

Transition from children's to adult services for young adults with life-limiting conditions in Ireland

Recommendations from an all-Ireland stakeholder workshop

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Executive summary

In September 2016 more than 80 people, including young adults with life-limiting conditions, their families, service providers and policy makers from all parts of Ireland, met in Newry, Northern Ireland to consider the challenges faced by young adults making the transition from children's to adult services, and to agree priorities for action. The workshop was led by Dr Helen Kerr with Dr Peter O'Halloran. Delegates heard presentations by a young adult with a life-limiting condition; from a parent of a young adult; from Richard Whateley, Together for Short Lives Transition Taskforce and also a summary of research recently completed by Dr Kerr, in the island of Ireland. This research is outlined further in the evidence brief on page 5.

This research, carried out between 2012 and 2016 by researchers from Queen's University Belfast¹, Trinity College Dublin², and Kingston University London³, identified key interventions and processes that contribute to a more effective transition from children's to adult services. The participants in the workshop were asked to consider the findings from the research, to add to them if necessary, and then to rank them in order of importance.

Participants met in nine groups of about nine people, each with a facilitator, to discuss the research. The groups were as follows:

- Young adults and parents/carers
- Medical staff
- Service providers in specialist palliative care roles
- Allied health care professionals
- Nurses (three groups)
- Range of service providers including those from the non-statutory sector and commissioners (two groups)

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Each group ranked the interventions and processes in order of importance, and these rankings were combined to give an overall result from the whole workshop. The key priorities for action identified are:

1. Effective communication, cooperation and commitment to joint working between children's and adult services
1. Engagement of a transition coordinator
3. Interdisciplinary and interagency joint working
4. Person-centred approach to care being demonstrated by service providers
5. Involvement of parents/carers
6. Early commencement to the transition process
7. Developing the young adults' autonomy throughout the transition process
8. Orientation of young adults to adult services

Reflection on the Transition workshop

Whilst there was broad agreement on the nature of the key interventions, the differences in order of priority between stakeholder groups was illuminating. The young adult and parent/carers group identified the employment of a transition coordinator and the development of the young adults' autonomy as the highest priorities. On the other hand, the overall consensus – in which service providers greatly outnumbered young adults and their families – prioritised effective communication and collaboration between children's and adult services, employment of a transition coordinator, and interdisciplinary and interagency joint working. This difference is consistent with the two broader models of successful transition emerging from the research, outlined later in this report: one focused on adult and children's service providers communicating and collaborating, with the help of a transition coordinator who fosters a sense of confidence among adult service providers that they can manage the complex care of the young adult, and empowers them to make the necessary preparations in terms of facilities and staff training; the other focused on the young adults, with service providers collaborating to develop an autonomous young adult, whilst actively involving parents/carers. Of course, these models are not mutually exclusive in that a

knowledgeable, confident young adult who is growing in decision-making abilities is best placed to take advantage of services – but only if those services are properly resourced and run by staff with appropriate skills.

It is also worth noting that – unlike other groups - specialist palliative care providers ranked an early commencement to the transition process as the second most important priority. This may reflect their appreciation that planning for increasing support as a young adult's condition deteriorates is best done over time and well in advance so that personal and practical arrangements can be made.

The role of parents/carers in the transition process was not seen as the highest priority by young adults or by parents/carers themselves. This may reflect the invisibility of the parental role, even to those most closely involved. In our research we found young adults greatly valued both practical and emotional support from their parents, and that parents were alive to the challenges of transition, often before professionals. Service providers, on the other hand reported that some parents/carers had difficulty ceding control to the young adult. This indicates a need for conversations amongst all parties, clarifying goals and expectations around the degree of autonomy that is desirable and practical for the young adult, and how parents can continue to support the young adult throughout the multiple changes entailed in the transition period.

Workshop evaluations

Those attending the workshop were asked to complete evaluations. Overall, the Transition workshop was evaluated very positively. In response to the question 'How useful was the workshop in providing information on interventions related to an effective transition to adult services?', 93% of responses indicated either useful or very useful. In response to the question 'How useful was the workshop in developing the key priorities of action related to an effective transition to adult services?', 96% of responses stated either useful or very useful.

Evidence brief

This research was completed in 2016 by Dr Helen Kerr as part of a Doctoral Fellowship. The research was supervised by Dr Peter O'Halloran, Queen's University Belfast; Dr Honor Nicholl, Trinity College Dublin and Professor Jayne Price, Kingston University London.

Why did we start the research study?

Improvements in care and treatment have led to more young adults with life-limiting conditions living beyond childhood which means they must make the transition from children's to adult services. The transition process can be a very stressful time for young adults with reports of unmet needs. There are reported risks associated with a poor transition related to risk of non-adherence to treatment and loss to follow up. Despite reports to suggest good transition programmes can improve outcomes, there is a lack of evidence on transition services in palliative care, with few models of good practice identified.

What did we do?

We sought to identify the factors associated with an effective transition from children's to adult services for young adults with life-limiting conditions on the island of Ireland. The process commenced with a realist literature review which identified the factors associated with an effective transition from children's to adult services (Kerr *et al.*, 2017). A mixed methods design was used with four phases of data collection. The first phase involved the development and distribution of a questionnaire survey to statutory health, social and educational organisations and organisations in the non-statutory sector known to be providing services to young adults with life-limiting conditions making the transition from children's to adult services. The survey sought to establish a picture of what transition services exist. The second phase involved interviews with young adults and the third phase comprised of focus groups with parents/carers. The final phase of data collection involved interviews with service providers from statutory and non-statutory organisations.

What answers did we get?

- Eight interventions were identified considered to contribute to an effective transition from children's to adult services for young adults with life-limiting conditions.
- A range of enabling contextual factors were uncovered considered to influence the effectiveness of these interventions.
- Possible responses triggered in individuals when interventions are introduced were identified which may also influence whether interventions are effective.

- Intended outcomes associated with an effective transition from children's to adult services was outlined.
- The eight key interventions underpin two complementary models for successful transition; one focused on adult and children's service providers; the other on young adults and their parents/carers.

What should be done now?

- Research should be undertaken on the development and evaluation of transition interventions identified as the key priorities of action at the Transition workshop.
- Regional transition guidelines should be developed which translate these research findings into practice.
- Service providers should review their organisational environment to ensure effective use of current resources in light of the factors considered to promote an effective transition to adult services, outlined in this research.

Background to the research study

Transition from children's to adult services for young adults with life-limiting conditions has emerged in the last decade as a significant health and social care issue. This is due to a growth in the number of young adults with life-limiting conditions graduating from children's services and needing to make the move into adult services. The improved survival of young adults with life-limiting conditions is as a result of improvements in the early detection and medical advances in a range of life-limiting medical conditions (Fraser *et al.*, 2011; Schwartz *et al.*, 2011; Scott, 2011; Department of Health (DoH), 2006).

A commonly used definition for the transition from children's to adult services is the "purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems" (Blum *et al.*, 1993, p. 570). The limited data available suggests that young adults with life-limiting conditions are still not receiving the preparation they need throughout the transition process (McManus *et al.*, 2013). Unmet needs include a lack of emotional support (Kirk and Fraser, 2014), deficiency of information (Kirk, 2008), challenging issues related to inpatient experiences (Beresford and Stuttard, 2014) and a loss of services such as short breaks when in adult care (Noyes *et al.*, 2014). A poorly planned transition is associated with measurable adverse outcomes in a range of medical conditions such as an increased risk of non-adherence to treatment, loss to follow-up and unmet needs, in addition to social and emotional outcomes (Sloper *et al.*, 2010; Annunziato *et al.*, 2007; DoH, 2006). Difficulties throughout the transition to adult care can be so acute for young adults that a report in the United Kingdom (UK) characterised their transition experience as one of a "cruel and arbitrary division of services" (Marsh *et al.*, 2011, p. 8). It is reported that many organisations have yet to respond to the need to provide effective evidence based interventions which lead to positive outcomes (Care Quality Commission, 2014, Marsh *et al.*, 2011), making the transition from children's to adult services a growing concern. The limited evidence available suggests good transition programmes can improve outcomes such as higher satisfaction, improved perceived health status, increased independence/self-management ability and disease specific educational needs being met (Mackie *et al.*, 2014; Chaudhry *et al.*, 2013). However, a systematic review identified an acute lack of evidence on transition services in palliative care, with few models of good practice (Doug *et al.*, 2011).

PPI involvement

A research advisory group was formed in the planning stages of this research. Membership included a young adult with a life-limiting condition, a parent, clinicians, academics and researchers. Advice and guidance was sought from this group throughout the research study such as forwarding the newly developed questionnaire for feedback and advice on sensitive terminologies to use.

Aims of the research study

To identify the organisational factors, and interactions between factors, involved in promoting or hindering an effective transition from children's to adult services for young adults with life-limiting conditions.

Methods

Ethical approval

Ethical approval was secured from the Office of Research Ethics Committee, Northern Ireland (ORECNI) and from a range of organisations in which data collection was undertaken, both in the Republic of Ireland (RoI) and Northern Ireland (NI).

Setting

A realist evaluation approach using a mixed methods design was adopted with four phases of data collection throughout the island of Ireland. The island of Ireland includes two jurisdictions: the RoI and NI. The RoI has 32 counties with an approximate population of 4.59 million and NI has six counties with an approximate population of 1.83 million (Northern Ireland Research and Statistics Agency, 2014). Each has their own separate governments, health and social care systems and organisational infrastructures. In the RoI, health and social care services are delivered through the Health Services Executive (HSE) in four geographical locations: Dublin North-East, Dublin Mid-Leinster, Southern, and Western (HSE, 2015). In NI there are six Health and Social Care Trusts (HSCT)s: Belfast HSCT, South Eastern HSCT, Southern HSCT, Northern HSCT, Western HSCT and the Northern Ireland Ambulance Service. The former five HSCT's provide integrated health and social care services in five geographical locations throughout NI and the Northern Ireland Ambulance Service provides services across all of NI.

Phases of data collection

The first phase of data collection involved the development and distribution of a questionnaire survey to statutory health, social and educational organisations and also organisations in the non-statutory sector, known to be providing transition services to young adults with life-limiting conditions. Forbes *et als.* (2002) five item survey questionnaire was used as a basis for the development of a new 21 item questionnaire which reflected the developments in transition services from 2002. The aim of this questionnaire survey was to secure a picture of what transition services exist in the island of Ireland. The questionnaire was distributed in the North-East HSE area in the RoI and throughout NI.

The second phase of data collection involved interviews with young adults with life-limiting neuromuscular conditions aged 18-24 years. The third phase of data collection involved two focus groups with parents/carers of young adults with a life-limiting neuromuscular condition, one in the RoI and one in NI. The final phase of data collection involved

interviews with service providers from statutory and non-statutory organisations. Phase two, three and four, involved data collection throughout the island of Ireland.

In using a realistic evaluation approach, in addition to the identification of interventions, contextual factors were also identified that were considered to influence whether the interventions were effective. This approach also facilitated the identification of the responses triggered within individuals as a result of the interventions, which was also considered to have an influence on the effectiveness of interventions. A realist literature review was completed in advance of data collection which identified a range of factors associated with an effective transition to adult services for young adults with life-limiting conditions (Kerr *et al.*, 2017).

Findings

Sample characteristics

Data collection was undertaken in four phases between April 2014 and March 2015. 104 individuals from 29 organisations participated in the survey questionnaire. Eight young adults participated in interviews, six in the RoI and two in NI; ten parents/carers participated in two focus groups, seven in the RoI and three in NI, and 17 service providers participated in interviews; eight in the RoI and nine in NI.

Eight interventions were identified associated with an effective transition from children's to adult services for young adults with life-limiting conditions in Ireland. Enabling contextual factors were also uncovered which were considered to influence outcomes associated with an effective transition to adult services. Reactions triggered in individuals in response to interventions were also deduced. Finally, intended outcomes were identified related to an effective transition to adult services.

Intervention one: Early commencement to the transition process

An early commencement works by bringing the coming change to the attention of all those involved and provides an opportunity for a phased and gradual approach to the transition process. However, although an early commencement is necessary it is not sufficient as it must be paired with the effective use of the time in particular ways. This includes, but is not limited to, consideration of the range of interventions outlined in this research.

Despite support for an early commencement each group of participants (young adults, parents/carers and service providers), it was reported an early commencement was not always available with a reluctance demonstrated by some children's service providers to commence the transition process early. This reluctance may, in part, be as a result of children's service providers having a lack of confidence that equivalent adult services are

available and capable of providing continuity of care when the young adult transfers to adult services.

Responses from service providers in the survey questionnaire highlighted the age range to commence the transition process in the RoI was 12-19 years and in NI, 12-18 years.

Intervention two: Effective communication, cooperation and commitment to joint working between children's and adult services

This intervention works by facilitating the passage of information from children's to adult services on the evolving needs of the young adult. With this information, adult services can assess and prepare an environment that is capable of providing continuity of care for the young adult when they transfer to adult services.

In this research, young adults reported the consultant appeared well informed of their circumstances at their first appointment in adult services, indicating for them there was effective communication between services. Parents/carers agreed that communication between children's and adult services in education was effective, however they reported that communication between children's and adult services in health care could be improved.

There were also issues reported by some children's service providers in identifying relevant adult services to transfer the young adult to, in addition to a reluctance demonstrated by some service providers in adult services, to engage early in communication with children's services. This reluctance delayed the passage of information regarding the young adults' needs, potentially leading to an adult service that was not ready to provide continuity of care when the young adult transferred to adult services. Service providers in children's and adult services shared the reluctance for adult service providers to engage early may be, to some extent, due to staff in adult services having a lack of experience and knowledge in caring for a range of complex medical conditions.

Intervention three: Orientation of the young adult to adult services

This intervention works by commencing an induction and socialisation process for the young adult contributing to an early connection with the unfamiliar environment of adult services.

In this research, young adults recognised the potential value of orientation strategies such as meeting with adult staff and visiting the adult service environment in advance of the transfer to adult services, although, only one young adult in this research reported the availability of these two orientation strategies. However, a number of service providers shared a range of orientation initiatives used in practice such as the availability of transition

clinics or farewell visits in which the young adult returned to children's services to bid farewell following their first visit at adult services.

Intervention four: The engagement of a transition coordinator

A transition coordinator role works as a patient advocate by using their knowledge of the availability and organisation of services to gain the attention of relevant service providers to engage and mobilise new services in the adult environment.

In most organisations, transition responsibilities were an extension of service providers' roles, however, in NI it was reported there were a number of dedicated transition coordinator posts employed in the statutory and non-statutory sector. Services providers in which transition responsibilities were an extension of their role reported time to fulfil the responsibilities of the role was a challenge.

Intervention five: Interdisciplinary and interagency joint working

This intervention relates to disciplines and agencies providing specialist services that are used to assess and manage the young adults' range of needs. This is considered to trigger an increase in the young adults' confidence that their range of needs will continue to be met, leading to their continued engagement throughout the transition process.

In this research study, it was reported that in addition to statutory organisations preparing the young adult for the transition to adult services, a number of non-statutory organisations were reported by young adults and parents/carers to provide specific transition support in both the RoI and NI, which was very much valued.

Young adults, parents/carers and service providers also shared the role of the General Practitioner (GP) was marginalised while the young adult was in children's services and this was reported, to some extent, to be due to the direct access young adults had to specialist statutory services while in children's services. As this direct access is not available when the young adult moves into adult services, the role of the GP is then called upon.

Intervention six: Developing the young adults' autonomy throughout the transition process

This intervention relates to preparing and facilitating the development of the young adults' autonomy so they can increasingly take over responsibility for their own health care management. As there is an expectation in the adult environment of an independent autonomous young adult, increasing autonomy is considered to be an indicator of transition readiness.

In this research, young adults and parents/carers spoke at length about the importance of the development of the young adults' autonomy throughout the transition process. However, one parent stated that despite promoting her sons' autonomy with regards independent living, the young adult preferred to continue to live at home with his mother, highlighting it may not be the desire of all young adults to live independently. Therefore, developing the young adults' autonomy must be considered in the context of what the young adult is not only capable, but also interested in achieving.

Overall, there was a consensus from young adults and parents/carers that throughout the transition process the development of the young adults' autonomy could be focused on more by service providers. However, in contrast service providers considered they did contribute to the development of the young adults' autonomy. This dichotomy may reflect that service providers are not being transparent to young adults and their parents/carers regarding the reasons for the strategies they have introduced to promote the young adults' autonomy. Some service providers suggested that some parents/carers could be a barrier in the development of the young adults' autonomy due to perceived challenges in increasingly ceding control to facilitate the young adult becoming more independent.

Intervention seven: A person-centred approach to care being demonstrated by service providers

A person-centred approach contributed to the young adult feeling listened to and valued, implicitly communicating a message of their central and influencing position in their care, contributing to their engagement in the transition process.

In this research, there was universal agreement across participants of the need to demonstrate a person-centred approach to care, however, although service providers reported this approach was adopted in practice, some young adults and parents/carers reported it was not always their experience. In this research, this appeared to be, in part, due to different interpretations of what a person-centred approach involved between service providers, young adults and parents/carers, highlighting the importance of service providers being aware of the young adults' perspectives of this approach.

Intervention eight: Involvement of parents/carers

Parents/carers provided a consistent and reliable source of practical and emotional support to the young adult, over a time of multiple changes throughout the transition process.

In this research, service providers shared the importance of the parents/carers ongoing involvement in supporting the young adult, both emotionally and practically, as they transition to adult services. Service providers also acknowledged that parents/carers also experience a transition as they move on from the support they have received from the long standing relationships with children's service providers over many years.

Findings: Enabling contextual factors

There was a range of enabling contextual factors that were identified that could influence the effectiveness of the eight interventions. These included;

- The availability and early engagement of relevant adult services who are committed to communicating with children's services throughout the transition process which should contribute to preparing an environment with adequate resources and skilled staff to provide continuity of care for the young adult.
- Children's service providers having knowledge of the differences in the culture, philosophy, organisation and availability of services in adult care so they can effectively commence the orientation process for young adults and their parents/carers prior to the transfer to adult services.
- A transparent approach from service providers regarding the motivations behind strategies to promote the young adults' autonomy.
- Consideration of the young adults' capability and interest in engaging in transition related activities including strategies to promote their autonomy.
- Service providers possessing knowledge of the person-centred approach to care which includes insights into the young adults and parents/carers expectations of how this approach should be delivered.
- The need for the availability of time for service providers to engage in implementing the interventions associated with an effective transition.

Findings: Responses triggered by interventions

The reactions within individuals in response to the interventions that were deduced from the data included;

- The young adult experiences a growing sense of confidence, self-efficacy and empowerment in taking increasing responsibility for their own medical management, contributing to a growing sense of ownership of their journey into adult services.
- Service providers in adult services also experience an increasing sense of empowerment as a result of being in possession of information from children's services related to the young adults' needs, in advance of their transfer.
- Parents/carers also feel more empowered as a result of continued involvement in supporting the young adult, as a result of continued access to relevant information throughout the transition process.

Findings: Two complementary models for successful transition

The inter-relationships between the eight key interventions produced two complementary models for successful transition; one focused on adult and children's service providers communicating and collaborating with the help of a transition coordinator who fosters a sense of confidence among adult service providers that they can manage the complex care of the young adult, and empowers them to make the necessary preparations in terms of facilities and staff training (Figure 1.); the other on the young adults, with service providers collaborating to develop an autonomous young adult, whilst actively involving parents/carers (Figure 2.). These models interact in that a knowledgeable, confident young adult who is growing in decision-making abilities is best placed to take advantage of services – but only if those services are properly resourced and run by staff with appropriate skills.

Figure 1.
Preparing health and social services for successful transition: an integrated model

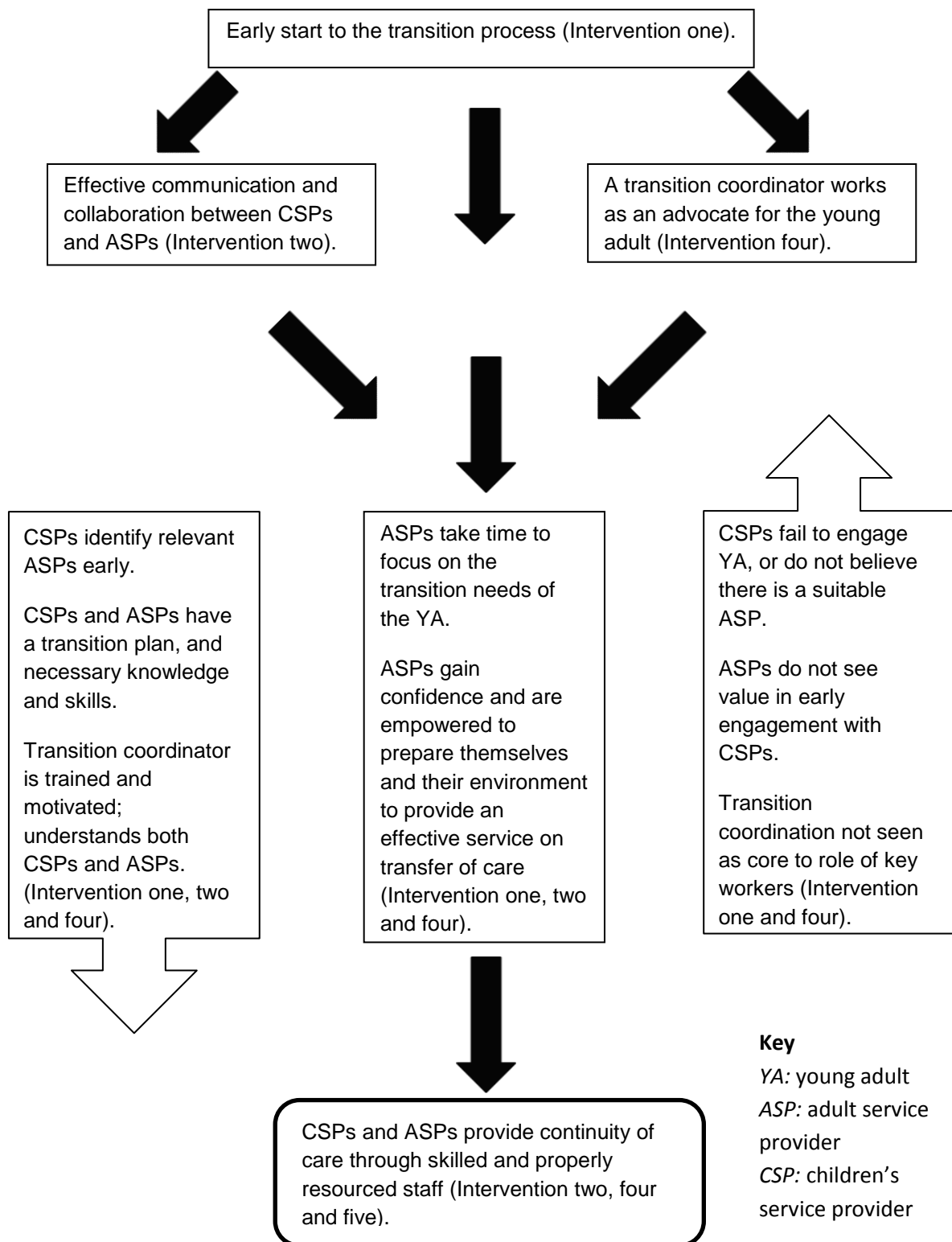
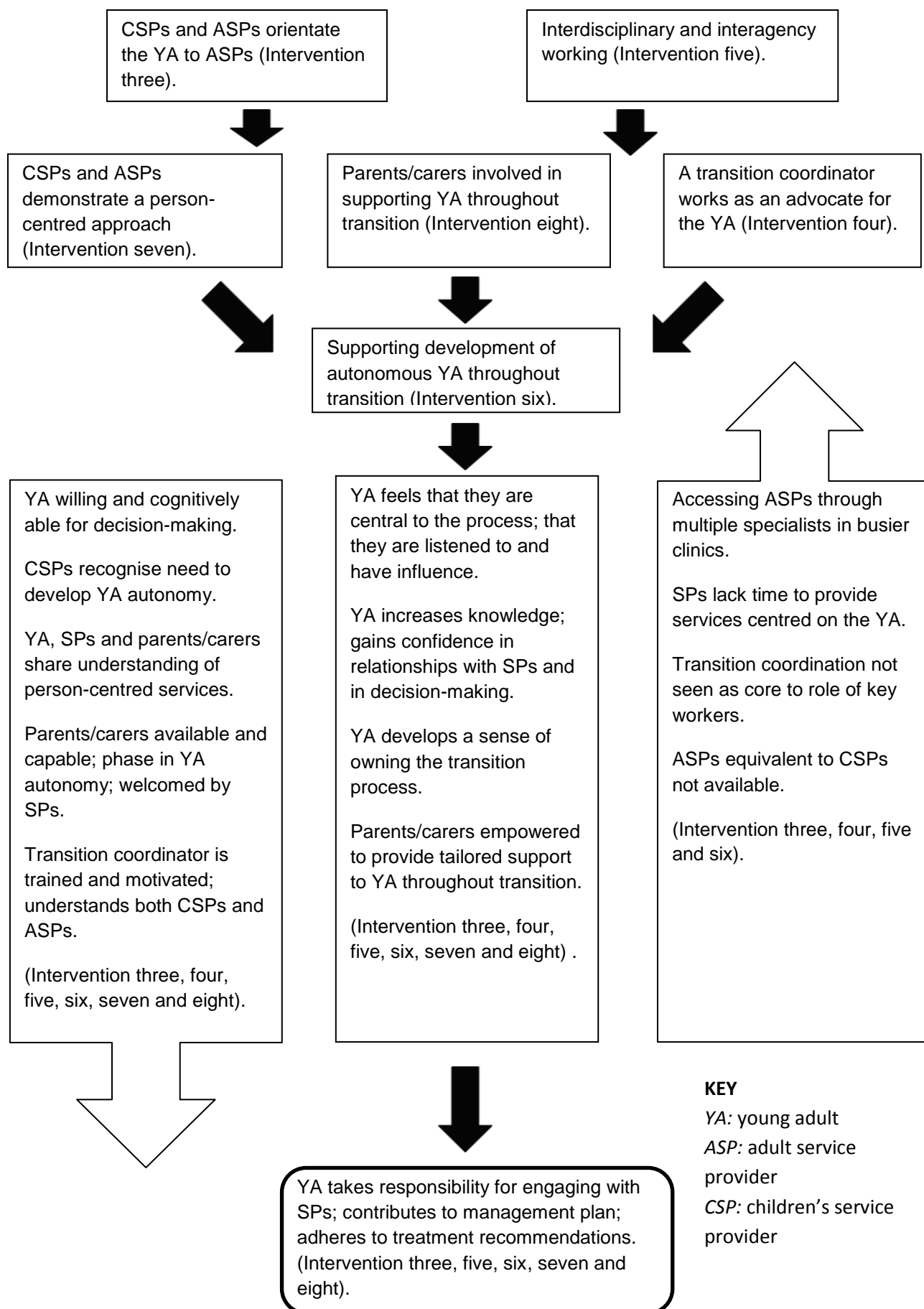


Figure 2.

Preparing a young adult for a successful transition: an integrated model



Recommendations

- Regional guidelines should be developed which translate these research findings into practice. A working group was established in 2016 to develop these guidelines with membership including Helen Kerr and representation from the statutory and non-statutory sector.
- Service providers should review their organisational environment to ensure effective use of current resources in light of the factors/interventions outlined in this research related to an effective transition to adult services.
- Service providers should consider evaluating interventions considered to lead to effective outcomes in the transition to adult services for young adults with life-limiting conditions.
- A template for an individualised, interdisciplinary and interagency transition plan should be developed in relevant organisations which show consideration for the eight key interventions and influencing contextual factors.
- A regional review of services should be undertaken in both jurisdictions to explore the range of potential organisations in adult care that young adults with life-limiting conditions could be referred to.
- Service providers in adult services should be educated on a range of chronic medical conditions that were previously not cared for in adult services to address any knowledge deficit.
- Organisations should develop a transition policy with regular reviews that reflect ongoing developments in the transition agenda.

Conclusion

An effective transition to adult care should be seen as a core responsibility for both children's and adult service providers, however, as transition is an emerging issue, organisations are in the process of responding to the need to develop services to ensure an effective transition to adult services is the experience for all young adults with life-limiting conditions. This research has thrown light on factors related to an effective transition and those attending the Transition workshop progressed these findings in the identification of the key priorities of action in the island of Ireland. It is evident that no single intervention or stakeholder group can guarantee a successful transition. Rather, service providers should take a diagnostic approach, working between services and with young people and their families to understand and address the interaction of human and organisational factors that are likely to produce a successful, person-centred transition in their particular context.

Recommendations have been made for further research and organisations on how to move forward in improving services.

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