

# Small Service, Big Impact



## Evaluation of a new short-break service for young adults with life-limiting conditions at St Oswald's Hospice

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## **Executive Summary**

The challenge of providing a short break service for young adults aged 18-25 with life limiting conditions was taken up by St Oswald's Hospice in 2010. This was at a time when health and social care services, nationally, were beginning to recognise that children who would have previously died before they were eighteen were now living into early adulthood. The Service began in May 2011 with funding in place to allow for a pilot scheme to run until March 2013.

The service development has been reported in a previous document; Living longer than you thought I would (Young and Cameron 2012). This report is an evaluation of the service carried out towards the end of the pilot phase.

### **Need**

Those young adults who had left the Children's Service and had gone on to access adult services were being offered short breaks in homes for the elderly or for those with brain injuries. In some cases there were no short breaks being offered as no appropriate service could be identified.

Parents had not been encouraged to make plans for their child as an adult due to there being no expectation that they would live to be adults.

Of equal importance in planning short breaks are the social needs of young adults and the Young Adults Service staff strive to ensure that this is achieved.

### **Practicalities**

Young adults were involved in planning the Young Adults Service from the outset; meeting with the architect and seeing their ideas become a reality.

Parents appreciate a service that they are confident in using and recognise

that their young adults need to have time with friends and away from them and the home environment. The challenge, identified at an early stage, was providing a Young Adults Service alongside the Children's Service based in the same unit.

## **Staffing**

Young adults appreciate the staff members' sense of humour and see them as friends. Families are confident that their young adult's medical needs are being met. Increased staffing and changes to the existing rota system have maximised opportunities for young adults.

## **Finance**

There is a widely held belief amongst families that commissioners do not understand that their young adults need to access a service that provides medical care, as well as physical care and that alternatives that cost less are not able to do this.

The cost of running the service is much greater than other services being offered due to the high level of medical care provided. Due to the fact that commissioning of services was undergoing huge changes at the time when the pilot phase of the Service was due to end this caused difficulty in planning ahead and uncertainty.

## **What makes St Oswald's Special?**

The time and staff ratios are seen as the biggest factor in what makes the Service special by families, young adults and professionals. Families are confident that they can take a break without worrying about the care the young adult is receiving in their absence.

## **Future**

Overwhelmingly young adults, their families and professionals want the Young Adults Service to continue. Now that the service is established the ongoing concern for everyone involved is what will happen when the young adults reach the age of 25.

## Background

During the last ten years there has been an increase in the number of research studies published about transition to adulthood for young people who are disabled; in particular these studies have focused on the barriers young people and their families face. There is now recognition that a holistic plan that considers the young adult, their family or other carers should be in place, and that planning for this must begin at the age of 14 years. This is to bring it in line with the time when transition planning for young people who are disabled commences in the education sector.

The research highlights the increasing numbers of children and young people with life limiting conditions who are surviving into adulthood, and the lack of service development to support them as young adults in health and social care. It is recognised that adult health providers may have little or no experience of treating life limiting conditions that have, until recently seen sufferers die in childhood. Fraser et al (2011) reported that in 2010: there were twice as many children in England with life limiting conditions than had been reported previously. There have been annual increases in the number of children presenting with life limiting conditions during the preceding ten years and that there was a 44.8% increase in 16-19 year olds with life limiting conditions such as congenital anomalies (30.7%) and neurological conditions (13.7%). The report concluded that:

*The prevalence of Life Limiting Conditions in children in England is double previously reported estimates and is increasing. Our findings demonstrate an increasing need for services for children and their families, particularly those from ethnic minority backgrounds and especially in more deprived areas. This will increase the burden for specialist paediatric palliative care providers and young adult's services.*

(Fraser et al.e923)

The recently published Supporting Health Transitions for Young People with Life Limiting Conditions: Researching evidence of positive practice (STEPP Project report December 2012 p1.) reminds us that in early adulthood

*significant deterioration* in life limiting conditions is likely. The report highlights the fact that it has been the lack of evidence to date that has hindered the development of policies and services necessary to support this group of young adults. The Association of Children with Life Threatening Illness (ACT) (2009) found that progressive conditions often reach crisis during early adulthood, just at the time the change to adult service occurs.

St Oswald's, an adult hospice in Newcastle upon Tyne began providing short breaks for children and young people (aged 0-18 years with life limiting conditions) in a purpose built building, on the Hospice site in 2003. The service was offered to children and their families living in Newcastle, North Tyneside, South Tyneside, Sunderland, Gateshead, Durham and Northumberland. In 2006 an evaluation of the service was undertaken to determine from the perspective of children, families and professionals what difference the service had made to families' lives and what factors contributed to making the service 'Specialist' (Swallow, Forrester and Macfadyen 2005;2011).

Overall, participants were very pleased with the service and there were several suggestions and recommendations made about future service developments. One key suggestion from parents and staff (in relation to parents' concerns about what would happen when their child reached 18 years of age, as there were no comparable adult services available for them to make a transition to), was to increase the eligibility age range to enable the St Oswald's service to be offered to young adults aged 18 and over.

At the time of the Children's Service evaluation only one young person using the service had actually reached the age of 18 years; this young person had left the Children's Short Break Service and had made a successful transition to university. In the following years eleven young adults moved to a range of adult services elsewhere. Although there was no formal evaluation of these young adults experiences after leaving St Oswald's Children's Service, informal accounts obtained from families and colleagues indicate some of these young people made the transition to adult services quite successfully,

that the new service was meeting the young person's needs and that they were happy with the service provided.

Unfortunately, this has not been the experience for many, with reports of short breaks being offered to these young adults in old people's homes, or alongside adults recovering from an acquired brain injury. There are further reports that some young adults have lived for several years at home with no service provided outside the home, because no appropriate facility has been identified.

*We have looked for a suitable place for [young adult] 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.*

(Care Manager 2011)

Young adults and their families said that staff were kind in the new services but that the staff to young adult ratio was such that the young adults spent a lot of time alone with no one to speak to. One young adult said that there were three staff to care for twelve service users so that as soon as someone needed care that required two staff members (e.g. hoisting in and out of bed or a wheelchair) that left one member of staff to care for eleven young adults single handedly.

The time of transition can be particularly stressful (Cameron et al. 2009) since many young people will not receive the same level of support that they received from children's services once they enter adult services, and parents see the extent of their caring role increasing and not decreasing, as would be expected by parents of healthy children, once they become young adults (Hallam 2007).

*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 and deFur 1997)

During the years since the evaluation of St Oswald's Children's Service important policy initiatives and new legislation providing clear guidance on equality and inclusion for disabled people have emerged:

- Jointly delivered by the Department of Health and the Department for Education 2007, *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 lead fulfilling lives in a manner of their own choosing
- Under the Aiming High agenda £19 million was set aside to develop a Transition Support Programme. The core purpose of this programme 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 organizational culture to improve local service delivery
  - Providing targeted support to ensure that every local area is able to share learning about transition and improve service delivery
- 2007-2010 In support of the Aiming High agenda, the Department of Education and the Department of Health announced the Transition Support Programme, designed to raise the standards of transition in all local areas; this consisted of two main elements:
  - The National Transition Support Team, to coordinate the work with local authorities, Primary Care Trusts, named advisors and existing experts
  - Support the change at local level through a combination of direct grants and named advisors who will be available locally to

facilitate training, collate data and develop pathways and participation strategies

However, despite the implementation of the Transition Support Programme the system that is supposed to support these young people and their families remains fragmented and ineffective (Young and Cameron 2012).

During this time hospices across the UK were expressing concern 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.

In 2007 the Commission for Social Care Inspection reported that half of English councils responding to a survey said that young people's care packages were reduced significantly once they reached adult services (Commission for Social Care Inspection 2007 Growing up Matters: Better transition planning for young people with complex needs).

Against this backdrop, senior managers at St Oswald's heard more and more about the difficulties being experienced by young people with life limiting conditions across the seven areas where the Children's Service is offered.

The Head of Children's Service left her post at St Oswald's in August 2009 to take up an opportunity elsewhere. Before her departure, she wrote to parents of young adults who had formerly used the service but had now left because the young adults had reached the age of 18, informing them of her impending move. She asked for feedback on their experience of transition to adult services. Included in the feedback she received was a letter from a parent telling her in graphic detail 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 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.*

(Excerpt from a letter from a mother of a young adult who was a former user of the St Oswald's Children's Service)

Following receipt of this letter and after visiting another hospice with a dedicated young adults wing, it was decided that a Young Adults Service at St Oswald's should become a reality. The Care Quality Commission confirmed that there was no reason that two services (i.e. Children and Young Adults Service) could not run from the same building, therefore, plans began to take shape.

During the autumn of 2010 the Department of Health made £30 million available to support children and young people's palliative care services, including 'better transition from children's to adult services'. Service providers were invited to apply for this competitive funding source. A bid was made by St Oswald's to the Big Lottery Fund and money was secured for both Capital and Revenue expenditure. This provided the opportunity to make changes to the existing building in order to establish a Young Adult Service that would be piloted for an initial two year period and to employ staff to work in the Young Adults Service.

This evaluation complements and builds on an earlier report Living longer than you thought I would (Young and Cameron 2012). The report described in detail the process that was gone through in setting up and running the pilot Young Adults Service. This evaluation is the culmination of two and a half years of work and an opportunity to explore the service from the perspective of young adults, families, staff and other professionals involved in the care of young adults.

## **Theoretical approach to the study**

This study is underpinned by the Trajectory Framework and informed by the Social Model of Disability:

### **The trajectory framework**

The trajectory framework, a conceptual model built around the idea that chronic health conditions have a variable course that changes over time, was developed by Glaser and Strauss (1967) while using grounded theory to study the care of chronically ill patients. Their insight was that health professionals, patients and families use many different strategies to manage the shape of illness. So, the trajectory framework, which is inductively derived, can facilitate understanding of the problems associated with chronic illness.

*The term trajectory...refers to the total organisation of work throughout all nurse and patient interactions and refers to the impact of patient care processes on those interactions and the organisation.*

(Alexander 2007 p.912)

Although each chronic condition has a potential course that changes with time, this is often uncertain as its details cannot be fully determined ahead of time but depends on the action taken to shape that course and the turn of events that occur. Further development and refinement of the framework was based on long narrative histories recounted by chronically ill patients and their carers. This led to the identification of several different phases through which chronic illnesses may pass and that could be used to inform the practice of health care professionals. Therefore, because the views and experiences of families and professionals are the focus of this study, qualitative methods were used to meet its aims (Corbin and Strauss 2008).

## Research design

A Case Study design within an Action Research approach was used thus allowing us to involve *a member of the world being researched* (Reed and Proctor1995). Data were collected by Lynne Young (LY) with support from Veronica Swallow (VS) and Ann McFadyen (AM) and the project Steering Group as required. Action Research had two main aims:

- To capitalise on the insider knowledge within the Service, and so strengthen the rigour of the study
- To become immersed in it and to understand it from the perspective of participants who are trying to resolve or improve a situation.

Mereton-Cooper (2000)

Therefore, the involvement of practitioners in research taking place in their own environment seems a logical way to begin resolving or improving a situation. Action research has its philosophical origins in the *critical social theory paradigm*; the following table adapted from Harper and Hartman (1997) illustrates the relationship between the three prevailing research paradigms:

**Table 1:** Philosophical approaches to research

Research paradigm	Researcher assumption
<i>Positivism</i>	<i>There is an objective reality that exists independently of the observer, where phenomena are driven by natural laws that are accessible to observation and management</i>
<i>Interpretivism</i>	<i>Reality is mentally constructed and is socially and culturally based. Knowledge is viewed as being constructed in a social and historical context</i>
<i>Critical social theory</i>	<i>Perceptions, social and personal truths are constructed socially so that</i>

	<p><i>an understanding of social and power structures (race, class, gender) must inform theories about social life. All knowledge is seen as subjective and open to manipulation</i></p>
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Action research, therefore, rejects the positivist view and while it recognises and acknowledges the interpretivist view it aims to take it a stage further. While interpretivist research recognises the ability of individuals/groups to build realities socially, it does not enable them to challenge any controlling influences that might be experienced by them, (Waterman *et al.* 2001).

The interpretivist approach provides explanations but not solutions; problems require action to be taken to make improvement possible and action research aims to make those involved in the situation under investigation aware of what prevents them from realising their chosen goal. It aims to help those involved to recognise the processes, attitudes or ways of working that create barriers to effective progress and what can be done to raise the consciousness of individuals towards the kind of political or social action that can help them to achieve their aims.

### **Aims:**

The original aims for this evaluation were:

To determine, from the perspective of young adults, carers and professionals involved with the specialist short break service:

- What difference the service makes to the lives of young adults and carers in relation to:
  - The skill mix of staff providing the service
  - Partnership working
  - Access to leisure activities
  - Opportunities for young adults independence

- Peer support for young adults
- What factors contribute to making this a Specialist Service?

Analysis of the data led to these aims being reviewed and revised as the rich data collected indicated that there were newly emerging and very important themes that couldn't be ignored.

## **Sample**

- Young adults were selected using an opportunistic sampling approach and according to the following inclusion criteria:
  - Currently registered with the service at St Oswald's as a service user able to communicate their views on the service using verbal and/or non verbal means

Exclusion criteria:

- Unable to communicate using verbal/non/verbal means
- Care managers, carers and staff:
  - Using a snowball sampling approach we invited:
    - The parents/care managers/carers and others who are significant to the young adult (e.g. medical staff) of all young adults accessing the service
    - A randomly selected sample of members of the multi-professional team at St Oswald's

Semi-structured interviews or focus-groups were conducted with two Young Adults, four mothers, two external professionals and twelve professionals from the new service.

## **Data collection involved:**

Individual interviews or focus groups

Interviews or focus groups (depending on participants' individual preferences) were held at a time and place convenient to the participants. Discussion was based on topic guides designed to stimulate discussion, gain insights and generate ideas in order to pursue topics in greater depth, (Richie and Lewis 2003) (Appendix 1).

Interviews were conducted by LY (using topic guides generated from the literature review and ongoing analysis) who has previous experience of conducting research interviews and of working with vulnerable young adults with limited communication abilities; she was supported by VS and AM who have extensive experience of these methods and of working with vulnerable service users and carers. All discussions were digitally recorded and later transcribed.

## **Data analysis**

Data were analysed using the Framework Techniques (Richie and Lewis 2003; Swallow *et al.* 2003). This method is systematic, thorough and grounded in the data but also flexible and enables easy retrieval of data to show others, thereby providing a clear audit trail. In addition it allows both between and within case analysis and involves a process of:

- Familiarisation with the data
- Identification of themes
- Indexing
- Charting
- Mapping and interpretation

*It is a matrix based analytic method which facilitates rigorous and transparent data management such that all the stages involved in the*

*'analytical hierarchy' can be systematically conducted. It also allows the analyst to move back and forth between different levels of abstraction without losing sight of the 'raw' data.*

(Ritchie and Lewis 2003, p220)

Establishing the credibility of qualitative research increases the likelihood that findings will be applied to practice, (Guba, 1990; Seale *et al*, 2000), the ultimate test of trustworthiness is whether we believe the findings strongly enough to act on them. By using these methods of data collection and analysis we were able to produce a richly detailed report incorporating an audit trail of original interview transcripts, field notes, coding frames of key themes in the data and examples of charting according to thematic references; the research process is thereby made transparent thus enhancing its trustworthiness.

### **Ethical considerations**

The study has been conducted in accordance with University of Manchester requirements for research studies, Anonymity and confidentiality have been maintained at all times. Vulnerable clients have the same rights to confidentiality as any other person (RCP Guidelines 2007) and it was explained to the young adults and their parents/carers, as well as other participants, that in order to protect confidentiality and anonymity all hard copy and computerised records will be stored in a locked filing cabinet and/or a password protected computer accessible only to VS and LY. After transcription data were fully anonymised and links enabling individuals to be identified were held manually in a secure place, to be accessed only by VS, AM and LY, when necessary to match up data.

Consent was obtained from all participants who agreed to enrol after receiving both written and verbal explanations. Wherever possible this consent was written, however, due to varying disabilities it was necessary for some individuals to have an advocate of their choosing sign on their behalf.

There is increasing discussion in literature and policy regarding the importance of involving service users in the decision about whether or not to take part in research and these discussions also informed the conduct of the study.

Every effort was made to ensure that consent was informed and freely given, by encouraging families to take time to consider and to discuss the project with relatives or primary health care staff. In addition, families were assured that declining to enrol or later withdrawing would not jeopardise subsequent care by the service or relationships with professionals.

All digitally recorded interviews were stored securely and erased after completion of the study and dissemination of findings. Any findings reported during the dissemination process were fully anonymised to ensure participants can not be identified. This is particularly important because the young adults may not be in a position to challenge the way in which research findings about them are presented.

In this study there was no potential for physical harm, indeed our experience from other studies including the study involving families and staff in the St Oswald's Children's Short-Break Service (Swallow *et al*, 2006; Swallow *et al*, 2011) is that families often enjoy and appreciate the opportunity to talk in confidence about their experiences of health care. However, any possibility of psychological exploitation was minimised and hopefully avoided by following carefully the guidelines for conducting research with vulnerable groups and by providing the opportunity to talk in confidence with a Social Worker.

As far as possible the principles of beneficence and non-maleficence were observed (RCP Guidelines 2007) and participants' rights were respected at all times. For instance every effort was made to: avoid invasiveness and intrusions into family life by arranging interviews at a time and place convenient to the family; and by trying to ensure that any benefits which may result from the study are greater than any potential disadvantages to the young adult and family. In line with published guidance (Department of Health

2000), written and verbal information was presented in a way which was appropriate for the participants' ability and level of understanding.

The next section of the report will describe the views and experiences of participants as presented and the major themes from analysis of the transcripts will be explored.

The next section of the report will also describe the experiences of young people with life limiting conditions during the transition to adulthood.

## Young adults' experience

Young adults with life limiting conditions have generally had years of experience, as children, of specialist health care from a range of different health professionals and support from an allocated social worker to coordinate their care including the provision of short breaks. Young disabled adults have the same aspirations and wishes for their future as their non disabled peers; to live independently, follow a course in further education, find employment and meaningful relationships.

However, the transition to adulthood for disabled young people takes much longer than it does for their non disabled peers (Caton and Kagan 2007; Hudson 2003). There are fewer specialist services available to support their particular needs and without careful planning they can experience a gap in the provision of health care (Morris 1999 in Knapp et al. 2008).

Research demonstrates that very few disabled young people are actively involved in planning for their own future, (Morris, 2002; Smart, 2004). Morris suggests that this is because there are actually few options available that would meet the young person's wishes. She goes further and suggests that what is important to young people is often not the same things that are important to professionals. Clegg et al (2006) reported that the causes of distress to young people with severe intellectual disabilities' and their parents were: the changes for the young person moving between services; worries about decision making; being unsure what they could request; what was available; and what could happen if the caring role became too much for the carer. Cameron and Murphy (2002) state that:

*Young people with communication difficulties had no independent voice in transition planning.*

(P.105).

It is important that alternative means of communication are identified as a means of ensuring that young people's and young adults' views are heard. Murphy and Cameron (2008) carried out research using Talking Mats and

Cook and Hess (2007) using photography, both teams highlighted the importance of finding alternative means of communication to allow young people's views to be heard. Cook and Hess (2007) remind us that: *...a way must be found to allow young people to express their views using a medium that would be accessible to them and have some value to professionals.* (p.32)

Young adults with life limiting conditions generally live at home; those who want to live independently cannot currently access the funding to allow them to do so. They continue to live at home with parents who are getting older, the space they need for wheelchairs and other equipment increases and they are inevitably isolated at home once they complete their education.

Parents may treat their disabled young adult as a child for longer than their non disabled siblings because of their vulnerability and personal care needs. Alternatives likely to be offered as activities to young adults when they are no longer in full time education are day centre placements with elderly people. Short breaks, if agreed, will be in homes for the elderly or those recovering from acquired brain injury.

This leads to parents, who are often desperate for a break from the relentless caring for their grown up son or daughter, feeling guilty because the young adult goes to stay somewhere they do not want to be in order to give the parent a rest from caring. The place where short break care is provided may have a low young adult to staff ratio meaning that the young adult spends a lot of time alone. The young adult accepts the short break care offered because they know that their parent needs a break. This situation reduces the benefit of a break for both. Glidden and Jobe (2007) reported that parents, particularly mothers of young people with disabilities, are generally suffering higher stress levels than those of non disabled children.

The Young Adults Service at St Oswald's offers planned short breaks on a monthly basis. Assessments of need are made by care managers and this determines, for each young adult, the nights offered to individuals. The nights

are divided over the year with some to be taken each month; this will equate to two to six nights a month. Parents are encouraged to take a longer break each year so that they can have a holiday. The breaks are planned several months in advance.

During their stays a range of activities are available, the unit has Sky television, there are game consoles and computers. The garden outside is wheelchair accessible and a range of trips out can be arranged upon request. Young adults are encouraged to bring their own transport which staff are insured to drive.

There is a Young Adults Group for those aged 16-25 which meets on the third Monday of each month, or, during the summer months at weekends to enable the group to attend activities of their choosing with longer time for travel and to take part. Since it began in 2011 the Young Adults Group have been power boating on the Tyne, spent a day at Kielder Outdoor Adventure Centre, visited a brewery (complete with tasting session) and several other memorable activities. The young adults are consulted and choose the activities that they would like to take part in, the staff facilitate this.

At St Oswald's it was not possible to elicit the views of all the young adults but two cognitively able young adults agreed at an early stage that they would be Young Adults Champions. Staff consulted with them regularly as the service developed to ensure that the young adults had a voice. When the young adults are at home between short breaks, email contact has been maintained with both the Young Adults Champions, having contact with the Transition Project Lead. This has continued during the pilot phase of the service and has led to some lively debates.

The next section of the report will describe the views and experiences of participants as presented and the major themes from analysis of the transcripts will be explored.

## **St Oswald's current Young Adults Service**

There are several things referred to in the findings of the evaluation that it will be helpful for the reader to understand:

### **Young adults living space**

When the Children's Unit at St Oswald's was built it included a splash pool. This pool was soon found to be unsuitable for the children to use and at the time the Young Adults Service was being planned it had been out of use for several years. Managers knew that for regulators to agree the new service proposal there would have to be some separate young adult living space identified. The pool area is close to the bedroom corridors and the grant that was applied for included the refurbishment of this area into a lounge area with beverage bay and adjacent computer suite.

Young people (aged 16-18 years) and young adults were consulted and invited to meet the architect whilst plans were being drawn up. The young people and young adults wanted modern décor, a beverages area and state of the art computer and audio equipment. All of these things were included in the room and when further money became available the young adults were involved in the design of the adjacent garden area. This included folding doors onto a large patio area, barbeque and raised flower beds.

All bedrooms in the unit are single occupancy with two bedrooms sharing a bathroom. The bathrooms are fully equipped with ceiling hoists and rise and fall baths. Young adults, when resident, use one bedroom corridor and children use the other one.

### **Staff**

Staffing was increased for the opening of the pilot Young Adult Service; there was an increase in nursing and non-nursing staff. Non-nursing staff were employed as support workers and their role included activity planning and driving the mini bus. Once the service began some young adults came to stay

with their own transport. Support staff have been added to individual's vehicle insurances and this has helped with spontaneous activities as St Oswald's existing mini bus is used across the hospice site and has to be booked in advance.

Shift patterns were reviewed during the planning of the service and twilight shifts were included as part of the support workers role. A twilight shift is from 6.00pm to 2.00am. This enables the young adults to go out on evening activities without having to return for shift changes. It also increases staffing at a crucial time and enables the young adults to choose when they go to bed.

A new role was introduced when the Young Adults Service began. A Primary Worker was identified for each of the young adults. This name was specifically chosen as each young adult has a Key Worker and the Transition Project Lead (TPL) and Children and Young Adults Service Manager (CYASM) did not want there to be any confusion or expectation that the worker at St Oswald's would become the case manager.

The role of the Primary Worker is to be up to date with all plans and details of the young adults care and wider involvement with health, social care and education. Each young adult is aware of who their Primary Worker is and knows that they can talk to them about any issue, this does not stop them having conversations with any other staff should they choose to do so.

### **Young Adults Group**

The TPL and CYASM 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. As a result of this a plan to develop a Young Adults Group at St Oswald's began to take shape. It was decided to include young people aged 16 and over as a part of transition to the Young Adults Service.

The group includes those with physical disabilities who are cognitively able and those with physical and learning difficulties. Siblings of group members

have also been encouraged to attend. The group meets on the third Monday of each month from 4.00pm to 6.00pm, however, during the summer months this often changes to a day time activity on a Sunday so that 'off-site' visits can be arranged. Activities have ranged from musicians coming along to the group, a Scalextric competition, a brewery visit and power boating on the River Tyne.

### **Young Adults Champions**

Whilst developing the service it was important that young adults had a voice as the service had to meet their needs both for physical care and for recreation. As explained in this report two young adults were asked to act as Young Adults Champions and lots of very lively discussions took place and are ongoing.

This has empowered the young adults who are often overlooked by well meaning professionals. The young adults have suggested the activities for the Young Adults Group and staff have acted as facilitators.

The young adults are delighted with the living space they had such influence over and now that the garden is complete they are looking forward to growing and planting things in the garden area.

The following section of the report will explain the change in focus of the evaluation and report on the findings for each group of participants.

## Findings

This evaluation was undertaken to explore the experiences of: young adults (aged 18-25 years) using a new specialist Young Adults service at St Oswald's Hospice; the views of their care managers; carers and the Young Adults Service staff.

Evaluation research, as its name implies, is concerned with the evaluation of such occurrences as social and organisational programmes and interventions. The essential question that is typically asked by such studies is: *Has the intervention (e.g. a new policy initiative or an organisational change) achieved its anticipated goals?* (Green 1994, 2000 quoted In Bryman 2008 p.42)

The aim of the study was to determine what difference the service makes to the lives of young adults and their carers. The original proposal stated that this question would be explored in relation to the following themes:

- The skill mix of staff providing the service
- Partnership working
- Access to leisure activities
- Opportunities for young adult's independence
- Peer support for young adults

After several focus groups and individual interviews were held the research team met to discuss emerging themes and reviewed the original plan

*Themes and subthemes are the product of a thorough reading and re-reading of the transcripts...data is then displayed in terms of subthemes.*

(Bryman 2008 p554)

The team agreed that the data collected, whilst providing evidence for some of the original topics were indeed suggesting slightly different themes than expected. An agreement was reached that changes would be made and further data extraction would focus on:

- The need for the service
- Practicalities
- Staffing
- Finance
- What makes the service special
- Future

The biggest change in focus was that the research team would no longer be focusing on partnership working. The focus group and interview participants did not engage in discussions about partnership because at the time the interviews took place there were massive changes in health and no one really knew who their partners were from day to day.

Professionals were reluctant to say anything about what was happening as no one knew if they would have a job once things settled down and there was real fear about sharing opinions (even in a context of confidentiality) because of this. As partnership was a major discussion point in an earlier publication about the Young Adults Service (Young and Cameron 2012) it was agreed that the new focus would not include partnership working.

The key emergent themes will be discussed in detail in the following pages. In reporting the data certain conventions have been used, these include:

- Verbatim accounts are shown in italics
- A gap in the data presented is indicated by a short space in the text ... with three full-stops

### **Findings – Young adults**

Interviews were undertaken with two young adults. Both had accessed the Children's Service for a number of years. One left at 18, and returned after a break of four years. The other young adult had no break in his stays due to his birthday coinciding with the start of the Pilot Young Adults Service.

Both young adults agreed that their interviews would be audio taped and later transcribed and that the contents would only be shared with the research team.

## **Need**

When talking about accessing the Children's Service one young adult remembered it *took a lot of fighting to get and took about 18 months*. The other was referred by his Occupational Therapist and remembers the hardest thing about coming to St Oswald's for the first time being his parents leaving him with someone else which they had not done before. Both were keen to say how much they enjoyed their time at St Oswald's as children and their anxieties when approaching 18.

For the young adult who left at 18, there was never any doubt that he would do so because at that time there was no choice. He does remember how worried he was and when asked in the research interview what he had thought would happen after he left the Children's Service he said:

*I thought I was just going to end up in a really bad care home, which I kind of did.*

He began to have short breaks in a care home for older people and those recovering from brain injuries.

When asked about his experiences he said:

*Well, if I am being honest, it was like prison. Well, actually it probably wasn't like prison because they gamble, but, anyway, it was just miserable. I didn't look forward to going in. As further explanation he said it was the fact I was shut in a room. The staff didn't really have time to talk or anything.*

It would seem from both of these accounts that there were no suitable short breaks available for young adults with life limiting conditions.

One young adult talked about how much he had enjoyed attending two conferences about transition:

*It was quite interesting, to see what was happening elsewhere, in other parts of the country. That's quite interesting.*

(Marie Curie 2012)

## **Practicalities**

The young adults were pleased to have been part of the planning at the development stage of the service. They were both present to meet the architect when the new lounge area was being discussed. They were part of the consultation group for the policies and procedures that were put in place. When talking about the use of the lounge one of the young adults said:

*I agreed it.... it's worked very well.*

Both young adults talked enthusiastically about the twilight shifts that were introduced when the service started. Support staff work from 6.00pm till 2.00am and this enables evening activities that do not have to be curtailed because of shift changes:

*Support workers now do twilights, yeah they go to two o'clock in the morning I think. So it's good.*

*Yeah that's made it better the fact that I can go out on a night and not have to be in for handover time at 9.00pm.*

Young adults were happy that they were involved in decision making on a daily basis:

*Some of the support workers can also drive my car. Basically, I just decide...if I've got my van then I would say I can decide on the day where I'm going. I have had quite a lot of input."*

## **Staffing**

Both young adults recognised and appreciated that although there were some

new staff, they had known most staff members for several years before the Young Adults Service was operational and felt that they knew them really well. They reflected on the time they spend at St Oswald's and agreed that whilst it is nice to go out on trips it is equally important to them to spend time with staff who they see as their friends:

*They are really nice people that's why I have been coming for so long.*

*Getting on with the staff really, trusting them.*

Personal care is not an issue:

*That's why I am used to it I think, in fact I am very happy , I'm used to them doing it so, it feels good.*

Staff have a lot of time to spend with young adults, this is different from their experiences when they have been in hospital:

*I think it's different for people, I think in hospital I was like...they don't get the chance to take their time and get to know people. There is a lot faster pace so you can get, can't really build up relationships and stuff.*

*They've got a lot more time [at St Oswalds], in hospital you haven't got long when you see someone for five minutes.*

### **What makes St Oswald's special?**

Stays at St Oswald's are special because:

*I can get around, it's a bigger place, more to do.*

*The gardens are really nice.*

*Just chatting with the staff...I like a good chat.*

*Different from hospital stays because there is more time and people...In hospital it's all rushed, they've got to do things quick because they need to get to the next person.*

*It's nice to get away from home sometimes to see some different four walls. Here you get time to talk to people.*

It is clear that young adults recognise that in hospital, and other settings, staff ratios do not allow the time that staff at St Oswald's have to spend with them. It is also very clear that, the time to enjoy the company of staff, being able to go out late and get up early are very important to them. When asked how they would describe the Young Adults service to their friends they said:

*It's like home, a home away from home.*

*Like a hotel really. It's a nice place to go, like a holiday home.*

Both young adults talked animatedly about the staff and agreed that it is their sense of fun and humour that makes the service special:

*Are they cheeky? Yeah they give as good as they get. Oh that's good and do they get plenty of cheek -sometimes.*

*I think the sense of humour. Everybody's got a sense of humour, here, which I think always helps, everybody's fun, and the fact that they've got time to talk to everyone. That's why I have been coming for so long.*

## **Findings - Parents**

At the time the evaluation was carried out there were eight young adults accessing the service. A letter of invitation to take part in the evaluation was sent to each family. Four families agreed to take part and in each instance it was the mother and main carer who was interviewed.

It was particularly helpful that there were two parents of young adults who had left the service when they reached the age of 18 years [as until 2010, 18 years was the age limit for accessing the Children's Service] , and two parents

of young adults who became eligible to continue accessing the service after the age of 18 [because their 18<sup>th</sup> birthdays coincided with the pilot Young Adults Service being established]. This enabled dialogue with study participants about the way these two different forms of service provision affected them and their respective families.

## **Need**

The parents of the young adults who access the Young Adults Service were not encouraged to plan for their child's transition to adulthood, as until recently children with life limiting conditions such as theirs were expected to die in childhood. This has meant in real terms that little or no planning for transition has taken place. Fraser et al (2011) reported that there was a 44.8% increase in the prevalence of young people aged 16-19 with life limiting conditions between the years 2000 and 2010. This highlights that some thought must be given, nationally, to the process of support during transition in order for transition to be a meaningful experience for those involved.

Other changes also impacted on the young adults and their families at the time of transition:

*After the age of 16 you're not entitled to a physio, you're entitled to someone to manage your physio, someone who will come in and... show someone else how it is done.*

The parents who took part in our evaluation of the Young Adults Service said that while they understood that their child became an adult when they reached 18 years of age, they, and their young adult, still struggled to understand that they have to leave a service that is meeting their needs; furthermore, the young adults' needs for support such as that provided by the Young Adults Service are likely to increase as time goes by:

*Obviously you are classed as an adult when you're 18, but [son's name] needs from when he was 2,3,4,5,6 are the same [as they are now] and he's 22 now, so his needs from when he was a little baby have stayed the same. That hasn't changed, except his age.*

*I feel it's wrong because, yes he's 18 but 18 is just a number ...his condition isn't going to get any better and it is getting worse more diagnoses now [additional health problems being identified as he gets older].*

The parents of young adults who had to leave the service at 18 both had different experiences; one had looked for a suitable alternative for three years after he reached the age of 18 and had in fact looked at four other services that could not meet her son's needs.

The other parent was happy with the personal care that the alternative service provided but due to there being only one nurse on a shift for all the service users, there were no social outings for the young adults:

*I could not fault them as carers...when he was in respite at [name of service] he never got out on trips, never went anywhere. Because obviously if a nurse left the place there was no nurse left to care for the others.*

*There would be maybe a couple of board games around the table on a night ... but that was it. They didn't have a sensory room and things to stimulate him.*

## **Practicalities**

One of the things that all parents expressed was how good and necessary it was for their young adult to have a break and get away from their parents/carers:

*He gets the break away from home which is nice, getting away from every day life at home.*

*Wonderful to be amongst his friends and to mix with them and to...well, for him to get away from us.*

*He's away from me and... which has got to be a big relief.*

*He's 22, he doesn't want his mum and dad around him all the time.*

Parents said that they too needed to recharge their batteries so that they could continue to be carers, and they often articulated that this is very easy for them to achieve when their young adults are at St Oswald's. They spoke of how they trust staff at St Oswald's where the young adults are offered both medical and social support.

Parents sometimes compared the care at St Oswald's with their experiences in other settings, including hospitals, and stated that those other settings do not enable them to make the most of relinquishing the caring role.

When discussing their experiences of using care providers other than St Oswald's, they talked of medication errors occurring, under stimulation and a lack of understanding of the young adult's condition. These experiences have meant that instead of a relaxed break parents have been worried and felt guilty about leaving the young adults.

It appears from parents' accounts that no other care setting or hospital can offer the high level of staff/young adult ratio that is available at St Oswald's. The lower staff/young adult ratio in other care settings does not instill confidence in the parents:

*We were offered an old people's home [because that's the only service available] because he is 18, he's not an old person, no disrespect to the elderly but my son's not an old person, he needs to be around kids his own age, to be able to go out and not just sit in a chair and just stare out of a window. That's not what I want for [son's name] and if he had gone there he would have seeped into depression, so that's not good for an 18 year old.*

*I wouldn't even leave him for five minutes elsewhere. I don't let nobody do his medication. But as I say when I bring him here [St Oswald's], I*

*never worry.*

Parents are also concerned that staff at St Oswald's may worry because although they offer the young adults activities to undertake, the young adults may not wish to take part in these. These concerns have been shared with parents at reviews and when they come to collect the young adults after stays. Parents feel that as long as there are things that the young adults can choose to do, then no one should be concerned if they do refuse any of the activities.

## **Finance**

Parents talk about the cost of individual care packages and understand the pressures that health and social care services are under. However, parents realise that those responsible do not understand that whilst other services cost less to provide than St Oswald's does, those services are not able to meet the needs of the young adults. Parents find this difficult and stressful. There is a lot of pressure for parents to accept and agree to short breaks that cost much less than those provided by St Oswald's . There is always a perceived threat by professionals that services will be withdrawn:

*Sometimes get the message from health and social care 'just be grateful'-parents can be frightened to argue in case they lose something else.*

*About a year, year and a half to actually fight with the system to be allocated 15 days [access to St Oswald's per year] which we feel is very unfair when we are doing 24/7 with [son's name] at home.*

In this particular case a change of care manager led to the young adult's assessed need for 56 days per year being reduced to 15. Another young adult's assessment that was completed prior to moving to adult services saw his support being drastically reduced, this was challenged by his parents and other professionals involved. His mother's view of that is that:

*They [professionals] were trying to get him to go with the places that were cheaper ... obviously nowhere near the quality of care you get at St Oswald's. But I wasn't having it.*

Parents agreed that it was hard to keep fighting the system but if advising others in the same situation they would say

*...hang on for what you want, and don't give up till you get it.*

## **Staffing**

Parents' greatest concern when their young adults have their short break is to know that their medical needs are being met, this is closely followed by knowing that they are having a good time:

*There's a nurse there... they [the nurse] would use their initiative if he needed to go to hospital... there's a physio... there are people that make him laugh.*

*They've all got nursing skills, not just being a carer.*

All parents recognise that staff have many skills including the need to be patient, friendly, approachable and trustworthy. They also need to have a good understanding of the different conditions that individuals have. Parents also believe that the young adults have known most of the staff for so long that they view them as friends. Whilst recognising that all these things are important one parent said:

*You can't teach life experience and it's nice [for staff] to have been around a bit before you come (to St Oswald's). You know, to have seen lots of different things and dealt with lots of different people.*

## **What makes St Oswald's special?**

Parents were very keen to discuss all aspects of the service at St Oswald's but became particularly animated when asked to talk about what makes the service special. Parents said that the most special thing was that they [parents] could go and have a break without worrying at all about the care of

the young adult.

Parents said that as a result of their son being able to access short breaks at St Oswald's, they [parents] had been able to do other things as well. For instance, one mother has returned to work and taken holidays with her husband. Those parents with more than one child have appreciated the time they have been able to give to their other child. Parents reflected that others would think that a hospice would be a sad place, but actually it is always a happy place:

*I wish I could put my finger on what makes it special... from the minute you walk in the door...there's laughter going on.*

Parents were asked what the young adults would say if they were asked the same question, and responses of:

*It's fantastic, absolutely fantastic...it's home from home.*

*Wonderful to be among friends.*

*I'm doing what you do when you go to Joe's at a weekend but within my remit, within my capability of doing that.*

*The atmosphere is happy. It's fun. It basically is a holiday.*

One of the young adults wanted to live independently but there was no agreement to fund the care he would need to accomplish that. His mum said that at the moment:

*He is so happy with his package of care at home and care at St Oswald's and he's like why do I want to move I've got everything... I'm happy here, I'm happy there.*

## **Future**

One parent suggested that a welcome extension of the service would be a Hydrotherapy Pool but did acknowledge that hydrotherapy is accessed at

another facility and staff do take the young adults to that. The only other recommendations from parents was a hope and wish that the service will continue.

## **Findings - Staff**

A cross section of staff working in the Children and Young Adults Service were interviewed. A total of twelve staff participated in the research and data were collected through three focus group interviews and three individual semi-structured interviews. Interviews were audio taped and later transcribed and anonymised. Some of those interviewed had been working in the unit from its inception and others were staff recruited to work with young adults during the Pilot Scheme.

Some staff were anxious about how information would be disseminated but were reassured that anything included in the report would be anonymised.

From an interviewer's stance it was interesting to hear about the dynamics in the team and the conflicts between the different staff groups were openly discussed.

## **Need**

Staff were very anxious about what services were being made available, or not, to young adults who were leaving St Oswald's at the age of 18.

*We did part company [with young adults when they reached 18] and crossed our fingers and hoped.*

There was a consensus that the individuals that caused them to worry most were those that had severe learning disabilities. It was this group that were in senior staff's minds when discussions began about providing a service that would allow the young adults to stay at St Oswald's:

*I think my vision of it was probably much more around the young adults with a learning disability. I think they were an easier group to*

*contemplate carrying on with, because although chronologically they were young adults, intellectually ... they are still children, and I think it was very easy to see how we could continue providing care for one of the children who at seventeen and a half will be no different at eighteen and a half.*

When staff began to explore the possibility of providing a service they visited other services and found that other hospices were offering a compromised service, hanging on to young adults by default because there was no where suitable for them to move on to. This meant that the sheer numbers accessing the hospices was overwhelming them and adults in their mid thirties were sharing space with babies and young children.

Staff knew that locally those who did get a short break service after 18 were spending time in homes for the elderly or for those recovering from brain injury. Nursing cover was usually one nurse per shift and staffing ratios did not allow time to be spent with the young adults.

### **Practicalities**

Staff generally felt that they had been naïve about how the service would operate with children and young adults. They had not considered the shift in decision making from parents to young adults, the need for policies, procedures and practices that would be different. They reflected on how easy it was to forget about appropriate bedtimes choices or about clothing:

*Trying to keep the focus on the young adult, as opposed to on the parent or carer.*

*Those with no speech at all and no method of communication, we are still maybe speaking on behalf of them and hoping that this is what they want to do.*

Most worrying to all staff is that they arrange activities for the young adults and the young adults don't want to take part. Staff feel that they are not doing

their job properly, or that this would be the perception of St Oswald's managers:

*Quite often they are offered, and they don't want to go anywhere.*

*They just want to go on the PlayStation, or sit with their laptop and they don't want to go out, they don't want to do anything else, they don't want to....*

There was a recognition that staff need to be 'technically minded' as the Xbox, PlayStation and laptop are the favoured pastimes of the young adults and they are very frustrated by staff that are unable to help them when they have difficulty. It is difficult to arrange activities that will be meaningful for both those that are cognitively able and those that are not:

*If you are the age of 50 you still have to know what's the latest game out, what's the latest music that they like; you have to be in their mindset and you have to acknowledge their wants and likes and desires.*

Staff struggle with information-sharing with parents, some parents take the view that their children are now adults and should be making their own decisions, some do not. One young adult became ill when his parents were abroad on holiday and he did not want them to know and this was a struggle for staff:

*It was a really, really difficult situation because I think you try to look at it yourself as a mother, and I would've been very upset as a mother, abroad, knowing my son was getting a 999 ambulance to come and pick him up, if I hadn't been told, regardless of how old he was....His mam had been aware that he hadn't been great anyway, I think it's very difficult.*

A young adult has been making plans for when he is ill with a volunteer Psychologist, as he finds it too difficult to talk to staff and the subject has been taboo in his own family:

*He's busy making a plan for himself about what he wants to happen when he becomes very poorly... he knows he needs to do it, but he hasn't got the emotional tie to her [the psychologist] that he probably has to other people.*

Staff do not like having two separate living areas and feel that they are quite isolated when children and young adults are staying and both areas are in use; they also struggle to maintain the separateness when young adults would rather spend their time with children in the main living area.

There have been compromises agreed as the service has developed and young adults join the children at mealtimes when appropriate. Young people aged 14 and over can spend time in the young adults lounge by invitation and until the 9.00pm watershed. However, staff still feel that it is difficult to meet the needs of both groups together.

Doctors who work within the Adult Service at St Oswald's have no experience of working with the conditions that these young adults have, as until recently young adults with these conditions did not survive to adulthood. This has been a challenge. Meetings have taken place both formally and informally as the service has developed and when the conditions are explained as a set of symptoms that doctors have experience of this seems to help the doctors concerned to better understand the young adults' needs:

*Medical staff concerned about the label of the conditions young adults have... If you call it a condition never seen in adults before, it's like 'oh, I've never seen that before'.*

Although it is only the support workers who work twilight shifts, there was some discussion in each interview/focus group about the positive effect these have had on the team's ability to be flexible around activities and bed times.

Staff recognise that finishing work at 2.00am can be risky for staff but due to the well lit car park and surveillance system this risk is minimised. When the

female staff leave at 2.00am, other staff go out to the door with them to be sure they get safely to their cars. The support staff suggested that more flexibility about the start and end of twilight shifts would be a help to the team.

On occasion there are young adults staying who do like to go to bed earlier and this is known in advance. The staff suggested that on those occasions a move to a 4.00pm to midnight shift would enable them to be around whilst day staff have their meal break and that they in turn could go home earlier:

*I think that 4-12, sometimes would be more useful if they're going to be in bed by 12, because then you're covering tea times and bath times.*

## **Finance**

Staff have known throughout the Pilot Scheme that the cost of providing the service was being supported by a Department of Health grant. They have always known that to continue this arrangement, an agreement must be reached with commissioners about funding.

The Young Adults Group has been funded by donations from other sources and the continuation of that is also a concern.

In the wider arena, individual health budgets have been piloted in several sites nationally and are likely to be rolled out to individuals in the near future.

All of this has been going on alongside the service development.

At the time of the focus groups and interviews no continuing funding had been agreed and staff were very concerned that the service would have to close and that jobs would be at risk.

## **Staffing**

Staff believe that those nursing staff who are dually registered to work with children and adults, have found it easier to adapt to the challenges of providing the new service:

*The ones who are dual trained like myself, who have looked after adults, it's quite easy for them to do that. But the girls who have never looked after anybody over the age of, say 16/17, it's hard for them to get into the mindset of being an adult looking after an adult.*

Staff need to have clinical skills and knowledge of the conditions that the young adults have. They need to want to work with young adults, they must have a sense of humour, and they need to be flexible and outgoing.

It was suggested that there should be a Team Leader with responsibility for young adults; they would be responsible for ensuring that the team gave some dedicated time to young adults. It was recognised that the strength of the team is its multi disciplinary makeup. It is also seen as important to have previous experience of caring for people with a disability and that a new member of staff without that prior experience would struggle to cope with the needs of the young adults at St Oswald's.

The rota does not always include support staff when young adults are staying, therefore, more proactive planning of activities is necessary so that in the absence of support workers staff are able to engage in activities that have been planned and risk assessed.

The young adults currently using the service have all accessed it as children and often seek out nursery nurses to do their personal care. The nursery nurses who took part in this evaluation did not see this as a difficulty and explained that they swap around with other staff if the young adults approach them for support.

*It's because he knows me.*

They acknowledge that this might have to be managed differently for any new young adults who may access the service in the future.

Young adults prefer staff, when accompanying them on activities, not to wear their uniforms; they also seem to prefer younger staff to go with them and are

more likely to say yes to an activity with younger members of staff. Staff speculate that this is because being with older staff is like being with your parent or grandparent and being with younger staff does not draw peoples attention to the young adult in the same way as being with older staff would.

*They definitely love it when you are in your own clothes.*

The data gathered during interviews highlighted divisions within the team. All staff recognise that having a high level of nursing staff available ensures a service that provides the best of health care, however, there is a view held by professional staff within the team that there is more talk and less work when there is a greater amount of non nursing carers on shift. Conversely non nursing carers are frustrated that nurses are unwilling to go out to support young adults during activities.

*I just think when there's a high percentage of non- qualified on shift together there's a lot more nattering goes on, and not necessarily much doing.*

Conversely another professional commented.

*I don't know if necessarily the adults always need the nursing care. The support staff or the more qualified healthcare assistants could support them, in a way you don't necessarily need a qualified member of staff.*

Although this has come to the fore during the evaluation of the Young Adults Service, there has been an expectation that nurses accompany children on activities since the Children's Service began. This would suggest that this issue has been longstanding.

### **What makes St Oswald's special?**

What makes the service specialist is not necessarily what makes it special. As specialists, staff are:

*Identifying what the needs are for each individual person and building up an individual care plan, and then... bringing in the professionals around them to meet their needs.*

Staff believe that the most important thing that makes St Oswald's Young Adults Service special is the high staffing levels that give them time to meet the physical care needs and to provide for social needs as well:

*It's a big thing, that one to one plus one. Because we always have one to one, but it's always an extra.*

The service provides a beneficial short break to the young adults and massive support to their families:

*It's very special because we all think they are special; we all think that they are very special individuals and we will do everything in our power for those young adults. And we have got the time, and we have got the staffing.*

*One of the unexpected developments... is the young adults group which meets either at a weekend if there's something that we are going to do that's through the day in the summer months, or the third Monday in the month.*

During every step of the service development young adults have been the focus and they have had a strong voice. The living space has been developed through close consultation with them and the young adults are very proud of what has been achieved. The garden has been developed as money has become available and again this has been done in consultation with the young adults.

Young adults can access physiotherapy, complementary therapy and have symptom control whilst having their short breaks. These are things that are not regularly available to them at home once they are adults:

*It [Young Adults Service] provides more than we ever expected; it's provided a help and aid to the future, even when they leave us at 25 or whatever. I think the transition work that's gone on to help them in the future away from St Oswald's has been bigger than we ever expected. I think the social activities that have been tailor made for them have far outweighed our expectations.*

## **Future**

All staff agreed that it would have been much easier to set up a separate Young Adults Service from the outset and although some staff would miss the young adults if this were to happen, they are generally agreed that a separate service with a separate staff team would be the best way forward.

There is a view that a separate service would be staffed differently and not necessarily be nurse-led.

Staff have concerns about accepting new referrals for young adults that they have not nursed as children but accept that this will be part of any future development.

As young adults are quite isolated at home some staff would like to develop a day service but have not given any time to consider the practicalities of doing so.

Until a separate service can be established, staff think it is important to review the current booking system for young adults and that more young adults should be staying at St Oswald's together.

When the makeup of the staff team is reviewed some consideration should be given to employing a Team Leader with a mental health background and a Counsellor:

*I think that these young adults have a lot going on, and they need somebody who can help them... I would also like counsellors that have more knowledge about end of life with young adults.*

## **Findings - Doctors**

Four doctors were interviewed during one focus group and one individual interview. It was explained that discussions would be digitally recorded and transcribed.

The view of doctors who work within the Adult Service was that they are still somewhat distant from the young adults and their needs:

*Here is this little group they seem to fall between two stones... and we could have done with a bit more thinking about that [before the service went live in May 2011] but we didn't do the thinking, and things like the on call rota and the role of the specialist registrars... it has been a great shock to the specialist registrars because it was a group they had never looked after before, you can get irritated and say, well they should be looking after them as children, but the fact is they don't and they're not allowed to, they are training in adult medicine and have no paediatric experience. The training body and deanery would not support them looking after children except in an observer role, so they are unfamiliar with the conditions and some of the disabilities that the young adults have. So that was a whole new way of thinking.*

There was recognition that the group of young adults with life limiting conditions has been, and continues to be very small, and that as life expectancy for different conditions increases then there is every possibility that the size of this group will grow.

## **Need**

Doctors recognised that the choices for young adults if they left St Oswald's at 18 were limited and that they needed more care than could be provided by current adult services. They feel that the Young Adults Service at St Oswald's has stepped in to fill this gap. Although doctors recognise that the limitations of the available living space at St Oswald's, and the fact that the service was a Pilot Project, they thought it might have been possible to offer support to more individuals.

Discussion around transition was about young adults taking more control of decision making affecting their health and lives in the community and parents relinquishing some of their control over this. As palliative care doctors, the

respondents in this group reflected that the Young Adults Service does not provide the same service as St Oswald's Adult Service:

*Not palliative care as I understand it, more about transition than the person themselves.*

One of the doctors had a quite different view [from his colleagues] to the changes that were to be made when the Young Adults Service was being planned and felt that the difference was in fact not so great:

*Because I didn't see much difference from urgent respite or respite where needed [emergency respite when patients are not coping at home, this is agreed by reviewing the waiting list and prioritising need] to what the Hospice is currently doing. So everybody saw it as a big transition going, well this is planned respite and that's nothing like what you do in the adult unit. I'm going, 'well no, very often actually some of what we're doing is respite it just happens to be when required and when needed', in so far as if somebody is seeing the outpatients they go 'we are really struggling, so let's get this sorted out and we will get you in'.*

This comment led to further discussion about the young adults likely to be referred to St Oswald's in the future. Currently those with some life limiting conditions, such as Cystic Fibrosis, are unlikely to be referred. This is because although they have this condition individuals are likely to be quite healthy and able to live very full and active lives until their condition is well advanced. Respondents also felt that there is a need to think about those that may be temporarily referred to St Oswald's, have their issues resolved and be discharged. An example of this was a young person who needed a double lung transplant and was very ill. She had a successful transplant when she was seventeen and no longer accesses the service. There is a recognition that increased staffing and the setting at St Oswald's ensures that a holistic package is put in place for each individual and their family that cannot be replicated in a hospital setting:

*Not always the resources, I don't think, I think sometimes you come onto, I don't know about the paediatric wards but some of the adult*

*wards and there are two qualified staff and there is a health care assistant who is specialising a bay, this is in a major North East hospital [St Oswald's and hospices generally have much higher staffing levels than hospital wards]... it's about there's a philosophy isn't there that comes in, it's about the whole person, the whole family approach and it isn't required all the time. But sometimes in these complex difficult situations it is required and perhaps we're not always good enough at saying, actually I think we can do this better and, you know, you can't do it in your settings, because there is a little bit of a conveyor belt about. [hospice care is arranged around the patient and the whole family, including social work support, bereavement counselling, complementary therapy and the general care of the family during difficult times].*

## **Practicalities**

Doctors reported that they had been asked to look after young adults at St Oswald's with clinical conditions that they [doctors] had no previous experience of managing. Although a regular update email is sent by staff in the Children and Young Adults Service to the doctors concerned, listing the diagnoses of young adults using the Service this does not necessarily tell the doctor what the current problem is for each individual young adult. The system in place does ensure good contact is maintained with doctors in the adult unit but they still don't feel they understand the young adults' conditions:

*I don't feel like they are on my radar.*

*I haven't got a problem if they are dying, I can manage that, it's the living that I have a problem with.*

*I think the disability is not the challenge, I think with this group of people it's the weird conditions that we're not familiar with, because the principle I approach people with learning disabilities with, is the same principle I approach anyone and you find your way with them, whereas*

*actually not knowing this particular condition might be a gap in my knowledge that I struggle with.*

There has been a limited amount of symptom management for young adults and doctors recognise that regular chest physiotherapy is helping young adults to stay well. There is a view that one of the most valuable things the young adults get from accessing the St Oswald's Service is peer support, and that involvement in decision making is a new way of working with young adults who may have had no or very little control over their lives when they were children or young people .

Doctors acknowledge that although attempts have been made, there has been no real lasting joined-up working with the Adult Service and where the young adult will go for end of life care is still a '*thorny subject*'.

## **Staffing**

When asked what attributes nursing and non nursing staff need in order to work effectively with young adults, the first answer was:

*They need to be cool.*

When this was explored a bit further this meant that they had to relate to young adults in a way that was not patronising, recognising that they are working with adults whose needs may be different to non-disabled adults. Staff need to have a mixture of skills, they need '*street cred*'. They should not be easily shockable, they should be good mixers and entertainers.

*It's a blend of being able to nurture young adults, there is still something in the nurturing side, but there is still something about being an adult with them.*

Staff must be able to get young adults out and engaging with the wider world more actively than they did as children; this can only be achieved by having a multidisciplinary mixture of staff:

*Nurses have a set way of thinking through a problem, people who have a bit more social-challenging someone to push themselves which nurses generally don't do, they provide safe guidelines to be cared for - fundamental to the team. But it's good to have people who think laterally about how to get the positives out of somebody [see past the presenting disability and illness and treat them as a young adult].*

*Support workers are employed to provide personal care and social activities.*

When appointing nursing and non-nursing staff, doctors thought it important to look for staff who would:

*Recognise that other services were struggling with this group but that we [St Oswald's] wouldn't.*

Discussions around the background of staff recruited to work with young adults concluded that staff recruited from the community would be less rigid in the demarcation between children and young adults. This is because when working in the community staff are working with the whole family and not just the patient.

## **Finance**

Funding issues are a bit of a mystery to doctors who find it difficult to understand that commissioners will only pay one third of the cost of care in the Hospice, whilst paying the full cost in other settings. Doctor's accounts in the interviews suggest that they do think that in the current climate, the type of service provided at St Oswald's is one that could be viewed as a niche market with the potential to attract revenue:

*Whether funding for life, I have no idea, but to be honest, it's more likely to follow in niches than it is in the standard stuff which other people rightly or wrongly are saying, 'well we can do this'.*

## **What makes St Oswald's special?**

Doctors suggested that the ability at St Oswald's to deal with medical, social, emotional and psychological issues under one roof is very special and unusual. Whilst the young adult is the focus of the service provided the needs of the whole family are taken into account and staff have the ability to see the whole picture.

*There is something about the environment, I mean the physical environment, but it's not just the physical environment, it's about the philosophy.*

Families have usually had a lot of different experiences in accessing facilities to meet the young adults' needs, and are pleasantly surprised by the acceptance and attitudes that staff at St Oswald's have to the abilities of the young adults and the family dynamics:

*I would say that it [the service provided by St Oswald's] is successful, that it has done what it said on the tin...it provides ongoing support for young adults who do not have anything else that can address their needs, either physical or emotional. It provides a lot of fun...as well as looking at what needs tweaking in their lives to keep them on top.*

## **Future**

The topic of the future led to some animated discussion and agreement that things can be done better between the Young Adults Service and the Adult Service in terms of communication and caring for individuals. Doctors wonder if it might be that the Young Adult Service will become a more acute service and what the longer life expectancy might mean in the future. All participants agreed that it would be good to offer the service more widely, to include young adults that have not previously accessed the Children's Service. For example, there is ongoing work with the Muscle Team which, as it develops is likely to lead to more referrals from the patients who are currently supported by that team regionally.

*I think for us, you've got an issue of children to adults, but I think we have got to respond to that and, you know, adults with a low disability can be a challenge for us on the Adult Inpatient Unit, because of unfamiliarity, not because, just because of, you know, we just find it it's new and it's different.*

Staff currently work in either the adult unit or the children and young adults unit. It would be beneficial for staff to spend at least some time in each unit so that disability becomes more familiar to adult staff and the adult unit less of a mystery to staff from the children and young adults unit.

In the Adult Service there seems to be no difficulty in accessing the services of an occupational therapist and this enables rapid access to aids and wheelchair repairs. It was suggested that this should be investigated as in the Children and Young Adults Service access to wheelchair repairs and new aids appears to be a lengthy and frustrating issue.

It may be that as young adults get nearer to the age of 25 years, attendance could be changed to day care only, in order to get them used to a time without overnight breaks. Now that a decision to continue to offer the service has been made, it is time to work towards agreement about managing young adults and working closely with the Adult Service to ensure a seamless response at times of crisis, or at the end of life:

*I would like there to be more of a flow of people to and from the young adult side.*

*We have to become more familiar and more flexible, is that possible, even in palliative care we get into ruts don't we?*

If a separate unit was built it would be separately staffed, there would still be integration issues with the adult unit but the new unit would not be so closely identified with children and this may help the development of working with the adult unit.

## **Findings - External Professionals**

Invitations to take part in the evaluation were sent to all social workers and care managers of young adults accessing the Young Adults Service. The Muscle Team at the Institute for Genetic Medicine, were also asked to contribute. The response was disappointing but at the time of the initial invitation there was great uncertainty about the continuation of the service and negotiations were ongoing with commissioners.

Once an agreement was reached with commissioners a further invitation was sent to care managers. Unfortunately no one responded to this. The findings reported are limited by this, however, the response that were received will be reported following the same format as those of other participants.

## **Need**

Professionals shared their concerns that they are working with an emerging group of young adults with life limiting conditions who, until recently, would have died in childhood. This has meant in real terms that there are no suitable short break services for this group and professionals have found themselves with the dilemma of parents needing a break and young adults being offered inappropriate services that they have not enjoyed. They feel that parents do not get the full benefit of the breaks as they feel guilty and worry about the quality of care provided in non specialist services:

*We hoped all our young adults with life limiting muscle conditions would be able to access the Hospice without having criteria for nursing intervention as a pre-requisite for entry.*

Those who could not access the Young Adults Service were described as receiving *basic care* in other services.

## **Practicalities**

The word 'hospice' is felt to make families and children apprehensive because of their understanding of what a hospice's role is. Once they have visited they begin to think differently and after staying can't wait to return. Professionals believe that if young adults, who have not accessed the service as children, are offered the Young Adults Service then this is likely to be the same process. The Muscle Team would like the referral pathway to be improved.

Actually what they would like is the criteria to be changed so that those who do not need nursing care can access the service. In effect, this would mean that the service would be spread so thinly that no individual would get the level of service identified in their care plan.

## **Finance**

At the time of interviews funding for the continuation of the service had not been agreed. Professionals whilst being very clear that there was no where suitable for the young adults to move on to also knew that the full cost of providing the service would not be sanctioned by commissioners.

Professionals were worried about the effect closing the service would have on their individual young adults but equally worried about voicing their views in a report that might well find its way into the hands of commissioners.

## **Staffing**

Professionals believe that St Oswald's have the staff skill mix to enable provision of a service to those with complex needs. These staff are able to provide social activities for the young adults that they would not experience anywhere else:

*Staff are focused on the whole experience.*

## **What makes St Oswald's Special?**

Professionals recognise that hospice provision is quite different to other residential services in that it provided holistic care to both young adults and families, and supports complex needs, be it for short breaks or end of life care.

*Once the patient is accepted, the Hospice provides an excellent service dealing with respite and support for them and their families.*

*We cannot stress enough how committed the staff are at St Oswald's to providing a specialist service to help children and their families.*

## **Future**

Professionals say that parents are very happy with the Young Adults Service but are worrying about what will happen when the young adult is 25 years old and no longer able to access St Oswald's. One suggestion is to extend the age range to 30 years old:

*There are limited places, limited availability for the number of children that fulfill the entrance criteria, and we feel that as Duchenne Muscular Dystrophy boys are living longer due to better management. The places should be offered up to age 25 to 30.*

Another suggestion is that if the capacity to offer overnight stays to an increased number of young adults cannot be realised that an outreach service be developed.

## Discussion

This evaluation was carried out to examine the impact of a new pilot service for young adults with life limiting conditions using semi structured interviews and focus groups to gather information. This discussion will consider the themes identified from the data extracted:

- Need
- Practicalities
- Staffing
- Finance
- What makes St Oswald's special?
- Future

### Need

Respondents recognise that young adults with life limiting conditions are an emerging group that until recently have not been on the radar of those responsible for policy or service development across the UK. Getzel and deFur (1997) found that all young people with disabilities face extra challenges at the time of transition. Those with profound learning disabilities, autism, severe physical disabilities, life limiting illness/disability have particular difficulties in making a successful transition.

Historically young adults and their families were expected to leave St Oswald's at 18 and received services that were not able to meet both their care and social needs. Respondents recognise that whilst it is important that individual's care needs are met their social needs are of equal importance:

*A Young Adults Group treats the biggest symptom of the young adults palliative care and that is the symptom of social isolation.*

(Williamson quoted in Young and Cameron 2012)

Parents and young adults who had experienced short break provision in adult services were agreed that the personal care that young adults received was

good. However, the staffing ratios left no time for other than basic care requirements to be met. Staff were kind to the young adults but had no time for conversation other than when providing personal care.

Professionals highlight that regular chest physiotherapy is unavailable once children reach 18 and access adult services. This is to the young adults detriment an area that all respondents agree is one of the most important advantages that the development of the Young Adults Service has provided.

Once a month a physiotherapist assesses and advises on the condition and treatment of individuals when the young adult is having their short break. This improves the health of the young adults and gives parents confidence that they are using the right exercises at home and not missing some physical change in the young adult that needs attention.

## **Practicalities**

In the early planning stages of the Young Adults Service staff concerns were concentrated on those young adults with a learning disability and the alternative services that were available when they left St Oswald's. However, staff report that the real challenge as the service developed was meeting the needs of young adults who are cognitively able. Having been used to deferring to parents for decision making, it was a completely different way of working to ask young adults when decisions had to be made and information shared.

Setting up a new service within an existing service has raised issues about how staff work together and support each other when children and young adults are staying together. Staff report feeling isolated when working in separate areas. The introduction of a twilight shift has been hailed as a success by staff and young adults and has enabled activities to be enjoyed without interruption, but some flexibility in the start and finish times of twilight shifts would be seen as an advantage on occasion. Being able to drive the young adults own vehicles has been very successful but limited by the

amount of young adults who bring their adapted vehicle to St Oswald's.

Peer support was seen as a positive outcome of the new service by some respondents whilst others recognise that young adults who have used the service as children regard the staff as their friends and gravitate to them for company and conversation more than to their peers.

Parents recognise that they benefit from a break knowing that their young adult is receiving the care that they need. They also recognise that the young adults need to have a break from their parents in a place that they are happy and comfortable.

Young adults are pleased that they have been consulted on aspects of the new service and feel empowered because their suggestions have been acted on. This in turn has meant that they are happy to continue to offer their views knowing that they make a difference to plans and that they are speaking on behalf of all the young adults.

Respondents share concerns that the Young Adults Service does not have strong links with the adult hospice and acknowledge that this is an area that needs further development.

## **Staffing**

Respondents all agreed that staff working with young adults have to be multi skilled. Whilst their physical care and knowledge of the conditions of the young adults is very important, it was also felt that having a sense of humour and being able to organise and lead activities was just as important. Being able to drive the mini bus and the young adult's own vehicles was seen to be an advantage.

Staff need to be up to date with the latest technology and know what's going on in the wider world of young adults.

Tensions in the team do not appear to be evident to either the young adults or their parents. The fact that St Oswald's are able to employ the level of staffing that they do is greatly appreciated by parents. They believe this enhances the short break experience and that it cannot be replicated either in a hospital or other residential provision.

## **Finance**

Finance has been a fairly thorny issue whilst evaluating the Service. At the time that interviews and focus groups were held finance was at the forefront of everyone's thinking. There was a very real threat that the Service [which was supported financially by a Department of Health grant] would have to be shelved when the pilot phase ended. However, respondents did understand that providing a high level of staffing means a high cost service. This, at a time when there were the biggest changes in the health service, the Young Adults Service's main customer, since its inception.

Commissioners responsible for purchasing care packages have little understanding that lower cost services cannot meet the needs of the young adults who access the Young Adults Service.

Overall, respondents found it difficult to understand that finance could not be found to support the continuation of the Young Adults Service, when it has proved itself to be meeting the needs of a very specialist group.

## **What makes St Oswald's Special?**

The holistic care (i.e. meeting clinical as well as psychosocial and emotional needs) that young adults and families receive from St Oswald's is what makes the service special. Young adults appreciate the staff's sense of humour and fun and being cared for by people who have time to meet their individual needs.

The Young Adults Group is recognised as providing opportunities and support

for activities that would otherwise be out of the young adults reach due to the practicalities of travel, access and support.

Parents and professionals are appreciative of the time short breaks gives for parents to spend quality time with other family members, secure in the knowledge that the young adult is in safe hands, in an environment that they are happy to go to.

## **Future**

At the time of the evaluation everyone involved hoped that the service would continue. Parents and young adults raised anxieties about what will happen when they are 25 and can no longer access the service.

All staff felt that a separate service, whilst not possible during the pilot phase, would be the preferred option in the future. This would remove any current restrictions on bookings due to the age range catered for.

Staff would be able to choose whether to work with children or young adults and the make up of the staff team in a separate service might be quite different. Whilst it is recognised that a nurse must be available, it might not be necessary to have a nurse led unit as the Children and Young Adults Service is currently.

Doctors and staff in the Hospice identified the need to work more closely with the St Oswald's Adult Inpatient Ward. They perceive that the service would be improved by doctors and other staff in the Children and Young Adults Service working closer together. Doctors expressed their disquiet at not really understanding the young adult's conditions.

There is a recognition, by respondents, that there are young adults with life limiting illnesses and disabilities with needs that are different to the current cohort of young adults accessing the Young Adults Service at St Oswald's. As clinical outcomes improve then the long term survival of young adults with life

limiting conditions will increase. There are a group of individuals with conditions, for example Cystic Fibrosis, that will never need regular short breaks but may well need end of life care.

## **Conclusions and suggestions**

The evaluation took place during a time of great uncertainty for the Young Adults Service. This affected the willingness of those invited to take part. Despite this, a lot of very interesting and pertinent views were obtained during focus groups and interviews. The service is viewed very positively by everyone who took part, and any difficulties that are created trying to run two separate services, side by side are not visible to young adults or their parents.

Everyone involved in the evaluation is very relieved that there is an option that can meet their needs, being offered to young adults at 18, so that they continue to enjoy their stays at St Oswald's. There is however, a huge question mark over what will happen when these young adults reach 25. The service cannot currently accommodate anyone over the age of 25 as it would not be appropriate to increase the age range under the current arrangements.

## **Suggestions**

- Consider the upper age limit for the Young Adults Service in light of increased long term survival rates
- Have more young adults staying for short breaks at the same time
- Build a separate unit for young adults
- Build a hydrotherapy pool
- Closer working with the adult hospice
- Develop an outreach/day care facility
- Investigate what would make access to an Occupational Therapist and Wheelchair Services easier
- Consider those who may be temporarily referred to the Young Adults Service whilst health issues are threatening their lives

# Appendix 1

## Topic Guide

### Parent Interviews

#### Introduction and Background

##### **1. Knowledge and understanding of the service**

- How did you first find out about the service?
- What did your young adult know about the service before their first visit?
- How was information given and by whom?
- Having experienced the service, how would your young adult describe the service to his/her friend?
- Any anxieties /concerns about using the service

##### **2. Views and experiences in relation to the skill mix of staff**

- General e.g. what makes a good worker?
- Qualities e.g. what should they be like?
- Skills, e.g. what should they be good at?
- Knowledge e.g. what should they know about?
- Experience e.g. what kind of things should they have done before?
- Any particular concerns/anxieties about

##### **3. Impact 'short breaks' have had on access to leisure activities**

- How would your young adult describe the leisure opportunities at St Oswald's?
- Any difference in your young adult's opportunities to access leisure activities since joining the service.

##### **4. Views on what makes the service 'specialist'.**

- E.g. facilities, philosophy, staff skill mix

**5. Views on involvement in decision making**

- When did the young adult first hear about the service
- How would you describe your feelings when the service was first mentioned?

**6 Suggestions on how we can improve the service.**

**7. What difference, if any, does it make to you being able to access the Young Adults Service at St Oswald's**

Please give examples

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