St Oswald's Hospice

Improving Transitions for Young People

Engaging GPs: Improving Outcomes

Final evaluation

2020

Supported by:

together for short lives

Illustrations about impact

What does the project do? It gives people the opportunity to have a bit of a life … when care and health are taken out of the equation, provided well, people can then enjoy things together, look, think, live … If care and health is not right that's all there is, just worry about this tube, or this spasm, or this med … Just worry, no life.

Quote from an NHS medic

They have really kept us out of the dark so to speak, it's a lot clearer when they've been involved.

Mother of child in transition talking about the project

Family have received excellent support from paediatric teams and feel anxious about losing this and having to start again with adult teams.

Reassured re the purpose of transition clinic to support through the next few years and identify issues if/when they arise. Explained that we work closely with GP and other specialists to ensure good communication.

Notes from visiting doctor

Families were worried:
About losing paediatric support
That decisions were not being made in the young person's best interests
About how the condition was being managed
That conditions will not be treated with sufficient intensity
About having the child removed from their care
… and there was a general frustration with their GP.

From project data

They are like having a strong advocate, one with teeth.

Comment from stakeholder organisation

About St Oswald’s Hospice

St Oswald’s Hospice is a local charitable hospice caring for people from across the North East. The Hospice provides expert and specialist care free of charge to babies, children, young people, adults and their families. Adults who use their services have life-limiting conditions including Cancer, Motor Neurone Disease and Multiple Sclerosis, and many others. The services help families too, offering support when they need it most.

St Oswald’s is one of only a few hospices in England caring for both adults and children. Services to babies, children and young adults include a short break service and end of life care when needed. The service cares for children with some of the most complex conditions in the North East, who spent almost 2,000 nights at the Hospice in 2019/20. Care is at the heart of everything they do and in the latest CQC inspection their care was rated as *Outstanding*.

More information: www.stoswaldsuk.org

St Oswald’s Hospice

About the authors

Barefoot Research and Evaluation is a social research organisation based in Newcastle upon Tyne, working across the North East and Cumbria. They have carried out work on a diverse range of social welfare programmes in the voluntary and public sector, specialising in participatory development and research with the groups who are underrepresented or who lack a voice. Dr. Christopher Hartworth, who set up Barefoot, has 25 years’ experience of research and evaluation, beginning in developing countries in poverty alleviation programmes and continuing in the North East of England in work with disadvantaged communities.

More information: www.barefootresearch.org.uk

Barefoot
Research and Evaluation

i. Executive summary

This is an evaluation of a project which aimed to support people with palliative care needs who were transitioning between children's and adult services in Newcastle upon Tyne. It was delivered by St Oswald's Hospice, a local charitable hospice, and was funded by Together for Short Lives. Initially, the project was a 30 month initiative, which was ended at month 24.

The impact of COVID-19

In addition to shutting the project down early, COVID-19 has had a fundamental impact on the project: firstly, the lockdown in March which prevented face-to-face contact which not only affected the project but also the evaluation; secondly, it caused the diversion of health and social care resources into the pandemic (and the attention of those professionals that the project was working with); thirdly, it has created another level of fear/stress amongst the project's target group due to COVID-19's disproportionate impact on physically and learning disabled people, which make up 59% of total fatalities; fourthly it has significantly impacted the charity's ability to fundraise charitable and voluntary income, creating a funding shortfall and threatening service provision. As with a number of community services, after provision was closed down by lockdown, services have emerged with new methods of engagement, with greater use of more accessible video conferencing means and socially distanced face to face meetings where essential.

The project

The project team consisted of a lead palliative consultant, a senior social worker and an adult nurse. Upon referral and rapid appraisal, potential patients would be contacted and a visit arranged. Based on the information and the subsequent assessment, a care plan would be put in place, adapted or contributed to, which directed future work. The social worker provided ongoing needs led care and support throughout the duration of the contact and beyond as required. The consultant plays a central role in the intervention, operating as coordinator of a network of specialists in conjunction with the local GP.

Evaluation findings

The project had a total of **13 referrals** for people between the ages of **17 and 29 years**. The original predicted target was 30 patients per year to a maximum of 80 across the project lifespan. In relation to gender and ethnicity, there have been slightly more males than females and all have been White British. The age ranges of the referrals indicate the project is not just delivering services to young people going through transition from children to adults' services, but also to adults who have been over 18 for some time. This may indicate that transition issues, if they are not tackled at the transition time, endure until a number of years into adulthood.

The majority of **referrals have come from either paediatricians, adult physicians or through St Oswald's Hospice**, with few coming from outside of the project's sphere of influence. The majority of these referrals came from organisations who had come to the project launch, had attended another seminar with the project team, or were to become a member of the newly formed Neurodisability Multi-Disciplinary Team (MDT) at the Royal Victoria Infirmary (RVI) in Newcastle. The project's *de facto* inner circle demonstrates the potential for close collaborative working, strong relationships and referrals going both ways when agencies know each other well. Familiarity, understanding and need are key success factors in effectively used referral routes; awareness-raising alone may not be enough as teams may think that they already have transition issues covered

The **palliative conditions vary in complexity**, although most needs can be described as significant, including people using assisted ventilation, acute and chronic pain, sleep problems, worsening spasticity. Almost a third of service users communicated non-verbally, and a further 15% required assistive technology to support their communication. The majority of referrals have varying degrees of learning disability, some profound and some capable of supported independent living.

From an analysis of project data, we can see that people came to the project with **three or four main issues** needing intervention, including: sleep problems; breakdown or nonexistence of relationship with consultant or GP, making management or planning difficult/impossible; a lack of suitable respite; and no care plan.

Sitting behind these issues were a **series of concerns**. At the top of that list expressed by families, was a general **frustration with their GP**, such as not knowing the GP or not feeling understood. This was followed by concerns around **losing paediatric support**; concerns that decisions were **not being made in the patient's best interests**; worries about how the **condition is managed**; concerns that the **condition will not be treated** with sufficient intensity; worries about having the **child removed from their care**; and general worries based upon **previous poor experiences**. All of these issues were brought into the project and discussed with the families, with the aim of a **negotiated successful resolution**, for example, addressing identified needs through facilitating referrals into specialist teams.

In relation to the type of provision from the project, we can see a **range of services/functions** that have been provided, including; coordination; advice and information; emotional support; end-of-life planning; problem identification, and treatment intervention. If we consider the areas of highest coverage as the areas of highest need, we can see a three-way division between coordination, information and support, and treatment interventions.

Outcomes

Understanding outcomes to be changes in practice or in behaviour, we make the following findings in relation to the Improving Transitions Project:

Creating new and developing existing knowledge and practice partnerships: the project has created a professional peer support structure that can be accessed by medical teams affected by transition-related issues. This improves the service response by adding value to and problem-solving for what is already provided.

Effectively coordinating: in conjunction with the practice and knowledge partnerships, the project has also provided an effective central coordinating role. There were reports that the project creates a bridge between the abundance of children services and the disparate range of adult services.

Preventative interventions: there is an undercurrent of preventative work to the activities of the improving transition project, as well as timely and responsive care and treatment; whereas prior to the project, emphasis would have been on reaction, not prevention. The project plays a more direct role in prevention as they can use their specialist knowledge to intervene in people's lives before situations escalate, which may not have otherwise happened.

Improved end of life planning: the project has provided families with the opportunity to talk about their plans for death on a regular basis and it forms a key part of the intervention; subject to the individual, the care plan will include end of life plans, including such things as instructions about resuscitation.

Other findings

The project has addressed **an evident gap in provision**, with stakeholders responding positively about the new service. **It has also confirmed that there is a need to tackle transition issues.** The project accurately identified the need/location of the problems that existed and was able to respond.

Need is forecast to grow and referrals to rise as awareness of the service increases: the relatively small number of referrals after nine months service provision (before the advent of COVID-19 lockdown) was not seen as an issue by the local medical community. It was felt that referrals would naturally develop particularly with the advent of the multi-agency meeting and the new partnerships.

Relationships with GPs continue to develop: the project set out to support GPs to care for young adults with complex needs during and after transition. This has been more difficult to achieve than expected as a result of a majority of patients not regularly seeing their GP, which meant that although GPs may be aware of the patient, they were unlikely to have spent enough time with them to have the opportunity to identify unmet needs, or suggest the service to offer additional support.

Need and expectations have been a factor in interventions: the project has needed to be clear and specific about what they could and could not provide in certain situations. Families sometimes expected that they would provide different services, such as therapeutic interventions.

Conclusion

It is difficult to make a complete set of judgements relating to a project, when it ends prematurely because that additional time may have been developmentally or otherwise important. COVID-19 also clouds the general service delivery environment and has had a major impact on this and on a multitude of other services. We are able to make our observations on impact to date on beneficiaries and other community stakeholders who have used the service. The first of these is that the project has positively impacted on professional networks, with medical professionals reporting feeling more confident in providing their services, knowing that there was a coordinating improving transitions intervention provided a sense of expertise as well as a coordinating function. The second is that the project has experienced a relatively slow start [NB: as a pilot project, the target numbers only existed as estimated projections]. However, our research has indicated that there can be an extended development time necessary to change awareness, confidence and referral practices, which was made more difficult by COVID-19. We also know how stressful and distressing the experience is for families and how beneficial it can be to have an informed advocate on your side. It was also felt that St Oswald’s Hospice was perfectly placed to provide the Improving Transitions Project as it compliments and adds value to existing provision for adults, children and those in transition.

If we return to the original objectives of the project as specified in the original brief, we can see progress has been made across a number of objectives. There is sufficient evidence to indicate that the following objectives are being met:

- Improve the quality and efficiency of the support offer to young people whilst also extending our support to more young adults with palliative care needs.
- Work more closely and effectively with primary care teams across the North East, liaising with doctors, early in the transition process, to ensure consistent, high quality support for any young adult with palliative care needs in their care.
- Providing good quality education, training and information about this patient group for all GPs will improve the support they offer to young people with complex needs.

The project also contributes to St Oswald's Hospice *Our Vision 2025* initiative includes a commitment to "*lead the development of palliative care services within the region by working more closely with other organisations.*"

Recommendations

Our recommendations are to continue service provision, and as the repeated suggestion from stakeholders, maintain emphasis on awareness raising and partnership development. There were proposals to embed a continuing focus on awareness raising and communications within project activities, such as preparing project updates/newsletters that can be shared across the region and regular meetings with stakeholders. It was also suggested to ensure awareness raising activities incorporated a variety of areas, as suggested by one respondent:

> *All community, neurodisability, respiratory, spinal, orthopaedic, ENT, neuromuscular, neurology, palliative care paediatricians, oncology, BMT, all GP child health leads, community nursing. Adult physicians - respiratory, Orthopaedic, Neurology, neurorehab, etc. Ensure all parent carer partnerships in the region are aware of the service.*

There were reports by certain stakeholders that there has been sufficient investigation of transition and its related issues and now is the time to create a pathway of care that can be used by GPs to support their patients.

> *A robust pathway of handover to GP whilst linking to [the Improving Transitions Project] will be simple and easy to carry out.*

It would be remiss of the evaluators should we not recommend further evaluation after 12 to 24 months to ensure learning/production of knowledge.

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1.0 Introduction

This is an evaluation of a project which aimed to support people with palliative care needs who were transitioning between children's and adult services in the North East of England. It was delivered by St Oswald's Hospice, a charitable hospice based in Newcastle upon Tyne, and was funded by Together for Short Lives. Initially, the project was a 30 month initiative, which was ended at month 24.

In addition to shutting the project down early, COVID-19 has had a fundamental impact on the project in 2020: firstly, the lockdown in March which prevented face-to-face contact which not only affected the project but also the evaluation; secondly, it caused the diversion of health and social care resources into the pandemic (and the attention of those professionals that the project was working with); thirdly, it has created another level of fear/stress amongst the project's target group due to COVID-19's disproportionate impact on physically and learning disabled people, which make up 59% of total fatalities; fourthly it has significantly impacted the charity's ability to fundraise charitable and voluntary income, creating a funding shortfall and threatens service provision. As with a number of community services, after provision was closed down by lockdown, services have emerged with new methods of engagement, with greater use of more accessible video conferencing means and socially distanced face to face meetings where essential.

1.1 Evaluation

The evaluation was designed initially as a participatory evaluation, engaging service users in group based face-to-face critically reflective work. It was intended that throughout the project delivery, young service users could be identified who would participate in a review group. This group would have met regularly and critically appraised progress against indicators that they would define. However, as a result of COVID-19 restrictions, this has not been possible. Instead the evaluation has responded to the change in circumstances and adopted a standard mixed method evaluation, incorporating an interrogation analysis of quantitative and qualitative project data, consultation and critical reflection with project stakeholders including project beneficiaries, and a review of the literature. The evaluation was conducted by an independent sector specialist[1] between the months of July and October 2020.

Box 1.0 What is Transition?

'Transition' is the purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with long-term conditions [with palliative needs for this project] as they move from child-centred to adult-oriented healthcare systems[2,3]. Generally, there are thorough and wide ranging interventions and support for children, which reduces significantly into adult services, sometimes described as a cliff edge. Services for children who live into adulthood because of advances in healthcare, are particularly absent and the need is keenly felt. Added to this is the unsuitability of adult services, particularly palliative ones, for young people.

The importance of healthcare transition and its challenges are recognised in the 2016 UK National Institute for Health and Clinical Excellence (Guideline 43 and Quality Standard 140)[4,5]. Newcastle University has recently completed a five year National Institute for Health Research funded transition delivery and research project[6], responding to the absence of research and guidance and legislation the area. They identified beneficial features of a transition programme based on evidence, review and experience, including: coordinated team; parental involvement, written transition plan; age-banded clinic; to meet adult teams before transfer; and transition manager for clinical teams. They subsequently made them recommendations as evidence-based factors of good practice, which are found within the Improving Transitions Project.

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[1] wsww.barefootresearch.co.uk

[2] Blum, R.W., Garell, D., Hodgman, C.H., Jorissen, T.W., Okinow, N.A. & Orr, D.P. (1993), Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolesc Health,14(7):570–6.

[3] Colver, A. McConachie, H., Le Couteur, A. G., Dovey-Pearce, K., Mann, J. E., McDonagh, M. S. Pearce, L., Vale, H., Merrick. & Parr, J. R. (2018) A longitudinal, observational study of the features of transitional healthcare associated with better outcomes for young people with long-term conditions, BMC Medicine 16:111

[4] National Institute for Health and Care Excellence or NICE. (2016) Transition from Children's to Adults' Services for Young People Using Health or Social Care Services, Guideline 43. London: National Institute for Health and Care Excellence.

[5] NICE. (2016). Transition from Children's to Adult Services. Quality standard 140. London: NICE.

[6] Colver, A., Rapley, T., Parr, J.R., McConachie, H., Dovey-Pearce, G., Le Couteur, A., McDonagh, J.E., Bennett, C., Maniatopoulos, G., Pearce, M.S., Reape, D., Chater, N., Gleeson, H. & Vale, L. (2020) Facilitating transition of young people with long-term health conditions from children's to adults' healthcare services – implications of a 5-year research programme, Clinical Medicine, Vol 20, No 1: 74–80

Case study: Transition and tragedy

Alex is 19 years old and has cerebral palsy*. Alex is a larger than life character, communicating with his mum and dad through assistive eye gaze technology (which he likes to use to tease people) and self-propelling using a powerchair. He lives at home with his older sibling, who is 24 years old and who also has a complex medical condition which requires 24-hour care. Alex has been brought up by his mum and dad in their own adapted bungalow and for the most part managed Alex's and his sibling's care, with social and medical support; Alex's mum was the wage earner and his dad was the full-time carer, which he enjoyed.

They came to the attention of the Improving Transitions Project as a result of Alex being rejected from an adult social care respite service as a result of Alex's health which had deteriorated. The local authority provider did not feel that they were able to safely deal with his needs, unlike his sister who could participate fully. Their GP who had been to the Improving Transition Project launch, approached St Oswald for support. The Improving Transition Project was first asked to address Alex's past spasticity which was causing significant problems for his management, especially dressing and toileting. This was dealt with through Botox injections facilitated through the project, which were which proved to be very successful and improved Alex's spasticity considerably. In January 2020, Alex's father tragically took his own life, with no apparent underlying mental health condition. The effect of this were extremely traumatic and life changing, and Alex's mum had to stop working to care for him full-time. The Improving Transitions Project has stayed in contact with the family, and facilitated bereavement counselling for Alex's mum. Short respites are also planned with Saint Oswald's.

* Names and some details have been altered.

1.2 Project background

Advances in medicine have led to increasing lifespans of people who may have previously not lived into adulthood. The increased life expectancy of young people with life-threatening and life-limiting conditions has raised the importance of managing the transition from children to adult services[7]. Families generally find a cliff edge of services, and once coordinated and bountiful children's services are reduced to often unknown and disparate ones. This often corresponds with families facing significant physical and emotional stress as their child physically becomes an adult as their condition deteriorates and caring becomes more difficult. The situation can become negatively reinforcing; as parents/carers get older they become less effective at providing care (e.g. as a result of losing strength or an injured back), which can have cumulative effects on their mental and physical health. This is not uniquely NHS service-related and it can apply to hospice provision where children's services are dominated by respite and adult services by end of life care, with little in the middle.

Even though these needs have been recognised for some time, there have been delays in creating a response, and in many areas, like the North East, there have been limited, if any, transition services developed until the arrival of this project. The Improving Transition Project developed from the experience of St Oswald's Hospice children and young adults service which was very similar to the national experience, of an increasing and uncoordinated need. St. Oswald's Hospice broadly found two groups of young adults with different needs: young adults with significant physical and learning disabilities living in households that continue to provide care 24 hours a day, often with the support of paid carers; and young adults with significant physical disabilities who are able to speak up for themselves and would like to go to college and live independently. Whereas the majority of the former will have care packages in place, the latter likelihood of success can be dependent on the local authority and how much and what type of resources they have, e.g. one local authority may have supported independent living, another may have care homes available.

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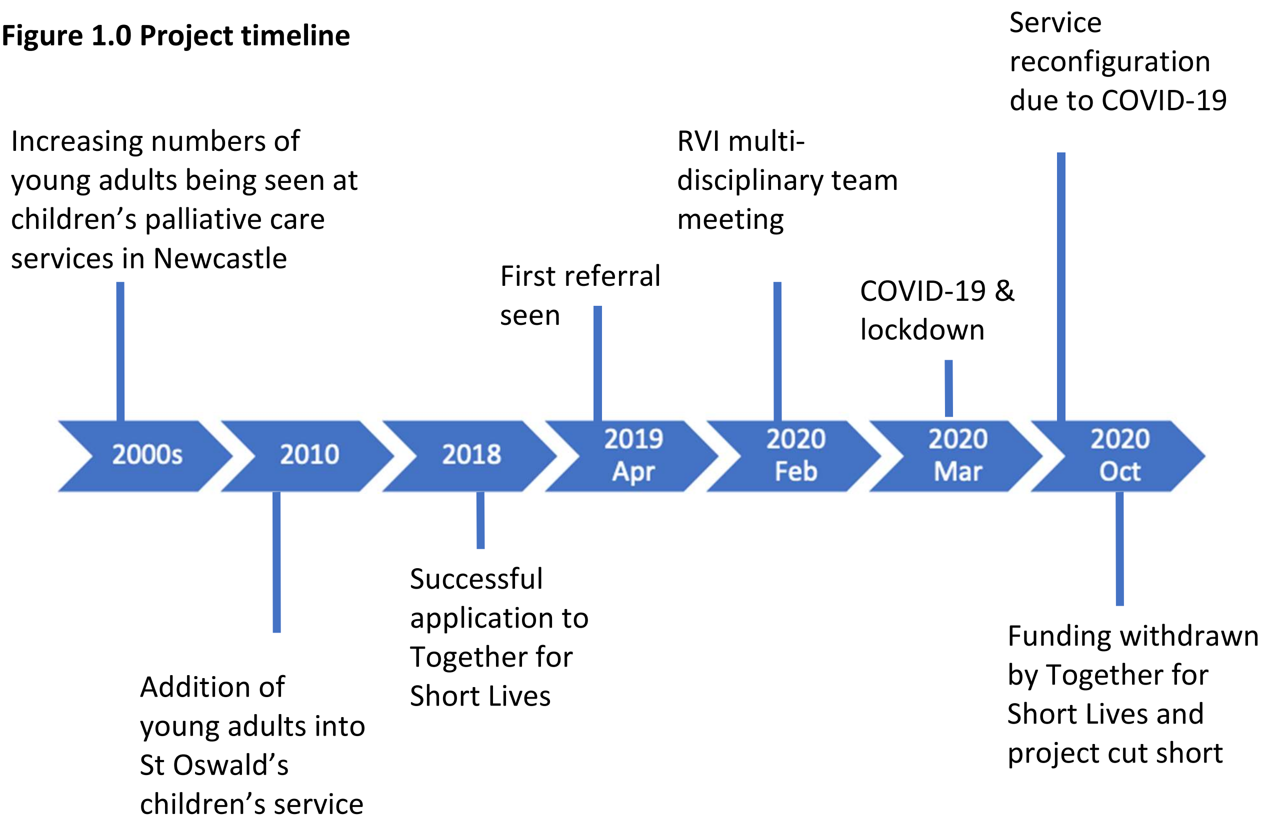
[7] Doug, M., Adi, Y., Williams, J., Paul, M., Kelly, D., Petchey, R. & Carter, Y. H. 2009. Transition to adult services for children and young people with palliative care needs: a systematic review, in *Arch Dis Child* 2011;**96**:78–84. doi:10.1136/adc.2009.163931

After successful funding application to Together for Short Lives, the project began awareness raising through developing and distributing project information and visiting relevant key health fora, such as local clinical commissioning group meetings. The project held a well-attended and relatively high profile launch which was intended to assist the project in developing awareness. Referrals into the project started in April and they had 13 people referred in the first year, which was down from their target of 30. To a certain extent, this was expected as awareness was initially low and it would take time for steady referrals to develop. In February 2020, the project team attended a multi-disciplinary meeting at the RVI concerning young adults in transition and there were enthusiastic offers of referrals and partnership working. This has developed into a monthly group to meet to discuss adult patients with neurodisability and learning disability who fall under a number of specialist teams and have complex needs. At the last meeting, there were representatives from the home ventilation team, intensive care, an epilepsy specialist, a community paediatrician, learning disability nurses and a respiratory consultant. In March 2020, the COVID-19 pandemic stopped the service seeing people face to face, and support was transferred to telephone-based support. In October 2020, funding was withdrawn.

Figure 1.0 Project timeline



1.3 Service offer

The project team consisted of a lead palliative consultant, a senior social worker and an adult nurse. Upon referral and rapid appraisal, potential patients would be contacted and a visit arranged. Based on the information and the subsequent assessment, a care plan would be put in place, adapted or contributed to, which directed future work. The social worker provided ongoing needs led care and support throughout the duration of the contact and beyond as required. The consultant played a central role in the intervention, operating as coordinator of a network of specialists in conjunction with the local GP. It was intended that there would be a connection/coordination between patients and St Oswald's Hospice and their range of palliative, respite and support services. As stated, COVID-19 has had a significant impact on how the project interacts with service users, moving from a face to face service to a telephone/online-based service.

The following figure is a schematic of the role of the Improving Transitions Project, comparing it to the experiences of young people and families within children's services and in an absence of service. As can be seen, it displays service configurations: whilst young people are within children's services; when they enter into the world of adult services when they are in transition; and with the Improving Transition Project. Scenario two shows the project's attempts to bring the GP into the centre of the service provision. Scenario three shows the business as usual situation where contact with GPs is sporadic, slow to develop and reactive leading to ad hoc contact and relations with adult services.

Case study: Moving into a new area

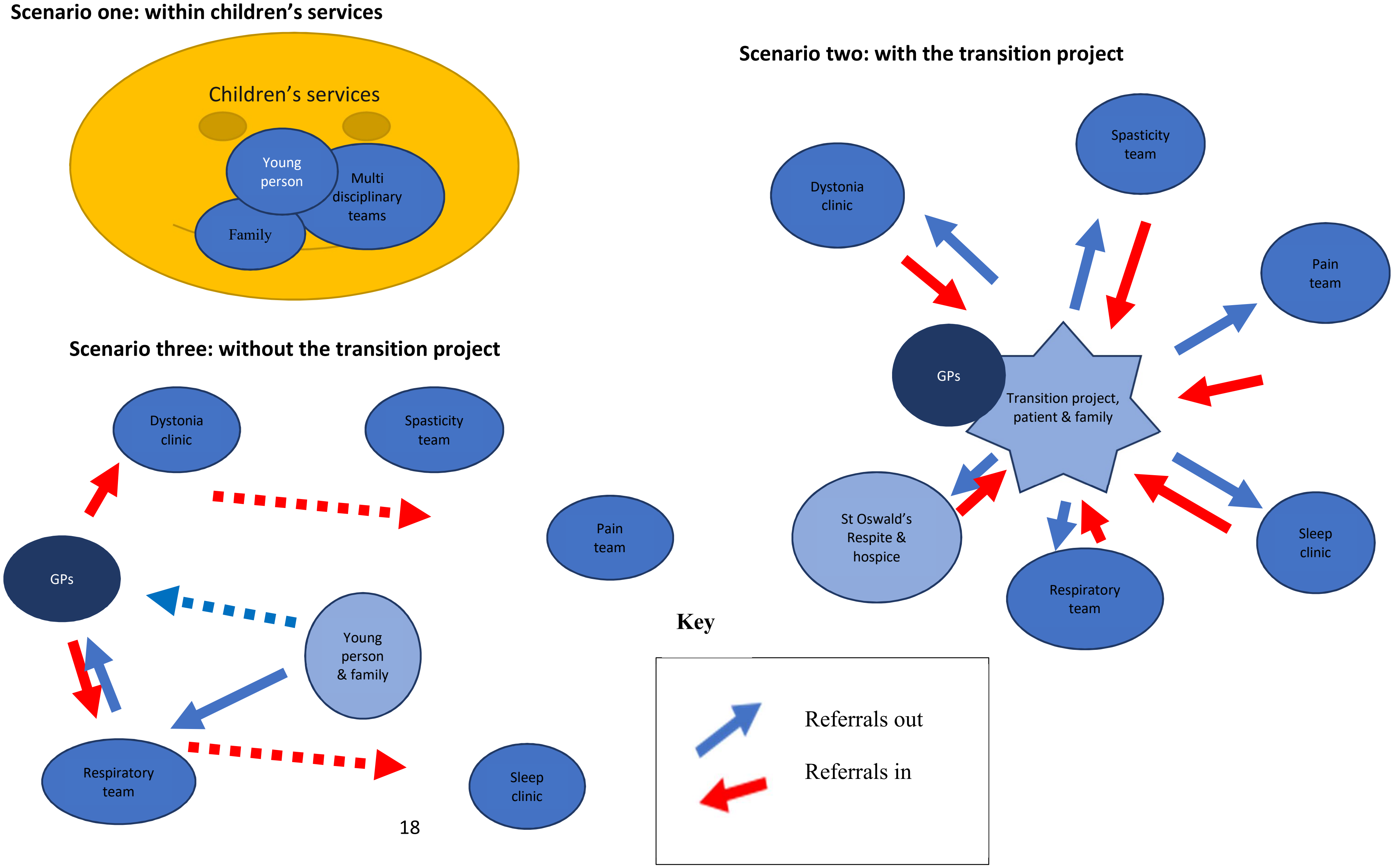
John* was 22 years old and had cerebral palsy. He was unable to verbally communicate or self-propel, but would respond emotionally with his family. He lived with his mum and new step dad and they had recently moved from outside of the region. In their original home, they had arranged things themselves to cater for all of John's health and social care needs. John was referred to the Improving Transitions Project by the hospital consultant to help with discharge planning towards the end of a hospital stay, which had resulted in increased care needs and significant distress for his family. The medical lead for the project explained:

It was this change in his needs that brought the frustration about the care package to a head.

The family had mistakenly assumed that the package of support would follow them into their new local authority, which is reported to be a relatively common experience amongst families who move. As a result of the disappointment, frustration and worry of no support being in place, John's mum often presented as angry. John's mum was very much the expert and repository of a specialist knowledge about her son, and as such there was a worry that should anything happen to her, then John's care would suffer. There was therefore an emphasis on arranging John's care plan and package as soon as possible. The Improving Transitions Project offered support to the family, and could provide services such as respite, but it appeared that the care planning process was progressing well without their involvement. In discussion with John's family, it was felt that they should continue with the current health and social care arrangements as it was felt that St Oswald's would add an additional layer of bureaucracy/decision-making, which would complicate and confuse the care planning process. The project has stayed in contact with the family to provide emotional support and symptom management advice alongside John's GP and district nurses.

* Names and some details have been altered.

Figure 1.1 Schematic of service configurations: children's; with; and without the transition project



Scenario one: within children's services

Scenario two: with the transition project

Scenario three: without the transition project

Key

2.0 Findings

This section presents the findings of the evaluation, firstly from an examination of quantitative and qualitative project output data, interviews and questionnaires with stakeholders, including GPs, specialist consultants and project staff. We have separated the findings into outputs and outcomes: the former, which are understood to be physical characteristics associated with the project, such as a service user, where they live or what type of service was delivered; the latter are changes associated with the project, such as the development of a policy area, improvements in a service users' well-being or satisfaction levels of specialist teams.

2.1 Outputs

The project has had a total of 13 referrals for people, between the ages of 17 and 29 years. The original predicted target was 30 patients per year to a maximum of 80 across the project lifespan.

In relation to gender and ethnicity, there have been slightly more males than females and all have been White British.

Figure 2.0 Gender of service users, 2019/20

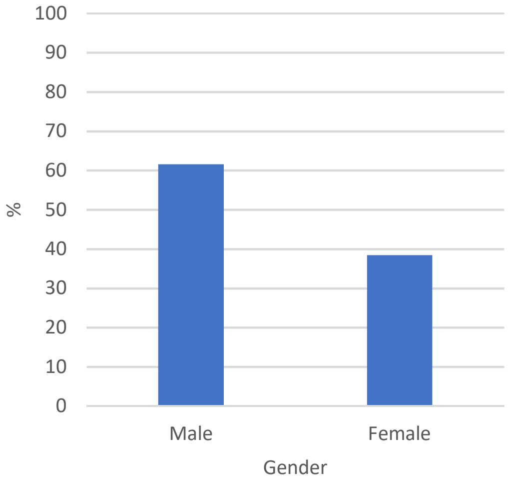
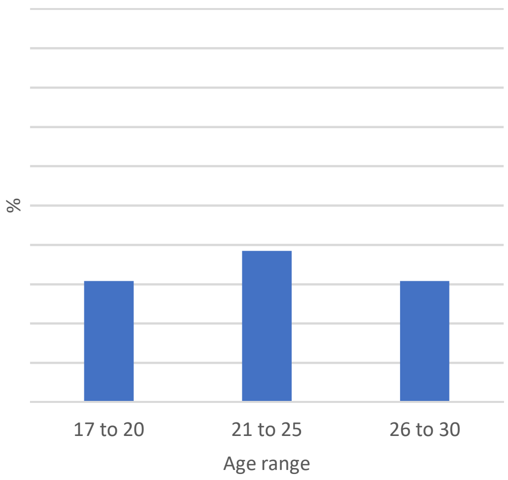


Figure 2.1 Age range of service users, 2019/20



The age ranges of the referrals indicate the project is not just delivering services to young people going through transition from children to adults, but also to adults who have been over 18 for some time. This may indicate that transition issues, if they are not tackled at the transition time, endure until a number of years into adulthood. As illustrated by one stakeholder:

> *Transition problems only became apparent after young people had already transitioned to adult care … so you need retrospective as well as preventative interventions …*

The following figure may also indicate a latent need across a much wider area it shows where service users have come from, with Newcastle upon Tyne dominating total referral numbers, followed by Northumberland and one from Hartlepool. The restricted geographical area, i.e. only three areas out of 12 across the North East, indicates only a small area which has so far benefited from the project.

Figure 2.3 shows that the majority of referrals have come from either adult physicians, paediatricians or St Oswald's Hospice, with few coming from outside of the project's sphere of influence. The majority of these referrals came from individuals who had come to the project launch, had attended another promotional or educational event or were to become a member of the newly formed Multi-Disciplinary Team (MDT) at the Royal Victoria Infirmary (RVI) in Newcastle. The project's de facto inner circle demonstrates the potential for close collaborative working, strong relationships and referrals going both ways when agencies know each other well. Familiarity, understanding and need are key success factors in effectively used referral routes; awareness raising alone may not be enough as teams may think that they already have transition issues covered.

The number of referrals from GPs and other paediatricians have been small. If we compare these small numbers to estimations of need from different clinicians, there is a disjuncture, illustrated by the following example:

> *'If we consider Cerebral Palsy (CP), a recent study (Judith Rankin et al) estimates that roughly 10,000 children with* severe CP *will transition to adults in England and Wales in 2020 … there should be a reasonable number in our region with severe CP, therefore complex disability transitioning to adult services'.*

It would appear that there is the potential for higher numbers as the service becomes better known.

Figure 2.2 Location of service users, 2019/20

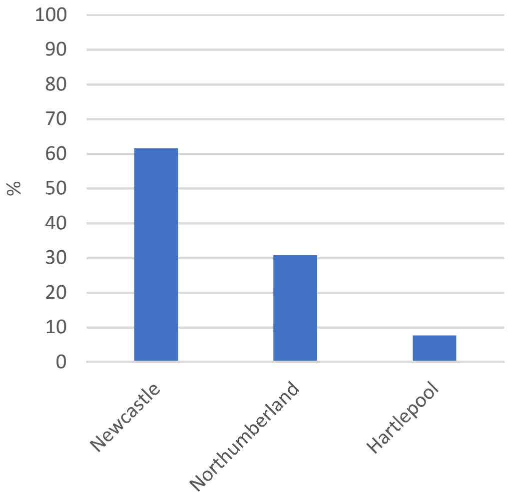
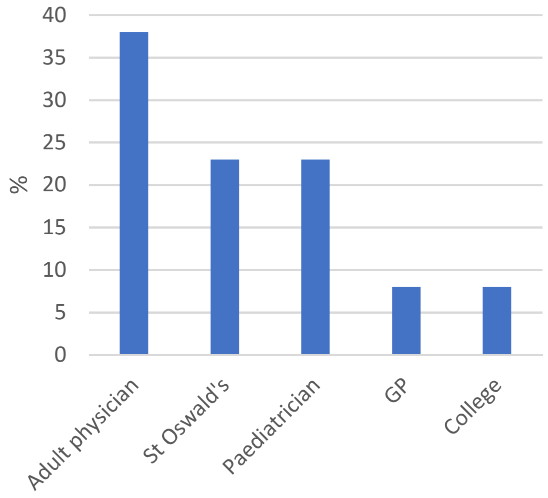
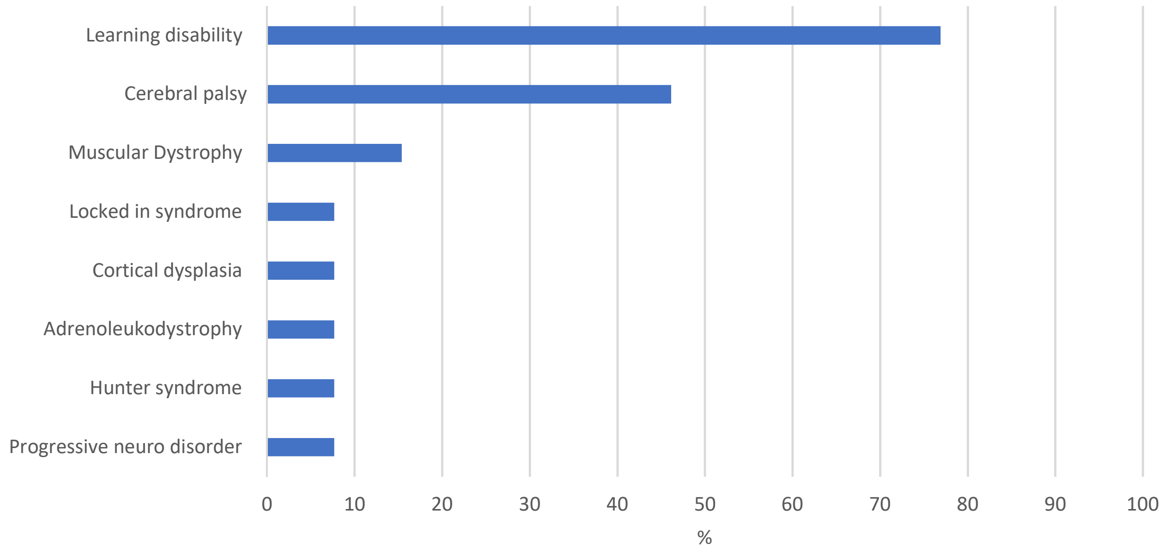


Figure 2.3 Referrer, 2019/20



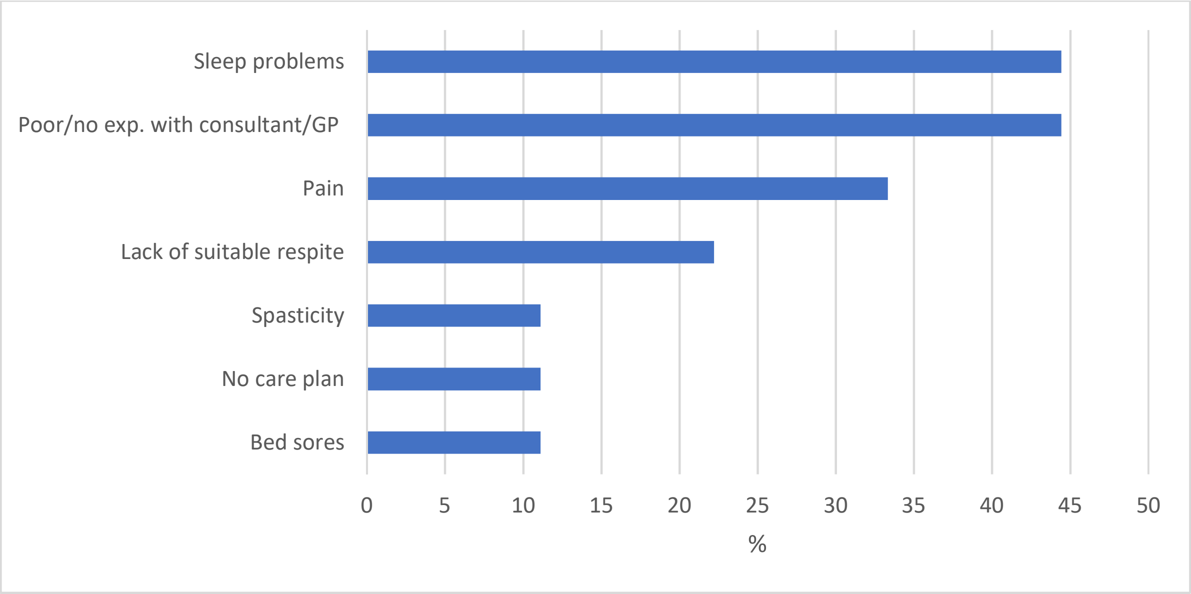
The following figure shows the range of conditions which often exist in addition to most of the young people having moderate to profound learning disabilities. Their palliative conditions vary in complexity, although most needs can be described as significant, including people needing assisted ventilation, acute and chronic pain, sleep problems, worsening spasticity. Almost a third (n=4) of service users had no verbal communication, and a further 15% (n=2) required assistive technology to support their communication. The majority of referrals have varying degrees of learning disability, some profound and some capable of supported independent living.

Figure 2.4 Conditions of service users, 2019/20



We can see that people came to the project with three or four main issues needing intervention, including: sleep problems; breakdown or nonexistence of relationship with consultant or GP, making management or planning difficult/impossible; a lack of suitable respite; and no care plan. Physical symptoms were a key feature in the reasons for referral and in the project's interventions.

Figure 2.5 issues presented by young people and families, 2019/20

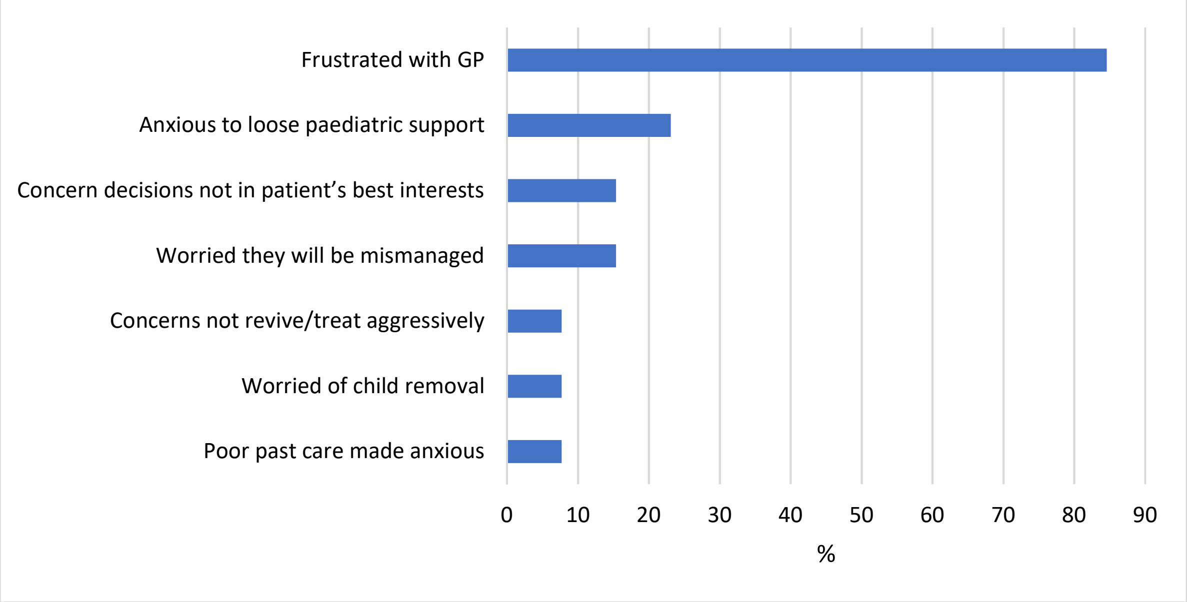


Sitting behind these issues were the following concerns (see following figure). At the top of that list expressed by families was a general frustration with their GP, such as not knowing the GP or not feeling understood. This was followed by concerns around losing paediatric support; concerns that decisions were not being made in the patient's best interests; worries about how the condition is managed; concerns that the condition will not be treated with sufficient intensity; worries about having the child removed from their care; and general worries based upon previous poor experiences. All of these issues were brought into the project and discussed with the families, with the aim of a negotiated successful resolution, for example, addressing identified needs through facilitating referrals into specialist teams. Some illustrative case notes include:

> *Not wanting to be labelled as "not coping", as she doesn't want patient to be taken into care so reluctant to seek support, also doesn't know how she would access any emotional/ psychological support as would need someone to care for patient*

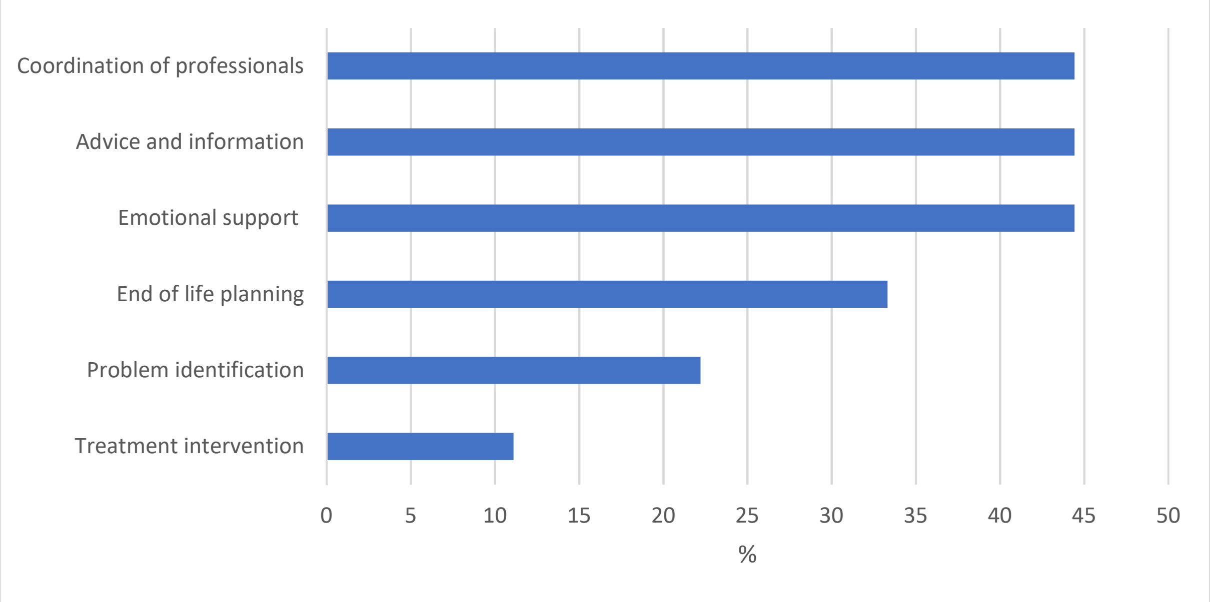
> *Concern that when he looks very unwell clinicians that do not know him may fail to recognise his potential to benefit from aggressive treatment or to understand the good quality of life he enjoys*

Figure 2.6 Concerns of parents, carers and service users, 2019/20



In relation to the type of provision from the project, we can see a range of services that have been provided, including; providing a coordinating role; providing advice and information; emotional support; end-of-life planning; problem identification, and treatment intervention. If we consider the areas of highest coverage as the areas of highest need, we can see a three-way division between coordination, information and support, and treatment interventions.

Figure 2.7 Services provided by the project to young people and families, 2019/20



2.2 Outcomes

The research for the evaluation has identified a number of outcomes, or changes, that have occurred as a result of the Improving Transitions project. They include the following:

Building internal and external professional knowledge and capacity: as a pilot project, it represents a great potential for learning. This has been demonstrated on a number of levels in the project, not least in the adaptations needed to deliver a service in the time of COVID-19.

St Oswald's Hospice has benefited from further understanding the need and how to respond, as well as the importance of continuing awareness raising around the project.

Direct project stakeholders, such as specialist teams, have experience of the supported transition process and can see benefits. This ultimately improves the effectiveness of their services as they are able to provide preventative as well as reactive services and treatments. This is similar to the experiences of the GPs who have been supported to become more active, moving away from that tendency to, in the words of one stakeholder, "*do what they are asked*".

There have also been specific learning episodes during the project, such as an incident when a parent of one of the patients/clients took their own life. In this is case, a debrief by the neurodisability multi-disciplinary team (MDT) lead to procedural improvements, illustrated by the following:

> *Key learning points for MDT: Intentionally checking in with carers/parents at every opportunity to give them a chance to share any concerns they have about themselves (preferably without the patient bring present). Use MDT to ensure continuity and share any concerns – team approach should enable us to follow up issues without needing to increase frequency of appointments.*

The knowledge exchange relates not just to treatment options but also to the development of trusting and constructive clinical relationship with parents as well as patients.

There have also been benefits to a wider audience, for example during lockdown COVID-19, an online study morning on neurodisability attracted almost 80 participants from a range of specialties and professions from across UK. Event evaluations demonstrated positive learning outcomes.

Creating new and developing existing knowledge and practice partnerships: the project has created a professional peer support structure, that can be accessed by medical teams affected by transition. This improves the service response by adding value to and problem-solving for what is already provided. This was started at the launch event which brought together a number of directly affected stakeholders who started to discuss the particular needs of this patient group around continuity of care, and consistency between professionals. There has been a subsequent commitment from specialists involved to share information, including goals of treatment, so that all involved can support each other's plans and ensure continuity. Wherever possible, the project has made those specialist hospital teams aware of support in community as well as the importance of involving the St Oswald's Hospice palliative care team and GP in discussions about treatment and plans. These networks are also growing, for example in future meetings, reported the project lead:

> *We will also have someone from the spasticity service at Walkergate Park and we've had interest from other teams as well.*

There was a direct link between the development and sharing of knowledge and impact on patient care. For example, a member of one of those specialists teams, reported:

> *I think in the long term, being part of this team will give us the opportunity to impact the care of more patients through supporting the teams already involved in their care .... It's also a stronger platform for educating health care professionals and raising awareness of the needs of young adults with complex needs.*

An effective coordinating role: in conjunction with the partnership and knowledge development, the project has also provided an affective central coordinating role. There have been reports that the project creates a bridge between the abundance of children services and the disparate range of adult services. Most patients have had multiple professionals involved at different levels in their lives and when they are in paediatric services these are integrated and coordinated. An example of this coordination is shown below from the lead consultant's notes:

> *Keen for Emergency Healthcare Plan to support his care in any setting. Discussed need for this plan to have input from the different specialists involved. Supported Intensive care doctor in drafting this and contacting the other teams.*

The project has taken a sensitive approach to coordination and partnership working, keen to add value and compliment wherever possible. For example:

> *Keen not to disempower other professionals and aware of number of specialists involved.*

These links and timely coordination results in tangible outputs, for example:

> *[The] discussions with respiratory team resulted in them doing the Emergency care plan because they knew him so well.*

Preventative work: there is an undercurrent of preventative work to the activities of the Improving Transition Project, as well as timely and responsive care and treatment; whereas prior to the project, emphasis would have been on reaction, not prevention. There are also various levels of prevention, for example by making GPs more proactive engages them in developmental healthcare, which is more likely to affect change before situations become too severe. The Improving Transition Project plays a more direct role in prevention as they can use their specialist knowledge to intervene in people's lives before situations escalate, which may not have happened otherwise. For example, constipation related problems due to medication can become severe (in 2019, 12 people with learning difficulties died as a result of constipation[8]) and have a major impact on health and well-being, and management must be discussed in conjunction with pain reduction.

Improved end of life planning: The project has provided families with the opportunity to talk about their plans for death on a regular basis and it forms a key part of the intervention; subject to the individual, the care plan will include end of life plans, including such things as instructions about resuscitation. However, it must be cognisant of the need to focus on life and living and sometimes families choose to avoid the subject. For example in one encounter it was explained:

> *Fear that palliative care will force him to talk about death when he wants to focus on getting the most out of life*

This issue was also raised in the concerns expressed by families; that they are worried without adequate care and understanding, there will not be such an intensive emphasis on this and keeping young people alive. However, there were times when people wanted to talk about death. For example, an excerpt from the casenotes reads:

> *… himself introduced thinking about death and dying on second clinic review.*

The project has also enabled a number of difficult conversations in related areas, which otherwise may not have happened, or may have taken place in an insensitive way:

> *[One team was] keen for us to discuss resuscitation as felt he should not be for CPR. Began to broach this, and made progress in patient acceptance that he will reach a point where he would choose being cared for at home over further intensive treatment, however he is not ready for that point yet.*

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[8] Heslop, P., Blair, P., Fleming, P., Hoghton, M., Marriott, A., & Russ, L. (2013). Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). *Bristol: Norah Fry Research Centre*.

As can be seen in figure 1.0, the project is central to their entire process, keeping the patient and family at the core. The Improving Transitions Project links or refers in the young person to a number of different speciality teams as directed by the coproduced plan.

Reassurance and reduced anxiety: as a result of the project young people and families have benefited from the peace of mind which comes with knowing somebody is on your side. The supportive role taken is an important project element as there are often complex emotions to be taken into account and sometimes managed. The advocating and supportive position taken, provides reassurance and reduces anxiety within families.

> *Informed patient's mother that we are working more closely as a team to support the patient and her.*

2.3 Other findings

The project has addressed **an evident gap in provision**, with stakeholders responding positively about the new service. One referring adult physician illustrated this by saying:

> *It answers a clearly unanswered question about who is best to help care for this complex group, where there is currently a gap as they transition into adult medicine from paediatrics and lose their paediatrician.*

The project has confirmed that there is a need to tackle transition issues: The project has accurately identified the need/located the problem that existed and was able to respond. For example, see the following excerpts from case notes:

> *Family have received excellent support from paediatric teams and feel anxious about losing this and having to start again with adult teams*

> *Family keen to ensure that health professionals understand patient's needs quickly if he is admitted urgently. Anxious about whether this can be done when he moves to adult services*

The project has found that there is a particular need to create and maintain continuity with adult services for certain conditions which may fluctuate in severity and impact and so not always be a treatment priority. If a treatment had occurred whilst the patient was under 18 years old, they would have been carried out in the context of children's services. When periodic treatment is subsequently needed, it would not be possible to approach the same team and the patient/family will need to address this themselves, i.e. requesting a referral to adult services. There is always a risk that as a result of a lack of knowledge/support or care, necessary treatments may not be put in place. For example:

> *Had botulinum toxin in past for spasticity, but as he had not needed this for some time, had not been transitioned to adult spasticity team.*

There was also a unanimous expression of need from stakeholders. For example, one respondent said:

> *The idea of having a team/professional who understands multiple comorbidities a young person with complex disability will have at the time of transition is good. Currently there is no adult service akin to paediatric neurodisability/community paediatrics who acts as a key professional looking at the child holistically. This project offers such a service and would be useful to many adult GPs and 'ologists who see a young person in isolation.*

From this need, the Improving Transitions Project has been able to identify and access necessary treatment services for families, that otherwise would not have been present, may have been incorrect/inappropriate or been too late.

Need is forecast to grow and referrals to rise as awareness of the service increases: the relatively small number of referrals after nine months service provision (before the advent of COVID-19 lockdown) was not seen as an issue by the local medical community. It was felt that it may have been a result of relevant young adults not being seen by referring agencies or it may be that those agencies in a position to refer, did not know about the Improving Transitions Project. As reported by one referring physician:

> *It is still a young and unknown service.*

Either way, the evidence in the evaluation would indicate that need will only increase from this point forward. Another physician reported the position of single issue conditions using the example of cerebral palsy:

> *If we consider Cerebral Palsy [CP], a recent study (Rankin et al*[9]*) estimates that roughly 10,000 children with severe CP will transition to adults in England and Wales in 2020. I don't have population stats to our region at hand but, there should be a reasonable number in our region with severe CP, therefore complex disability transitioning to adult services.*

Families and young people have respond well to the service: the majority of service users **were reported to** engage well with transition team. One physician who had referred into the service on a number of occasions, reported:

> *My patients were very happy with the service provided.*

Another physician reported, echoing the findings contained in the previous section about the importance of social and emotional support.

> *The patients that I have referred in have found it helpful including for family support alongside symptom control.*

Relationships with GPs continue to develop: the project set out to support GPs to care for young adults with complex needs during and after transition. This has been more difficult to

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[9] Glinianaia, S.V., Best, K.E., Lingam, R. & Rankin J. 2017 Predicting the prevalence of cerebral palsy by severity level in children aged 3 to 15 years across England and Wales by 2020. *Developmental Medicine & Child Neurology*, **59**(8), 864-870.

achieve than expected as a result of a majority of patients not regularly seeing their GP. Patients reported that as a result of the wraparound support received from paediatric services, they did not see the point of attending the GP even for annual reviews. This meant that although GPs may be aware of the patient, they were unlikely to have spent enough time with the patient to have the opportunity to identify unmet needs, or suggest the service to offer additional support.

Need and expectations have been a factor in interventions: the project has needed to be clear and specific about what they could and could not provide in certain situations. Families sometimes expected that they would provide different services, such as therapeutic interventions. This is illustrated by an excerpt from casenotes:

> *We had to be very clear with the patient's mum about our roles and where we could and couldn't help. We were happy to listen, but were not a counselling service; we were happy 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.*

The level of need found in certain families has highlighted the lack of age-appropriate care and respite for medically complex young adults in the region. This has also highlighted the need to be clear in advance about how the project will support people with concerns around their care provision. This needs to be communicated clearly to patients/families, so that expectations are realistic.

3.0 Conclusion and recommendations

3.1 Conclusion

It is difficult to make a complete set of judgements relating to a project, when it ends prematurely because that additional time may have been developmentally or otherwise important. COVID-19 also clouds the general service delivery environment and has had a major impact on this and on multitude of other services. We are able to make our observations on impact to date on beneficiaries and other community stakeholders who have used the service. The first of these is that the project has positively impacted on professional networks, with medical professionals reporting feeling more confident in providing their services, knowing that there was a coordinating Improving Transitions intervention provided a sense of expertise as well as a coordinating function. The second is that the project has experienced a relatively slow start [NB: as a pilot project, the target numbers only existed as estimations]. However, our research has indicated that there can be a considerable development time necessary to change awareness, confidence and referral practices which was made more difficult by COVID-19. We also know how stressful the experience is for families and how beneficial it can be to have an informed advocate on your side. It was also felt that St Oswald's Hospice was perfectly placed to provide the Improving Transitions Project as it compliments and adds value to existing provision for adults, children and those in transition.

If we return to the original objectives of the project as specified in the original brief, we can see good progress has been made. There is sufficient evidence to indicate that the following objectives are being met:

- We are seeking to improve the quality and efficiency of the support we offer these young people whilst also extending our support to many more young adults who have palliative care needs.
- To improve the young adults' emotional wellbeing/mental health.

- To work more closely and effectively with primary care teams across the North East, liaising with individual doctors, early in the transition process, to ensure consistent, high quality support for any young adult with palliative care needs in their care.
- Providing good quality education, training and information about this patient group for all GPs will improve the support they offer to young people with complex needs.

The project also contributes to St Oswald's Hospice's *Vision 2025* initiative includes a commitment to "*lead the development of palliative care services within the region by working more closely with other organisations."*

3.2 Recommendation

Our recommendations are to continue service provision, and as the repeated suggestion from stakeholders, maintain emphasis on awareness raising and partnership development. There were proposals to embed a continuing focus on awareness raising and communications within project activities, such as preparing project updates/newsletters that can be shared across the region and regular meetings with stakeholders. It was also suggested to ensure awareness raising activities incorporated a variety of areas, as suggested by one respondent:

> *All community, neurodisability, respiratory, spinal, orthopaedic, ENT, neuromuscular, neurology, palliative care paediatricians, oncology, BMT, all GP child health leads, community nursing. Adult physicians - respiratory, Orthopaedic, Neurology, neurorehab, etc. Ensure all parent carer partnerships in the region are aware of the service.*

There were reports by certain stakeholders that there has been sufficient investigation of transition and its related issues and now is the time to create a pathway of care that can be used by GPs to support their patients.

> *A robust pathway of handover to GP whilst linking to [the Improving Transitions Project] will be simple and easy to carry out.*

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