

**An Evaluation of the Implementation of the
10-Steps Transition Pathway to Adult
Services at Alder Hey Children's Hospital**

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A report for Alder Hey Children's NHS Foundation Trust

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Executive Summary

The 10-Steps Transition Pathway to Adult Services at Alder Hey Children's Hospital was developed to improve the process of transition for young people with long-term health conditions moving between children's and adult services.

In February 2017, Edge Hill University in collaboration with the transition team at Alder Hey commenced an external evaluation of the implementation of the 10-Steps Transition Pathway at Alder Hey Children's Hospital as part of a PhD project. The aim of the evaluation was to investigate how the 10-Steps Transition Pathway was being implemented by healthcare professionals across the trust and to identify areas for improvement.

Between July 2017 and January 2019, twenty-six semi-structured face to face and telephone interviews with healthcare professionals involved in the development and/or implementation of the 10-Steps Transition Pathway at Alder Hey Children's NHS Foundation Trust, were undertaken. A qualitative review of programme documentation complemented this. Data were analysed thematically and resulted in three overarching themes: extraneous factors, organisational factors and individual-service level factors that helped to support and/or hinder implementation of the 10-Steps Transition Pathway.

This report highlights key features of the 10-Steps Transition Pathway that were either successfully adopted by practitioners or overlooked, and factors which facilitated and hindered implementation efforts. It concludes with ten key recommendations for practice.

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1. Background

1.1 Transition to Adult Services

Transition has been described as a “purposeful, planned process that addresses the medical, psychosocial and educational and vocational needs of adolescents and young adults with chronic physical, neurodevelopmental and medical conditions as they move from child-centred to adult-orientated health-care systems” (Colver et al., 2019: 23). Transitioning from adolescence into adulthood can be a challenging time for all young people, however for those young people with long-term health conditions the journey can be even more problematic due to changes in the delivery of their care (RCN, 2013; Campbell et al., 2016).

Ensuring that services provide a planned and co-ordinated transition process is a key priority for healthcare organisations (NICE, 2016). Research suggests that young people who experience poor transitions between children’s and adult’s health care services, suffer physically, emotionally, socially and educationally in the long term (DOHSC, 2006). Furthermore, poorly planned and delivered transitions are associated with discontinuity of care (Dogba et al., 2014), risk of non-adherence to treatment (DOHSC, 2006), poor clinical outcomes and increased health care costs (Moore Hepburn et al., 2015) and negative consequences relating to morbidity and mortality (DOHSC, 2006). Effective transitions on the other hand, have been evidenced to lead to improved experiences and long-term outcomes (CYPHOS, 2012).

1.2 The 10-Steps Transition Pathway to Adult Services

Since 2014, Alder Hey Children’s Hospital has embarked on a journey to improve the process of transition for young people with long-term health conditions moving between children’s and adult services. This work stemmed from a Care Quality Commission (CQC) inspection undertaken in May 2014 which identified the need for improvement to transitional services at Alder Hey (CQC, 2014). The 10-Steps Transition Pathway to Adult Services (Appendix A) is central to this process of quality improvement and was developed alongside the Trust Transition Policy through trust wide consultation and engagement (Rogers, Brooks, Aizelwood & Kaehne, 2018). It is a multi-disciplinary, collaborative pathway consisting of multiple interventions aimed at both supporting and facilitating transition for young people, their parents and

carers and professionals in both children's and adult's healthcare services. The pathway incorporates key standards of good practice in transition services (DOHSC, 2008; NICE, 2016), with the aim to standardise transition practice across the trust, improve the process of transition for young people and their families and lead to improved long-term health outcomes.

1.3 Evaluating the implementation of the 10-Steps Transition Pathway

Implementation of the 10-Steps Transition Pathway commenced in 2016. The transition team based at Alder Hey adopted a phased approach to implementation of the 10-Steps Transition Pathway with early implementation efforts being initially targeted to four identified specialities within the trust. In the first twelve months, the transition team worked with Clinical Business Units (CBU) transition leads and transition champions to facilitate implementation. Implementation was then scaled up with the support of the transition team and transition champions to additional specialities within the trust between 2017-2019. Implementation of the 10-Steps Transition Pathway was monitored by the trust transition steering group chaired by the Medical Director and Executive Lead for Transition (Brook & Rogers, 2016).

In February 2017, Edge Hill University in collaboration with the transition team at Alder Hey commenced an external evaluation of the implementation of the 10-Steps Transition Pathway at Alder Hey Children's Hospital as part of a PhD project. The aim of this evaluation was to:

1. Investigate how the 10-Steps Transition Pathway was being implemented by healthcare professionals across the trust;
2. To identify areas for improvement

2. Evaluation methods

2.1 Methodology

A single qualitative embedded case study design informed by Realist Evaluation was employed to evaluate the implementation of the 10-Steps Transition Pathway.

2.2 Methods of data collection

2.2.1 Review of transition pathway documentation

Documents pertaining to the development and implementation of the 10-Steps Transition Pathway were provided by the transition team and reviewed by the researcher. Documents provided insight into the objectives and purpose of the 10-Steps Transition Pathway and highlighted potential facilitators and/or barriers to implementation. This aspect of the evaluation supported the development of the semi-structured interview schedule.

2.2.2 Interviews with key stakeholders

Between July 2017 and January 2019, twenty-six semi-structured face to face and telephone interviews were undertaken with healthcare professionals working for Alder Hey Children's NHS Foundation Trust. Interviews were conducted by an independent researcher from Edge Hill University. Healthcare professionals were purposefully selected based on their involvement in either developing and/or implementing the 10-Steps Transition Pathway.

2.3 Data analysis

Qualitative data from documentation review and semi-structured interviews were analysed thematically using Braun and Clarke's (2006) thematic analysis framework and data management software NVIVO. Data were further subjected to context, mechanism, outcome analysis, which is informed by the study's methodology, realist evaluation. This report describes the main thematic findings from the evaluation.

2.4 Ethical review and governance

The evaluation was granted approval from both Edge Hill University's Faculty of Health and Social Care Research Ethics Committee (FREC) and the Health Research Authority (HRA).

3. Findings

Findings from the evaluation suggest that the work of the transition team and implementation of the 10-Steps Transition Pathway had a significant impact on

transition practice across services within Alder Hey. Practitioners described feeling involved in the change process and supported by the transition team to improve transition processes within services and make changes to their practice. Practitioners recognised the importance of using the 10-Steps Transition Pathway to support young people moving between services and valued the flexibility of the pathway. Practitioners described using the 10-Steps Transition Pathway flexibly alongside existing transition processes and adapting the pathway to meet the needs of their patient group. The active involvement and support of the transition team helped paediatric practitioners to form and improve important relationships with adult providers. These findings are discussed in more detail in the next section of this report.

Findings from the evaluation are structured around three main themes: extraneous factors, organisational factors and individual-service level factors that helped to support and/or hinder implementation of the 10-Steps Transition Pathway.

3.1 Extraneous factors

Extraneous factors are defined as those that are external to the organisation itself yet played an important role in influencing practitioner decision making around implementation of different interventions within the 10-Steps Transition Pathway. Practitioners highlighted three dominant factors external to Alder Hey which impacted on implementation decisions. These are: inter-organisational commonalities and differences, geographical proximity of paediatric and adult hospitals' and funding for transition. These are discussed in detail below.

3.1.1 Inter-organisational commonalities and differences

Similarities in the structure and delivery of services in paediatric and adult organisations was identified as a key enabler of implementation. In services where existing transition processes were well-integrated and relationships with adult services were established, services had a similar structure for the delivery of care. In these services, similar ways of working had been developed over the years and appeared to be motivated by the nature of young people's conditions and their treatment requirements in adulthood. In this context, inter-organisational

commonalities supported practitioner decision making on implementation of the 10-Steps Transition Pathway.

However, practitioners across other services highlighted important inter-organisational differences which affected how they responded to the 10-Steps Transition Pathway. A lack of equivalent adult services, moving between tertiary to non-tertiary hospitals and different approaches taken to supporting patients were commonly raised by practitioners as barriers to transition. Where inter-organisational structures were not in place to support transition, practitioners described feeling ‘disheartened by the lack of services’ and feeling transition was ‘too hard’ to achieve.

Several practitioners’ commented on the nature of paediatric services describing these as more ‘nurturing’, ‘protective’ and ‘supportive’ than adult services. How often young people were able to be seen in adult services compared to paediatric services was further highlighted by practitioners as a key difference. Practitioners suggested that perceived disparities between paediatric and adult services at times generated anxiety for young people, their parents and professionals with practitioners finding it difficult to ‘let go’ of young people. The inter-organisational differences described by practitioners appeared to affect their decision making around implementation of the 10-Steps Transition Pathway. For some practitioners, implementing steps within the transition pathway within their own services was considered to be contra productive if their adult counterparts were not equally collaborating with implementation, and/or inter-organisational structures were absent.

3.1.2 Geographical proximity of paediatric and adult hospitals’

The geographical proximity of paediatric and adult hospitals was identified by several services as both a facilitator and barrier to implementation of joint transition reviews. Joint transition reviews were more likely to be implemented where paediatric and adult services were in close proximity to one another. For young people receiving their adult care out of area, joint transition reviews were less likely to be implemented and transfer rather than transition was more likely to occur. Practitioners suggested joint transition reviews were more feasible and easier to organise where services were in close proximity. Inter-organisational professional networks were also more established between paediatric and adult services that were closely located. Not having

established links with key professional's in out-of-area adult hospitals was one of the main reason given by practitioners as to why it was more difficult to implement joint transition reviews.

3.1.3 Funding

Implementation of joint transition reviews were further affected by the wider financial context of adolescent care. Practitioners across two services commented that adult services were funded to attend joint transition reviews and transition was integrated within adult professionals job roles. As a result, joint transition reviews were more likely to be implemented in services that had existing funding for transition. In contrast, practitioners in services that did not have funding were less likely to implement joint transition reviews and implementation was dependent on the 'good will' and 'motivation' of individual healthcare professional's across both services. In most services, pre-transition joint reviews were more likely to be implemented than post-transition joint reviews. Lack of capacity within teams and in particular resource implications for consultants were given as reasons why post-transition reviews were more difficult to implement.

3.2 Organisational factors

Practitioners highlighted six organisational factors which enabled and/or hindered implementation of the 10-Steps Transition Pathway. These include: well-established, existing transition processes, shared professional values, time constraints, technological challenges, inclusive/partnership approach and service-specific key professionals to co-ordinate transition. These are discussed in detail below.

3.2.1 Well-established, existing transition processes

In some services, existing transition processes were well-established and integrated into usual care. Several practitioners within these services viewed the 10-Steps Transition Pathway as being very similar to and compatible with their established transition processes. Some practitioners discussed the possibility of using the pathway flexibly alongside their own processes, whilst others expressed a preference to remain with existing transition practice. In these services practitioners reported none or fewer changes to their transition practice, however commented that the new pathway had formalised transition practice across the trust.

Alternatively, several practitioners in services that reported having no existing transition process prior to the introduction of the pathway and those whose processes were in place but not as well-established, described considerable changes to their transition practice as a result of the 10-Steps Transition Pathway. Changes to practice included setting up joint transition reviews, changing the way joint transition reviews were delivered to allow adult practitioners to take more of a lead, beginning transition preparation at an earlier stage and introducing planned transition appointments.

3.2.2 Shared professional values

Practitioners across services shared a set of professional values about transition preparation in which it was seen to be an integral part of routine adolescent care. Practitioners reported that conversations to prepare young people for transition were happening from an early age. However, it was evident that in some services transition preparation was being done informally most of the time rather than being recorded using a transition preparation tool or transition plan. Practitioners' ability to implement transition preparation tools were reported to be hindered by time constraints and technological challenges which are discussed below.

3.2.3 Time constraints

Difficulties in using transition preparation tools and transition documents were associated with time constraints. Practitioners across several services commonly reported that the use of transition preparation tools generated extra paperwork which required additional time resources that were not available to support implementation. Practitioners stated that priority was given to discussing the medical aspects of a young person's condition with them over transition preparation during routine clinics which impacted on their use of transition preparation tools.

3.2.4 Technological challenges

In later interviews practitioners also cited technological issues as a common barrier to implementation of transition documents. Practitioners described difficulties associated with locating and using documents on Meditech. Although some practitioners had received training from the IT department, they described feeling

‘confused’ and ‘not understanding’ how to use transition documents. Practitioners also communicated that they felt transition documents needed to be more focused on what young people need to know about transition.

3.2.5 Inclusive partnership approach

The inclusive partnership approach adopted by the transition team to the development, training and implementation of the 10-Steps Transition Pathway was viewed positively by practitioners. Many practitioners described how the transition team had consulted with them and drawn upon their knowledge and experiences of transition. Several practitioners described feeling ‘supported’, ‘valued’ and ‘encouraged’ to move transition practice forward and make changes to improve transition in their service. In particular, the perseverance and dedication of the transition lead nurse was recognised by many practitioners as key to moving implementation of the 10-Steps Transition Pathway forward. Active participation and involvement of practitioners in the change process helped to facilitate high levels of commitment to implement the pathway for some practitioners. However, other practitioners communicated that they felt the transition team required more capacity to be able to accommodate the amount of work required to make significant changes. Additionally, support for the 10-Steps Transition Pathway from senior leadership in Alder Hey was recognised as important, however, a perceived lack of support and ‘buy-in’ from senior managers in adult organisations’ impacted on how practitioners interacted with the 10-Steps Transition Pathway.

3.2.6 Service-specific key professionals to co-ordinate transition

The 10-Steps Transition Pathway and transition training delivered to practitioners emphasised the importance of identifying a transition key worker to co-ordinate transition. However, difficulties in identifying who the key worker would be, particularly when multiple services were involved, were often reported by practitioners across services. It was also suggested by some practitioners that it was not clear in the transition pathway who should take on responsibility for this.

Two services had identified key workers who would be responsible for co-ordinating transition. In these services, transition was more defined as part of their job roles. However, they were not given any additional resources, such as time for transition. There were also differences between these services and others which included smaller

numbers and existing transition processes which made the key worker role more achievable. Some practitioners reported that they were reluctant to take on the key worker role when it was not formally part of their job role and time was not allocated for transition tasks.

3.3 Individual-service level factors

Practitioners highlighted five individual-service level factors that were important to the implementation of the 10-Steps Transition Pathway. These are: perceptions of transition and the 10-Steps Transition Pathway, motivation and interest in transition, use of professional autonomy and agency to benefit young people, collaborative relationships between individual practitioners across paediatric and adult services and improved knowledge and changes to practice resulting from the 10-Steps Transition Pathway. These are discussed in detail below.

3.3.1 Perceptions of transition

In some services, practitioners perceptions of transition, transition programmes and a perceived lack of engagement from adult services acted as a barrier to implementation of the 10-Steps Transition Pathway. Previous experiences of using different transition pathways that were viewed negatively affected how some practitioners regarded the new transition pathway. A number of practitioners described feelings of frustration due to what they perceived to be a lack of engagement from adult services in relation to transition. Feeling that adult services were not cooperating with the transition pathway impacted negatively on some practitioners decision making about implementation. Furthermore, practitioners in one service described difficulties around getting all professionals in their own service to support the 10-Steps Transition Pathway. Practitioners expressed that the 10-Steps Transition Pathway had not been received positively by senior clinical team members in their service and this directly affected how they implemented the pathway. However, it is important to note that senior clinical team members in this service were not interviewed as part of this study. Findings in relation to this are therefore based on the perceptions of practitioners.

3.3.2. Motivation and interest in transition

Individual motivation and commitment of practitioners across both paediatric and adult services supported implementation of the 10-Steps Transition Pathway, and in particular, joint transition reviews. As previously discussed in this report, joint transition reviews were sometimes dependent on the motivation and good will of individual healthcare professionals from both sectors. In one service, a practitioner communicated that joint transition reviews would not happen if it were not for individual professionals from the adult sector who were committed and motivated to make changes. However, they recognised the dangers in relying on singular individuals and described how joint transition reviews in their service were not always possible as they depend on the availability of one consultant in one adult service. This was not the same for services who had well-established, existing transition processes, shared inter-organisational commonalities and funding to support transition. In these services, joint transition reviews were more embedded in routine transition practice.

3.3.3 Use of professional autonomy and agency to benefit young people

In most services, practitioners described value in using the 10-Steps Transition Pathway with some young people. Decisions to use interventions within the pathway, such as transition tools and documents, were determined by practitioners perceptions of the young person's needs rather than the process itself. Perceptions of individual needs were however informed by information provided by the young person themselves and their families as well as professionals knowledge and understanding of the young person's condition. Individualised, person centred approaches were at the heart of professional decision making with regards to implementation of the 10-Steps Transition Pathway

Many practitioners commented on the relevance of transition preparation tools and transition documents to those young people who had fewer complex needs. In some instances, practitioners reasoned that not all young people would require a transition preparation tool and decisions to use the tool should be determined by the needs of the individual. In services with well-established transition processes, practitioners communicated that 'Ready, Steady, Go' was not condition-specific enough to their patient group and they continued to use their own transition preparation tools or used it alongside their own tools. Practitioners across most services expressed their agency

choosing to use the pathway flexibly, prioritise and adapt tools/documents based on perceived relevance and 'benefit' to each individual. The flexible design of the 10-Steps Transition Pathway supported this.

In some instances, practitioners expressed that they were unable to 'see the benefit' of implementation and exercised their professional autonomy in not implementing certain steps within the pathway. An example of this is a practitioner who noted that they did not 'see the advantage' of using the transition exception register as they did not feel it 'would bring value to the patient's care'.

3.3.4 Collaborative relationships

Collaborative relationships formed between professionals across paediatric and adult services were highlighted by multiple practitioners as an important factor that supported implementation. Practitioners had developed good relationships with their adult colleagues in local hospitals that pre-dated the introduction of the 10-Steps Transition Pathway. Relationships with adult professionals from out-of-area were however not well-established which impacted on implementation. For services that did not have funding to support transition, relationships were driven more by the individual motivations and interests of professionals in paediatric and adult sectors. For one service in particular, the introduction of the 10-Steps Transition Pathway had helped them to establish a vital relationship with a key professional in adult services.

Practitioners in services who reported having good, well-established relationships with their adult counterparts further communicated how they were able to use joint transition reviews to work collaboratively with their adult colleagues. Joint transition reviews supported the sharing of information between professionals, education, contact and engagement, which in turn resulted in paediatric practitioners having an increased sense of confidence and trust in their adult colleagues. For some practitioners having trust and confidence in adult professionals provided a good message to young people and their parents supporting them to develop trust and confidence in adult services.

A few practitioners reported poor or strained relationships with adult professionals. They appeared to result from issues associated with communication. This affected the

establishment of trust and confidence that was evident in services who described having strong relationships with their adult colleagues.

3.3.5 Improved knowledge and changes to practice

Improved knowledge and changes to practice were key outcomes reported by practitioners across services. Practitioners frequently stated that transition training had made them more aware of transition thus improving their knowledge. A few practitioners stated that their knowledge of a young person's route into urgent care had improved as a result of the training offered. Whereas for other practitioners improved knowledge related to having a better understanding of where young people fit in to transition and what healthcare professionals should be doing to ensure that young people are fully involved. For many, the visual pathway diagram supported this by providing structure and guidance. Several practitioners communicated that transition training had enabled them to reflect on their practice to identify where the gaps were within their services and what they needed to improve on. In some services, multi-disciplinary team (MDT) meetings were being used as a platform to share learning and discuss implementation of the transition pathway. Staff in these services reported that they felt better informed about where implementation efforts were up to as a result of MDT discussions.

One of the most common changes reported by practitioners across several services was starting to identify and prepare young people for transition at an earlier age. In many services, transition training had further supported practitioners to either establish joint transition clinics or change the way in which they were delivered. In one service, practitioners had identified the need to make their transition clinics more MDT focused, whilst in another, one practitioner had requested additional time for transition clinics. In a different service joint transition clinics were changed in order for adult sector professionals to take more of a leading role. Further changes to practice included changing the structure of appointments with young people to ensure that young people were offered the opportunity to be seen without their parents in preparation for adulthood.

3.4 Summary of findings

Key findings:

1. The work of the transition team supported implementation of the 10-Steps Transition Pathway which had a significant impact on transition practice across services within Alder Hey
2. The active involvement and support of the transition team helped paediatric practitioners to form and improve important relationships with adult providers
3. Similarities in the structure and delivery of paediatric and adult services supported implementation whilst inter-organisational differences created a barrier which affected how practitioners responded to the 10-Steps Transition Pathway
4. Joint transition reviews were more likely to be implemented where paediatric and adult organisations were in close proximity to one another
5. Funding supported implementation of joint transition reviews in some services, however in others implementation was dependent on the 'good will' of individual healthcare professional's across both services
4. The 10-Steps Transition Pathway had more of an impact in services with no pre-existing or less-established transition processes
5. Transition preparation forms an integral part of routine adolescent care, however conversations are not always recorded formally through the use of a transition preparation tool or plan
6. Time resources were not always in place to support implementation of transition preparation tools and documents
7. Technology created a barrier for practitioners when accessing and using transition documents on Meditech
8. Active participation and involvement of practitioners in the change process facilitated high levels of commitment to implement the pathway

Key findings:

9. Practitioners experienced difficulties in identifying key workers to co-ordinate transition
10. A perceived lack of engagement from adult services impacted negatively on practitioner decision making in some services
11. Practitioners expressed their agency choosing to use the pathway flexibly, prioritise and adapt tools/documents based on perceived relevance and 'benefit' to each individual
12. Collaborative relationships between paediatric and adult professionals supported implementation of joint transition reviews
13. Transition training improved practitioners knowledge of transition and facilitated changes to practice across services

4. Conclusion and recommendations

This report has described how the 10-Steps Transition Pathway is being implemented by practitioners across Alder Hey Children's NHS Foundation Trust to improve the process of transition for young people. The extensive work carried out by the transition team and the support provided to practitioners has been recognised as having a significant contribution to changes made to transition practice across services within the trust. Extraneous, organisational and individual-service level factors that help to support and/or hinder implementation of the 10-Steps Transition Pathway have further been highlighted. Findings discussed in the previous section of this report indicate several clear recommendations for practice. These are stated below:

- Continue to improve networks with adult organisations, particularly those that are outside of the local area, utilising the training and implementation of the 10-Steps Transition Pathway
- Consider the earlier involvement of adult organisations in implementation of the 10-Steps Transition Pathway
- Consider undertaking joint transition reviews online for young people who are transitioning to an out-of-area adult service
- Continue to work with commissioners from adult organisations to evidence the need for additional funding to support the implementation of joint transition reviews
- Ensure that practitioners are made aware of the importance of recording conversations that take place as part of transition preparation
- Consider the additional time resources that practitioners require to effectively use transition preparation tools and documents with young people
- Assess the workability of transition documents built onto Meditech through consultations with practitioners and young people using them to identify: a). are they specific enough to what young people need to know about transition and b). do practitioners know where to find them and how to use them appropriately?
- Consider using service specific transition co-ordinators who work across both Alder Hey and adult organisations. If this is not feasible, support practitioners to identify who should fulfil the transition key worker role in each service,

providing additional time for practitioners to fulfil their responsibilities within their current job roles

- Through consultation with practitioners, review current internal barriers to transition within teams who do not have well-established transition processes
- Consider making transition training mandatory for practitioners across Alder Hey and extending the offer to key practitioners in adult organisations

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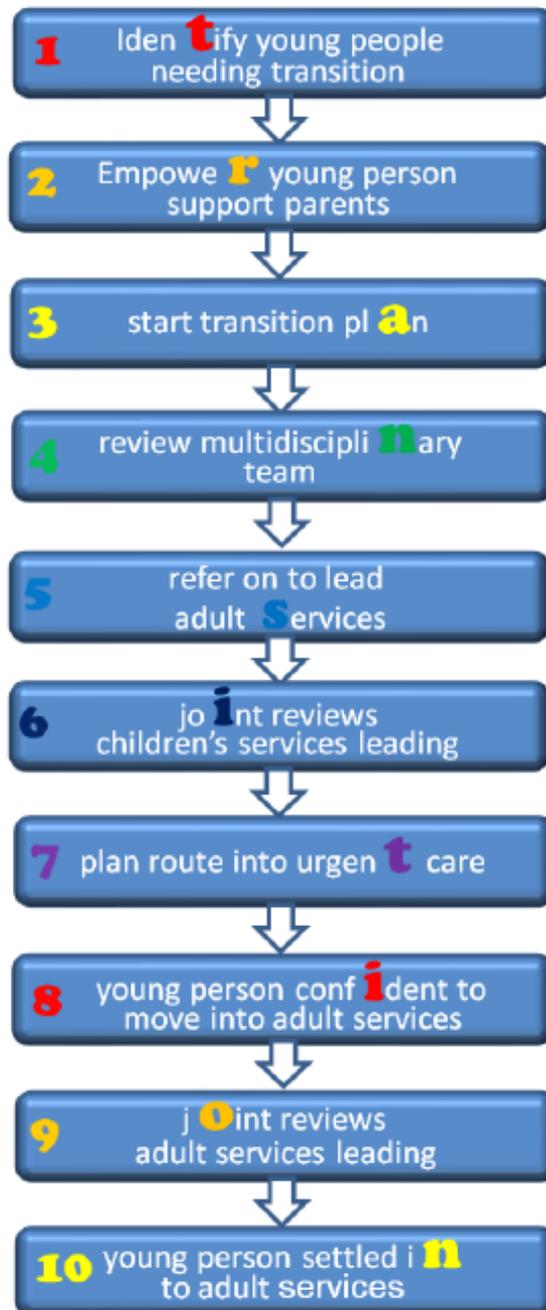
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Appendix A: 10-Steps Transition Pathway to Adult Services



10 Steps Transition Pathway Transition to adult services for young people with long term conditions



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University
