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Programme theory developed from a mixed methods realist evaluation

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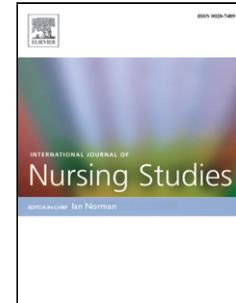
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**Title:**Facilitating Transition from Children's to Adult Services for Young Adults with Life-limiting conditions (TASYL). Programme theory developed from a mixed methods realist evaluation.

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**Background:** Improvements in care and treatment have led to more young adults with life-limiting conditions living beyond childhood, necessitating a transition from children's to adult services. Given the lack of evidence on interventions to promote transition, it is important that those creating and evaluating interventions develop a theoretical understanding of how such complex interventions may work.

**Objectives:** To develop theory about the interventions, and organisational and human factors that help or hinder a successful transition from children's to adult services; drawing on the experience, knowledge, and insights of young adults with life-limiting conditions, their parents/carers, and service providers.

Design: A realist evaluation using mixed methods with four phases of data collection in the island of Ireland. Phase one: a questionnaire survey of statutory and non-statutory organisations providing health, social and educational services to young adults making the transition from children's to adult services in Northern Ireland and one Health Services Executive area in the Republic of Ireland. Phase two: interviews with eight young adults. Phase three: two focus groups with a total of ten parents/carers. Phase four: interviews with 17 service providers. Data were analysed seeking to explain the impact of services and interventions, and to identify organisational and human factors thought to influence the quality, safety and continuity of care.

Results: Eight interventions were identified as facilitating transition from children's to adult services. The inter-relationships between these interventions supported two complementary models for successful transition. One focused on fostering a sense of confidence among adult service providers to manage the complex care of the young adult, and empowering providers 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. 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.

No single intervention or stakeholder group can guarantee a successful transition. Rather, service providers could work with young adults and their parents/carers to consider desired outcomes, and the range of interventions, in light of the organisational and human resources available in their context. This would allow them to supplement the organisational context where necessary and select interventions that are more likely to deliver outcomes in that context.

Keywords: Transition to adult care Realist evaluation Palliative care TASYL study Theory development

### **What is already known about the topic**

- Young adults with life-limiting conditions experience unmet needs in the transition from children's to adult services such as deficiency of information and loss of services.
- There is emerging evidence that transition interventions can improve outcomes but interventions are often ill-defined and exist in complex social systems, making it difficult to link interventions to outcomes.

### **What this paper adds**

- Identifies eight key interventions that are underpinned by two complementary models for successful transition; one focused on adult and children's service providers; the other on young adults and their parents/carers.
- Develops a theoretical understanding of how contextual factors may interact with intervention mechanisms to influence transition outcomes.

## **Introduction**

The number of young adults with life-limiting conditions living into adulthood is increasing internationally (Fraser *et al.*, 2011; Benini *et al.*, 2008; Blum, *et al.* 2005) as a result of early detection, advances in medical treatment strategies and improved health services (Lotstein *et al.*, 2008). These young adults, with their families, typically face chronic, disabling, progressive diseases which require a range of complex services. They may also be making the transition from children's service providers to adult service providers (transition) just as their health is deteriorating, making the existence of programmes for effective transition increasingly important (Mellor and Hain, 2010).

Transition can be defined as 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). Transition is the overarching process with the transfer being the event of the young adult moving from children's to adult services. An effective transition provides high quality, coordinated, uninterrupted health care that is patient-centred, age and developmentally appropriate, culturally competent, flexible, responsive and comprehensive (McDonagh and Kelly, 2003). Limited evidence suggests good transition programmes can lead to higher satisfaction, improved perceived health status, greater independence/self-management and better provision for disease specific educational needs (Mackie *et al.*, 2014; Chaudhry *et al.*, 2013).

Despite transition being on the international healthcare agenda for over thirty years, young adults with life-limiting conditions are still not always receiving the services 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), issues related to adult inpatient experiences (Beresford and Stuttard, 2014) and loss of services such as short breaks (Noyes *et al.*, 2014). A poorly planned transition is associated with measurable adverse outcomes related to morbidity such as non-adherence to treatment and loss to follow-up, together with negative social and emotional outcomes (Sloper *et al.*, 2010;

Annunziato *et al.*, 2007; Department of Health, 2006). Difficulties throughout the transition process can be so acute for young adults that a report in the United Kingdom characterised their transition experience as one of a “cruel and arbitrary division of services” (Marsh *et al.*, 2011, p. 8). Many organisations have yet to respond to the need for effective evidence based interventions which lead to positive outcomes (Care Quality Commission, 2014, Marsh *et al.*, 2011), making the transition from children’s service providers to adult service providers a growing concern.

Life-limiting conditions in children relates to those conditions “for which there is no reasonable hope of cure and from which children will die” (Together for Short Lives, 2013, p. 3). They are further delineated in the Directory of Life-Limiting conditions (Hain *et al.*, 2013) which provides a list of almost 400 International Classification Disease codes associated with diseases that can limit life in children such as cystic fibrosis and human immunodeficiency virus. As young adults with life-limiting conditions may also be accessing palliative care services, these services were also a focus in the study. Palliative care is considered to have three overarching levels: level one focuses on providing care which demonstrates palliative care principles; level two provides general palliative care from professionals with training in palliative care and finally; level three includes professionals whose core role is providing palliative care, known as specialist palliative care. An increasing level of specialism exists from level one to level three (Thornes, 2001).

In 2011, a systematic review of transition for young adults with palliative care needs acknowledged the complexity of the transition process and concluded there was an acute lack of evidence on transition services in palliative care, with few models of good practice (Doug *et al.*, 2011). Our recent realist review of the literature focusing on the transition to adult services for young adults with life-limiting conditions (Kerr *et al.*, 2017) identified six interventions, broadly defined as acts performed to improve health (World Health Organization, 2017), that were thought to promote a successful transition (Table 1.). However, these interventions were often ill-defined and existed in complex social systems, making it difficult to link interventions to outcomes. Nevertheless, drawing on this literature, we were able to outline initial theories about how the interventions may work for different people in different situations (Kerr *et al.*, 2017). There is an emerging consensus that those creating and evaluating complex interventions should start by developing a theoretical understanding of the likely process of change, and that this should include drawing on the views of stakeholders (Rutter *et al.*, 2017; Hawe, 2015; Craig *et al.*, 2008). In this realist evaluation we aimed to consider the initial theories identified in our review in the light of data provided by a range of stakeholder organisations and individuals, in order to produce more robust theory about how interventions may work in a range of contexts (Wong *et al.*, 2016).

**Insert Table 1.****Approach to evaluation**

The overarching framework for this study was realist evaluation (Pawson and Tilley, 1997). Realist evaluation acknowledges that programmes can work differently in various contexts and seeks to determine “what works, for whom, under what circumstances, and how” (Wong *et al.*, 2016, p. 1). Given the complexity of transition processes, realist evaluation provides an approach that is suited to gaining an understanding of how interventions may function in differing organisational contexts.

In realist evaluation, programmes, or interventions, are assumed to be the embodiment of theory (Astbury and Leeuw, 2010) in that those designing or implementing an intervention always have a theory about how the intervention will have an effect. This may be a ‘common sense’ theory or one based on previously developed theoretical constructs (Wong *et al.*, 2016). Realist evaluation seeks to uncover these (often implicit) theories and so contribute to building an explanatory account of how a programme works (Porter and O’Halloran, 2012; Astbury and Leeuw, 2010). The starting point for realist evaluators is, therefore, identification of relevant theory which can then be subjected to empirical testing. Our research was observational in nature and not designed to demonstrate effectiveness. Rather, it focused on developing programme theory, based on the insights of young adult patients, their parents/carers, and service providers, and reports from a range of service organisations in the Republic of Ireland and Northern Ireland.

Theory is expressed in the form of context-mechanism-outcome configurations which describe how an intervention may work (Parlour and McCormack, 2012; Pawson and Tilley, 1997). Context-mechanism-outcome configurations are a structured way of defining programme theories (Westhorp *et al.*, 2011) by examining “how the context and mechanisms influence the outcomes of an intervention” (Marchal *et al.*, 2012, p. 201). Similar interventions may have different outcomes in different contexts, so realist researchers place significant emphasis on identifying the context of causal explanations (Maxwell, 2012; Pawson *et al.*, 2004).

Context is comprised of individuals, interpersonal relationships, institutional settings and infrastructure (Pawson 2013). Interventions are thought to work through mechanisms triggered in particular contexts. Mechanisms are located in the reasoning, perceptions, beliefs and resources of those affected by the programme (Higgins *et al.*, 2015; Pawson and

Tilley, 2004). The outcomes are the result of mechanisms operating in a particular context (Pawson and Tilley, 1997) with intended outcomes being what programmes strive to achieve (Chen, 1989). Interventions work differently in different circumstances, which means simple replication of interventions in varying contexts may not produce the same outcomes. However, theory-based understandings which take context and mechanism into account are potentially transferable (Moore and Evans, 2017; Wong *et al.*, 2016).

The development of context-mechanism-outcome configurations proceeded in three broad stages (Figure 1.). Stage one involved a realist literature review (Kerr *et al.*, 2017) which identified six interventions (Table 1.) and produced initial theories expressed as conjectured context-mechanism-outcome configurations about how the interventions may work. At stage two empirical data was collected relevant to the conjectured context-mechanism-outcome configurations in four phases of data collection. Stage three was data analysis where we tested the conjectured context-mechanism-outcome configurations against the data, allowing us to refine and consolidate our context-mechanism-outcome configurations (Pawson and Tilley, 2004).

**Insert Figure 1.**

## **Aim**

To develop and refine programme theory – in the form of context-mechanism-outcome configurations - about the interventions, and organisational and human factors that help or hinder a successful transition from children's to adult services; drawing on the experience, knowledge, and insights of young adults with life-limiting conditions, their parents/carers, and service providers.

## **Methods**

### **Ethical approval**

Ethical approval was secured from the Office of Research Ethics Committee, Northern Ireland (14/NI/0001) and from a range of healthcare and non-statutory organisations in which data collection was undertaken, both in the Republic of Ireland and Northern Ireland.

### **Design and setting**

A realist evaluation approach featuring three stages was used along with a mixed methods design with four phases of data collection in the Republic of Ireland and Northern Ireland. The integration of the three stages of the realist evaluation with the four phases of the mixed methods design is demonstrated in Figure 1. The Republic of Ireland has 32 counties with an approximate population of 4.59 million and Northern Ireland has six counties with an

approximate population of 1.83 million (Northern Ireland Research and Statistics Agency, 2014). In the Republic of Ireland, health and social care services are delivered through the Health Services Executive areas in four geographical locations: Dublin North-East, Dublin Mid-Leinster, Southern, and Western (Health Service Executive, 2015). In Northern Ireland, health and social care is delivered in six Health and Social Care Trusts: Belfast Health and Social Care Trust, South Eastern Health and Social Care Trust, Southern Health and Social Care Trust, Northern Health and Social Care Trust and Western Health and Social Care Trust and the Northern Ireland Ambulance Service. The former five Health and Social Care Trusts provide integrated health and social care services in five geographical locations throughout Northern Ireland and the Ambulance Service provides services across all of Northern Ireland (Health and Social Care Online, 2016). Specialist health and social care services in the Republic of Ireland and Northern Ireland are often centralised in the capital cities of Dublin and Belfast respectively.

### **Mixed methods research**

Mixed methods research is an approach to theory and practice that considers multiple viewpoints, perspectives, positions and standpoints (Burke Johnson *et al.*, 2007), and is, therefore, appropriate for investigating a complex area of practice. We used the explanatory sequential mixed methods design (Creswell and Plano Clark, 2011), however, our approach used the quantitative component first, followed by the qualitative components.

### **Phases of data collection**

Data collection and analysis used an iterative approach with each phase of data collection building on insights derived from previous stages. Phases one and four recruited organisations and professionals providing services for young people with the full range of life-limiting conditions, whilst phases two and three focused on young adults with life-limiting neuromuscular conditions and their parents/carers, as a paradigmatic case. It is only within the past decade that improvements in care and treatment have markedly extended lives to the point that these young people have made the transition to adult services (Muscular Dystrophy Campaign, 2010). Therefore, they are likely to have experienced the transition process within a developing service and to be acutely aware of the challenges involved.

Phase one: The research team developed and distributed an online questionnaire survey to statutory health and social care, and educational organisations, and non-statutory organisations known to be providing transition services to young adults with a range of life-limiting conditions in both the Republic of Ireland and Northern Ireland. The 21 item survey instrument drew on a questionnaire originally developed to identify current practices in relation to transition in health and social services and education in two geographical areas in



the United Kingdom (Forbes *et al.*, 2002). It was further developed based on our review of the literature which identified six context-mechanism-outcome configurations, and in the light of extensive consultation with stakeholders and our research advisory group which included service providers, a young adult with a life-limiting condition, a parent, and representatives from the non-statutory sector. The questionnaire was then piloted, with eight responses received from 14 participants, resulting in further refinements. The questionnaire asked for a description of the services provided, policy or guidance documents in use, approach to managing transition, any organisational and human factors that helped or hindered transition, and suggestions for improvement. Data collection took place across all of Northern Ireland, but due to the larger geographical area in the Republic of Ireland, we surveyed only Dublin North-East Health Services Executive area, which includes the capital city of Dublin and borders with Northern Ireland. As there is no register of organisations providing transition services to young adults with life-limiting conditions, the sampling frame was developed through extensive networking to identify relevant organisations.

Gatekeepers were secured in these organisations and were identified again, following networking to isolate key people who would have insights into transition services in their organisations. Gatekeepers were asked to distribute the questionnaire to individuals involved in transition services within their organisations, and also to provide a list of local non-statutory organisations and educational organisations they collaborated with in the transition process. The final question in the survey questionnaire requested the name of organisations which service providers collaborated with in the transition process, and all of these organisations were contacted inviting participation. Participants were forwarded two reminders at three and seven weeks. 402 individuals in 55 organisations were invited to participate. In the following phases, participants were invited to comment on the usefulness of each of the conjectured context-mechanism-outcome configurations generated from the literature review and further developed from the survey, and any other preceding rounds of data collection.

Phase two: Semi-structured interviews with 8-12 young adults aged 18-24 years with life-limiting neuromuscular conditions such as Duchenne muscular dystrophy and spinal muscular atrophy, from both the Republic of Ireland and Northern Ireland. As this is a relatively small population we recruited from throughout both the Republic of Ireland and Northern Ireland. Presently there is no national register of individuals with neuromuscular conditions in the Republic of Ireland or Northern Ireland. Muscular Dystrophy Ireland and Muscular Dystrophy United Kingdom agreed to place an advertisement inviting participation on their social media forums. We also met with young adults in social groups facilitated by Muscular Dystrophy Ireland and the Northern Ireland Hospice to introduce the study. The

context-mechanism-outcome configurations guided the development of the interview schedule, in addition to consultation with the advisory group focusing on what helped or hindered transition and why. Questions included: In your experience what helps in making a successful transition to adult care? What was it in particular about those things that made them so helpful? In your experience what were the barriers to a successful transition? What was it about those barriers that was particularly difficult for you? If you could design a transition plan, what would be the key ingredients? A pilot interview was undertaken resulting in minor alterations to the interview schedule. Most interviews took place in the participants' homes.

Phase three: Two focus groups with parents/carers of young people with life-limiting neuromuscular conditions: one in the Republic of Ireland and one in Northern Ireland. Inclusion criteria included participants being a parent/carer of an 18-24 year old young adult with a life-limiting neuromuscular condition who was not currently in the end of life stage of their illness. It was hoped to recruit between 6-8 participants in each focus group. The recruitment approach was not geographically restricted throughout Ireland due to the potential small numbers. Gatekeepers in one non-statutory organisation in the Republic of Ireland and one in Northern Ireland, approached individuals to introduce the study and provide the researchers contact details for further information on participation. A nominal group technique approach was used in an attempt to generate a ranked list of responses to focused questions (Potter *et al.*, 2004). A pilot focus group was facilitated leading to minor modifications. The first question was 'in your experience what facilitated a good transition from children's to adult services?' The second question was 'in your opinion what are the realistic changes that could be made to improve the transition to adult services?' The context-mechanism-outcome configurations guided the development of these questions and also the discussions in the focus groups.

Phase four: Interviews with service providers from statutory and non-statutory organisations in both the Republic of Ireland and Northern Ireland providing services to young adults with a range of life-limiting conditions. Up to 20 service providers were to be purposively selected based on their indication in the survey questionnaire that they would be interested in participating in an interview, in addition to their potential to provide further detailed descriptions of transition from an organisational perspective. Potential participants were invited via an email invitation and interviews took place in the participant's workplace. All interviews and focus groups were recorded and transcribed verbatim.

### **Rigour related to data collection and analysis**

To enhance content validity, the survey questionnaire was distributed to the research advisory group for feedback on whether the items reflected the constructs under investigation. Feedback from the pilot study was an additional measure to enhance content validity in the survey questionnaire. To enhance reliability in the survey questionnaire, steps were taken to ensure questions were not ambiguous, double-barrelled or leading (Parahoo, 2014) with the pilot test confirming these did not exist. In the qualitative components, reflexivity was undertaken in which the researcher openly reflects on their own values and preconceptions which may affect responses (Parahoo, 2014).

In data analysis, independent validation of the young adults' interviews was undertaken which involved each of the four members of the research team validating the data and then meeting to draw together the themes from the data. There was a consensus on the emerging themes which contributed to validating the context-mechanism-outcome configurations. Additional measures to enhance validity included the purposeful selection of participants for interviews for phase four of data collection, who had completed the survey as part of phase one of data collection. Selection was based on the participant's potential to explain the organisational approach to the transition to adult services. The use of verbatim quotes to support written account of findings and recording non-verbal aspects of communication in data collection (Roberts *et al.*, 2006) also contributed to enhancing reliability. Further measures included using a computerised data analysis package and ensuring technical accuracy in recording and transcribing data. An audit trail was maintained for all phases of data collection and analysis enhancing credibility, dependability and confirmability, dimensions associated with demonstrating the trustworthiness of study data (Lincoln and Guba, 1985).

### **Data analysis and development of programme theory**

Our aim was to develop and refine programme theory in the form of context-mechanism-outcome configurations. To that end we started with initial theory synthesised from our review of the literature and engaged in analysis and theory development at each phase of data collection through a process of discussion and consensus building among the authors. Our review of the literature and engagement with stakeholders informed the development of our survey of service providers. Reflection on the results from the survey in turn underpinned the focus of the interviews with young adults, which then informed the focus groups with parents/carers. Interviews with service providers allowed us to tap into their experience but also to put our developing theory to them for consideration and feedback. No single stakeholder or stakeholder group could provide a complete picture of how the

interventions might work. Consequently, the researchers considered each piece of data in relation to whether it supported, refuted, or modified developing theory (Creswell and Plano Clark, 2011; Pawson and Tilley, 2004). Thus, data analysis was an iterative process, with the researchers piecing together their understanding of how interventions may work from the insights provided by different stakeholders in the four phases of data collection (Pawson and Tilley, 1997).

Survey questionnaire items were analysed with descriptive statistics where possible and responses from the open-ended questions were coded. For the qualitative components, field notes were completed by the interviewer, and the co-moderator in the focus groups, during and immediately after each data collection encounter. All transcripts were transferred into the NVIVO 10 software program (QSR International, 2012) which helped to index, code and retrieve data and also provided an audit trail. Data were coded against the realist formula of context, mechanism, and outcome, and analysed by authors HK and POH, seeking to explain the impact of services and interventions, and to identify organisational and human factors influencing the quality, safety and continuity of care. All authors then subjected the developing context-mechanism-outcome configurations to systematic testing against the empirical data, following each phase of data collection (Pawson and Tilley, 2004). Once the context-mechanism-outcome configurations were developed, authors HK and POH scrutinised them looking for commonalities and differences in contexts, mechanisms and outcomes, in order to produce models integrating the context-mechanism-outcome configurations where this was feasible. These were then agreed with all the authors.

## **Results**

### **Sample characteristics**

Data collection was undertaken between April 2014 and March 2015. There were 104 individual responses from 29 organisations in the survey questionnaire representing a 26% individual response rate and 53% organisational response rate. Of the 29 organisations, 13 were in the Republic of Ireland and 16 in Northern Ireland. 16 of the 29 organisations were from the statutory sector which included health and social care (n=14) and education (n=2), and 13 were from non-statutory organisations which included hospices (n=4) and the voluntary sector (n=9). Service providers represented a range of professions, examples include nurses (n=30), medical staff (n=26), managers/directors of services (n=16), allied health care professionals (n=13), transition coordinators (n=5) and teachers (n=1). Organisations provided services to young adults from all four categories of life-limiting and life-threatening conditions (ACT, 2009). Eight young adults aged between 18 and 22 years

participated in interviews, six in the Republic of Ireland and two in Northern Ireland. All young adults had made the health and social care transition into adult services and two of the eight young adults had yet to make the educational transition from school. Seven face to face interviews took place at the young adults' place of residence and one interview was facilitated at Muscular Dystrophy Ireland. Ten parents/carers participated in two focus groups, seven in the Republic of Ireland and three in Northern Ireland. All were parents/carers of a young adult with a life-limiting neuromuscular condition, however, only one of the ten was a parent of a young adult who had participated in Stage two. The focus groups took place in the capital cities of Dublin, Republic of Ireland, and Belfast, Northern Ireland. Seventeen service providers participated in face to face interviews; eight in the Republic of Ireland and nine in Northern Ireland. Service providers represented a range of professions and included nurses in a range of roles (n=8), medical staff (n=2), allied health care professionals (n=2), managers/directors/head of services (n=1), disability officer (n=1), commissioner (n=1), family support worker (n=1) and teacher (n=1).

Following stage two and stage three of the realist evaluation process which involved data collection, analysis and testing of the context-mechanism-outcome configurations, refinements were made to the six initial context-mechanism-outcome configurations (Table 1.), and two more were generated from the data, resulting in eight context-mechanism-outcome configurations thought to facilitate transition to adult services for young adults with life-limiting conditions (Table 2.). Below, we present a selection of data to illustrate each context-mechanism-outcome configuration, then set out a summary of the refined context-mechanism-outcome configurations in which the intervention, context, mechanisms and outcomes are identified.

### **Insert Table 2.**

#### **Refined context-mechanism-outcome configuration 1: Early commencement to the transition process**

Participants in each phase of data collection explained that the value of an early commencement was to provide time to plan and prepare for the transfer to adult service providers.

*"I definitely think you should start at a young age, even if they have like a year or two or three left in children's services, just to let them know that it's going to come to an end..."* (Young female adult, Republic of Ireland, 04).

*“I think it [early commencement] takes the fear away. It saves that crash, bang, wallop and all of a sudden it's in front of you.”* (Nurse in children's hospice, Northern Ireland, 01).

However, it was reported the transition process did not always commence early and that some children's service providers seemed reluctant to start the transition process.

*“It was important, but the reality of it is, it [an early commencement] doesn't happen. I think, if they did start it earlier, that would be great.”* (Parent/carer, Republic of Ireland, 06).

*“A lot of the people like my nurses and occupational therapists just didn't want to start [the transition process]...but it was just almost like they weren't letting go because they'd obviously known me for so long.”* (Young female adult, Northern Ireland, 01).

This reluctance may be, in part, as a result of children's service providers lacking confidence that equivalent services were available and capable of providing continuity of care when the young adult transferred to adult service providers.

*“The paediatricians don't have the confidence and the trust that adult services can provide the same service in the same way.”* (Transition coordinator, Health and Social Care Trust, Northern Ireland, 06).

These views were supported by data from the survey which showed that starting transition was often left late: the age range to commence the transition process in the Republic of Ireland was 12-19 years and in Northern Ireland, 12-18 years, with a mode of 16 and 14 years respectively; with eight of 29 organisations reporting some young adults aged over 25 years remained in children's services.

*Summary of context-mechanism-outcome configuration 1:* Early commencement of the transition process (intervention) brings the coming change to the attention of everyone involved and provides time for a response to be formulated by all stakeholder groups (mechanism). Although an early commencement is necessary, it is not sufficient as time made available must be used productively to implement other interventions. Early intervention is thought to lead to a young adult who will adhere to disease management plans and take responsibility for their interactions and engagement with adult service

providers (outcome). These outcomes are more likely to be achieved if professionals have the knowledge and skills to use the time effectively (context); and a transition plan to ensure a structured yet flexible approach in addressing the informational needs of the young adult (context). Disabling contextual factors include children's service providers who restrict their engagement to simply making the young adult aware that transition will happen rather than actively engaging in a planned process; who do not see the young adult as central to the process; and do not believe there is a viable adult service to receive the young adult; matched by adult service providers who do not appreciate the value of an early engagement with children's service providers (context).

### **Refined context-mechanism-outcome configuration 2: Effective communication, cooperation and commitment to joint working between children's and adult services**

Survey data indicated that the strategy for transition most commonly employed by organisations was to work on communication, information sharing and collaboration between children's service providers and adult service providers. Nevertheless, some children's service providers reported issues in initially identifying relevant adult service providers, and then a reluctance demonstrated by some adult service providers to engage early in the transition process, perhaps due to a lack of knowledge and experience of caring for young adults with life-limiting conditions.

*"You're trying to engage adult services, but they don't want to know until its right in their face ..... It's alien to them ..... They haven't had these children. This was new, so they've never had to deal with this....the adult team, they don't know how to deal with them."* (Transition coordinator, Health and Social Care Trust, Northern Ireland, 06).

*"You're trying to engage adult services, but they don't want to know until its right in their face."* (Transition coordinator in Health and Social Care Trust, Northern Ireland, 06).

It appears these sometimes tense negotiations went on in the background, with young adults and their parents/carers largely unaware, because most reported a positive experience in terms of continuity of communication between children's service providers and adult service providers. Young adults reported they were informed of their new consultant's name and geographical location of the new adult service provider at their last hospital appointment in children's services. On their first appointment with the adult service providers, the consultant appeared well informed.

*“All my information was already passed on to the adult services, so they knew of the background when I came in...”* (Young adult female, Republic of Ireland, 04).

There were mixed reports from parents/carers regarding communication between children’s service providers and adult service providers in health and social care with some sharing examples of positive communication and others sharing negative experiences.

*“The change from the child medical services to the adult medical services was pretty seamless...”* (Parent/carer, Republic of Ireland, 01).

Young adults and parents/carers also reported positive communication in the education sector.

*“I have to say that the coordination between the second level school and the university was exceptional...it was difficult to see what they could have done more.”*  
(Parent/carer, Northern Ireland, 03).

*Summary of context-mechanism-outcome configuration 2:* Effective communication, cooperation and collaboration between providers of children’s and adult services (intervention) empowers adult service providers with relevant information, leading to an enhanced sense of agency and confidence when preparing themselves and their environment for the transfer (mechanism). Consequently, the young adult is more likely to be received by skilled staff and adequate resources (outcome). This outcome is likely to be achieved where there is early identification and engagement of a relevant adult service provider by children’s service providers; where line managers provide time for the services to engage with each other; and where there is finance to buy appropriate equipment (baths, hoists, beds) to provide continuity of care (context).

### **Refined context-mechanism-outcome configuration 3: Orientation of the young adult to adult services**

Young adults recognised the potential value of orientation strategies such as meeting with adult service providers in advance of the transfer.

*“It would make you feel more comfortable then when you did transfer, if you knew them [staff in adult services] in advance and knew the faces.”* (Young female adult, Republic of Ireland, 04).



In the survey, service providers reported a range of transition initiatives designed to help orientate the young adult, such as transition clinics or farewell visits in which the young adult returned to children's services to bid farewell following their first visit with adult service providers. However, only one young adult in this study reported the availability of orientation strategies which involved meeting with adult staff in advance of the transfer to adult services.

*"I wouldn't have been in contact with anyone from [name of adult hospital]. It was only once I moved, then we were introduced."* (Young female adult, Republic of Ireland, 04).

Testing the initial context-mechanism-outcome configuration 3 ('orientating the young adult to adult services and optimising relationships with children's and adult service providers who demonstrate a person-centred approach') (see Table 1.) against the study data convinced us that we needed to develop further theory to explain what was happening. Orientating the young adult was important, but equally important was that service providers adopted a person-centred approach to care. Consequently we recognised an emerging context-mechanism-outcome configuration 7: 'Service providers demonstrating a person-centred approach to care,' which we discuss later in this paper.

*Summary of context-mechanism-outcome configuration 3:* Orientating the young adult to adult services (intervention) engenders a sense of ownership in participating in the transition to adult care (mechanism). This leads to a young adult who attends clinic and engages with medical treatment (outcome). This outcome is more likely to be achieved if service providers have the time to deliver services that place the young adult at the centre of their care (context). Disabling contextual factors are busier clinics in the adult environment; not having direct access to inpatient wards in adult care (reported to be available in children's services); mixed sex wards in adult care and meeting with a number of specialists in adult services rather than one paediatrician in children's services (context).

#### **Refined context-mechanism-outcome configuration 4: The engagement of a transition coordinator**

Young adults, parents/carers and service providers supported the notion of a transition coordinator.

*"...if there was one person that could find it all out for you and then give all the information to you at once, that would be helpful."* (Young female adult, Republic of Ireland, 04).

The survey showed that in Northern Ireland there were a number of statutory and non-statutory organisations funding a specific transition coordinator post, and this was the approach to transition most frequently espoused in the hospice sector. However, this approach was reported not to be available in the Republic of Ireland. In other cases, transition responsibilities were an aspect of service providers' roles as key workers, although it was argued that protected time should be available to fulfil the responsibilities of this role.

*“Transition, it has to be the core of their post. It cannot be an add-on, because it doesn't work. Key-working takes a lot of time...”* (Nurse in children's hospice, Northern Ireland, 01).

*Summary of context-mechanism-outcome configuration 4:* A transition coordinator (intervention) works as an advocate for the young adult by using their experience and knowledge of services to identify and gain the attention of relevant service providers on the young adult's behalf, which leads to the young adult feeling more confident in communicating with relevant service providers (mechanism). This results in a more streamlined transition process as appropriate service providers are engaged and mobilised to ensure there is no gap in service provision (outcome). This outcome is more likely to be achieved if the transition coordinator is well motivated and prepared for the role and has knowledge of the culture and organisation of both childrens and adult services (context). A disabling contextual factor is the lack of time for service providers who have these responsibilities as an additional (non-core) aspect of their role (context).

#### **Refined context-mechanism-outcome configuration 5: Interdisciplinary and interagency joint working**

These processes embodied a collaborative approach to the transition process with a range of service providers working collectively with the same aim.

*“If you have one plan, it's multidisciplinary, you've had everybody involved in pulling this together, you can see the benefits of one influencing each other, instead of having standalone things that's happening.”* (Commissioner, Northern Ireland, 07).

However, some parents/carers reported the absence of joint working between disciplines and agencies in health care.

*“When you look at the adult service now, its chaos, between one doctor and the fellow next-door to him, much less a multi-agency, disciplinary approach. They can't communicate the most basic of information.”* (Parent/carer, Republic of Ireland, 03).

A number of non-statutory organisations were reported by young adults and parents/carers to provide specific transition support in both the Republic of Ireland and Northern Ireland.

*“...there has been a couple of problems, [name of non-statutory organisation] have been brilliant. They have been outstanding.”* (Parent/carer, Republic of Ireland, 02).

An interesting finding was that young adults, parents/carers and service providers all reported that the family physician/general practitioner was marginalised while the young adult was in children’s services. This was thought to be due to the direct access young adults have to specialists while in children’s services.

*“One of our faults as paediatricians was that we keep children, who we’ve been looking after very much close to ourselves and we have, in the past, and still do to a certain extent, exclude the GP (general practitioner). We keep them updated, but if children have complex needs, or a very specific diagnosis that’s quite rare, they tend to bypass the GP (general practitioner) and come straight to us, and we have been very much at fault in encouraging that...but in the long run, I don’t think that does a lot of good for the child because as they transition into adulthood, they’re being handed back to a GP who maybe doesn’t know them very well.”* (Paediatric medical staff in Health and Social Care Trust, Northern Ireland, 05).

*Summary of context-mechanism-outcome configuration 5:* Interdisciplinary and interagency joint working (intervention) provides an opportunity for the young adult to engage with, and develop confidence in a wide range of service providers over the transition period (mechanism). This reduces the likelihood of a gap in service provision when the young adult transfers to adult service providers and enhances the young adults’ engagement (outcome). These outcomes are more likely to be achieved if service providers have the necessary skills to meet the young adults’ needs; they are less likely to be achieved where equivalent services are not available in the adult sector (context).

### **Refined context-mechanism-outcome configuration 6: Developing the young adults’ autonomy throughout the transition process**

The survey data showed that this approach was most frequently used by specialist palliative care services. Young adults and parents/carers spoke at length about the importance of the development of the young adults’ autonomy throughout the transition process. However, an

interesting insight was provided by one parent who stated that young adults may not want to become more independent.

*“My point down here, [is] how independent the individual wants to be has a bearing, and [name of young adult], I don’t think he really is that independent. He doesn’t seem to be wanting to be that independent.”* (Parent/carer, Northern Ireland, 03).

*“Most of them say ‘I’m staying here!’ [at home with parents] but, it’s not a matter of you going, ‘Oh, you’re not allowed to do anything – stay here, you’ll be nice and safe.’ You would prefer them to be a bit more independent.”* (Parent/carer, Northern Ireland, 03).

Another interesting insight was provided by a parent/carer regarding the potential value of promoting independence as for some young adults, the transition occurs at a time when they may becoming more dependent due to the progression of their medical condition.

*“It’s going the opposite way because their self-management, obviously, it would make things easier for them, but they’re deteriorating, so they’re learning to do more things that they’re probably not going to be able to do in the long run, so it kind of goes the opposite way.”* (Parent/carer, Republic of Ireland, 04).

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.

*“I think they [organisations] can do with more self-management skills, they definitely can, especially their financial situation and things like that, and also what’s available for university and skills too.”* (Parent/carer, Northern Ireland, 02).

Some service providers considered parents/carers did contribute to the development of the young adults’ autonomy, however, one service provider had a strong opinion that some parents/carers could actually be a barrier in the development of the young adults’ autonomy due to their perceived reluctance in ceding control.

*“Sometimes we would see that parents can be a huge disadvantage to them [young adults] in independence. I often say sometimes their parents are the biggest disability they have.”* (Support worker, non-statutory organisation, Republic of Ireland, 14).

*Summary of context-mechanism-outcome configuration 6:* Supporting the development of an autonomous young adult throughout the transition process (intervention) increases the young adults' knowledge, confidence and sense of agency in their decision making ability (mechanism) leading to greater engagement in negotiating their own medical management when in adult services (outcome). This outcome is more likely to be achieved if children's service providers are aware of the need to facilitate the development of the young adults' autonomy and parents/carers adopt a phased approach in ceding control to enable the growth of the young adults' independence (context). The young adult also needs to be willing, and cognitively able, to engage in strategies to promote their autonomy (context). A disabling contextual factor relates to time constraints for service providers in implementing strategies to promote the young adults' autonomy (context).

**Refined context-mechanism-outcome configuration 7: Service providers demonstrating a person-centred approach to care**

From the young adult's perspective, the strength of the relationships with children's service providers was reported to go beyond a professional relationship as one young adult described them as part of their family. The importance of forming strong relationships with adult service providers was considered crucial by young adults due to the permanence of adult service provision and the potential longevity of these new relationships.

*"They [children's service providers] become a part of your family...so then you just 'let go' from that and then [you are] given on to someone else, but the doctor that you have from 18 up, that's for life, and if you don't make a good relationship there, then what's going to happen?"...It's like you're married to them—you're here for life."*  
(Young female adult, Republic of Ireland, 03).

There was universal agreement across participants of the need for service providers to demonstrate a person-centred approach to care, however, although service providers reported this approach was adopted, some young adults and parents/carers reported it was not always experienced.

*"I always found with health [services] that people didn't look at you as a person. They were more about the disability, they wouldn't really have taken into account that there's a person here... but when they had you in the room, you felt more like an animal in the zoo...[you] kind of felt lost in a meeting that may have been about you..."* (Young male adult, Republic of Ireland, 02).

*“He [name of YA] was attending a...consultant...two weeks ago, and the consultant asked me what was wrong with him. Now, [name of YA] was well able to talk up for himself, and I just thought that’s just ignorant...“How was he?” and he’s there!”*

(Parent/carer, Republic of Ireland, 01).

One young adult made a recommendation on how a person-centred approach could be displayed by medical staff.

*“...maybe the doctors need to be more aware that it’s a person that they’re dealing with and that it’s not just about the disability. They need to talk to the people, how they are emotionally coping with the condition, as well as the actual physical condition they have.”* (Young male adult, Republic of Ireland, 02).

In addition, children’s service providers displaying a positive attitude towards the transfer to adult care was to enhance the young adults’ confidence in transferring, contributing to the intended outcome of the young adult engaging with staff in adult services.

*Summary of context-mechanism-outcome configuration 7:* A person-centred approach being demonstrated by service providers (intervention) was considered to contribute to the young adult feeling listened to and valued and, therefore, instilled in them a sense they were not only central to the processes of their care, but they had an influence in directing their care (mechanism). This was considered to lead to an increasing sense of involvement and ownership in their care, enhancing their interest and engagement in their medical management (outcome). This outcome is more likely to be achieved if service providers are aware of the characteristics of a person-centred approach (context) and have the time to deliver this approach (context). A shared understanding of the meaning of a person-centred approach between young adults, parents/carers and service providers may contribute to an increased likelihood of this approach being perceived to be delivered, by young adults (context).

#### **Refined context-mechanism-outcome configuration 8: Involvement of parents/carers**

A new context-mechanism-outcome configuration emerged from the data related to the involvement of parents/carers in the transition process. Although the realist literature review identified parents/carers as having a supportive role for young adults in the transition process, the evidence base was weak and was, therefore, not identified as a key intervention.

Young adults reported the valuable and crucial role of their parents/carers in supporting their transition to adult services.

*“The transition - that was taken on by my parents...”* (Young male adult, Republic of Ireland, 07).

Some young adults reported that the transition process was driven forward by their parents, with one young adult stating their mother initiated the transition process due to a reluctance of service providers.

*“My nurses and occupational therapists just didn’t want to start, and Mum was banging on the door saying ‘We need to move to adult services’.”* (Young female adult, Northern Ireland, 01).

Service providers also shared the importance of the parents/carers ongoing involvement and support to the young adult but also acknowledged the transition parents/carers experience as they too lose the support they have received through long standing relationships with children’s service providers.

*“It’s the parents that have the coordination role.”* (Family support worker, non-statutory organisation, Republic of Ireland, 14).

*“The transition was greater for the parents in many cases than it was for the patients.”* (Clinical Nurse Specialist providing services to adults in hospital, Republic of Ireland, 17).

*Summary of context-mechanism-outcome configuration 8:* The involvement of parents/carers in supporting the young adult throughout the multiple changes entailed in the transition process (intervention) empowers them to provide ongoing support to the young adult (mechanism). This leads to increased engagement by the young adult with their medical management and adherence to disease management strategies (outcome). This outcome is more likely to be achieved if parents/carers (who are aging) are willing, available and capable of continuing to support the young adult (context) and service providers recognise and welcome the potential resource parents/carers can be to the young adult who consents to their involvement (context).

### **Comparative analysis**

As the research was undertaken in the Republic of Ireland and Northern Ireland, it was interesting to identify commonalities and differences between service availability, service delivery and service users' experiences of these services. For the purposes of this paper we drew on the survey findings insofar as they contributed to theory development, so the full survey findings will be the focus of a subsequent paper. However, some key findings are highlighted here. In terms of differences, 5/13 (38%) of organisations in the Republic of Ireland reported they had young adults over 25 years who remained in children's services compared to 3/16 (19%) of organisations in Northern Ireland. 5/16 (31%) of organisations that participated in Northern Ireland also reported having completed an evaluation of transition initiatives compared to 1/13 (8%) of organisations in the Republic of Ireland. In Northern Ireland a number of dedicated transition coordinator roles were reported to be available in the statutory and non-statutory sectors, whereas, no participants reported the availability of this role in the Republic of Ireland.

Commonalities extracted from the survey included a similar number of organisations having a transition policy in the Republic of Ireland (6/13, 46%) and Northern Ireland (7/16, 44%), although it is worth highlighting that on further analysis, 4/5 (80%) of Health and Social Care Trusts in Northern Ireland reported the availability of a transition policy compared to 3/6 (50%) of hospitals which participated in Republic of Ireland. Commonalities were also shared by services providers, young adults and parents/carers related to the transition process not commencing early enough; that service providers in both the Republic of Ireland and Northern Ireland could do more to promote the development of the young adults' autonomy; and that non-statutory organisations in both the Republic of Ireland and Northern Ireland have a key supportive role throughout the transition process. Overall, there were models of good practice which were considered to embody many of the interventions related to a successful transition in both the Republic of Ireland and Northern Ireland, with similar contextual factors and causal mechanisms at work.

### **Summary of contextual factors**

A number of context-mechanism-outcome configurations displayed discrete enabling and disabling contextual factors. For example, triggering of the mechanism in context-mechanism-outcome configuration 2 (enhanced confidence of adult service providers) was dependent on children's service providers identifying relevant adult service providers who were committed to communicating early in the transition process. There were also contextual factors shared across context-mechanism-outcome configurations. These included the availability of time for service providers to engage in implementing the



interventions associated with an effective transition, in addition to a young adult who is capable and willing to engage in transition related activities.

### **Summary of mechanisms**

A range of mechanisms were triggered across a number of context-mechanism-outcome configurations. These included the young adult experiencing a growing sense of self-efficacy, agency, empowerment and confidence in taking increasing responsibility for their medical management and adopting a sense of ownership of their journey into adult services. The mechanism of empowerment of service providers in adult care was triggered by being in possession of relevant information related to the young adults' needs, delivered using a phased approach as a result of an early engagement with children's service providers. Empowerment and a sense of agency were triggered in parents/carers as a result of continued involvement in the transition process and being in possession of relevant information required to provide ongoing support to the young adult.

### **Synthesis of context-mechanism-outcome configurations**

This study developed programme theory through the exploration of interventions considered to lead to desirable outcomes in the transition process for young adults with life-limiting conditions. Furthermore, in adopting a realist evaluation approach, contextual factors considered to influence outcomes and causal mechanisms triggered were uncovered which have remained unexplored in the literature.

Looking across the context-mechanism-outcome configurations it is possible to discern a number of interrelationships which support two complementary models for successful transition; one focused on service providers, the other on the young adults and their parents/carers. Given that mechanisms are located in the reasoning, perceptions, beliefs and resources of those affected by the programme (Pawson and Tilley, 2004) it is not surprising that young adults respond to interventions in different ways to service providers. It is evident that context-mechanism-outcome configuration 1, 2 and 4 exert their main effect on children's service providers and adult service providers (Figure 2.). It appears that effective communication and collaboration between children's service providers and adult service providers, ideally facilitated by a transition coordinator who acts as an advocate for the young adult, can help foster a sense of confidence among adult service providers that they can manage the complex care of the young adult, and empower them to make the necessary preparations in terms of resources and staff training. This is contingent on intervening with an early start to the transition process (reflected in its priority in Figure 2.). These preparations take time and so obviously a late start (which was evident for some

participants) puts them at risk. Appropriate preparation leads to the key outcome of continuity of care for the young adult. This interaction of interventions, mechanisms and outcomes is more likely to develop in a context where children's service providers identify adult service providers in good time; develop a transition plan; and share the necessary knowledge and skills. If a transition coordinator is employed, success is more likely where the coordinator has appropriate training and understands both children's and adult services. Continuity of care will be at risk if there is lack of contact between children's service providers and adult service providers (because children's service providers cannot find a suitable adult service provider to transfer care to; or because adult service providers do not appreciate the value of early contact); or if managing transition is not seen as part of the core role of key workers and so time is not made available.

**Insert Figure 2.**

**Insert Figure 3.**

Context-mechanism-outcome configurations 3-8 operate largely in relation to the young adult who is making the transition (Figure 3.). It appears that children's service providers and adult service providers should have an explicit goal of collaborating to develop an autonomous young adult, whilst actively involving parents/carers, and where possible supported by a transition coordinator. This should lead to a young adult who feels that they are being listened to; that they are central to the transition process and can influence events; who gains confidence in interacting with children's service providers and adult service providers; such that they develop a sense of ownership of their transition process. Parents/carers, meanwhile adopt an approach where they gradually hand over decision-making to the young adult. The expected outcomes are a young adult who takes responsibility for engaging with adult service providers, contributes to their own management plan, and adheres to treatment recommendations. These interactions and outcomes are more likely to be seen where children's service providers recognise the need to develop the young adults' autonomy and share an understanding of the nature of person-centred services with adult service providers, parents/carers, and the young adult. There also needs to be a basic willingness and ability to engage in the transition process amongst parents/carers and young adults. If a transition coordinator is employed, success is more likely where the coordinator has appropriate training and understands both children's and adult services. These outcomes are at risk where suitable adult service providers are not available or services lack time to provide person-centred services; where the young adult

must access services through multiple specialists; or where managing transition is not seen as part of the core role of key workers and so time is not made available.

These two models for successful transition overlap and interact (note that concepts from context-mechanism-outcome configuration 4 occur in both models) 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. They also illustrate the multiple impacts of a well-trained and knowledgeable transition coordinator – the only intervention to feature in both models - both to advocate for the young adult and to promote effective collaboration between children's service providers and adult service providers.

### **Discussion**

Most of the interventions we have identified as important to the transition process will be found elsewhere in the literature. However, what this study adds is an understanding of *how* these interventions might work, where they may most usefully be focused, and crucially, in what circumstances they are more likely to succeed or fail. This is demonstrated chiefly in the 'context' components of the context-mechanism-outcome configurations and the related models (Figures 2 and 3), which highlight multiple aspects of the context that are considered by those using or providing services to either help or hinder the interventions. For example, an early start is recommended, in most cases no later than when the young adult is 14 years old (Chambers, 2015; Care Quality Commission, 2014; The Transition Partnership, 2012). However, our research shows (Figure 2.) that whilst this may be necessary it is not by itself sufficient to produce the desired outcomes – something not clearly captured in the literature. An early start needs to be combined with communication and collaboration between children's service providers and adult service providers (Fegran *et al.*, 2014; Riley *et al.*, 2010; Kirk, 2008), which can only take place if children's service providers identify relevant adult service providers in good time (Noyes *et al.*, 2014; White *et al.*, 2012; Towns and Bell, 2011; Freed and Hudson, 2006; Scal, 2002), and is more likely to succeed if service providers have the necessary knowledge and skills, and there is a transition plan, and a recognised transition coordinator. On the other hand, outcomes are put at risk if the need for collaboration between children's service providers and adult service providers is not valued by the respective parties, or where transition is not seen as part of the core role of key workers. Furthermore, our research shows that a major goal for these efforts should be continuity of care, which can then function as a key outcome indicator for service providers.

Our research also threw light on some of the key concepts cited in the literature. For example, service providers adopting a person-centred approach (Noyes *et al.*, 2014) was

thought to be a key intervention underpinning the development of an autonomous young adult. We found that service providers considered this involved building a rapport and relationship with the young adults; for the young adult, it was being seen as a person first before their medical condition was addressed; and for parents/carers it was being involved in the decision making process. Given these differing views, it was important that expectations were discussed to develop a shared understanding of person-centred care.

Similarly, the development of autonomy is considered to be an indicator of transition readiness in the young adult (Sawicki *et al.*, 2011; van Staa *et al.*, 2011a). Our research adds to this by outlining the mix of interventions that can contribute to this outcome – including active efforts to orientate the young adult to adult service providers, interagency collaboration, and adopting a person-centred approach – but also by teasing out the mechanisms – the underlying processes - by which this may happen (Figure 3.). Again, we have identified contextual factors that make success more likely, such as children's service providers recognising the need for the young adult to develop autonomy, and working for a shared understanding of person-centred services; as well as those which put the outcome at risk, such as the fragmentation of services into multiple specialities and lack of staff time. Clearly identifying the expected outcome of these interventions should allow service providers to evaluate the success of their interventions.

We also found that the goal of achieving autonomy was potentially problematic in practice. The literature suggests that the rhetoric of empowered independence may work to the young adult's detriment if it is out of step with the capacities of a young adult with a serious illness (Schmidt *et al.* 2016). It could result in an expectation that the young adult must 'succeed' in what is considered to be the less supportive environment of adult services, rather than adult service providers configuring their services to be more easily navigated by the service users (Tanner *et al.*, 2016). In our study service providers reported that they promoted autonomy, whilst young adults and their parents/carers were not aware of these efforts – perhaps not recognising the strategies of the service providers as having that aim. We also found that some young adults did not wish to develop their autonomy, at least in relation to independent living. Possible rationale could be that taking responsibility for their self-care and adulthood may be one of the most difficult challenges related to the transition process (Sharma *et al.*, 2014; Webb *et al.*, 2001) and it may coincide at a time when they are becoming more physically dependant. Related to this, and as noted in the literature (Nieboer *et al.*, 2014; van Staa *et al.*, 2011b), we found service providers reported that some parents/carers had difficulty ceding control to the young adult perceiving them to be a barrier in the development of the young adults' autonomy. However, this was not reported in this study as an issue by young adults or their parents/carers. Indeed, a new context-mechanism-outcome

configuration emerged (context-mechanism-outcome configuration 8), centred on the judicious involvement of parents/carers to support the young adult throughout the multiple changes entailed in the transition process. There is weak evidence for the involvement of parents/carers in the literature but we found young adults greatly valued both practical and emotional support from their parents/carers, and that they were alive to the challenges of transition, often before professionals. All of this indicates a need for conversations amongst all parties, clarifying goals and expectations around the degree of autonomy that is desirable and feasible, and how this is to be achieved.

Further insights emerging from our research concerned the marginalisation of the general practitioner whilst the young adult is in children's services (Care Quality Commission, 2014). Children's service providers tend to provide fairly holistic care and general practitioner may feel that they lack necessary expertise and be hesitant to involve themselves. However, as young adults continue with their general practitioner when they move to adult service providers, general practitioner are potentially well-placed to facilitate continuity of care if they are appropriately involved over the course of the transition and beyond.

Finally, it is important to note the striking finding that many of the mechanisms at work to produce key outcomes are reported to hinge on the thoughts, feelings, perceptions and beliefs of individual stakeholders. For adult service providers, their confidence and self-efficacy in relation to preparing an appropriate service and, for young adults, in engaging with service providers. It is easy to neglect these mechanisms in favour of more concrete initiatives; but because changes in practice ultimately depend on changes in the behaviour of the people involved, it is vital to take them into account. Specifically in this case to take steps to increase the confidence, self-efficacy (Bandura, 1998), and trust in relationships of the various parties, especially adult service providers, the young adults, and their parents/carers. This is consistent with the literature on the importance of productive relationships in health services (NHS Institute, 2008; Meads and Ashcroft, 2000), and with insights from previous realist evaluations (e.g. Higgins *et al.*, 2015; Jagosh *et al.*, 2015).

### **Strengths and limitations**

One of the strengths of this study is that realistic evaluation provides an explanatory account of how the context and mechanisms contribute to whether interventions work, or not. Explanations are framed in the format of conjectured context-mechanism-outcome configurations which are subjected to testing and refinement through data collection and analysis and as this study has demonstrated, has contributed to the development of programme theory. The selection of a mixed methods methodology also enhanced this study as data originated from multiple sources and hence, a more comprehensive and

accurate picture of the organisational approach to transition to adult services was obtained. Mixed methods research attempts to respect the wisdom of both quantitative and qualitative approaches (Burke Johnson *et al.*, 2007) and addresses the limitations associated with the sole use of quantitative or qualitative (Doyle *et al.*, 2009; Burke Johnson and Onwuegbuzie, 2004).

A limitation in this study related to the challenges in recruiting young adults and parents/carers in Northern Ireland. Despite an extensive range of recruitment strategies to address this such as the publication of study information in the Together for Short Lives Newsletter, a University webpage being developed with recruitment information and the use of social media forums, only two young adults and three parents/carers participated. This was in contrast to the Republic of Ireland, with its larger population, in which recruitment numbers were achieved. We sought to include primary physicians/ general practitioner in this study but gatekeeping issues and lack of availability limited involvement from this group. A further limitation was the dearth of responses from the educational sector with one School and one University participating. Finally, as life-limiting neuromuscular conditions was the focus in Stage two and Stage three of data collection, there are limitations on the transferability of these findings to all life-limiting conditions.

### **Conclusions and recommendations**

This realist evaluation has identified a number of organisational and human factors that interact to promote or hinder transition from children's to adult services for young adults with life-limiting conditions. These are based on eight interventions, and the mechanisms they trigger to produce outcomes in particular contexts. From these, we have produced two complementary models for successful transition; one focused on service providers, the other on the young adults and their parents/carers (Figures 2 and 3).

Our key recommendation is that stakeholders, and especially service providers, do not focus simply on implementing interventions in isolation but rather take a diagnostic approach, seeking to understand how they can most effectively work to produce important outcomes in their unique context. By a diagnostic approach we mean service providers might consider the range of interventions discussed in the light of the organisational and human resources available in their context, and the outcomes considered as highest priority. This would allow them to supplement the organisational context where necessary and select interventions that are more likely to work in that context. For example, service providers might reasonably decide that employing a transition coordinator (or at least making transition coordination a core component of the role of key workers) might be an effective intervention – especially as this has an impact on both service providers and young adults. However, we would

recommend that when planning this intervention, service providers make sure that the transition process is started in good time; that the transition coordinator is well-trained, understands both children's service providers and adult service providers, and focuses on enabling adult service providers to gain confidence to prepare themselves and their environment, and on empowering the young adult and their parents/carers to develop a sense of ownership of the process. Service providers might then plan to evaluate the role by its impact on continuity of care and on the positive engagement of the young adult with adult service providers. A similar diagnostic approach should be taken with other potentially effective interventions. Our research indicates that no single intervention or stakeholder group can guarantee important outcomes. Rather it is the combination and interaction of organisational and human factors that must be recognised and addressed to achieve a successful transition.

In terms of research, we recommend that those evaluating transition interventions consider using our programme theory to inform the development and testing of interventions; include process evaluations to provide insights to aid implementation (Craig *et al.*, 2008); and recognise that stakeholders may have differing priorities in relation to outcomes.

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There are no known conflicting interests.

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Figure 1. Stages of realist evaluation

Phases in mixed methods sequential design

Figure 2. Preparing services for successful transition: an integrated model

Figure 3. Preparing a young adult for a successful transition: an integrated model

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**Table 1.** Interventions to promote a successful transition identified in a realist literature review (Kerr *et al.*, 2017)

1. Early start to the transition process
2. Effective communication and collaboration between children's and adult service providers
3. Orientating the young adult to adult services and optimising relationships with children's and adult service providers who demonstrate a person-centred and individualised approach
4. The engagement of a key worker
5. Interdisciplinary and interagency joint working
6. Development of an autonomous young adult throughout the transition process



**Table 2.** Context-mechanism-outcome configurations thought to promote successful transition from children's to adult services for young adults with life-limiting conditions

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