



THE EVALUATION OF THE “YOUNG ADULTS PROJECT”

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Evaluation of the Young Adults Project: a partnership between Martin House and St Leonard's Hospices and young adults

1 Introduction

This is a report of the evaluation of the 'Young Adults Project' (YAP) run by Martin House (a hospice for children, young people and young adults) in West Yorkshire and St Leonard's (an adult hospice) in York. It was one of the first projects funded by Together for Short Lives' Transition Programme. Funding was received to run the project for two years: 2018 and 2019. The Martin House Research Centre at the University of York (UoY) was commissioned to independently evaluate the project.

2 The origins of the Young Adults Project

In 2016, Martin House Hospice (MH) approached St Leonard's Hospice (StL) to collaborate in the development of a new provision for young adults with life-limiting conditions (LLCs) in the region.

The motivation on the part of MH to initiate this collaboration was the absence of any day provision for young adults in their 'catchment area', and concerns about the appropriateness and sustainability of MH providing short breaks and end-of-life care to individuals in their mid-twenties and older. At the time, StL had almost no experience of providing end-of-life care to this age group and their day service was not designed with this age group in mind. They were keen to explore the potential to extend their provision to accommodate this age group.

MH and StL articulated the following aims of this new provision:

- to enrich the lives of young adults.
- to provide opportunities for their self-development.
- in locating the service at StL, for young adults to experience an adult hospice setting and thus support transfer of care to StL.

The provision, designed in consultation with young adults using MH, was a day service named the 'Young Adults Project' (YAP). It was designed to run on an annual cycle and take the form of monthly, half-day sessions held at StL's day centre attended by the same group of young adults (n≈12) and supported by MH and StL staff. The plan was for sessions to comprise periods of unstructured time and opportunities to take part in individual or group activities chosen by the young adults. At each session, MH staff (doctor, clinical psychologist) would be available for one-to-one consultations if requested. Sessions would begin and end with a meal.

The project was piloted during 2017 (going forwards, we refer to this as the 2017 pilot) and included an internal evaluation involving brief interviews with young adults attending at the start and end of the project cycle. During this year, Martin House was successful in securing a grant from Together for Short Lives to run the project for two years (2018-2019). Findings from the 2017 pilot were shared with the UoY evaluation team and are summarised in Figure 1.

Figure 1: Findings from the 2017 pilot

- The young adults were content with the frequency and duration of sessions.
- StL Day Centre worked well as a space to run the project. However, young adults had not been interested in being shown other areas of the hospice.
- Throughout the pilot, MH staff found themselves being more directive than they had wished or anticipated; and acted as the primary source of ideas. Many of the decisions were not co-owned by the young adults attending.
- Similarly, there had been little evidence of increased self-determination and self-organisation among the majority of those attending YAP. For example, parents/carers, or MH staff, had typically taken the lead in coordinating attendance.
- The project had not resulted in the closer social connections between group members that had been hoped for. At the end of the pilot they were described as remaining a 'collection' of young adults, rather than a 'group'.
- The participation and sustained involvement of StL's care staff during sessions was less than had been hoped.
- Designed to entice people with poor appetites, StL's usual menus had not proved popular. New menus were devised with the young adults, and served communally, rather individually plated up.
- Midway through the year, the idea emerged of holding an 'end-of-year' event to increase public awareness of the lives of young adults with LLC. This resulted in a public exhibition in December 2017 showcasing some of the young adult's work and project activities. Planning and organising this became a key focus of activity. It gave a sense of purpose to the group and sessions. The event itself was regarded as a success, which staff believed the young adults had enjoyed and found rewarding.

The 2017 pilot confirmed the suitability of the project's setting, and session duration and frequency. However, it had revealed that many of the young adults had little experience of taking initiative and working in a group. Overcoming this passivity had been very challenging

with few real successes. To overcome this, it was decided that future project cycles would have a group project as a core activity from the outset, culminating in some sort of 'event' at the end of year. It was felt this would provide a sense of group coherence and give purpose to, and continuity between, sessions. It was also regarded as having the potential to develop young adults' confidence and skills. MH and StL agreed that StL staff would continue to be encouraged to attend sessions. In addition, they would offer appointments with their complementary therapy team.

3 The Young Adults Project

3.1 Project aims

The aims of the project, refined in light of the learning from the 2017 pilot, were as follows:

For the **young adults**:

- to develop their skills and confidence to actively participate in planning for and doing things in their lives.
- to increase their ability to function well in group activities with peers.
- to provide an opportunity for one-to-one consultation with MH or StL staff involved in running the project.

For **Martin House**:

- to learn about 'what works' and 'what does not work' for young adults with LLC in terms of extending the ways in which MH works with and supports young adults.

For **St Leonards**:

- to better understand the needs of young adults who may benefit from using palliative care services.

3.2 Description of the project

The project was funded to run for two annual cycles and ran during 2018 (Year 1) and 2019 (Year 2). Like the 2017 pilot, it comprised 10 sessions taking place on an approximately monthly basis from 1:30pm – 6:30pm over a calendar year. It was held at the day centre facility at St Leonards Hospice, York.

The overall structure of each session remained similar to that used during the pilot:

- session starts and ends with a meal together.
- session organised around periods of:
 - unstructured time,
 - whole group discussions and activities,

- individual and small group activities/ ‘mini-projects’ (running over more than one session), for example: creative projects, supporting pursuit of existing or new hobbies and interests.
- available during each session was the offer of a one-to-one consultation with MH staff (doctor, clinical psychologist) and a complementary therapy appointment with a member of StL staff.

It was also intended that, occasionally, sessions would take place at an activity/experience-based venue chosen by the YA and, in addition, the group would arrange other outings/meet-ups at entertainment or leisure venues.

3.2.1 Project participants

The project was designed and resourced to accommodate up to 12 young adults (without significant learning disabilities) already using MH’s teenage/young adult facility, Whitby Lodge. Carers were encouraged *not* to stay during sessions but were invited to join the meal at the end of the session. During sessions, MH and StL were available to provide care.

3.2.2 Project staff

The project lead was a consultant clinical psychologist based at MH. MH (including members of Whitby Lodge care team, a doctor) and StLs’ staff (care team, medical director) were involved in delivering or supporting the project. An individual with community development/youth work expertise external to MH was appointed to attend project sessions.

3.2.3 Setting

As with the pilot, the project took place at St Leonard’s Hospice day centre in York. This is a spacious, ground floor area comprising a very large meeting room, a ‘café-style’ space within a large foyer area, and a large accessible outside paved garden.

3.2.4 Transport

MH is a regional hospice with a large ‘catchment’ area spanning North, East and South Yorkshire as well as the city of York. The project grant included the young adult’s transport costs. MH was able to offer to arrange/provide transport, but young adults were encouraged to make their own arrangements.

3.2.5 Post-project plans

Midway through 2019, MH and StL decided not to continue the project after the Transition Programme funding ended. News of the project’s demise served to galvanise the young adults into planning alternative ways they could continue to gather, and how such meetings could be funded. By the end of the project, the young adults had identified a working group to take forward formalising the group (named *Striding Forwards*) and, for fund-raising purposes, moving towards registering the group as a charity.

4 The evaluation

The objectives of the evaluation were:

- over the duration of the project, to investigate and describe the experiences and outcomes of young adults.
- over the duration of the project, to investigate and describe the experiences and observations of staff involved in delivering the project.
- based on these findings, to consider how they might inform the development of transition and young adult provision by the hospice sector.

4.1 The evaluation team

The evaluation was designed and carried out by the Martin House Research Centre. The team comprised: Prof Bryony Beresford and Drs Tom Ainscough, Andrew Papworth and Jo Taylor. The evaluation team was not involved in delivering the project.

4.2 Design of the evaluation

Qualitative and quantitative methods were used to collect evaluation data. Table 1 summarises the sources of data used to evaluate the project over its two annual cycles: 2018 (Year 1) & 2019 (Year 2).

Different approaches to collecting evaluation data between Years 1 and 2 was deliberate and informed by initial analysis of Year 1 data. In particular, in Year 2, we wanted to investigate and understand the dynamics of the sessions. Data from young adult interviews and staff highlighted issues of variable levels of engagement and passivity among the young adults which seemed important to explore and understand.

Table 1: Sources of data

Source of data	Year 1	Year 2
Young adults	Individual interviews: <ul style="list-style-type: none"> • Start of project (Session 2) • Midpoint (Session 6/7) • End of project (Session 10) 	
	‘Reasons for attending’ checklist <ul style="list-style-type: none"> • Start of project • End of project 	
	Satisfaction rating scale <ul style="list-style-type: none"> • Start of project • End of project 	
Observation of sessions		Non-participant observation of 6/10 sessions
Staff	Brief interviews with YAP project lead (start, mid-way and end of project)	Focus group with MH and StL staff involved in supporting YAP (held after 2 sessions)
	Individual reflections noted in Session Record	Individual reflections noted in Session Record
Session records	Attendance Content of session Staff involved & duration	Attendance Content of session Staff involved & duration

4.2.1 Individual interviews with young adults

All young adults received information about and were invited to take part in the evaluation. Participation was voluntary.

Brief individual interviews took place at an early stage in Year 1, and then midway and at the end of the year. A ‘Reasons for Attending’ checklist and ‘Feelings about attending the project’ rating scale (1-5) were completed within the interview and open-ended questions used to explore expectations and experiences. A topic guide ensured consistent and comprehensive coverage of topics across all interviews. Three members of the evaluation team undertook interviews (BB, TA, JT) with, where possible, young adults being interviewed by the same team member on each occasion.

Interviews took place during sessions. All those attending sessions when the evaluation team were conducting interviews agreed to be interviewed. Ten young adults took part in individual interviews, with 8 interviewed at the start and end of the first year of the project. Interviews typically lasted between 10 and 15 minutes. Interviews were audio-recorded, with detailed notes made of recordings.

4.2.2 Session records

A proforma, designed by the evaluation team, was completed by staff after each session and recorded:

- attendance: this included absences and, if known, reason for non-attendance. Attendance of staff other than project leads was also recorded.
- activities undertaken during the session
- use of one-to-one time with project leads or other MH or StL staff and, where appropriate reason for that consultation.
- the Project Team's reflections and observations of each activity, including reflections on what worked well and less well.

4.2.3 Staff interviews and focus group

Brief interviews with the project lead took place at the start, mid-way and end of Year 1. Field notes recorded these interviews. Five staff took part in a focus group early into Year 2, including one member of staff from the adult hospice. Some (n=3) had been involved from the project outset, including the pilot year. All had at least twelve months experience of being involved with the project. The focus group was conducted by BB and AP, and audio-recorded. A detailed summary of the discussion was prepared using the recording.

4.2.4 Observation work

Using the participant observer approach, a member (AP) of the evaluation team observed six sessions over the course of the project's second cycle (Year 2). Fieldnotes were made during and after each session. Prior to observation work starting, the young adults agreed for AP to attend and observe the sessions as part of the evaluation.

5 Findings

5.1 Delivery

The project was delivered as specified above across 2018 (Year 1) and 2019 (Year 2).

A total of sixteen young adults attended one or both cycles of the project. The great majority had also attended the 2017 pilot. Almost all attending in 2018 chose to continue attending in 2019. Two participants withdrew from the project and two joined part-way through a cycle. Attendance rates were high, with only around 20/~120 absences over each cycle of the project.

All required transport to attend the project. Some were dependent on Martin House staff to provide transport. The furthest distance travelled to attend was over 40 miles. Difficulties with transport or ill-health were the most frequent reasons for non-attendance.

5.2 Young adults' experiences of Year 1

5.2.1 Outcomes

Ten young adults completed our 'reasons for attending' checklist at the start of the 2018 cycle. We can regard these as the outcomes the young adults hoped to achieve from attending the project. At the start of the project, almost all young adults identified a number of psychosocial and personal development outcomes, but they varied considerably in terms of what they regarded as the most important outcome, see Table 2. We also used a smiley-face Likert scale (1=very negative to 5=very positive) to explore the young adults' feelings about attending the project. At the start of the project, ratings were positive or neutral (n=2: rating 3; n=7: rating 4; n=2: rating 5).

At the end of the year, we asked the young adults to identify from the checklist what they had gained/benefitted from the project. There was evidence that some outcomes had, to at least some degree, been fulfilled (e.g. something to do, new activities/experiences, meet up with other young adults). For others, the pattern was less consistent (e.g. to challenge myself, to have a chance to chat about things important to me, make new friends, to learn a new skill, and to spend time with MH staff). Three young adults reported achieving outcomes that had not been desired outcomes at the start of the project. The outcome most frequently identified as most valued was 'something to do/getting out of the house' (n=5/8). Few young adults selected 'to see what an adult hospice is like' as a reason for them attending the project. None identified this as an important or valued outcome. Feelings about attending the project (assessed using the Likert scale) were typically the same at the beginning and end of the project. In no instance was a more negative rating given.

Similar to data collected using the checklist, qualitative data collected during our interviews with the young adults revealed considerable individual differences in what the young adults had most enjoyed or valued from attending the project. All described specific activities (e.g. photography, crafts) or excursions (e.g. flight simulator) which they had particularly enjoyed over the year. Sometimes what had been created/produced, or the fact they had successfully taken part in a new and challenging activity, were described as personal achievements. However more frequently they were simply spoken about as fun and/or social things they had done. Some with an existing friendship group among those attending enjoyed the additional opportunity to meet up which the project afforded. There was little evidence of interest in new friendships nor, during the first year of the project, of these being formed. All liked and enjoyed spending time with project staff. For a few, this was more important than spending time with peers. None said they preferred the Project to their short breaks at MH.

Table 2: Young adult reported outcomes

	Outcome selected	Most important outcome (n=9)	Outcome partially met	Most valued outcome	Outcome not identified at start of project
Reason (<i>italics = additional reason identified by YA</i>)					
Something to do / get out of house	7	1	6/7	5	2
Time out from parents/family	5	0	2/3	0	3
To try new activities/ experiences /go new places	8	2	6/6	1	1
To see what an adult hospice is like	4	0	2/4	0	1
To meet up with other YA	8	1	6/6	0	1
To challenge myself	6	0	3/5	1	1
To have the chance to chat about things important to me	6	1	3/6	0	2
To make new friends/new people	7	0	3/5	0	1
To learn a new skill	6	1	2/5	0	1
To spend time with MH staff	7	0	3/7	0	1
<i>To develop an existing skill / interest</i>	1	1	No	1	1
<i>To get involved in a project/ with other young people</i>	2	1	No	0	0
<i>To make a positive contribution</i>	1	1	No	0	0
Number of outcomes selected					
Number of outcomes selected			Number of young adults		
10			2		
9			1		
8			3		
7			1		
5			1		
1			1		

5.2.2 The setting

Setting the project in an adult hospice did not emerge as being relevant to the young adults. Almost all were disinterested in finding out more about StL and none preferred the Day Centre setting to MH facilities. Indeed, they all referred to the fact the setting was not “the same” as MH. Reasons articulated included the unfamiliarity of the setting and StL being perceived as run in a more formal way compared to MH.

5.2.3 Challenges

We asked the young adults what they had found difficult or did not enjoy about attending the project. Four themes, raised consistently across all interview time-points, emerged:

- being unclear about purpose of session or project.
- identifying a shared endeavour.
- others in the group (differing viewpoints/priorities, “mucking about”).
- “It’s not the same as Martin House”.

The young adults described feeling uncertain about the purpose or plan for individual sessions and held diverse views about the overall purpose of the project beyond the rather non-specific idea of it being a new type of provision which MH and StL were trialling.

The young adults were challenged by the expectation on them to generate ideas for activities/experiences and the co-created nature of the project. Many acknowledged being passive when these were discussed, expecting (or hoping) staff to take the lead. They did not appear to realise that efforts to shift decision-making responsibilities onto them was an explicit aim of the project. Some found the process of reaching consensus, or being the minority view, difficult. Some of the young adults reported finding the behaviours of others in the group irritating – particularly poor engagement during group discussions/decision-making. Again, none reported being aware that extending/developing group working skills/experiences was an aspect of personal development the project was aiming to develop.

When asked for their views about how the project could be improved when it ran in 2019, there was general agreement that the timing and duration of sessions was about right. Sometimes, this viewpoint was settled on after weighing up meeting more frequently for a shorter period against the effort this would involve and uncertainty whether a shorter session would work better. A number said they would like more sessions to take place away from StL, though specific venues/activities were not typically mentioned. Also suggested were additional social get-togethers for those interested (e.g. evening in a pub, cinema trip). However, given the geographical spread of the group, the young adults questioned where best for these to be held. Issues of feasibility – particularly transport - were raised.

Overall, interviews with young adults at the end of the first year of the project indicated that it provided young adults with a positive way to spend their time. The project’s approach to offer new experiences and activities and time with peers appeared to be valued. Less consistent was the extent to which the young adults believed the project had contributed to their personal development. At the same time, all the young adults had found some aspects of the project challenging and frustrating. During our final round of interviews at the end of 2018, all expected they would attend the project in 2019.

5.3 Staff views and experiences

This section draws on reflections entered into the Session Records, a series of brief interviews with the project lead during Year 1, and the focus group held with project staff early into the project's second year.

5.3.1 Impacts on young adults

Staff were consistent in their view of the value of the project and the positive impacts it had. Areas of growth or change among the young adults identified by staff included:

- deepening or extending of relationships within the group,
- growth in confidence,
- taking initiative,
- exposure to others' views.

Crucially, they reported that progress in these areas had taken many months to achieve, and had only been *consistently* observed in Year 2. Given most young adults had also attended the 2017 pilot as well, this actually constitutes over two plus years of attendance. A small, but telling, example comes from this entry in the Session Record towards the end of Year 2:

“Supper – really relaxed, comfortable atmosphere. All will now eat rather than declining. Seem comfortable to be helped in this setting. No one rushing to go home at the end.”

This notion of an extended process during which new experiences, achievements and setbacks accumulate to support personal growth and serve create a cohesive group is reflected well in this entry in the project's final Session Record:

“This last session was an excellent tribute to the group of young individuals who have grown and developed so much throughout the life of the project. There has been no blueprint or map for their journey, but they have all travelled well...”

Staff believed the structured, group-based approach taken by the project (e.g. emphasis on group activities, group decision-making, whole group discussions) had supported these achievements. However, they had not anticipated the process of ‘forming’ the group would be as challenging as it proved to be.

“It takes time, longer than people think: learning to work with the group, rather than being worked with as individuals. It's a new model – it takes much time to adjust.”

Staff recalled instances, events and activities which they regarded as ‘visible markers’ of the project's achievements. Examples include the young adults playing a key role in two training/awareness-raising sessions for StL staff, creative projects, a consultation event with staff from NHS England, and being involved in short pieces for regional news shows. Opportunities which ‘stretched’ the young adults, requiring them to overcome fears or a lack of confidence in their abilities, were highlighted as a critical element to the project. The

following Session Record entries (completed during Year 2) illustrate this. The first concerns a training session the young adults held for StL staff and, second, a visit to the project by NHS England.

“[Group] very anxious beforehand. Very pleased indeed with themselves afterwards.”

“All really enjoyed talking to NHS England. All opted to do it, although all didn’t know what to say. Proud of themselves for doing it afterwards.”

Over and above specific activities, staff identified two significant step changes in the development and progress of the group, *and* in their learning of how to work with the young adults. First, part way through Year 1 (2018), and in contrast to the more usual passive dynamic, a few of the group put forward the idea of creating a series of spoofs on well-known films. This quickly garnered the interest and involvement of others and became one of the main activities of the sessions for the remainder of the year. Staff believed one of the reasons it gathered momentum and ownership by the whole group was because there were a number of ways the young adults could get involved and contribute. They were proud of the young adult’s achievements which culminated in a public showing of the films at an evening reception held at the University of York.

Second, and taking place in Year 2, was the group’s response to the news that the project would not be extended beyond 2019. Rather than being accepted passively, staff described being pleasantly surprised by the group’s decision to find a way to continue meeting. This extract recorded in the Session Record following news of the closure of the project gives a sense of this new dynamic in the group.

“Very positive about setting up a new group, Striding Forwards! Accepting of MH and STL’s not continuing. Confidence grown. [They said..]... ‘Give it a try’, ‘I’ve never done this before, I don’t know what I’ll do, but I guess like everyone, I’ll learn.’!”

Staff described securing the continuation of meeting together as becoming the group’s shared cause, and working towards this became a key activity in remaining sessions. A few young adults were reported as stepping up to assume positions of responsibility and staff deliberately took on support or advisory roles as the young adults grappled with issues of fundraising, identifying potential venues and setting up as a charity. Whilst staff were excited about what they were observing in the group, they carried concerns about the fragility (or, perhaps, naïvety) of the young adults’ determination and confidence, particularly when support from the project team ceased.

“Still need encouragement and support to achieve their aims, but much less so than when we started.”

“Resilience not high.”

Additional, more specific, benefits of the project identified by staff was it had provided a useful forum in which difficult/sensitive topics could be discussed, something which did not

typically happen during their stays at MH. This was something which over half of the young adults identified as a reason for taking part in the project. However, not all reported this outcome had been achieved.

Finally, staff believed the opportunity for one-to-one consultations between young adults and MH staff during project sessions had been beneficial. For example, consultations with the team's doctor had pre-empted a symptom/condition management escalating or allowed more regular checks on the young adults' health. We note, however, that none of the young adults we interviewed had spontaneously mentioned valuing this aspect of the project.

5.3.2 Delivering the project

Staff found working on the project rewarding, particularly once benefits and progress were observed. However, it had also proved, perhaps unexpectedly, very challenging. This was partly attributed to a lack of clarity, or shared understanding of project objectives. This issue had emerged during the 2017 pilot and persisted into the period the project was funded by TfSL.

Related to this, MH staff reported they had not anticipated, nor been prepared for, their role being very different to when the young adults came to stay at MH. One member of team made this reflection in a Sessions Record:

“...it is demanding ...sometimes leading and sometimes stepping back to enable growth and development.”

Staff also recognised that they had not fully appreciated that young adults might be confused or unsettled by the fact that staff they knew well treated them differently at project sessions and placed unfamiliar demands on them. Nor had they fully understood the impacts of a new setting on young adults' abilities or capacities to respond to these demands.

Thus, MH staff described feeling de-skilled and lacking in confidence, and found the lack of engagement and passivity of the young adults puzzling and demoralising. This appeared to affect the extent to which they were able to support each other as a team. In hindsight, all believed preparation and (on-going) training/supervision in this different role (as facilitator as opposed to carer) would have been valuable. A whole team approach to project/session planning (including articulating how different elements of the programme contributed to achieving project objectives) and de-briefs after each session were identified as strategies which may have supported (sooner) achievement of the project's objectives and been supportive for staff. However, they noted the difficulty of achieving these things because different shift/rota patterns made meeting together difficult, and some of the team were, voluntarily, transporting the young adults to and from sessions.

Team members contrasted the experiences of MH staff with that of the external team member in terms of how the young adults responded to them. They observed clear benefits

to the project team including an individual with no existing relationship with the young adults.

It is also clear from the Session Records that, in being involved in the project, staff had come to more fully understand the everyday lives of the young adults, and the barriers they face. As members of the team reflected in Session Records:

“Clear how socially isolated most of them are.”

“Again aware of multiple barriers they face. Huge effort, planning and reliance on others for so much.”

5.3.3 Co-delivering the project with St Leonards

In terms of StL staff involvement, this was similar to that observed during the 2017 pilot with only a couple of staff attending on a relatively consistent basis. Staff believed the lack of clarity around the project (reported above) made it difficult for staff unfamiliar to the young adults to find a meaningful role during sessions. This, coupled with the young adults’ very different age profile and complexity of healthcare needs, made StL staff feel deskilled and uncomfortable. An alternative approach to support understanding and awareness among the adult hospice staff was, however, devised: two training/awareness raising sessions with the young adults. This was well-received by StL staff. The decision to offer complementary therapy appointments – something not provided at MH – was believed to have worked well and served as a positive exemplar to the young adults of services provided by adult hospices.

5.4 Our observations of Year 2

During Year 2, we used participant observation to further understand and evaluate the project. A member of the evaluation (AP) attended the majority of sessions. Some of the events and situations covered in the section have already been reported, from the perspective of the staff team, in the previous section.

During the early sessions of the second year, a similar dynamic to that reported in Year 1, particularly the first half of that year, was observed. There was a clear tension between staff wanting the project to ‘succeed’ and wanting it to be led by the young adults, but coming up against an apparent lack of ideas and engagement in planning and decision-making. Thus, typically, after trying to facilitate the young adults involvement in planning group activities etc., these discussions were led, in the main, by the project staff *and* the young adults’ carers, with only the more self-confident young adults joining in, if at all. A formality of interaction between staff and young adults, and dominance of staff and carers, was observed, particularly during the whole group discussions. Around this time, some of the young adults voiced concerns that work towards the end-of-year production/event would, again, be rushed. However, this concern did not appear to be sufficient to stimulate more pro-active

involvement. What is not clear to us was whether this was due to a lack of engagement, energy, confidence or ideas.

At this stage, it was clear staff were very aware that the momentum established towards the end of Year 1, when work on a set of short spoof films had energised and brought the group together, had been lost. Spasmodic attendance due to ill-health or problems with transport appeared to act as barriers to re-establishing this momentum and 'sense of group'. The fact that only a minority of the young adults were actively participating added to the fragility of any resumption of group identity and purpose. Quite frequently, a young adult who had been driving a particular activity forwards during one session was unable to attend the next session. During these sessions we also observed little mixing between the young adults outside of structured activities; they tended to socialise in already-established friendship groups.

Later in Year 2, however, the young adults became more cohesive and vocal. The key turning point was when the staff revealed that the YAP was unlikely to continue for another year. The young adults expressed disappointment and concern about this news – indicating, in itself, the value they placed on the project. However, they quickly decided they wanted the project/group to continue in some form and began to assume the initiative in deciding how they wanted the project to continue and how they would achieve this. Project staff supported this, particularly the member of the team with previous experience of fund-raising and forming a charity. From this point onwards the sessions were structured differently and planning for the future became one of the core reasons to gather. Small groups were used to discuss particular issues regarding future plans which were then fed back to the larger group. Working in this way appeared to have a significant impact on the dynamic and atmosphere of sessions, and the amount of progress made. While these smaller groups were facilitated by staff, the young adults appeared more comfortable in this context, contributed more and challenged others' ideas more readily. However, there remained a reticence among the young adults when it came to sharing and discussing ideas with the wider group.

During this period there was increasing evidence of the young adults having a more obvious 'voice' during sessions and were also mixing together more readily across friendship groups during the second half of the year. A clear example of this was a more collective, and young-adult led approach, to planning the end-of-year event. In contrast to the first year of the project (and the earlier pilot), this was not a public/exhibition-type event but a party at an events venue.

Another area of progress, or group development, observed during the project's second year was a number of between-session meet-ups (e.g. comedy club, boat trip, bowling). These were not necessarily attended by the whole group. Feedback at subsequent sessions suggests all had proved very successful. It was clear that project staff were heavily involved in making arrangements, and that this was a complex process (e.g. access issues, late night transport arrangements etc.), made more complicated by the fact that arrangements were

being made for a group, rather than one individual and their carer. We observed a number of occasions when ideas were explored but then shelved because transport was too difficult, or the venues/activities were not accessible for individuals using motorised wheelchairs. Staff appeared to find this both a frustrating and illuminating process. The young adults, however, were typically phlegmatic, appearing more resigned to these setbacks. It is possible this had been young adults' experiences many times before, and this might explain the apparent apathy towards getting involved in planning trips and excursions.

Finally, and on a different note, we saw no evidence that spending further time at StL had served to generate interest in the hospice. Many young adults continued to be sceptical about its ability to provide care to themselves, and young adults generally, and continued to compare the hospice unfavourably with MH.

6 Reflections and implications

We used a range of methods and data sources to evaluate this project. Findings suggest that, to some extent, the project objectives for the young adults had been achieved. However, progress towards their achievement proved slow and challenging. Here it is important to remember that many of the young adults had taken part in the 2017 pilot and thus had been involved in the project for three years by the time it came to an end. We cannot comment on the extent to which project-specific outcomes generalised across the young adult's lives. Nor do we know whether or not outcomes have been maintained since the project finished.

A key challenge and barrier to the project achieving its potential was the fact that aims of the project were very different to the short-breaks the young adults enjoyed at MH, but the same staff were involved. At MH, the nature and dynamic of the relationship is one of caring, with staff seeking to 'cosset' the young adults during their short-breaks. This was in marked contrast to the hopes and expectations staff had for the young adults when they attended the project. Both staff and young adults found it difficult to adjust to, and assume new roles. Staff struggled to remain passive and non-directive. At the same time, the young adults did not (readily) become active actors in the running and direction of the project. This appeared to reinforce staff's expectations for the young adults and their judgements regarding their potential and capabilities (again, these will have been informed of their prior knowledge of them in a short-breaks context). In contrast, the member of the project team who was not a member of the MH (or St L) staff interacted with the YA quite differently. Whilst partly attributable to skills in youth work, the absence of existing (and different) relationships with the young adults allowed him, from the outset, to work in a very different way with the young adults.

A second barrier was an apparent lack of a shared understanding of the underlying purpose of the project, particularly in terms of young adults' outcomes. Thus, young adults and staff readily identified project outputs (e.g. group trips, end of year exhibitions, media coverage), but did not typically perceive them as being the means by which young adults' psychosocial

and personal development outcomes would change or develop. As a result, the focus of attention was primarily on the achievement of outputs even if that compromised the purpose and intended outcomes of the project. A clear example of this was the way staff took over the planning of events or activities to ensure they happened. This was observed across the course of the project.

Interestingly, it was the announcement of the project's closure (midway through Year 2) that generated a step change in the young adults' investment in, and ownership of, the project. It also presented the greatest learning and self-development opportunities. Project staff were surprised but very pleased by this response. We would argue that the work of the project to that date had served to position the young adults to be able to respond positively to this development. Importantly, towards the end of Year 1 (2018), working together on the end-of-year film project had demonstrated to the group that they could take greater initiative and work collectively and creatively. However, during the early months of the project's second year (2019), it seemed this had not generalised across the project more widely and, until the news of the project's closure broke, staff continued to take the lead and the group struggled to identify shared endeavours and a sense of being 'a group'. What was observed in the second half of Year 2 is strong evidence of the young adults' problem-solving and leadership capabilities, particularly those of the sub-group which undertook working towards establishing them group as an independent entity.

The MH staff identified a number of key learning points from the project. They have been alerted to the very different nature of projects such as this compared to providing short breaks. Such projects challenge (and contradict) their existing ways of working and 'being with' the young adults. This has significant implications in terms of staff knowledge and skills and the challenges. Furthermore, staff who are good (often instinctively so) in a care role, may not be good at or comfortable with this very different role. Working on the project also exposed them to aspects of young adults' lives, and the impacts of restricted life experiences on personal development, which they had not previously encountered or fully appreciated.

Few StLs' staff became involved in the project. Coupled with the fact they were unfamiliar with this particular patient group, the relatively undefined nature of the project and role of staff were barriers to StL staff engagement. Again, perhaps, expectations around involvement were naïve and needed more planning and preparation. However, sustained interest and involvement from senior/strategic leads was evident.

The time taken for young adults, and the group, to begin to flourish and fulfil the aims of the projects was a key theme emerging from our evaluation. To some extent this was inevitable given the project was exploring and testing new ways of working with young adults. However, and already noted above, a clearer and shared articulation of the project aims, and how elements of the project contributed to those aims is likely to have proved helpful and assisted the team to plan sessions, review progress and identify sticking points or ineffectual ways of working. Similarly, and also noted above, a greater attention to staff training and

supervision, and collective debriefing and planning of sessions, would likely to have benefitted the project. However, it was also clear that the young adults' skills, confidence, and (often restricted) life experiences impacted the way they engaged with and responded to the project. A discrete time-limited project cannot, on its own, redress these issues and experiences. In addition, it was clear that the young adults' health (including energy levels) could affect participation. Thus, whilst implementing learning from this project in the conception, design and delivery of future projects may well improve young adult and staff's experiences, yield earlier progress, and improve outcomes there will be limits to this.

6.1 Recommendations

We make the following recommendations regarding the development of transition/young adult provision by hospices.

- Children's hospices should consider integrating approaches that support self-determination and active agency of children/young people into routine practice/ways of working within their short-term breaks provision.
- Hospices should be aware that shifting or broadening their provision to address outcomes relevant to transition, *but which are unfamiliar to the hospice* is a complex undertaking.
- Hospices should be mindful that, compared to their peers, young adults with LLC may have more limited life experience and restricted opportunities for self-determination. This should be accounted for in the design, objectives and duration of projects/service development activities.
- The aims and objectives of projects/service developments, and change mechanisms, should be clearly articulated using a theory of change and shared among all involved. Aims and objectives should closely inform the project/service design. This necessarily requires the meaningful involvement of young people/adults.
- From the point of project conception, hospices should seek to involve individuals with relevant expertise, either by bringing in external consultants, and/or strategically extend the skillset/experience of staff.
- Training and supervision of staff, and carers supporting young adults where this is relevant should be incorporated into the project specification, including sufficient resourcing.

We also make a recommendation for grant-making organisations and service commissioners:

- If not already doing so, grant-making organisations looking to support transition projects, and service commissioners, should require, or at least recommend, project/service leads to use a theory of change framework to conceive, develop and present their project/service. Key stakeholders should be involved in the development of a theory of change.

6.2 The impact of the project on regional developments

As reported in Section 3.2.5, midway through the second year of the project, the decision was taken by MH and StL not to continue the project *in its current form* once funding from the Transition Programme ended. Towards the end of the second year of the project, findings from the evaluation were shared with senior staff from MH and StL. There was a strong commitment to develop day service provision for young adults in the region, and for this to be closely informed by findings from this evaluation. These senior staff have shared evaluation findings with children and adult hospices across the region.