contain. In January 2011 young people aged 16 and above, along with young adults, were invited to tea in the children's unit to meet the architect. The young people had already been working on ideas for how they wanted the room to look. The architect brought some drawings of what he thought might work. A lively discussion took place, with parents involved. Parents were much more concerned with the practicalities of the heating and space than the young people and young adults whose priority was high tech equipment and modern décor.

As the dedicated living space was under development the TPL continued to consult young adults. In the nicest possible way, families had to be reminded it was the young people and young adults' views that needed to be heard. To that end, two cognitively able young adults were asked to become Young Adults' Champions and meet with and email the TPL regularly to ensure that their voices were heard. (Young adults were asked but could not come up with a better name than 'Champions', and this has continued to be their preference.)

Lifelites is a charity that provides high spec electronic entertainment equipment for children's hospices (for contact details, see 'Further resources' section at the end of the publication.) The charity agreed to provide equipment for the young adults – one of the first young adults' units they had serviced in the UK. A wish list was drawn up, and due to the generosity of Lifelites supporters, the list was achieved. The only other thing that was requested was a laptop so that anyone staying who did not have their own could have use of it. This was given by the Co-op Funeral Service. When the Lifelites equipment was fitted, young adults were able to try it out and as a result some changes were made. The original computer was changed for a tablet so that it could be used from a wheelchair tray. Monitors were replaced by a large wall-mounted screen and projector.

A colleague from Lifelites described what they saw as the difference between working with children and young adults:

> *'Lifelites has been donating technologies to help children in hospices for over ten years. Supplying to this age group, we develop quite a specific package which would provide the entertainment and education facilities that would enhance the time they spend at the hospices. In the case of children, naturally most of the activities using the technologies had been care staff led. With the advent of the young adults' unit we had to think again. St Oswald's own survey of potential service users gave us lots of clues; intelligence was also gathered from their care staff.'*

'We could see that greater independence was required than our static computers could give them. We also knew that young adults are even more switched on to technologies than we are when it comes to new technologies so we felt we had to respond to their requirements. In particular, the introduction of the touch screen tablet meant that the young adults would have better access to the technology than a desktop touch screen computer would give them. It was important too that everything was high quality. To a great extent, we wanted to give them something that they might not have had access to at home and help to encourage them to make the best use of this unique facility. By incorporating state of the art entertainments and gaming into the amazing space that was provided, we felt we were able to add a real "wow" factor to the facilities and give these young adults somewhere they knew they could call their own and be as independent as possible.'

Once everything was working and in place, the room consisted of a computer suite, a television area that included a games station and music, a beverages area, a dining area and access to a yet to be developed garden. The young adults did not want a cooker; no surprise there – how many young adults see this as a desirable piece of equipment? A lockable cupboard was fitted to store any alcohol, 18+ DVDs and magazines. In planning for the new space, a Young Adults' Champion made it clear that continuity was important as well as innovation:

'It was important that we wouldn't lose the atmosphere that has already been created in the main lounge.'

The young adults' room was fitted with electronic doors for which staff and young adults have a fob to gain entry; exit is automatic when the doors are approached from inside the room.

Creation of a young adults' group

In November 2010, the CSM and TPL attended a conference and were greatly impressed by a speaker who relayed the challenges and satisfaction in setting up and running a young adults' group. The following words in particular struck the colleagues from St Oswald's:

'Starting and running a young adults' group at the time of the idea, four years ago, just felt like a good idea. I have now realised that a young adults' group is a true symptom management tool even more powerful than a syringe driver or ventilator. A young adults' group treats the biggest symptom of young adults' palliative care and that is the symptom of social isolation.'

On the train during the return journey, both agreed that this was something that could be achieved and now was as good a time as any. A meeting was set up to discuss this and staff from adult inpatients and day services were asked if they would like to assist in the monthly meetings. Funding was found and the inaugural meeting took place in April 2011.

It was decided to include young people aged 16 and over in the group. This meant that there was a mixture of individuals with physical disabilities who were cognitively able and those with physical and learning disabilities. The CCM and TPL debated the make-up of the group but came to the decision that one group could be enjoyed by all since many of those who were non-verbal enjoyed being in the middle of things. This has proved to be the case since, and there has never been any further need to consider splitting the group. In support of this decision, the TPL noted her experience from a previous group with mixed-ability participants:

'When I heard her [a non-verbal member of the group] laugh really loudly, I knew someone else was doing something they probably shouldn't do'.

Siblings have been encouraged to attend, and families are asked to choose for themselves whether they join in the group activity or have some time to themselves. A mixture of both has been the result and families have supported each other over the months.

The timing of the meetings has been from 4-6pm. This has created some difficulties for the rota, with early staff going off duty at 3.30pm and late staff being busy with other residents. This has been less of an issue if young adults have been having a planned stay when the young adults meet. A member of staff from day services has continued to help out, but inpatient staff were too busy on the ward to continue. The group met originally in day services to try to break down the barriers between adult services and the children and young adults' service. The room was lovely but did not really meet the needs of the group as the television and drinks had to be brought in specially, so after a few months the meetings transferred to the young adults' lounge.

Regular consultations with the group have led to varied activities. Memorable events have included: a family fun day at an outdoor museum, a visit to a fire station; meals out; a speedboat trip on the Tyne (more on this later); and a brewery visit. During the winter months there have been trips to the Metro Centre and other activities, including a visit from Dogs for the Disabled. The Christmas party included a surprise visit by footballers from Newcastle United. Even Sunderland supporters managed to smile!

In January 2012, meeting arrangements for the group were reviewed with young adults and their families and it was agreed that the time should stay the same. At the review several young adults took responsibility for planning activities for forthcoming meetings. A Young Adults' Champion commented:

'It feels good being able to have input into what activities we do.'

Getting the staff mix right…

The CSM and the Clinical Care Lead for the children's and young adults' service spent time with Human Resources reviewing job descriptions in anticipation of advertising for staff. The main changes were:

- Decision not to appoint nursery nurses, as this background was felt to be inappropriate for the support of young adults
- Creation of the role of support worker – this role included driving the mini-bus, to ensure that activities could be undertaken spontaneously.

An advertisement went out for the new posts in the spring of 2011, and there was a huge response. Once interviews had taken place, new staff took up their posts incrementally. This was mainly due to the time taken for clearances by the Criminal Records Bureau and for notice periods once contracts were offered. With hindsight, this gradual phasing in was a great help to new staff who had to have an induction period and also to existing staff who had to not only embrace fairly rapid change but also cope with what was an increase of eight staff.

…and preparing front-line carers for a new challenge

The TPL talked to other services, cross-referenced with CQC Standards, and produced draft policies on Safe Caring, Consent, Behaviour Management, Caring for Children alongside Young Adults, Sexuality, Bullying, Alcohol, ICT and an Agreement of Care. During the spring of 2010 these drafts were put out to consultation and agreed prior to the service opening.

The CSM and TPL agreed that each young adult should have a named worker who would be responsible for ensuring that information was kept up to date and relevant information shared with the staff team. While knowing they could approach any member of staff, each young adult would know who their named worker was so that they could raise any issues with them that they might feel anxious about raising in the wider group. Although this person would be the key worker for St Oswald's, it was important that this position was not confused with the key worker responsible for the young adult's care plan. Accordingly, the decision was taken that in St Oswald's this worker would be known as the primary worker.

Training needs were prioritised, and training days early in May included Safeguarding Adults and Mental Capacity Act training. Mental Capacity Act training included the necessary guidance on medical care and the day to day issues around mental capacity and evidencing decision making. The training encouraged staff to discuss their anxieties and concerns and went on to support them in addressing these concerns in a constructive way. One member of staff commented, for example:

> *'Sexuality was a massive anxiety for me in thinking about the needs of young adults.'*

Testing assumptions about good practice

During the early years of the children's service, a Pathway was developed that is held up as good practice by professionals locally and nationally. In each of the seven areas that accesses St Oswald's services there are two Pathway Coordinators, one from health and one from social care. No referral should reach St Oswald's without their agreement. The only exception might be a referral for end of life which would be acted on if the Coordinators were not available, perhaps at night or weekends. They would, however, be informed at the earliest possible time.

It was assumed that this Pathway would be replicated in the young adults' service. From very early on, the TPL had reservations about this working due to the different practices in adult services. Initially at least, it seemed more appropriate to make a direct approach to engage a small number of young adults. In any case, as a pilot service, we were not in a position to offer a service to the wider community. All in all, it was agreed that work on a model for referrals was not a priority.

Engaging at regional and national level

In March 2011, St Oswald's hosted a Square Table Event on Transition. The Square Table initiative was funded by the Department of Health and led by Children's Hospices UK and ACT. Square Tables were held across England, and have been described as a 'listening tour'. The events were an opportunity for children, young people and their families to meet with and share their experiences with professionals responsible for their care.

30 participants were invited, including young adults, their families and carers, other stakeholders and commissioners. Unfortunately, although there was much useful discussion and information sharing among those who were there, no one from adult services attended. This would have been an ideal forum for working together and for those from adult services to hear at first hand the experiences of transition and the issues that must be addressed.

The themes that emerged from the Square Table event included:

- the lack of joined-up working between children's palliative care services and adult palliative care services, adult services being, in practice if not in theory, more focused on the end of life rather than the holistic life-long service that characterises children's palliative care
- lack of transition services as one of the biggest challenges nationally – and one particularly pressing for the children's palliative care sector
- identification of adult hospices as 'key strategic partners for developing and delivering new services'.

Unlike many other children's hospices developing services for young adults, St Oswald's has a huge advantage in that the children's service and the original adult services are next door to each other, making communication relatively easy.

In the summer of 2011, St Oswald's became involved with the Marie Curie Cancer Care Young People and Transition programme. The hospice became a pilot site for exploring best practice in support of young adults and their families; and staff took part in a UK-wide learning network. (For more information, see www.mariecurie.org.uk/youngpeople)

The launch and the first months of the new service

The service went live on May 12, 2011. The opening was low key, both because it was a pilot scheme and because at that point St Oswald's was not in a position to offer the service to new referrals.

One of the first issues raised was that the doors to the garden from the Young Adult lounge were not big enough to allow someone bed-bound to access the garden. This has since been rectified. Other than that, everyone was very pleased and excited by what had turned into a light, modern and useful space for young adults.

Young adults accessing the service from this time were asked to sign a contract on the basis that 'with rights comes responsibility'. Included in the contract was an agreement about the use of the internet. The building has Wifi access and young adults were asked to agree to watch nothing in a public place that might give offence to others. All agreed to this. It was also agreed that young people aged 14 and over could access the young adults' lounge by invitation until 9pm but no later. The thinking here was that 9pm is the 'watershed' for adult programmes on television; and it seemed quite likely that young adults might like to take that opportunity to have a drink and/or watch an adult programme or DVD on television.

The contract covered other, related issues. For example, an alcohol policy was developed and young adults agreed to abide by it. All young adults were provided with a file containing a copy of the agreement of care, a guide to the service, alcohol policy and information about complementary therapy, chaplaincy and infection control. The file is designed to have documents added as information becomes available or the need arises for further specific agreements.

After concerns about the rapid changes and developments that had taken place, staff were very positive about what had been achieved, and many of their anxieties about caring for young adults were allayed. Staff comments included:

> *'It was fear of the unknown but I'm not sure now what I was worried about.'*

and

> *'Looking back it was, and still is, lovely to continue their care.'*

Risk assessment – a means of facilitating not preventing activity

Several of our young adults have a great appetite for 'adrenaline' events and activities. A huge challenge for everyone has been the idea that risk assessments are done to **facilitate** activities, not prevent them (although sometimes they may suggest an activity is not suitable for an individual or group). In September 2011, managers across the hospice took part in a Person Centred Risk training day; and this was followed up by the same training for staff in the Children and Young Adults' Service in November 2011. This training presented a very different model of risk assessment from the one familiar to most people, and it enabled staff to explore anxieties, along with solutions to challenges that they had encountered when caring for young adults.

The TPL carries out risk assessments for the young adults' group activities in consultation with the CYASM. There have been many challenges along the way – especially taking the lads speed boating on the river Tyne – but it was worth it to see the enjoyment they had from it. The TPL commented of risk assessment for that trip on the river:

> *'The boat trip was carefully risk assessed but no one bothered to tell us that once on the water the boatman would go as fast as the young adults wanted to go! The river Tyne is a very windy place. I was responsible for the risk assessment and watching from the river side as the boat skimmed the waves was an unforgettable experience! The young adults loved the whole thing. One of them said to me, "They don't let people like us do this kind of thing"'.*

At the time of writing (May 2012), things have settled down into a routine that seems to meet the needs of children, young people, young adults and families. Young adults have fixed night stays planned several months in advance but stays can be moved around if need be. Recently, a young adult had his stay brought forward so that he could have a review of symptom management. If he had not been able to come to the hospice, he would have faced a hospital admission, and it is likely that only the presenting symptom (breathing difficulties) would have been treated. At the hospice, however, clinical staff who knew him recognised that he was suffering from depression on top of the physical symptoms. With his full consent, he began treatment for depression, and soon reported an improvement that allowed him to begin enjoying life again.

It is a testament to the staff team that, despite their anxieties and the challenges of caring for both groups, the services are running seamlessly side by side and that everyone has learned so much in such a short space of time.

Initial results and first reflections

Did all go according to plan?

Most of the plans initially set for the service have been achieved. In two significant areas, however, initial planning has not been followed up by action.

→ **Developing a day/drop-in service** – this is still being discussed, but the staffing cost of a drop-in facility means that this could only be offered if a day care service was in place.

→ **Support for holidays** – this has been explored and is possible if funding was made available. In the current climate, it will not be a priority.

Through regular consultations with, and feedback from, young adults and from the work with 'Young Adults' Champions', we know that young adults are happy to stay at St Oswald's. In their turn, families tell us it's much easier to take a break when they know the young adults are happy to stay. A young adult was spoken to during a CQC inspection in January 2012 and the final report quotes him as saying: 'I visit here regularly and I always enjoy my stay'. It is also reported that he said that 'staff support and encourage him to carry out personal tasks to maintain his skills and promote his privacy and dignity'. In the same report, inspectors commented that 'young people are assisted and supported in a range of activities both inside and outside the hospice'.

In a current initiative, we are sending out questionnaires to young adults, their families and lead professionals, seeking further feedback. As the service was a year old in May this seems like an ideal time to collect data and reflect on what has happened so that we can plan for the coming twelve months. The general health of young adults is stable and the nursing staff have picked up and responded to any concerns.

The young adults are able to have regular physiotherapy, and complementary therapy by request, when they are staying. This is much appreciated as none of them get this level of service in the community once they are adults.

One commissioner has told us that planned stays at St Oswald's is the only part of the young adults' care package that is working.

Young adults take the lead in the planning of activities. For those who have their own cars that staff can drive, their options have increased as spontaneous activities are now possible.

The next phase of the development of the service is being looked at as the pilot phase ends in September 2012. In the current financial climate, it will be difficult to continue, much less expand, without some increased revenue.

In the last 12 months we have not heard of any new hospice setting out on the journey that we have made and that is worrying. Equally concerning has been the news that another hospice that has provided short breaks to a large number of young adults has made the decision to stop doing so due to financial pressures.

First reflections

Key figures in the team running the young adults service are Transition Project Lead, Children's and Young Adults' Service Manager, Clinical Lead, Team Leader and Children and Young Adults' Service Administrator. As a team, we reviewed the first months of the service in a series of reflective conversations. We focused in particular on what had surprised us – and what we would have done differently given a second chance. The themes that emerged from these conversations are summarised below.

What surprised us?

→ Despite staff wanting to provide a service for young adults, there was huge anxiety about nursing adults.

→ Naivety among staff about what the necessary changes would mean in real terms – caring for children and young adults together but separately.

→ Paediatric nurses being anxious about caring for young adults despite them having cared for the same group as children and young people.

→ Lack of appropriate services available for young adults in the wider community despite what was known about those who had left the service.

→ Lateness of Continuing Health Care Assessments impacting on service delivery and the level of stress that gave the young adults and their families.

→ The complexity of the process of contracting/commissioning – how in-depth and different it has been from the process with children.

With hindsight, what would we have done differently?

- → We would have slowed down the implementation of the plan – we had to move at a speed governed by timescales set out by the grants used to set the service up, and this was too fast at times.
- → Emphasised right from the start that a common sense flexible approach was necessary with young adults – everyone involved needed to understand from the beginning that if deemed competent, then young adults themselves would be shaping the service as it developed.
- → Drawn up rather different person specifications for support workers – as things are, experience has led to changes being made that will be used for any future appointments.
- → Tried to avoid recruiting and supporting eight new staff at the same time! Although circumstances meant that there was no alternative to this course of action, it was recognised as one of the biggest challenges.
- → Joint working between nursery nurses and support workers was a lengthy process and this would be approached differently.
- → Delays in support staff being able to drive the mini-bus were problematic but the learning from this will hopefully speed things up for staff appointed in the future.

These conversations led in turn to discussion of what the ideal approach would have been to developing a young adults' service at St Oswald's.

What would the ideal service have been?

The ideal would have been to build a separate unit within the hospice grounds and staff it with a new team dedicated to working with young adults. As the new building was being completed, more time would have been available for staff training and development.

Job descriptions and person specifications, for both qualified and unqualified staff, would have been designed to attract those with experience and/or qualifications in adult care. (Because the service was not started from scratch, practices were inherited that were difficult to change and that did not meet the needs of a young adults' service.)

However, there was an important flip side to dreaming of an ideal. The eight young adults who are currently receiving a service all had experienced short breaks in the children's unit. This made the transition smooth from a planning point of view. The service is held in high regard, and social workers and community nurses from children's services supported and encouraged a move into the adult service, allowing the service to start with higher than expected occupancy.

The next section looks at how St Oswald's would like to continue learning, and sharing learning, from the pilot service. There are questions and answers – followed in this uncertain climate by more questions – for all organisations commissioning or providing services for young people and their families.

Bringing it home

1. Of the different reasons given for making separate provision for young adults with life-limiting conditions, which has most resonance for you, and why?

2. How do you and your organisation respond, or intend to respond, to the emerging needs of young people and their families?

3. What key learning points do you take from the story of the young adults' service at St Oswald's? How might you and your organisation build on these?

Section 3

Learning together for the future

This section invites readers to join in constructive conversation about the future. We share our current thinking about how best to develop the pilot young adults' service at St Oswald's. We also identify specific aspects of the commissioner/provider split that continue to jeopardise our work with young adults and their families. We suspect that these obstacles can only be overcome through better collaboration. Please get in touch and let's make progress on this!

Effective learning is a two-way street

As a pilot site for the Marie Curie Young People and Transition programme, St Oswald's is explicitly committed to sharing our learning in a way that is useful to other individuals and organisations. An important part of this sharing, we believe, is engaging in real-time conversation with others who are concerned about finding ways forward in this difficult and uncertain economic climate. To be really useful, the conversational street has to be two-way. For example, we can offer insights into what has, and has not, proved to be effective support for young adults and their families. But, as outlined in Section 1, as a service provider, we need to be able to attract the backing of commissioners who can both recognise quality of service and access the money needed to fund it. At the moment, even finding relevant commissioners can be a considerable challenge, far less getting into discussions about quality. So, from commissioners of services for children and adults in health and social care, we hope to hear more about who you are – and how we, as service providers, can help you to meet the challenging goals facing you.

Starting the conversation at home, how are we at St Oswald's currently developing the young adults' service in response to what we have learned so far?

Looking to meet tomorrow's needs

At the behest of one commissioner, the TPL has worked closely with a new service that provides adults with holiday-type accommodation for supported short breaks. The young adults' group spent a 'pamper' day there so that they could see what was on offer without the pressure of having to choose a new placement immediately. It is hoped that by the time our first young adult reaches 25, other commissioners will be referring individuals to services like this. The TPL will continue to work closely with young adults, their families and professionals to ensure that transition remains on the agenda post 18, and that planning does not stop.

The TPL is constantly searching for, and exploring, services that might be available to meet the future needs of young adults – including short breaks, family holidays and independent living. Local independent providers are in conversation about the range of what will be needed and are developing appropriate services.

Children and young people have their care plans reviewed every six months. For adult services, the review system is yearly. Young adults accessing our service have very complex needs and a yearly review is not sufficient to ensure that changes are picked up and acted on; we also need some indication at the six month stage whether further funding will be available to maintain the individual's placement. Care managers were unhappy that we required six monthly reviews so we have agreed that St Oswald's will arrange the mid-year review and accompanying administration.

The Young Adults' Group has become very popular, with increased membership and growing wish lists of activities. The activities often present considerable challenges to the TPL and CYASM both in terms of identifying a suitable facility and carrying out risk assessment (more on this below). Siblings are invited to attend and families/carers dip in and out as they please. In this way, the group is meeting the support needs of the whole family and has led to discussions about how support to young adults' siblings and families can be done in the future. Families ask for support groups but they have not been well attended in their current format.

As indicated in Section 2, risk assessment, traditionally, is an issue that fills even the strongest heart with dread. It has been viewed for too long as something that stops you doing something or as a stick to beat you with if things go wrong. The concept has to be turned on its head if there's to be any chance of making possible the activities that young adults want and choose to do. Put simply, the underlying principle has to be: **risk assessments are carried out to let you do something safely.** On occasion, of course, a risk assessment will lead to a decision that a particular activity is unsafe and cannot happen. But, given some thought, most risky situations can have controls built in that reduce the risk to 'manageable' status. One thing we have learned at St Oswald's is that young adults want the same opportunities as their non-disabled peers; and if they can see that you are not saying 'No' out of hand, they will work with you to experience things in the safest manner possible. In this connection, it is also worth bearing in mind that the Mental Capacity Act (2005) states that if someone is deemed to be competent, they are entitled to make unwise decisions. Following through the implications of that ruling can be very challenging, especially perhaps for those who have worked with young adults when they were children.

Working In partnership with young adults and families

We made sure that Mental Capacity Act training was carried out even before the service officially opened. The Act is a very complex piece of legislation to work with, especially when caring for those who have learning disabilities and no verbal communication. It is difficult to get used to the concept that an individual may not be able to make a particular decision, but that this does not mean they cannot make any decisions, and therefore that refusals to help enable particular decisions must be evidenced. This is particularly so when perhaps only the day before the young adult was legally a child and staff had not been used to deferring to them for decision making.

The young adults we have worked with so far have all been known to the children's service for several years. This has meant, in practice, that strong relationships were already forged. For the three young adults who returned to St Oswald's after a break, they and their families were just hugely relieved to be back. Families were able to enjoy their breaks and the young adults felt that they had come back to stay with their friends (i.e., staff they knew well).

New to the families, the TPL concentrated on making herself available to them, consulting on everything, and being very honest about what could and could not be achieved. Strong working relationships were soon formed. On some occasions, it was probably an advantage that these relationships were new as the TPL had no pre-conceived ideas about family dynamics.

It has been, and will continue to be, difficult to help some of this group prepare for death. Historically, families have not had these conversations with young adults; after all, they expected them to die in childhood. As things stand, several of the families have still not entered into that discussion. What we know from the outside looking in is that young adults surf the net and talk to each other; and, through these means, they usually know very well what is happening to them. They in turn often shield their families from the reality of the situation. It will take some careful, timely conversations to address this issue. The primary worker role may develop to meet some of the needs identified here.

Re-visiting the commissioner/provider split

Unless positive action is taken, the environment outlined in Section 1 looks as if it will continue to be a hostile one for young adults with complex health needs and their families. For example, a manager from a major disability charity reported that she had recently met with commissioners from Northumberland and that they had 'painted a very gloomy picture' of future partnership provision in the locality. This would suggest increased difficulty in finding housing for those with complex support needs who want to live independently.

A clear overarching challenge for commissioners lies in the cost of meeting the needs of this small group of high need individuals in a time when budgets are being squeezed ever tighter. Commissioners must be able to evidence that they are getting value for money and justify what appears to be a huge cost when measured against other services.

How can these challenges be met? Two issues stand out:

→ **Commissioners need to develop a full understanding of the complex needs and aspirations of this group of young adults.** Might training and development be one way forward here, with the full involvement of young adults? Reports and case studies do not give anyone not directly involved a true picture of what the day-to-day care and wellbeing of this group entails.

→ **Providers of services, including hospices, need to plan and present their offers with great care.** At the moment, commissioners report that some providers take on contracts at a set fee and then, after the contract is agreed and the individual settled, the provider requests ever more money to meet identified needs that are over and above the contract. This approach exacerbates rather than solves the problem. Providers must state at the outset what the cost includes and give an undertaking that there will be no 'add-ons'.
At St Oswald's, we believe that the hospice should provide excellent care and, through this and associated evidence, convince commissioners that: 'The cost of doing it well with us is cheaper than doing it wrong with others.'

Tackling these two issues effectively involves identifying the more specific challenges underpinning them and pursuing these, working in partnership wherever possible, at different levels, from national to local. The difficulties encountered by the St Oswald's team in doing this led us to refer to these challenges as **'the ten trials of commissioning'.** We share them with you here, in the hope that you will add your experiences and views to the on-going dialogue. Together, surely we can get through the trials and work together to achieve a result that will improve the quality of life of these young adults and their families?

The ten trials of commissioning

1

Who are the commissioners?

The heading poses a real question…

In the course of the Marie Curie Young People and Transition programme, both commissioners and providers of services have highlighted the problems caused by complexity and fragmentation in the system. For example, in some areas, services can be commissioned by a plethora of primary care trusts, city councils, county councils and borough councils, plus region-wide specialist commissioning – with no consistency in the way in which these commissioning structures are organised. One of the programme team, himself an experienced commissioner, found it a real challenge to locate commissioning bodies and navigate his way though switchboards and departments to speak with the right people. This situation is compounded, of course, by the current reconfiguration of the NHS and rationalisation within local authorities due to funding cuts.

This fragmented picture is reflected in the situation in the North-East. The intended changes in NHS commissioning, and the delays with this, have meant that it has been extremely challenging for the St Oswald's team to identify the individuals who could or might commission the services offered.

Identifying the appropriate commissioners has, of course, been less of an issue in relation to young people known to the children's service who have made the transition to adulthood. As existing service users they, their social worker and family have sought to continue to use the service as adults.

Through tracking the progress of adults who have returned to St Oswald's, the TPL has managed to identify the commissioners involved. Several meetings, some of which have included the CYASM, have taken place between the TPL and relevant commissioners. People who have returned to us as adults have a history and knowledge of the services on offer. Coupled with dissatisfaction with their short break provision, this has enabled the team to present to commissioners a robust new plan that includes short breaks at St Oswald's.

These meetings have been very helpful; but to date we are struggling to identify the other commissioners in our catchment area that we need to reach. Within the seven partner areas, many professionals are themselves confused about who the relevant commissioners are, as it would seem that people's jobs and responsibilities are a constant movable feast in the current climate. You might know on Friday who the person is, but by Monday that may have changed.

2

What do commissioners want – for young adults and for themselves?

The TPL has worked very closely with the identified commissioners, and the commissioners have visited St Oswald's to see for themselves what the service has to offer. Commissioners have told us that they are commissioning services for young adults with life-limiting complex health needs from a variety of services. Many of the services are not meeting the needs of the individuals as well as professionals would like. However, without an alternative, these services continue to be commissioned. Commissioners tell us that they are given a costing for overnight/weekly care which is agreed and the young adult is then placed. Once the placement is established, providers begin asking for extra money to cover what has they have assessed the individual as needing. This leaves commissioners with a choice of stopping the service or paying the extra. As indicated earlier, since the needs of the parents and the dependency of the young adult both count as high on any scale, the commissioners have been left with little choice but to agree.

This ratcheting up of cost makes balancing budgets extremely difficult for commissioners. They tell us that what they want is a first class service that is up front about the cost, and that this, once agreed, does not increase. They accept that a cost of living rise will have to be factored in annually.

3

What will prompt commissioners to take timely action on referrals

This is the 64,000 dollar question!

An early decision was taken that the service at St Oswald's could only grow and be sustained by full cost recovery for new referrals. Following a Freedom of Information enquiry to all seven partner areas, the TPL is fairly sure that each of the areas is likely to have two or three young adults not previously known to the service who would fit the criteria.

The full cost of a night's stay at St Oswald's (including all overheads) is currently £1140[1]. Initially, the TPL thought that it would be impossible to attract commissioners for a service costing as much per night as others were charging for a week. However, in the North-East, we have a saying 'shy bairns get nowt' so it was a case of try, and see what the response is.

The first commissioner who came to visit told us that the short breaks she was commissioning from St Oswald's was the only part of the young adult's care that worked. She asked to talk about the criteria as care managers had been approaching her about the service and she needed to be clear about what would be an appropriate referral.

She went on to explain that she had three other individuals, unknown to us as children, who would probably be appropriate referrals. When it was explained that the service could offer 100 nights per year to each of the three if they were indeed appropriate, at the cost of £1140 per night, she immediately said that would be a third of the yearly cost of permanent placement if the family care broke down! After the visit she went to talk to her manager about this proposal and we have been told that the manager is very interested.

After consultation with the known commissioners, we produced a report detailing what the service provided by St Oswald's includes. The document gives assurances that there will be no extra or hidden costs added at a later date and that, although the cost seems high when compared with other services, when all the services are listed, the cost can be seen to be very reasonable. The report is available as a paper document and also electronically; and has been distributed to potentially interested parties across the region.

At the time of writing, no approaches have been made regarding new referrals. It is quite likely that the first referral will come at a time of crisis for a family. While we would prefer not to work in this way, we will respond positively since we believe that once the first 'new' young adult accesses the service, then others will follow.

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[1] This cost is relatively high due to the philosophy that has steered the development of both our children's and young adults' service – i.e., that we will not replicate services otherwise available in the statutory or private sector. This means that we concentrate on children and young adults at the very tip of the 'health pyramid'. This can typically mean we look after children and young adults who require the availability of 24/7 specialist nursing care, and the on-site presence of a full multi-disciplinary team (including specialist palliative care medical staff).

4

How is responsibility/funding split between health and social care – and what are the implications of future change?

One of the young adults who currently uses the service is jointly funded between health and social care. Professionals involved are very surprised that 100 per cent health funding has not been agreed, and an appeal is in progress. All other young adults have 100 per cent health funding.

The 100 per cent health funding appears at this time to be much easier from a commissioner's point of view, and money seems to be more accessible than if there is a shared funding agreement. It would seem that once an acknowledgement of the severity of the individual's condition is made, then the need for services is much easier to justify. Due to the criteria for accessing the service it is not envisaged that any individual with 100 per cent social care funding will be referred to the young adults' service.

5

Where might Clinical Commissioning Groups fit in?

Work across pilot sites in the Marie Curie Young People and Transition programme has shown that seeking collaboration and advocacy for this group at a time of such major change in commissioning is very problematic – their marginality is more obvious. The leads of Clinical Commissioning Groups say it is too soon to have detailed discussions. Meanwhile effort has to continue to get collaboration over:

- Continuing healthcare vs social care funding clashes (see above)
- Role in education of statements of special educational need – young people with statements of this kind get more support in transition compared with others not statemented
- Using learning disability resources for those young people in this group who have learning disabilities (estimated at 80 per cent)

A key question for the St Oswald's team is:

- How do we work with GPs to help them understand that palliative care for young adults is about making the most of life – that it's about far more than symptom control and those other aspects associated with end-of-life care?

6

How best to make the case for a small group of people with wide-ranging needs?

It is very difficult to get a true picture of the small number of young adults in the target group, but it is clear that across England a relatively small group of young people have reached adulthood who were never expected to do so. Through time this group will increase in size due to improved care and interventions by health professionals; and, with increased size, the demand for support will have to be answered. In the meantime, young adults in this position make up such a small group for each local authority area that no adequate service provision is in place. For example, it would be unusual for GPs to have more than one of these young adults on their caseload unless the disability is hereditary. As children, these young people are managed by paediatricians and other specialist services and therefore remain largely hidden to GPs until they become adults.

It is vitally important that GPs are closely involved in care planning for this group from the age of fourteen, as a minimum, so that they are aware of the extra issues and difficulties that transition will bring.

'Professionals pointed to a 'silo mentality' and a 'lack of joined up thinking' in planning services for young people facing transition to adult services.'

(The UK wide Square Table programme 2012)

7

What is the role of specialist commissioning?

Specialist commissioning exists to meet the needs of what is, in this case, currently a small group of individuals. These individuals have a high impact on services if something goes wrong – for example, family illness or breakdown.

Notes from the NHS Commissioning Board (2012) suggest that the Specialist and Primary Care Commissioning Lead will lead on the commissioning of specialised services:

'One of the NHS CB's key direct commissioning responsibilities will be for specialised services (nationally-defined set of high cost, low volume services currently commissioned at either national or regional level)'

(2012, p51).

So it is likely that the Specialist and Primary Care Commissioning Lead will be the main contractor – although contracted placements will be welcome from health and social care.

8

What will be the effects of individualised budgets in health?

At present, individuals who have 100 per cent health funding appear to have more money available to access the services they want and need. Individual budgets are currently being piloted across the country; and it is likely that learning from this process will be considered along with learning from the on-going roll out of social care budgets. Wherever possible, commissioners in health are likely to replicate the system put in place by social care. There is concern amongst providers of services, and families, that this approach might be used to reduce funding packages for many young people with complex health needs or life-limiting conditions.

9

What are proving to be the effects of individualised budgets in social care?

The provision of individual budgets is becoming well established in the funding of social care. A partner of St Oswald's, Newcastle City Council, was one of the pilot sites at the start of the process of testing the effectiveness of individual budgets. Council staff have learned from this experience, and are moving to a position where all children and young people will be provided with an individual budget. The assessment process for children and young people includes identifying the need for overnight short breaks, including how many nights are required. The cost is factored into the support plan but the money is paid directly to St Oswald's. The money is based on the 'charitable rate' (approximately £300 per night) that has existed since the children's unit opened. There is currently a debate about how the cost will be managed if families want to use more of their budget to have more overnights as, unless an agreement is part of the original assessed need, full cost recovery will be charged (see above). Other partners are facing similar issues.

As the personalisation agenda continues to be rolled out then individual budgets will become both an opportunity and threat. The opportunity will be for service users to be able to use their budget flexibly and in a way that they want. The threat is that the budget might not be sufficient to enable individuals to buy their services from where they want.

10

How do we best invest time and effort in meeting commissioner's needs?

It has taken a long time, and a lot of research and energy, to identify and engage with commissioners; and there are many that still remain unknown to the hospice team. Once commissioners' requirements are identified, it is reasonably easy to tailor the service and the information about it in the way that suits the commissioners best. Word of mouth is still the best advertisement that any service has, and the care managers of those currently using the service are talking about what we can offer. This is evidenced by the referrals and enquiries that we are currently receiving.

Once we are confident that the service can be sustained and grown, then careful development of literature will begin. If we are to display literature in, for example, GPs' waiting rooms and at provider events, then it must be attractive enough that people will be drawn to it. We know that glossy advertisements don't necessarily mean good service, but promotional literature is the means by which customers are attracted.

Bringing it home

1. Have you come across, or expect to come across, cases where care has been interrupted or disrupted by clashes between continuing healthcare and social care funding? Who needs to be involved in preventing such clashes in the future?

2. In your experience, what can be done to maximise the benefits associated with individual budgets? And to reduce the disadvantages?

3. Commissioners are well aware that services do not always live up to the glossy literature describing them. What do you suggest is the most effective way of linking images to real substance behind them?

Decisions

This section sets out in stark terms the basic choices facing St Oswald's as the pilot phase of the young adults' service draws to a close. Readers are invited to share their views with us – and to consider what else they can do to help improve the lives of these young adults and their families.

The pilot phase of this project ends in September 2012. Between now and then the following serious decisions have to be made.

Do we stop?

The young adults' service has always been a pilot project. Accordingly, we could decide that it is not viable for us to continue because of the cost and the current financial climate. No financial penalty would be incurred. But could we really see young adults leave after all the things we have done to improve their experiences?

Do we confine ourselves to providing a service to those young people already using the hospice's service?

We could continue to offer the service as it is to young people moving on from the children's service when they reach 18. This would be fairly simple to achieve; but there is the current financial climate to consider since the commissioners are providing less than a third of the actual cost. The next young person will be 18 at Christmas 2012. A small number of current users of children's services will reach 18 in the next few years, and some of the young adults will be 25 in the same period. Accordingly, we would be providing a service to roughly the same number of individuals for a few years.

Do we do something else?

We could stop what we are doing and use the young adults' lounge for teenagers. We could develop a day-care service. We could take a limited number of young adults as permanent residents. We could deploy new staff to do some limited outreach work. We could stop offering any service to post-18s and expand the children's service.

Managing discharges at 25

One thing we are very clear about is that we will cease to offer a service after the young adults are 25. If we did not do this, then we would soon be replicating the services that we know have not been meeting the needs of young adults. Currently, along with the young adults and their families, we are planning for the future. If the service does not continue, then quick action will be needed without time to plan. This would be very difficult for all involved.

Scoping exercise using qualitative and quantitative data

The young adults' service at St Oswald's offers a fine potential opportunity for shared in-depth learning about the needs, aspirations, experiences and preferences of young adults. The TPL works with young people from the age of 14; and a range of relevant information has been collated via a Freedom of Information request to all partners. It would be of considerable value to undertake a study of these young people through the transition process to document their experiences and ascertain whether it is indeed beneficial for them to be able to continue with a short break facility that will not be disrupted until they are 25.

Conclusion

The setting up of the Young Adults' Service was grounded in the realisation that young adults are 'dropping off a cliff at 18'. Why does this cliff face loom ahead of young people and their families? In the main, it is because the policy and legislation is written with children in mind. What begins at 14 as a statutory requirement for transition planning peters out once the young people reach their 18th birthday. At that point, individual care managers are left trying to create some kind of arrangement – but without the support of adequate policy or infrastructure. The fundamental change that would enable young adults to successfully navigate their way through transition would be one piece of legislation that ensured that health and social care continue to work together, with the same professionals involved, until the young adult is 25.

Postscript

Northumberland County Council had a plan to form a Transition Service ranging from 0-25 years. All our partners were watching this development closely, and all professionals were excited about it. The plan was derailed in the spring of 2011 by budget cuts and other priorities. This was, of course, a sign of the times. We need the collaboration of all those reading this publication to do what can and must be done to achieve a decent life for this group of young adults.

Bringing it home

1. **In your view, what decisions should we make, and why? Please get in touch with us by emailing LynneYoung@stoswaldsuk.org**

2. **What might you and your organisation do to bring about improved quality of life for these young adults and their families?**

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Further resources

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Lifelites: www.lifelites.org

Notes

Notes

All young people face challenges during the transition from childhood to adulthood. But young people who are disabled, with complex health needs and using a range of services, face additional, quite specific, challenges. For them and for their parents, 'transition' is not just between childhood and adulthood but between children's services and adult services. Research shows consistently that this latter transition is stressful and unsatisfactory for the majority of young people with complex health needs and their families – and also, in many cases, for those commissioning and providing services.

This publication aims to make a constructive contribution to the debate about how to change the current fragmented and ineffective system. It tells the story of why and how St Oswald's Hospice has created a new service for young adults, and with what effect. Meanwhile, times have changed in the world of commissioning, with huge potential impact for life-limited young people and their families. What collaboration now can ensure a decent quality of life for young adults and their families?

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