



**St Oswald's
Hospice**

Engaging GPs: Improving Outcomes

Learning and Recommendations
for other services

Quality time for everyone

Engaging GPs: improving outcomes

Learning and Recommendations for other services

CONTENTS

Introduction.....	2
Key contextual aspects:.....	2
Within the organisation.....	2
Within the region.....	3
Clinical learning.....	4
1. Role in assessing and identifying unmet needs and signposting to clinical teams who could help.....	4
Recommendations.....	5
2. Identifying Dying in long term neurodisability.....	5
Recommendations.....	6
3. Safe management of complex symptoms when multiple clinicians are involved.....	6
Recommendations.....	7
4. Advance care planning and making decisions.....	7
Recommendations.....	8
Carer support.....	8
1. Role when the main need is care package.....	8
Recommendations.....	8
2. Supporting Carer needs.....	9
Recommendations.....	9
3. Responding to family crisis.....	9
Recommendations.....	9
Relationships with other clinicians.....	10
1. Getting referrals to the service.....	10
Recommendations.....	11
2. Empowering and facilitating role for clinicians to extend their experience and confidence.....	11
Recommendations.....	11
3. Recognising existing structures and teams and taking time to hear their ideas and concerns.....	12
Recommendations.....	12

4. Multidisciplinary team working	12
Recommendations.....	13
5. Relationship with GPs.....	13
Recommendations.....	14
Wider impact.....	14
Recommendations.....	15
Organisational learning.....	15
Next steps.....	16
Conclusion.....	17

Introduction

This paper is written to support the evaluation of the Together for Short Lives Improving Transitions Fund project Engaging GPs: Improving Outcomes. The project team recognise that one of the most valuable outcomes of the project has been the learning that we gained through the process of developing, launching and running the project.

We have tried to think widely about the way the learning from this project could be applied to similar projects as they start out in different settings. Pulling together reflections and learning from individual clinical episodes, as well as the development of the service, the Transition team have identified key themes which are relevant to many other contexts.

KEY CONTEXTUAL ASPECTS:

To apply the project learning to another situation, it is important to understand some key contextual aspects about this particular project.

WITHIN THE ORGANISATION

The model we developed was for a team based in an adult hospice working 1-2 sessions (half days) alongside their existing hospice roles. The team included a palliative care consultant, a social worker with extensive experience supporting young people with disabilities, and an adult hospice nurse. The team generally saw patients in the outpatient department of the Hospice. Although the team identified unmet needs in all domains (health, social care, education, employment and housing etc.), their main emphasis was on health.

1. **The service was entirely new.** We did not have an existing caseload of patients or reputation for the new service we were offering. The team had knowledge of some local professional partners in health and social care, but needed to build on these contacts in the context of the new service,

and to find and form relationships with professional allies from many other services and specialties.

2. **The team had experience** in supporting young adults with complex needs from a clinical and social point of view. This enabled us to confidently explore needs, address challenging issues and to know when to refer or signpost elsewhere. It also placed us in a good position to promote the service through teaching sessions and clinical meetings, thus improving care for those young adults who were not referred to the service as well as the young adults we were seeing in person.
3. **The Hospice has a long history of supporting children and young adults with complex needs** through short breaks or crisis care. The history of supporting this patient group meant that the trustees and senior managers in the Hospice already had an understanding of their needs, and were committed to developing additional ways of supporting them. The Transition Service was intentionally separate from the existing short break service, and young people already attending the short break unit tended to continue to draw support from their short break team rather than attending the Transition Clinic.
4. **Open to service development.** The project was introduced at a time when other departments within the Hospice were developing their role in supporting young adults. We acknowledge the many years that others in the organisation had spent working with different teams to promote the needs of young adults with life-limiting illnesses.

WITHIN THE REGION

1. **Profile of Transition.** The project began shortly after the completion of the NIHR funded Transition Research Programme which was led by Newcastle University and Northumbria Healthcare NHS Trust. We were able to ask the chief investigator of the programme, Prof. Allan Colver, to support our launch event. The research programme itself, and the outcomes of the work raised the profile of issues around transition within the region. This and other national initiatives within different specialties triggered a wider recognition of gaps in service and the project team were asked to contribute to various regional specialty meetings to discuss Transition.
2. **Lack of children's palliative care.** Children's palliative care is not comprehensively established in the Northern region, with 4 small independent hospices providing a varied level of support and short breaks. Although the Paediatric Palliative Care Network has been active in developing a bid for a commissioned regional specialist palliative service, at the time of this project this had not come into fruition. As such, the majority of young people with life-limiting illnesses are supported by their local paediatric teams, GPs and community nurses and both they and their clinical teams may not have considered them to have "palliative needs."

3. **Well-developed adult palliative care coverage.** The Northern region covers a large and socio-economically diverse area. Adult palliative care services are well established with good coverage of community, hospital and hospice settings, and comprehensive education and training programmes for clinicians. Although there have been no dedicated Transition services within the region, many of the palliative care consultants have experience in supporting young adults with cancer, learning disability and other complex conditions and understand the relevance of good palliative care for this population.
4. **CCG already engaged in improving transition.** The project ran in partnership with NHS Newcastle Gateshead Clinical Commissioning Group (CCG), and with particular support from the CCG Clinical lead for Child Health. Working with local primary care services, the CCG had already identified a GP Child Health Lead in every GP practice to help develop a more child and young person friendly service, and had begun working with GPs and Paediatricians on an innovative transition pathway to build trust between the General Practitioner and patient from a young age. It was essential that the Transition project fitted well with these existing developments.

Clinical learning

Using case notes and personal reflections from the Transition team members, we developed the following themes indicating the areas where the team had an impact on the patient's care, or where the team developed or changed their clinical practice as a result of a patient episode. We have used these themes and reflections to create a list of recommendations.

1. ROLE IN ASSESSING AND IDENTIFYING UNMET NEEDS AND SIGNPOSTING TO CLINICAL TEAMS WHO COULD HELP

Although clinicians generally referred patients with a particular need in mind, a holistic approach to assessment identified additional needs and in particular highlighted the patient's own priorities. Once needs were assessed, the Transition Team were well placed to identify the best person to address those needs, as they had developed a broad knowledge of the services available across different Trusts/specialties or charitable organisations. By taking time to speak to specialist teams, the Transition Team built links, learned about optimal management of different symptoms and better understood the referral processes and service offers from other teams.

"It was tempting to simply organise a prescription of melatonin in response to poor sleep, however an assessment from the dystonia and sleep service identified additional unmet needs that would have continued to affect sleep if melatonin had been started before they had been addressed." ***All quotations from Project team reflective notes unless otherwise stated**

RECOMMENDATIONS

- Assessing holistic needs and identifying patient priorities needs to be a priority in any Transition service.
- Transition teams should ensure they know relevant local services well and invest time and effort in developing good working relationships with opportunities for mutual learning.
- When referring to other services or teams consider times when the referral needs to be followed up quickly to ensure the patient gets to benefit before their condition changes.

2. IDENTIFYING DYING IN LONG TERM NEURODISABILITY

During the period of the project, through clinical experience and through developing teaching material and receiving feedback from professionals, it has become increasingly clear that there is a lack of knowledge or evidence to support clinicians in identifying when an adult with long term neurodisability is reaching the end of their life. This has significant implications:

Access to palliative and end of life services. Adult Palliative Care services often focus on patients who have a prognosis of under a year, or who have significant symptom burden. Many people with neurodisability die without having been identified as having a short prognosis, and changes in their complex symptoms may be considered to be a longstanding consequence of a chronic condition. In these situations no referral to palliative services is made. Patients and their families lose the opportunities for the local physical, practical and psychosocial support that is offered to people with other conditions in the last months or weeks of their life.

Challenging decision-making. Making a decision requires information. Clinical decisions around treatments or interventions need as much knowledge as possible about the likely outcomes if the person does/does not have the treatment. For patients with neurodisability, the lack of evidence, experience and training means that clinicians struggle to know these outcomes, and may either treat over-aggressively, or deny patients interventions that would have helped them. While advance care planning can help to support decisions, there is also a huge need to understand and identify which patients are the most likely to do well with an intensive intervention in spite of the burden of the treatment, and which ones are unlikely to benefit, and may even be harmed by over-aggressive treatment.

Preparation for dying and pre-bereavement support. When a patient has been identified to be reaching the end of their life, they have the opportunity to prepare themselves and their family. This may be around fulfilling last wishes, making practical arrangements, stating preferences about their end of life care, or having time to say goodbye and speak to loved ones. This can be supportive

both for the patient and for their families and loved ones. When dying has not been identified, this opportunity is lost.

Carer/Staff support. For young adults in residential or college settings, an unanticipated death can have a huge impact on carers and professional staff. Supporting carers to identify that one of their clients is reaching the end of life can reduce this impact and enable them to take part in the person's end of life care, enabling the person to remain in the setting that is home to them rather than being rushed to hospital.

RECOMMENDATIONS

- Transition Teams should be prepared to communicate about the possibility of dying with patients, families and other clinicians. They need skills to do this in a way that holds the uncertainty of the situation, but talks positively about the benefits of being prepared in advance. They may also have a role in educating and supporting other clinicians in this area
- Adult palliative care services supporting people with neurodisability must develop referral/admission criteria based on needs and anticipated needs rather than prognosis.
- Research is needed
 - to critique existing Prognostic indicators/scores in circulation that are not appropriate for people with neurodisability
 - to develop evidence around useful prompts to support clinicians and carers to identify deterioration and dying in their patients with neurodisability
 - around the impact and mortality of specific symptoms in severe neurodisability e.g. Pressure sores; feeding issues.

3. SAFE MANAGEMENT OF COMPLEX SYMPTOMS WHEN MULTIPLE CLINICIANS ARE INVOLVED.

Many of the patients referred to the team had complex, longstanding symptoms with a long history of many different drugs and interventions and a large number of other clinicians involved at different points in time. Balance is needed between being responsive to the patient's needs and practising safely. Risks to safety include poor continuity of care, multiple professionals addressing different aspects of a symptom, and practising in situations where the evidence is limited.

"In one situation, the patient had specialists from two different hospital trusts as well as the primary care team, the community adult palliative care team and the social workers and college. Although his mum was incredibly organised and efficient and had years of experience in navigating the systems, there was a risk that she would become the only holder of all the threads of information about the patient, and would be responsible for interpreting clinical reasoning and communicating complex medical opinions between clinicians..."

...The specialists supporting the patient felt it was important to be able to share and work together, particularly when discussing management of complex symptoms to ensure that we maintained the fine balance with his other treatments. We also found it helpful to share our thoughts about his prognosis, and vulnerability, and ensure that conversations about anticipatory care planning were introduced in a sensitive and supportive way.” **Project team reflective notes**

RECOMMENDATIONS

- Good communication between clinicians is vital. As a minimum teams should include everyone involved in letters, but if appropriate follow up with phone conversations or virtual meetings.
- Be prepared to act as the patient’s advocate if the patient or their carers feel that other teams have not understood their concerns.
- Transition Teams must champion other services and ensure that their own service doesn’t inadvertently undermine the work of other teams. Encourage patient to attend existing appointments, give new treatments a chance to work, support recommendations from other clinicians etc. This also ensures that other teams do not become deskilled in working with young adults, and that they remain aware of the needs of this patient group.
- If recommending a treatment that is unusual, or for which there are few guidelines, ensure patient and clinicians understand the rationale for the treatment, and have a clear plan for any problems that might arise.

4. ADVANCE CARE PLANNING AND MAKING DECISIONS

The project team originally planned to complete Emergency Health Care Plans (local format for advance care plan) with every patient. We found that in many cases more flexibility was needed:

“One patient had clearly begun to think about her future wishes and although we didn’t complete a form at the time, having a discussion about this in clinic with her Mum present meant that when she had difficult decisions to make with the GP at home, she had already considered her wishes and the circumstances in which she would, or would not, want hospital treatment. As her Mum had been part of the conversations she was able to act as an advocate for her and they were well supported by the GP.”

Project team reflective notes

RECOMMENDATIONS

- The conversation about advance care planning is as important as the form itself and may need to take place over time with opportunity for consulting with different people. This ensures professional, patient and family understanding and engagement with the decision-making process.
- The clinician who knows the patient best is often the most appropriate person to complete an Advance Care Plan. Transition Teams may play a role supporting other teams or clinicians to take this on, rather than doing it themselves.
- Hospital passports or equivalent patient-held documents are important to ensure optimal care when the patient is unwell – even if advance decisions have not been made, ensuring the patient has an up to date record of their baseline health, preferred communication method and any adjustments that are needed can be valuable to support hospital admissions. Transition teams should work closely with Learning Disability Liaison teams to ensure they are encouraging patients to use the documents that are supported locally.
- Transition Teams cannot assume that the patient and their family understand the implications of the Mental Capacity Act for decision-making in young adults. Be prepared to explain decisions and choices and provide further information if needed.

Carer support

1. ROLE WHEN THE MAIN NEED IS CARE PACKAGE

For a number of patients, their main unmet need was around care provision. Despite having a social worker on the Transition team, it was difficult to fully advocate for the patient when we did not have a complete overview of their needs. These situations highlighted for us the severe lack of age-appropriate care and respite for medically complex young adults in the region.

“We had to be very clear with the patient’s mum about our roles and where we could and couldn’t help. We were able to support her in working with their case manager, but would not be able to bypass the systems that they were following to sort out care. Ultimately, I don’t think this was what she had hoped for from our service at that time.” **Project team notes**

RECOMMENDATIONS

- Transition teams need to be clear in advance about how they will support people with concerns around their care provision. This needs to be communicated clearly to patients/families, so that expectations are realistic.

- Where possible, get to know local case managers and care providers to better act as advocates for the patients, but also to better understand the reasoning and constraints leading to particular decisions.
- Where they identify service gaps within their region, Transition Teams may have a role in campaigning to improve the availability of appropriate services or working with partners to enhance the services they offer to make them more fit for purpose.

2. SUPPORTING CARER NEEDS

The team identified their role in listening to the experience and concerns of carers and in some cases gave advice about further sources of information or practical or emotional support. We also recognised that even families that appeared to be coping well, may have had underlying struggles that they may not readily discuss with professionals.

RECOMMENDATIONS

- The assessment of the carer's wellbeing should be seen as an important part of the holistic assessment.
- Giving the carer a chance to share their concerns and experiences can be very supportive for them and builds trust and understanding.
- Transition teams should ensure they have information about resources and services that are relevant to carers.

3. RESPONDING TO FAMILY CRISIS

The team experienced an unexpected situation following a crisis in a patient's family. While this could not have been anticipated, the team response demonstrated ways that they were in a good position to increase support when needed.

"Building good contacts with other specialists involved in caring for patients meant that in a crisis, they contacted our team for support and we were able to respond quickly with urgent respite and bereavement support." **Project Team notes**

RECOMMENDATIONS

- Make sure patients/families and professionals have contact details to quickly reach the Transition team in a crisis. As well as clear communication about ways of making contact, the relationships the team builds with the family and professionals around them ensures that people feel welcomed to get in touch when a crisis happens

- Identify referral processes for local bereavement support, and ensure there is provision to support people with learning/communication disabilities and for children.
- Include team support and debrief as part of your response to a crisis, and consider inviting external partners and other more isolated professionals to participate in this.

Relationships with other clinicians

As well as learning clinically, the project taught the Transition Team a lot about the challenges of establishing a new service within a region and gaining trust and engagement from other professionals

1. GETTING REFERRALS TO THE SERVICE

Many patients with life-limiting conditions may remain relatively stable for months or years; but are very vulnerable and at risk of sudden deteriorations and changing needs. The Transition Team hypothesised that having an expert clinical team that knows the patient when they are relatively stable would ensure appropriate support at the times that their needs change and would enable good advance care planning to take place. The team also recognised that their holistic approach often uncovered and addressed needs that had not been previously identified by the referring clinicians.

In practice, however very few patients were referred to the team unless they had a specific unmet need at the time. The barriers to referral of patients who appear to be stable may be at various levels. Clinicians may not understand the remit of the clinic, or simply may not see more stable patients enough to have an opportunity to suggest the clinic; the patients and their families may not see the need for an additional team to be involved when things are relatively settled; or may prefer not to spend more time focussing on their health.

We discovered some common themes among the referrers:

- Adult specialists who were aware of patient clinical needs that extended beyond their specialist area.
- Paediatricians who identified concerns about ongoing care beyond transition.
- Clinicians (GP or specialist) responding to an increase in need in a previously stable situation.

An important additional theme was that almost all the referrers had attended the project launch or another educational meeting with the team. In the few cases where this was not the case, they had initially asked support from another member of the hospice team who had recommended the Transition service.

RECOMMENDATIONS

- Invest time in promoting the service with potential referrers. Our experience suggested that leaflets/emails alone did not generate referrals. Personal contact through meetings and educational events and identifying local “transition champions” within different services and specialties led to more referrals.
- The Transition Team need to agree a clear understanding of referral aspirations and endeavour to make this clear to potential referrers and patients.
- Embed flexibility and responsiveness into the service model at the beginning. This may require additional resources and administration to enable patients to be seen at different locations or times.
- Agree a process for responding to patients who do not attend the clinic, particularly when first referred. Recognise factors including practical challenges to reaching clinic, poor understanding of the reason for referral, and personal choice. If patient chooses not to attend ensure that they and the referrer know how to re-refer in the future.

2. EMPOWERING AND FACILITATING ROLE FOR CLINICIANS TO EXTEND THEIR EXPERIENCE AND CONFIDENCE

The Transition Team found that reviewing a patient alongside a clinician from a different team helped clarify the role of the team as well as supporting the learning of that clinician through role-modelling. This is also an opportunity for the Transition Team members to learn from their colleagues. In addition through attending team meetings and educational events, the team raised the profile of the needs of young adults with life-limiting conditions and uncovered areas that other teams found challenging. The team’s contribution to these meetings emphasised our expectation that good care should involve a holistic approach, opportunities for advance care planning, carer support and inter-team collaboration.

RECOMMENDATIONS

- Seek opportunities to contribute to meetings with other specialty teams. As a team, identify key messages that should be communicated in all meetings or education sessions.
- Where needed, approach new referrals creatively and consider planning to see patients jointly with another clinician or in a different setting if appropriate. If time allows debriefing with the clinician afterwards can make the most of what you have both observed or learned.
- Teams need to agree clear parameters for joint working (e.g. frequency of reviews and expectations of referrer). This avoids confusion and ensures the patient’s and clinician’s needs are being met, and that the Transition team do not inadvertently commit themselves beyond their resources.

3. RECOGNISING EXISTING STRUCTURES AND TEAMS AND TAKING TIME TO HEAR THEIR IDEAS AND CONCERNS.

From the outset, the team was keen to collaborate with colleagues from across the region, and spent time consulting and discussing the service model, and then promoting the project. Unfortunately, we discovered some professionals had concerns about aspects of the service model once we began working. We learned a lot from this experience.

RECOMMENDATIONS

- Transition Teams should make as much effort as possible to involve local teams at the development stage of the project and to collaborate and consult widely throughout the project. While this may not avoid people coming to you with concerns later on in the project, it does mean you are more likely to have a robust project plan, and to have “champions” within different teams who are prepared to support you in overcoming any barriers that arise.
- As a team, agree to welcome any feedback from colleagues, and to learn from it and maintain good relationships. However this should not come at the expense of a flexible, patient-centred approach to your care.
- Where issues do arise, if possible, work within existing systems to find sustainable ways to overcome the barrier. This could include working with senior managers to establish service level agreements or honorary contracts. Working in this way raises awareness of the project at a senior level across organisations, and could open up other opportunities for the project to expand its scope.
- A time-limited project may cause concern among local stakeholders. Where possible, describe a clear plan for the sustainability of the service, including flexibility to respond to feedback and evaluation findings. Identify contingency plans to continue support for patients and professionals if funding is not available beyond the time-span of the original project.

4. MULTIDISCIPLINARY TEAM WORKING

The process of consultation and promotion of the project enabled the team to meet other professionals who were also keen to improve care for young adults. This led to the development of a cross-service Neurodisability multispecialty team with representation from respiratory, palliative care, intensive care, community paediatrics, general practice, learning disability, gastroenterology, neurology, neuro-rehabilitation and cardiology. The team included nurses, doctors and allied health professionals. As a team we discussed the patients we already shared, highlighted any concerns we had, and identified the professional who was best placed to meet specific needs. The team also offered a forum for learning and supporting each other, as most of the members described experiencing professional isolation within their speciality when working with this patient group.

In addition to clinical work, the group also planned and delivered an online study afternoon which had over 80 delegates attending. There are plans to use the group as a platform for further research, education and policy development. Members of the Neurodisability group are also involved in raising the profile of young people with neurodisability within their own specialties, and represent this patient group at a national level in several organisations. Being part of the Neurodisability group has meant that the individuals can draw on a broad multidisciplinary perspective when representing the patient group and has led to opportunities for palliative care to be included in developing Transition guidance at a national level (e.g. British Thoracic Society, Mitochondrial disease research priority setting, Intensive Care Society).

RECOMMENDATIONS

- Find out who also cares for your patients, and make time to meet with them to talk more widely about the needs of this patient group, working collaboratively when managing complex symptoms or medication changes to avoid complications and balance treatment priorities.
- Be willing to step back when your role is not a priority. Being connected through the other specialist teams gives a way to ensure you can step back in when the patient's needs change
- If you create a formal cross-agency Multidisciplinary team, agree terms of reference for the team to meet in a way that ensures patient confidentiality and that agreed plans are open and transparent, but that also facilitates professional-to-professional support and learning. If the team is working across several organisations take the time to make sure that information-sharing is done in a way that is responsible and compliant.

5. RELATIONSHIP WITH GPs

The project set out to support GPs to care for young adults with complex needs during and after transition. We found various barriers to this, and had to challenge some of the assumptions we had made in the development of the project:

Depending on GPs for referrals. We discovered that the majority of our patients did not regularly see their GP. Patients themselves said they did not see the point of attending the GP even for annual reviews, since they were used to being supported by other professionals. Ultimately this meant that although the GP may be aware of the patient, they were unlikely to have opportunity to identify unmet needs, or suggest our service to offer additional support.

New clinic overload. For most of our patients, transitioning from paediatric to adult services involved meeting multiple new teams and professionals, and navigating new systems for education, social care and hospital visits. Patients were busy and we had feedback that they struggled to fit in multiple clinic

appointments around college and day care attendance. We did not want our project to detract from the patient's ability to get to know the other new teams supporting them.

Promoting the service to GPs. We promoted our service to GPs through email bulletins, a survey, and presentations at their local meetings. This had very little impact on referrals. When we explored this further, GPs told us that they would frequently receive information about new services or initiatives and that it was difficult to recall the relevant service at the time it was needed, particularly for patients that they did not see regularly.

Offering educational opportunities could have led to a better understanding of the purpose of the project along with engagement from GPs already supporting this patient group and aware of their learning needs. A greater emphasis on training for GPs to identify and address their patients' unmet needs may have had an impact both on the young adults themselves, and on the number of referrals for our project.

RECOMMENDATIONS

- Transition Teams need to promote service to, and accept referrals from, as wide a range of professionals as possible. Ensure clear communication about the purpose of the service, the patients you want to see and the process for referring
- Involve GP in all correspondence and follow up plans. If appropriate, aim to discuss the patient with the GP either over the phone or in person. If a patient highlights a need that could be well met by their GP, encourage them to make an appointment and use the opportunity for the GP to get to know them and their needs.
- GPs are best placed to support the rest of the patient's family if there are concerns about carer or sibling health. Encourage family members to make contact with their GP for their own needs as well as for the patient.
- Recognise the expertise and experience you have within your transition team, and find opportunities to share this through offering teaching and training.

Wider impact

Over the timespan of the project, various related opportunities and developments have taken place. While this impact was not planned as part of the project, and fell outside the scope of the project, it is important to acknowledge them since the existence of the project is likely to have contributed to the opportunities.

The project itself enabled the team members to build on their existing interest in transition, dedicating time to networking, learning and listening to local partners and patients about the barriers to good care for this patient group. Without the project, this time and energy may have been directed elsewhere and the

expertise and reputation that the team have built in this area may not have developed to the same extent, or at the speed that it did.

Similarly, by engaging in these activities, the team have developed their own expertise and are better equipped to support patients, work with other clinicians and promote the service. The developments include:

- Advice calls to the team from regional adult palliative care specialists about Young adults with complex needs who they are supporting in their own locality.
- Transition recognised by Hospice trustees as an area of priority for which the organisation is gaining a regional reputation. Commitment to ongoing development of this area of work.
- Project lead developed social media profile, raising awareness of issues relevant to adult and paediatric palliative care, neurodisability and transition.
- Opportunities to contribute to research and guideline development at a regional and national level, and to represent Transition within specialty organisations.
- Invitations to speak and teach about Transition at national and local events and study days

RECOMMENDATIONS

- Accept opportunities and invitations that contribute to the broader aims of the project whenever possible. Ensure the service plan includes time and resources for learning and engaging with these opportunities.
- Find out what is already happening in your area/specialty/peer group, and invest in existing teams, projects and service developments where possible.
- While these opportunities may raise the profile and reputation of an individual, ensure the team keeps an eye to long term sustainability, training and succession planning.
- Don't be shy about contributing to the conversation about Transition at a regional or national level. Many clinicians lack experience and confidence working with this group and are eager to understand more about their needs and the challenges they face. Sharing your experience is a valuable way to do this.

ORGANISATIONAL LEARNING

Due to the very different contexts and backgrounds of independent hospices, there is a variety of experience and comfort in running small scale, time-limited service development projects such as this. The following section reflects the learning of the project lead in relation to the way the project fitted within the host organisation.

- Make proposal less ambitious even if you have capacity for more and think you'll get that number or referrals. Assume you are likely to get fewer referrals when starting out however effective your promotion is.
- Think carefully about communications and messaging to highlight that this is a new service with a different offer. We found a lot of people assumed that the new service was the same as the previous young adult offer (short break service) or the more general adult hospice service.
- Build in time/resource for additional scoping, networking and promotion throughout project as well as at the beginning. As the project develops it might reveal different contacts/ needs/ opportunities – ensure there is scope to explore these and develop the project in response, if appropriate. Also if the project is not going as planned, give yourself time to step back and re-evaluate.
- Reflect and keep notes as you go. Learning might not be what you expect, but it is good to see the patterns and developments. In this project many needs were less related transition itself, but were more around the challenges faced by adults with Neurodisability post-transition. Learning from this has led to a different model of care going forward.
- At the set-up of the project, we thought there was advantage in being a service that cut across several different departments within the hospice, giving us added independence, flexibility and responsiveness. We learned that embedding the new service into an existing team or department may have had additional benefits through tapping into a consistent infrastructure and ensuring engagement and buy-in from teams within the organisation. This also supports sustainability beyond the funded period and upskills other team members. Organisational changes that have taken place due to the COVID-19 pandemic have demonstrated that flexibility and cross-team working can be achieved in many different ways.
- The development from an initial idea to a completed, funded project needs process and oversight. A generic standard operating procedure (SOP) for service development and other funded projects would mitigate some of the possible challenges to running a similar project in the future and would ensure both the organisation and the funders get the most out of any project that is developed. It would also make it possible for members of staff with less experience to lead a project confidently.

NEXT STEPS

Evaluation and informal feedback have confirmed that the work that has been started is valued and will make a difference to young people in our region over time. The service paused from taking new referrals during the COVID-19 pandemic, while the team spent time on evaluating our work so far and focussing on the more immediate needs within the hospice, however referrals and additional requests for teaching began to increase during October 2019. The Hospice Management Team and Trustees have supported the team to continue

to develop a service model that is right for this region, with a view to seeking additional funding in the future.

Responding to feedback and numbers of referrals, the team plan to focus on the partnerships, training and awareness-raising work that has the potential to improve care and develop services on a much greater scale, while continuing to support patients face-to-face as needed.

In addition, the project lead has been appointed to join a commissioned regional children's palliative care team, where there is opportunity not only to identify potential patients for the Transition Service, but also to influence the quality of care for young people with life-limiting illnesses as they approach transition across the region. Besides this, both the Hospice and the Children's Hospital have a commitment to collaborating to develop research to improve the experience of this group.

Conclusion

Developing a service to improve transition for young people with life-limiting conditions provided many opportunities for learning, and the service model has evolved in response to this learning. We have developed specific recommendations relating to clinical care, carer support and relationships with other professionals as well as suggestions around project development. These recommendations represent both the things we did well, and the things we would tell ourselves as a team if we could go back in time!

Overall we want to encourage other teams that by standing up and telling local partners that we have seen a need and are "doing something" opened many doors to fruitful relationships that will extend far beyond the life of this project.