ORIGINAL ARTICLE

A cross-sectional survey of services for young adults with life-limiting conditions making the transition from children's to adult services in Ireland

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Abstract

Background Increasing numbers of young adults with life-limiting conditions are living into adulthood and consequently making the transition from children's to adult services. A poorly planned transition is associated with adverse outcomes such as non-adherence to treatment and loss to follow-up, together with negative social and emotional outcomes. However, there is little descriptive data on how organisations are currently managing transition.

Aim To obtain an overview of organisational approaches to transition on the island of Ireland, and to explore important organisational factors that may influence the effectiveness of the process.

Methods A cross-sectional questionnaire survey. One of the four Health Services Executive areas in the Republic of Ireland and the whole of Northern Ireland. Participants were service providers in statutory and non-statutory organisations providing transition services to young adults with life-limiting conditions.

Results The survey was distributed to 55 organisations. The overall response rate was 29/55 (53%). The approach to transition most commonly used focused on interagency communication and collaboration. Key factors in an effective transition were reported as: early commencement; effective communication between the young adult, their family, and services; the availability of appropriate adult services; and effective preparation through collaboration with the young adult and their family. However, implementation of these processes was inconsistent.

Conclusions The findings demonstrate that caring for young adults with life-limiting conditions presents a considerable challenge to organisations and that transition from children's to adult services is an important part of this challenge.

Keywords Life-limiting conditions · TASYL study · Transition to adult services

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Introduction

There were an estimated 1307 children and young people living with a life-limiting condition in Northern Ireland in 2010 [1] and an estimated 3840 in the Republic of Ireland [2]. Living with a life-limiting condition has a profound and pervasive effect for the young adult with far-reaching consequences for the family [3]. The disease trajectory is often unpredictable [4] and compounded by concerns related to the need to transition to adult services, often provided by a number of organisations, with anxieties about the continued availability of services to meet the young adults' needs [5]. There is also an educational transition to negotiate when the young adult leaves school [6] and transitions to further or higher education, or to the workplace.

Due to advances in medical treatment strategies, early detection and improved health systems [7], the number of young

people with life-limiting conditions living into adulthood is increasing [1]. Although these advances are long-awaited, improved survival means a growing number of young adults are moving from children's to adult services. This makes the existence of programmes for effective transition increasingly important [8]. Transition is 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' [9]. An effective transition from children to adult services provides high quality, coordinated, uninterrupted health care that is patient centred, age and developmentally appropriate, culturally competent, flexible, responsive and comprehensive [10]. However, many organisations struggle to provide effective transition services [11, 12], and a poorly planned transition is associated with measurable adverse outcomes such as non-adherence to treatment and loss to follow-up, together with negative social and emotional outcomes [13–15]. There is little published on the organisational approaches used in practice to facilitate transition for those with life-limiting conditions [16–18]. Therefore, we planned a questionnaire survey of transition services in Ireland in order to describe current practice and to explore important organisational factors that may influence the effectiveness of the transition process.

The objectives of the survey were;

1. To obtain an overview of transition services for young people with life-limiting conditions on the island of Ireland.
2. To identify organisational factors that help or hinder an effective transition to adult services.
3. To complete a comparative analysis of transition services between the Republic of Ireland and Northern Ireland.

Materials and methods

Study design

This paper reports on the results of a survey questionnaire which was one phase of a larger realistic evaluation study, using STROBE guidelines. The aim of the larger research study was to identify the factors associated with a successful transition from children's to adult services for young adults with life-limiting conditions (TASYL study) and used a mixed methods approach. The study had four phases of data collection, and the findings of the full research study are reported elsewhere [19]. Phase one involved the distribution of a survey questionnaire survey to health, social, education and non-statutory organisations providing transition services to young adults with life-limiting conditions to identify current practices and is the focus of this paper. A cross-sectional survey design was employed in which participants responded to a written questionnaire which was made available by post, email and online through a dedicated webpage.

Setting

The context of the study was the island of Ireland which consists of two countries; the Republic of Ireland and Northern Ireland. The Republic of Ireland has an approximate population of 4.59 million, and Northern Ireland has an approximate population of 1.83 million [20]. Due to potential challenges of data collection in the larger geographical area in the Republic of Ireland, one of the four Health Services Executive (HSE) areas was selected: Dublin North East area, as this includes the capital city of Dublin, north of the River Liffey and also borders with Northern Ireland. The remaining three health service executive areas are Dublin Mid-Leinster, HSE South, and HSE West [21]. Northern Ireland has five Health and Social Health Care Trusts: Belfast, Northern, Southern, South Eastern and Western [22], and all five Health and Social Care Trusts were included.

Organisations and participants

To develop a sampling frame, organisations considered to have a role in providing transition services to young adults with life-limiting conditions were contacted. There was no public list of such organisations, so identifying them was a challenge. We engaged in purposeful sampling through an extensive programme of networking, meeting with key individuals to discuss their work and to identify other organisations and key individuals they worked with, to try to build a picture of which organisations were involved in providing transition services. Organisations providing transition services to young adults with life-limiting conditions falling within the four categories of the ACT classification of illness trajectories [23] were eligible for inclusion in the study (Table 1). For further clarification, these conditions are delineated in the directory of life-limiting conditions which provides a list of approximately 400 international classification disease codes associated with diseases that can limit life in children [24]. Organisations included those from the statutory sector such as health and social care and education, and non-statutory organisations such as relevant voluntary organisations/ charities and hospices. Research governance arrangements meant that we had to make our approach to potential participants within most organisations, through gatekeepers employed in those organisations. These gatekeepers were selected on the basis that they were aware of the key services within their organisations that would be expected to be involved in transition services, and could identify key individuals who would be able to provide the necessary information

about those services. As part of the questionnaire, participants were also asked to provide details of other organisations that they worked with when delivering transition services, which provided an opportunity for us to identify more organisations to approach to invite participation in the survey.

The survey questionnaire

At the time of developing the survey questionnaire, a literature search identified only one five-item questionnaire that had been developed to collect descriptive data related to transition services [25]. This survey of transition services in Manchester and Greater London identified a number of approaches: the direct transition model which highlights the importance of communication and information sharing and interagency collaboration; the sequential transition model which focuses on constructing services as an extension to children's services or jointly between children's and adult services; the developmental transition model which focuses on active support for the young adults personal growth and development and finally, the professional transition model, which describes one key professional who takes responsibility for engaging key stakeholder groups to meet the young adults' needs in the transition process. We drew on this questionnaire and accompanying report to develop our own questionnaire, and supplemented the questions on the basis of a realist review of the recent literature [26]. This review identified six key factors associated with an effective transition. These are an early start to the transition process; effective communication and collaboration between children's and adult service providers; orientating the young adult to adult services using a person-centred approach; the engagement of a key worker; interdisciplinary and interagency joint working; and the development of an autonomous young adult throughout the transition process. The new questionnaire was reviewed by an expert advisory group containing six academic experts, four service providers and one young adult with a life-limiting condition. It was then piloted with 14 health care professionals in a health and social care trust in Northern Ireland. Eight responses with commentary were obtained from medical doctors, nurses in a range of

Table 1 Categories of life-limiting and life-threatening conditions [23]

Category one: Life-limiting conditions for which curative treatment has failed
  Examples: cancer, irreversible organ failures of heart, liver, kidney
Category two: Conditions where premature death is inevitable
  Examples: cystic fibrosis, Duchenne muscular dystrophy
Category three: Progressive conditions without curative treatment options
  Examples: Batten disease, mucopolysaccharidoses
Category four: Irreversible but non-progressive conditions causing severe disability, leading to susceptibility to health
  Examples: severe cerebral palsy, multiple disabilities such as following brain or spinal cord injury

positions, a social worker and a psychotherapist. The questionnaire was further refined in light of this feedback.

The questionnaire contains 20 items (Supplemental file). There were a range of question types which included closed, Likert-type and open-ended questions. Participants were asked about the transition services they offered, the approach to managing transition, the profile of their service users, organisational factors influencing the success of transition and their links to other organisations providing transition services.

Survey distribution

Data were collected in the survey between April and October 2014. Gatekeepers secured in a range of organisations who had information on the availability of transition services were forwarded a copy of the survey questionnaire along with an invitation to take part in the survey, with a request to forward to those involved in providing transition services in the organisation in which they worked. This meant that several people in the same organisation could receive the survey request because there might be a variety of relevant services within the same organisation. The email contained a link to a secure online version of the form which could be directly populated and saved by the participant. Alternatively, participants could email an attached copy of their completed questionnaire to the researchers or request a paper copy of the form which was sent with a prepaid return envelope. If no reply was received, further email requests were sent at 1, 3 and 7 weeks to enhance recruitment [27]. Potential participants who received the questionnaire were requested not to forward the questionnaire to others as the research team were keen to monitor distribution which would contribute to calculating an accurate response rate. If a potential participant could identify another person who may have a role in transition to adult services, they were asked to forward the name and email contact details to the gatekeeper or the researcher who would then forward an invitation to participate.

Analysis

All data were entered into a Microsoft Excel spreadsheet to enable counting of responses to closed questions, mapping of organisational relationships and theming of qualitative data in relation to the theoretical framework. Descriptive statistics such as the mean, mode and median were used to analyse appropriate data. Qualitative data were transferred into the NVIVO 10 software programme [28] which helped to index and code the qualitative components. A thematic analysis was completed for the qualitative component of the survey questionnaire, a process which takes the form of clustering similar data, with clustered ideas called themes [29]. Thematic analysis involves an iterative process which required going back

and forth to the data [30] using an inductive process. Of particular interest were data related to the six factors associated with a successful transition to adult services, identified in the realist literature review [26].

Rigour

Validity is the closeness of what we think we are measuring to what we intend to measure [31]. To enhance content validity, the survey questionnaire was distributed to the research advisory group for feedback on whether the items reflected the construct of the transition to adult services. Feedback from the pilot study also enhanced content validity with confirmation questions were unambiguous and related to transition to adult services. For the qualitative components, a measure used to enhance rigour has involved providing verbatim quotes to support findings [31]. A further measure has involved validation of the data which entails the data being authenticated with participants, or with other researchers [32]. In this research, validation involved the four members of the research team meeting to draw together the findings from the survey data leading to a consensus of the themes emerging. Ways used to enhance reliability in the qualitative components involved creating codes and themes to describe the data with the use of NVIVO computerised data analysis package and also ensuring technical accuracy in transcribing data from the questionnaire to NVIVO. An audit trail was maintained enhancing credibility, dependability and confirmability, dimensions associated with demonstrating the trustworthiness of study data [33].

Results

Organisational responses

The survey was distributed to 55 organisations: 20 (36%) in the Republic of Ireland; 35 (64%) in Northern Ireland. In the Republic of Ireland 13/20 (65%) responded and in Northern Ireland 16/35 (46%) responded. The overall response rate was 29/55 (53%). Of the 29 responding organisations, 16 were from the statutory sector, and 13 were from the non-statutory sector (Table 2). Of the 16 organisations from the statutory sector, 14 were from health and social care, and two were from the education sector. Health and social care organisations included responses from various departments in all five Health and Social Care Trusts throughout Northern Ireland and six hospitals in the Dublin North East Health Service Executive Area in the Republic of Ireland. Organisations from the education sector included a university and a school providing services for young adults with life-limiting conditions making the transition to adult services. Of the 13 organisations in the non-statutory sector, four were hospices and nine were

charities/voluntary organisations providing transition support and services to young adults with a range of life-limiting conditions such as cancer and disability services.

Individual responses

Four hundred and two individuals in 55 organisations were invited to participate, and there was a response from 104 participants representing a 26% individual response rate. Of the 104 participants, 31 (30%) were from the Republic of Ireland, and 73 (70%) were from Northern Ireland. This equates to a 19% response rate in the Republic of Ireland and a 31% response rate in Northern Ireland. Nursing and medical staff represented 54% of participants (Table 3). Medical conditions cared for included life-limiting haematological conditions, renal conditions, nephrology, urology, genetic and metabolic conditions, cardiology, neurology and inherited disorders. These medical conditions represented all four categories of the illness trajectory of life-limiting and life-threatening conditions [22] (Table 1).

Non-responders.

From an organisational perspective, 26 of 55 (47%) organisations did not respond. Fourteen of 26 organisations were from non-statutory organisations and included some hospices, and a range of organisations providing condition-specific services for life-limiting conditions which included cancer and neurological conditions. The remaining 12 statutory organisations included disability departments at colleges and universities, general practices/primary care practices and schools.

Responses

Quantitative responses

This section provides responses to a range of questions in the survey questionnaire.

Table 2 Organisational response

Country	Number of organisations forwarded invitations	Number of organisations participated (percentage response rate)	Statutory: non-statutory organisation
Republic of Ireland	20	13 (65%)	8:5
Northern Ireland	35	16 (46%)	8:8
Total	55	29 (53%)	16:13

Table 3   Roles occupied by participants

Role	Number (percentage of total participants)
Nurse	30 (29%)
Medical staff	26 (25%)
Managers/directors/head of service	16 (15%)
Allied health professional	13 (12%)
Social worker	5 (5%)
Transition coordinator	5 (5%)
Psychologist	2 (2%)
Teacher	1 (1%)
Other	6 (6%)
Total	104 (100%)

Question: Is there a transition policy and/or strategy in your service? Participants in 13 of 29 (45%) organisations had at least one participant who reported the availability of a transition policy in the organisation in which they worked (Table 4). Participants in six of 13 (46%) organisations in the Republic of Ireland and seven of 16 (44%) organisations in Northern Ireland had a transition policy. On further analysis, in the Republic of Ireland, three of the six (50%) hospitals reported there was a transition policy available, and in Northern Ireland, at least one participant in four of the five Health and Social Care Trusts (80%) reported there was a policy. Participants in the two organisations in the education sector (100%) reported the existence of a transition policy. Two of the four (50%) hospices had at least one participant who indicated there was a transition policy in the organisation.

Question: Is your service currently developing strategies, policies or processes related to the transition process? Participants from 18 of 29 (62%) organisations stated they were currently developing transition strategies (Table 4). At least one participant from nine of 13 (69%) organisations in the Republic of Ireland, and nine of 16 (56%) organisations in Northern Ireland, reported they were currently developing transition strategies/policies in their organisation. Most statutory organisations in both countries stated they were developing strategies (88%). In the education sector, both organisations (100%) were developing strategies.

Question: Has there been a formal or informal evaluation of the transition processes in your service? Participants in six of the 29 (21%) organisations stated an evaluation had been completed (Table 4). When comparing the Republic of Ireland and Northern Ireland, at least one participant in one of 13 (8%) organisations in the Republic of Ireland and in five of 16 (31%) organisations in Northern Ireland reported an evaluation had been completed. No participants in any of the six hospitals in the Republic of Ireland said an evaluation had

been undertaken, and at least one participant in two of the five (40%) Health and Social Care Trusts in Northern Ireland reported a transition evaluation had been completed. In the education sector, participants in both organisations (100%) stated an evaluation of transition services had been completed. No participants representing charitable organisations stated an evaluation had been completed, and one of four (25%) hospices reported the completion of an evaluation.

Question: Approach to managing transition Participants were asked to indicate on a five-point Likert scale how seldom or frequently they used one, or more, of the four models of transition related to Forbes et al. [25] work outlined in the methods section. The most frequently used model across all organisations in both the Republic of Ireland and Northern Ireland was the direct transition model which emphasises the importance of effective communication between children's and adult services and interagency collaboration. In the education sector, a university in the Republic of Ireland reported using all four models frequently, and the most frequently used by the school in Northern Ireland was reported to be both the developmental transition model which focuses on active support for the young adults personal growth and development and the professional transition model which describes one key professional who takes responsibility for engaging key stakeholder groups to meet the young adults' needs in the transition process. In the hospice sector, the professional transition model was the most frequently used.

Question: In relation to your organisation, at what age does the young person usually begin the transition process and formally transfer to adult services? In the Republic of Ireland, the transition process usually began at age 16 (range 12–19) and in Northern Ireland at age 14 (range 12–18). In both countries, transfer to adult services was

Table 4   Responses to questions

Question	Sector	Republic of Ireland (organisations responding 'yes'/total participating)	Northern Ireland (organisations responding 'yes'/total participating)	Overall total (organisations responding 'yes'/total participating)
Is there a transition policy and/or strategy in your service?	Statutory	4/8	5/8	9/16
	Non-statutory	2/5	2/8	4/13
	Total	6/13	7/16	13/29
Is your service currently developing strategies, policies or processes related to the transition process?	Statutory	7/8	7/8	14/16
	Non-statutory	2/5	2/8	4/13
	Total	9/13	9/16	18/29
Has there been a formal or informal evaluation of the transition processes in your service?	Statutory	1/8	3/8	4/16
	Non-statutory	0/5	2/8	2/13
	Total	1/13	5/16	6/29

usually at age 18, with a range of 16–20 years in the Republic of Ireland and 14–25 years in Northern Ireland (Table 5).

Question: Does your organisation have any young adults who remain in children's services beyond the age of 25 years? In the Republic of Ireland 5/13 (38%) and in Northern Ireland 3/16 (19%) organisations reported they had young adults over 25 years who remained in children's services.

Question: Which of the following categories for illness trajectory do the young people/young adults with life-limiting conditions who are using your service fall into? In question eight, participants were asked to identify which category of illness trajectory they cared for in the services they provided from the four categories outlined in Table 1. Fourteen participants (13%) identified only one of the four categories—five for category one, four for category two, no responses for category three and five for category four. Thirty-five participants (34%) identified as caring for individuals from all four categories in their service. The remaining participants (53%) identified providing services for individuals from either two or three categories with different permutations, or alternatively, there was no response.

Qualitative responses

In what follows, information in brackets following the quote relates to the participant's unique identifier, their role, sector and country.

Question: In your experience, what factors promote a successful transition to adult services in your organisation? The majority of responses focused on the need for effective communication between children's and adult services, or communication between service providers, and the young adult and their parents. Other factors included the ongoing availability of services in adult care such as respite care.

> When professionals from adult services actively engage in the process with paediatric services. (5, children's nurse, Health and Social Care Trust, Northern Ireland).

Question: What do you feel are the strengths of the services you provide in relation to the transition process? Many participants highlighted the longstanding relationships they

Table 5   Age transition process commences and age at formal transfer to adult services

Country	Republic of Ireland		Northern Ireland	
Measurement	Range	Mode	Range	Mode
Age transition process commences	12–19 years	16 years	12–18 years	14 years
Age at formal transfer to adult care	16–20 years	18 years	14–25 years	18 years

had with the young adult and their parents. An early commencement to the transition process, communication between children's and adult services, adopting an inter-disciplinary approach and the availability of knowledge-able staff were also highlighted as strengths.

> Children are often known to the service for years-trusting relationships with parents and young people have been developed. (31, member of multidisciplinary team, Health and Social Care Trust, Northern Ireland).

Question: What do you feel are the weaknesses of the services you provide in relation to the transition process? Weaknesses included the loss of services when the young adult transfers to adult care such as respite provision, challenges identifying a relevant adult service and a lack of staff with condition-specific knowledge in adult services.

> No appropriate respite facilities. Lack of knowledge and experienced staff. (53, manager, Hospice, Northern Ireland).

Some service providers stated that a proportion of parents were reluctant to step aside to facilitate the development of the young adults' autonomy. There were also concerns about how the young adult would increasingly self-manage their medical condition.

> 'Parents' reluctance to let children take over responsibility for their own health.' (57, nurse specialist, Hospital, Republic of Ireland).

> Concerns about young people taking responsibility for managing their condition. (89, manager, non-statutory organisation, Northern Ireland).

Question: What larger changes in transition services would you like to see? Larger changes included children's services becoming more active in promoting the young adults' autonomy by being less paternalistic, availability of respite provision in adult services and a more regional approach to transition.

> A regional approach to include [the] multidisciplinary team and nursing. (78, physiotherapist, Health and Social Care Trust, Northern Ireland).

Discussion

The survey results provide a broad picture of the key organisational components of transition interventions in a sample of organisations providing services to young adults with life-limiting conditions on the island of Ireland. We cannot claim this provides a reliable overview of transition services on the island of Ireland because there is no listing of all the organisations that might provide services and because 26 of 55 (47%) organisations that we were able to identify, did not respond. The majority of responses came from acute or specialist services, with non-responders predominantly from community or non-statutory organisations. On the other hand, organisations in the survey provided services for a wide range of life-limiting conditions and were drawn from all of Northern Ireland and a significant geographical region of the Republic of Ireland. So, whilst the picture is far from complete, it does provide a useful description of the conditions cared for and also of important organisational factors that may help or hinder transition.

Organisational factors that help or hinder an effective transition

Most organisations in both the Republic of Ireland and Northern Ireland reported using the direct transition model which emphasises the importance of effective communication between children and adult services and interagency collaboration. This was supported by the qualitative responses, which highlighted early commencement to the transition process, communication between children's and adult services, adopting an interdisciplinary approach and the availability of knowledgeable staff as strengths of the services. However, more than half of the responding organisations reported having no transition policy (although most reported that they were in the process of developing them). This suggests a lack of preparation for key aspects of a successful transition such as effective communication between services and inter-agency working [26]. An early start to the transition process is recommended as a foundation for effective transition [19, 26], with a consensus that this should commence when the young person is 13/14 years [12, 16, 34, 35]. In Northern Ireland, the usual age was 14 years, and in the Republic of Ireland, age 16 years. However, there was considerable variation, with ages ranging up to 19 years. As transition commonly occurs at age 18, this suggests that some arrangements are being made very late, which would undermine effective preparation of the young person and the receiving services. These results indicate the variability and lack of consistency between services, factors which are borne out by the qualitative data, which indicate weaknesses in terms of the availability of suitable adult services, appropriately trained staff, preparation of young people

and their families for transition, and the lack of regional policies on transition.

Only two organisations from the education sector (one in Northern Ireland and the other in the Republic of Ireland) responded to the survey but both reported that transition policies were available, transition strategies were currently being developed, evaluations had been completed and an individual responsible for supporting young adults in the transition process was identified. This systematic approach may reflect the fact that the education sector is routinely managing the transition of very large numbers of young people with a range of conditions as they progress through their educational career, and so has included those with life-limiting conditions under existing arrangements.

There was variability in the organisational approaches to transition. The most frequently used model of transition was the direct transition model [25] which emphasises the importance of effective communication between children's and adult services, and interagency collaboration. Forbes et al. [25] suggest this model is appropriate for patients whose medical condition has a minimal impact on their ability to develop naturally, using existing support systems. However, young adults with life-limiting conditions may have a range of complex needs [33] and typically require a wide range of support systems. Forbes et al. [25] suggest the professional transition model which relates to the availability of a supportive individual, such as a transition coordinator, is particularly suitable for young adults with a shorter life expectancy. Despite this, the survey results indicate that, with the exception of the hospices, most organisations in the statutory health and social care sector were unlikely to take this approach even though it is well supported in the wider literature [19, 26].

Twenty-eight percent of organisations reported young adults beyond the age of 25 years had remained in children's services. The rationale provided included a reluctance from young adults to transfer to adult care, no equivalent adult service being available and the young adult receiving end of life care. Despite this rationale, young adults should transfer to adult services at the most suitable time, in line with when they become an adult so they receive developmentally appropriate care. 'Parallel planning' should continue which involves continuing to support transition planning in times of uncertainty in the young adult's life as it is possible they may recover from significant periods of instability [16].

Comparative analysis

The direct transition model was the most commonly reported approach reported in both countries. In other respects, there were a number of differences. Northern Ireland had a greater number of Health and Social Care Trusts with a transition policy and also a greater number of organisations which had formally evaluated transition processes. The most commonly

reported age to commence the transition process was 16 years in the Republic of Ireland and 14 years in Northern Ireland. Three organisations in Northern Ireland reported employing a transition coordinator and none in the Republic of Ireland. A greater proportion of organisations reported that young adults over 25 years old remained in children's services in the Republic of Ireland in comparison with Northern Ireland. These differences may be influenced by the inclusion of transition to adult care as an issue in a range of government documents in the UK, which incorporates Northern Ireland [15, 35–41]. This is in comparison to only three documents sourced in the Republic of Ireland identifying transition to adult care as an issue [42–44] at the time of completing the survey questionnaire. An international cross-jurisdictional policy scoping review which included the Republic of Ireland also reported that Australia and the UK were the only two countries that had published documents detailing government supported transition strategies [45].

Strengths and limitations

One of the strengths of this survey questionnaire is it appears to be the first attempt to capture a picture of the organisational approach to providing transition services on the island of Ireland. One of the limitations experienced was the absence of a comprehensive list of organisations providing transition to adult services for young adults with life-limiting conditions in Ireland. Therefore, when distributing the survey questionnaire, there may have been organisations that provided transition services to young adults with life-limiting conditions that were not contacted to participate, or despite attempts, did not respond to the invitation to participate. A further limitation was the organisational response rate of 53%, despite three reminders being forwarded. There was also an absence of general practitioners/primary physicians and only two educational organisations bringing limitations to the generalisability of these findings. Consequently, the overview and description of services provided may generally represent transition services in one Health Services Executive area in the Republic of Ireland and throughout Northern Ireland but may not accurately represent all aspects of service provision in Ireland.

In conclusion, this survey has demonstrated that caring for young people with life-limiting conditions presents a considerable challenge to health, social, charitable, and education services, and that transition from children's to adult services is an important part of that challenge. Key factors in meeting the challenge of transition were an early commencement of the transition process; effective communication between the young person and their family, and children's and adult services, leading to an interdisciplinary, collaborative approach; the availability of appropriate adult services (including respite services) with suitably trained personnel; effective preparation for transition through collaboration with the young person and

their family; and a regional approach to transition. However, the survey indicated inconsistent implementation of these processes, in that transition, did not always start early (sometimes occurring in early adulthood), which was likely to undermine efforts at communication and collaboration with the young person and their family; appropriate adult services were not always available; and less than half of the organisations reported having a transition policy. The literature supports employment of a well-trained and knowledgeable transition coordinator as an appropriate service for this population, but this approach was taken by a small minority of services. Other important processes, such as orientation of the young person to adult services, and a focus on developing their autonomy were also uncommon.

On the basis of this research, it is reasonable to recommend that health, social, charitable and educational services work together to provide common policies on transition; that they carry out an assessment of the needs of young people with life-limiting conditions who are making the transition from children's to adult services; and that they consider a range of interventions to promote effective transition, with a view to providing a more appropriate and consistent service in Ireland. Organisations should review and/or evaluate transition interventions to determine if theory available on best practice is reflective in the delivery of care. A recommendation for further research would be to supplement the service provider's perspective reported in this study, with the service user perspective with a focus on the factors which contribute to a successful transition to adult services. The authors have undertaken an initial exploration of these perspectives on the island of Ireland (19), but further research would strengthen the transition theory developed. The combination of multiple perspectives will contribute to the further progression of transition theory regarding the factors associated with a successful transition to adult services, with service development reflecting the needs of service users.

Compliance with ethical standards

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.

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