

ORIGINAL ARTICLE

Transition to adult services experienced by young people with cerebral palsy: A cross-sectional study

Jennifer M. Ryan¹  | Michael Walsh² | Mary Owens³ | Michael Byrne⁴ | Thilo Kroll⁵ | Owen Hensey³ | Claire Kerr⁶  | Meriel Norris⁷ | Aisling Walsh¹ | Grace Lavelle⁸ | Jennifer Fortune¹

¹Department of Public Health and Epidemiology, RCSI University of Medicine and Health Sciences, Dublin, Ireland

²Office of the Chief Clinical Officer, Health Service Executive, Dublin, Ireland

³Central Remedial Clinic, Dublin, Ireland

⁴National Disability Children & Families Team, Social Care Division, Health Service Executive, Dublin, Ireland

⁵UCD IRIS Centre, School of Nursing, Midwifery and Health Systems, University College Dublin, Dublin, Ireland

⁶School of Nursing and Midwifery, Queen's University Belfast, Belfast, UK

⁷College of Health, Medicine and Life Sciences, Brunel University London, London, UK

⁸Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

Correspondence

Jennifer M. Ryan, Department of Public Health and Epidemiology, RCSI University of Medicine and Health Sciences, Beaux Lane House, Lower Mercer Street, Dublin D02DH60, Ireland.
Email: jenniferryan@rcsi.com

Funding information

Health Research Board and the Central Remedial Clinic, Grant/Award Number: APA-2019-004

Abstract

Aim: To assess if young people with cerebral palsy experience and health professionals provide practices that may improve transition from child to adult health services.

Method: Seventy-five young people (31 females, 44 males; mean age 18 years 5 months [standard deviation 2 years 2 months]) and/or parents and 108 health professionals completed a questionnaire describing their experience or the provision of nine transition practices.

Results: The percentage of young people reporting each practice was: appropriate parent involvement (90%); promotion of health self-efficacy (37%); named worker who supports the transition process (36%); self-management support for physical health (36%); self-management support for mental health (17%); information about the transition process (24%); meeting the adult team (16%); and life skills training (16%). Post-discharge, 10% of young people reported that their general practitioner (GP) received a discharge letter. The percentage of health professionals reporting each practice was: promotion of health self-efficacy (73.2%); self-management support (73.2%); information (69%); consulting the parent and young person about parent involvement (63% and 66%); discharge letter to a GP (55%); life skills training (36%); named worker (35%); meeting the adult team (30%); and senior manager (20%).

Interpretation: Many young people did not experience practices that may improve the experience and outcomes of transition. Young people should be involved in the development and delivery of transition to ensure it meets their needs.

Most children with cerebral palsy (CP) survive into adulthood¹ and thus require transfer from child-centred to adult-orientated health services. After transfer, many young adults with CP experience difficulty navigating services,^{2,3} fewer visits to specialist services,⁴ and unmet health needs.⁵ Adults

with CP report feeling abandoned² and many experience poor physical and mental health.^{6–8}

Transition has been defined as ‘the purposefully planned process that addresses the medical, psychosocial, educational and vocational needs of adolescents and young adults

This original article is commented on by Fogel on pages 156–157 of this issue.

Abbreviation: NICE, National Institute for Health and Care Excellence.

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial](https://creativecommons.org/licenses/by-nc/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2022 The Authors. *Developmental Medicine & Child Neurology* published by John Wiley & Sons Ltd on behalf of Mac Keith Press.

with chronic medical and physical conditions as they move from child-centred to adult-orientated healthcare systems'.⁹ Satisfaction with the management of transition may improve emotional and physical quality of life in young adulthood.¹⁰ The UK's National Institute for Health and Care Excellence (NICE) outlined recommendations on how the transition to adult services should be managed for young people using health or social care services.¹¹ There is evidence that some of these recommendations, such as appropriate involvement of parents and meeting the adult team before the transfer, are associated with better outcomes for young people.¹²

To improve the experience and outcomes of transition for young people with CP, we need to assess the current experience and management of transition against recommendations. However, we are aware of only one study that compared young people's transition experiences against recommendations.¹³ This study found that only 6% of young people with CP received a written transition plan, 13% had the opportunity to meet the adult team before transfer, 14% received holistic life skills training, 15% had a key worker to coordinate their care, and 48% received help to improve health self-efficacy.¹³ Further studies are required to determine if the transition experience of young people with CP is similar in different contexts. Similar experiences may indicate that it is possible to apply strategies to improve transition across contexts with minor adaptations.

We identified transition practices that may improve the experience and outcomes of transition based on a programme of research completed in the UK, the NICE guidelines, and relevant national strategies.¹¹⁻¹⁶ This study assessed if young people with CP and their parents(s) and carer(s) experienced the provision of these transition practices and if health professionals provided these practices to people with CP.

METHOD

We used a cross-sectional design to collect data on the experience and provision of transition practices. We developed an initial framework of transition practices based on a programme of research completed in the UK, the NICE guidelines, and relevant national strategies.¹¹⁻¹⁶ We modified this initial framework through discussions with members of the young person and parent advisory groups for this study and health professionals to produce the final nine practices described in Table S1. The final nine practices are very similar to those used in a programme of research in the UK¹³ but not identical. In the study protocol,¹⁷ we mapped the nine practices against the research programme completed in the UK, the NICE guidelines, and national strategies.

Participants

Young people with CP aged 16 to 22 years residing in Ireland, in all Gross Motor Function Classification System (GMFCS) levels, and health professionals providing services to people

What this paper adds

- Many young people with cerebral palsy (CP) do not receive support that may improve the experience of transition.
- Appropriate protocols and training for health professionals may improve the provision of transition and reduce inconsistency in care between and within organizations.
- Young people and their families should be involved in service design, delivery, and evaluation related to the transition to ensure it meets their needs.

with CP were eligible to participate. We shared information about the study through three national organizations that provide health and social care services to people with CP, disability officers in higher education, special education needs schools, professional bodies, and social media. We also used snowball sampling. We recruited participants between September 2020 and June 2021.

Data collection

We used two questionnaires to collect data from young people and health professionals. We collected socio-demographic and condition-specific data, as well as experience of transition practices from young people. We assessed GMFCS level by providing a description of each level in lay terms and asking participants to select the descriptor that best described their functional ability. We assessed presence of intellectual disability by asking participants if they had been diagnosed with intellectual disability. We collected data relating to health professionals' service, predominant transition model, and provision of transition practices. Members of the young person and parent advisory groups and three experienced health professionals who provide services to people with CP piloted the questionnaires. We made minor changes to the wording of questions, clarification of terms, and changes to the response options during piloting. Furthermore, we divided one question relating to self-management into two separate questions, one relating to the management of physical health and one relating to the management of mental health and emotional well-being, based on feedback from a young person with CP. The questions young people and health professionals were asked about each key transition practice are described in Table S1.

Participants completed either a paper or online questionnaire. The questionnaire for young people could be completed by: the young person alone; the young person with support from a parent, family member, or carer; or a parent, family member, or carer of the young person. Written informed consent was not obtained from those who completed

the online survey because it was anonymous and completion indicated consent. However, before completing the anonymous online questionnaire, participants confirmed they had read and understood the information leaflet, knew they could withdraw at any time, and were happy to complete the questionnaire. Where a person completed a paper questionnaire, they provided written informed consent. Young people under the age of 18 years similarly provided written informed consent when completing a paper questionnaire; their parent or guardian additionally provided consent for their child to participate.

Data analysis

Distribution of data was explored using Q–Q plots and cross-tabulations. Descriptive statistics (e.g. mean, SD) were used to describe data as appropriate. Associations between GMFCS level, intellectual disability, discharge from paediatric services, and young people's experience of each transition practice were examined using logistic regression. Separate logistic regression models were fitted with each transition practice as the dependent variable (i.e. experienced or did not experience the transition practice). GMFCS level, intellectual disability, and discharge status (i.e. pre- or post-discharge) were entered into each logistic regression model as independent variables simultaneously. When the discharge letter to the general practitioner (GP) was the dependent variable of interest, only respondents who were discharged were included in the analysis and only GMFCS level and intellectual disability were included as independent variables. Hosmer–Lemeshow goodness-of-fit tests were used to assess the fit of each model. There was no evidence from these tests to reject any model. Analysis was conducted using Stata v15.1 (StatCorp, College Station, TX, USA).

Public and patient involvement

We established two advisory groups for this study: a young person advisory group and a parent advisory group. Members of these groups supported this study by reviewing and suggesting modifications to an initial framework of transition practices, piloting questionnaires, and reviewing participant information leaflets and consent forms. Furthermore, we presented the findings to the groups and obtained their views on the findings, including their perspectives on the most pertinent findings, unexpected findings, and reasons for the findings. These views were incorporated into the discussion.

Ethics statement

This study was approved by the Royal College of Surgeons in Ireland's Research Ethics Committee, the Central Remedial Clinic's Research Ethics Committee, and Enable Ireland's Research Ethics Committee.

RESULTS

Seventy-five young people with CP were included (Table 1). Of these, 19 completed the questionnaire unaided (25%), 26 completed the questionnaire with support from a parent (35%), and 29 parents completed the questionnaire on behalf of the young person (39%). Eighty-four per cent of young people had spastic CP, 60% were in GMFCS levels I to III, and 28% had intellectual disability. Most were male with a mean (SD) age of 18 (2) years (range 16–22 years). Respondents lived in and accessed services in all regions of Ireland (Table 2). Thirty-four young people (45%) could see a variety of professionals on the same day or in the same place; 10 (13%) said this was not applicable because they only saw one professional.

Sixty-three young people (84%) were currently in education. Of these, 29 (46%) attended a mainstream school, 13 (21%) attended a special education needs school, 10 (16%) attended university, five (8%) attended a college of further education, and the rest were in another form of education. Five young people (7%) were currently in employment, of which three were in regular part-time paid employment. All young people in employment were also in education, resulting in 12 people (16%) in neither education nor employment. All young people lived with parents or other family members.

Forty (53%) young people had been discharged from paediatric services, of whom six (15%) could still access paediatric services and 22 (55%) had been referred to adult services. Fourteen young people (35%) did not know if they

TABLE 1 Characteristics of young people with cerebral palsy transitioning to adult services ($n = 75$)

	Mean	SD
Age, years:months	18:5	2:2
	<i>n</i>	(%)
Female	31	41
Currently in education	63	84
Currently in employment	5	7
Type of motor abnormality ^a		
Spastic unilateral	21	28
Spastic bilateral	42	56
Dyskinetic	3	4
Ataxic	2	3
Other	1	1
GMFCS level ^b		
I	27	36
II	10	13
III	8	11
IV	7	9
V	22	29
Intellectual disability	21	28

^aSix respondents stated that they did not know their type of motor abnormality.

^b $n = 74$. Abbreviation: GMFCS, Gross Motor Function Classification System.

TABLE 2 Regions of Ireland where young people resided and accessed services and where the service provided by the health professional was located

Region (population density from lowest to highest)	Young person (<i>n</i> = 75)		Health professional (<i>n</i> = 108)
	Residence, <i>n</i> (%)	Accessed services, ^a <i>n</i> (%)	Service located, <i>n</i> (%)
West	3 (4)	3 (4)	11 (10)
Border	6 (8)	6 (8)	13 (12)
Midland	5 (7)	5 (7)	8 (7)
Mid-west	8 (11)	7 (9)	12 (11)
South-west	2 (3)	2 (3)	11 (10)
South-east	7 (9)	9 (12)	20 (19)
Mid-east	7 (9)	6 (8)	17 (16)
Dublin	37 (49)	60 (80)	41 (38)

^aRespondents may have selected more than one response.

could access paediatric services and six (15%) did not know if they had been referred to adult services. Mean (SD) age at discharge was 17 years 10 months (1 year 2 months) (range 15–20 years). Young people's characteristics and experience of transition practices according to discharge status are presented in Table S2.

Health professionals (*n* = 108) working in services located in all regions of Ireland were included (Table 3). Most were physiotherapists and worked in a paediatric setting (Table 3). Nearly half worked in a service that provided general disability services. However, 21% worked in a service that provided both general and specialist disability services. Fifty-one respondents (47%) reported that people with CP constituted less than 25% of their caseload. Eighty respondents (74%) reported that their service was provided to people in all GMFCS levels. Sixty-seven (62%) reported that young people could see a variety of professionals on the same day or in the same place while eight (7%) reported that this did not apply to their service.

Of the professionals working in a paediatric or a paediatric and adult service, 58 (65%) reported that young people with CP were discharged from the service when they reached 18 years. This increased to 83% (*n* = 49) among health professionals working in paediatric only services. The predominant transition model in services was paediatric to the adult team (direct transfer; 48% of respondents), combined clinic (6%), and age-banded clinic throughout (e.g. child to adolescent clinic to adult service) or single doctor dually trained (1% each). A further, 35% reported no available adult service and 9% did not select a predominant transition model.

Transition practices reported as experienced by young people

The percentage of young people who reported experiencing each transition practice is reported in Table 4. Most young people (90%) reported that their parents were involved in their care at a level they deemed appropriate. Similarly, 81% of parents reported that they were involved in the young

person's care at a level they deemed appropriate. Promotion of health self-efficacy was experienced by 37% of young people, with a further 17% reporting not needing help to increase health self-efficacy. A named worker to help with the transition process was reported by 36% of young people. The named worker was most frequently a physiotherapist (37%), a social worker (33%), or an occupational therapist (11%). Other professionals who were identified as the named worker by one or two people each were a GP, paediatrician, and vocational training support worker. Similarly, 36% of young people experienced help to self-manage their physical health. However, only 17% experienced help to self-manage their mental health and emotional well-being. Twenty-four per cent received information about transition, while 13% received a written transition plan. Sixteen per cent met the adult team and 16% received life skills training.

Post-discharge, only 10% of young people reported that their GP received a discharge letter or report; 65% did not know if their GP received a letter. Additionally, 13% reported another health professional received a letter and 8% reported they or a parent or carer received a letter; 40% did not know if they, their parent or carer, or another health professional received a letter and 28% said none of these people received a letter.

Transition practices provided as reported by health professionals

The percentage of health professionals who reported that each transition practice was provided or available at their service is reported in Table 5. The most commonly provided practices were promoting health self-efficacy (73%) and supporting self-management (73%). However, only 8% and 7% of respondents had a protocol for promoting health self-efficacy and supporting self-management. Sixty-nine per cent provided information about the transition process, while 63% provided a written transition plan. Sixty-three per cent and 66% consulted the parent and young person respectively about parent involvement.

TABLE 3 Description of health professionals and the service they worked in ($n = 108$)

	<i>n</i> (%)
Profession	
Physiotherapist	56 (52)
Occupational therapist	28 (26)
Speech and language therapist	8 (7)
Social worker	3 (3)
Nurse	7 (7)
Manager	5 (5)
Dietician	1 (1)
Setting	
Adult services	19 (18)
Paediatric services	59 (55)
Paediatric and adult services	30 (28)
Service type(s)^a	
General disability service only	49 (45)
Specialist disability service only	21 (19)
General and specialist disability	23 (21)
Primary care	9 (8)
Private practice	2 (2)
Other	4 (4)
Scope of service^a	
Local	82 (76)
Regional	32 (30)
National	21 (19)
Service(s) provided^a	
Assistive technology	47 (44)
Dietetics	41 (38)
Education	31 (29)
Equipment	57 (53)
Financial	5 (5)
Medical	41 (38)
Nursing	
Occupational therapy	78 (72)
Personal assistance	23 (21)
Personal care	31 (29)
Physiotherapy	89 (82)
Psychology	60 (56)
Speech and language therapy	66 (61)
Social work	60 (56)
GMFCS level(s) provided to^a	
I	86 (80)
II	88 (82)
III	95 (88)
IV	94 (87)
V	93 (86)
Not stated	7 (7)

^aRespondents may have selected more than one response.

Abbreviation: GMFCS, Gross Motor Function Classification System.

When no adult service was available for the young person to transfer to, 56% sent a discharge letter to the young person's GP. A further 19% did not know if a letter was sent to the young person's GP. A quarter reported that a letter was sent to the young person, 49% reported that a letter was sent to another professional, and 12% reported that they did not know if a letter was sent to a health professional or the young person.

The least commonly provided practices were formal life skills training (36%), named worker (35%), opportunity to meet the adult team (30%), and senior manager with responsibility for transition (20%). A further 23% said that they did not know if a senior manager was responsible for transition.

Associations with the experience of transition practices

We observed associations between GMFCS level, discharge status, and four transition practices (Table S3). Presence of intellectual disability was not independently associated with any practice.

Appropriate parent involvement

Young people in GMFCS level III were less likely to report that parents were involved at an appropriate level than people in GMFCS level I (38% vs 88%, adjusted odds ratio [OR] = 0.06, 95% confidence interval [CI] = 0.01–0.67, $p = 0.023$). Parents of children in GMFCS level III and parents of children in GMFCS level V were also less likely to report that they were involved at the appropriate level, compared to those in level I (adjusted OR = 0.07, 95% CI = 0.01–1.06, $p = 0.055$ and adjusted OR = 0.08, 95% CI = 0.01–0.84, $p = 0.035$).

Post-discharge, young people were less likely to report that parents were involved at the appropriate level than those pre-discharge (70% vs 94%, adjusted OR = 0.06, 95% CI = 0.004–0.94, $p = 0.045$).

Information

Post-discharge, young people were more likely to receive information about transition compared to young people pre-discharge (40% vs 6%, adjusted OR = 12.50, 95% CI = 2.45–64.09, $p = 0.002$).

Promotion of health self-efficacy

Young people in GMFCS level III and young people in GMFCS level V were less likely to receive enough help to improve health self-efficacy compared to those in level I (29% vs 74%, adjusted OR = 0.12, 95% CI = 0.02–0.87, $p = 0.036$; 19% vs 74%, adjusted OR = 0.14, 95% CI = 0.03–0.66, $p = 0.014$).

TABLE 4 Transition practices experienced by young people ($n = 75$)

Transition practice	n (%)
Named worker for transition	27 (36)
Parent involved in young person's care (from the young person's perspective) ^a	40 (89)
Parent involvement at an appropriate level (from the young person's perspective) ^b	36 (90)
Parent involved in young person's care (from a parent perspective) ^c	43 (78)
Parent involvement at an appropriate level (from a parent perspective) ^d	35 (81)
Information about transition	18 (24)
Written transition plan	10 (13)
Promotion of health self-efficacy	28 (37)
Self-management support (physical health)	27 (36)
Self-management support (mental health and emotional well-being)	13 (17)
Young person meeting the adult team	12 (16)
Discharge letter to GP ^e	4 (10)
Formal life-skills training	12 (16)

^aOnly answered if the young person completed the questionnaire unaided or with the support of a parent ($n = 45$). ^bOnly answered if the young person completed the questionnaire unaided or with the support of a parent and said that the parent was/is involved ($n = 40$). ^cOnly answered if the parent completed the questionnaire alone or with the young person ($n = 55$). ^dOnly answered if the parent completed the questionnaire alone or with the young person and said that they were involved ($n = 43$). ^eOnly answered by people who were post-discharge ($n = 40$). Abbreviation: GP, general practitioner.

TABLE 5 Transition practices provided by health professionals ($n = 108$)

Transition practice	Number of responses ^a	Yes, n (%)
Named worker for transition	84	29 (35)
Parent involvement at an appropriate level (consult young person)	76	50 (66)
Parent involvement at an appropriate level (consult parent)	86	54 (63)
Information about transition	75	52 (69)
Written transition plan	83	52 (63)
Promotion of health self-efficacy	108	79 (73)
Self-management support	108	79 (73)
Young person meeting the adult team	108	32 (30)
Senior manager	108	22 (20)
Discharge letter to GP	63	35 (56)
Formal life-skills training	86	31 (36)

^aRemaining respondents selected 'not applicable'. Abbreviation: GP, general practitioner.

Meet the adult team

Post-discharge, young people were more likely to meet the adult team than young people pre-discharge (25% vs 6%, adjusted OR = 7.78, 95% CI = 1.36–44.60, $p = 0.021$).

DISCUSSION

Many young people with CP did not experience practices that may improve the experience and outcomes of transition. Except for appropriate parent involvement, all practices were experienced by less than 40% of young people. Provision of transition practices by health professionals was better but some practices were still provided by only 20% to 30% of health professionals. Young people with CP reported a similarly poor transition experience in the UK.¹³ Indeed, the percentage of young people experiencing the provision of several practices was lower in the UK. For example, only 6% received a written transition plan, 15% had a key worker to coordinate their care, 14% received life skills training, and 13% met the adult team before transfer.¹³ Our findings also provide further evidence of poor transition for young people with long-term conditions in the Irish health care system.^{18,19}

The findings indicate a lack of transparency around transition, with only 24% of young people receiving information about transition and 13% receiving a written plan. This is reflected in the fact that many who were discharged from children's services did not know if they had been referred to adult services. A large proportion also did not know if they could still access children's services or if their GP or another health professional had received a discharge letter. Young adults with CP consistently report a lack of information both about the transition process^{13,20} and about their condition, including the complications, consequences, and causes of CP.^{2,21} In the absence of information, young adults may turn to friends or family for support.²⁰ However, parents may not be able to help because they often need information about the transition process.^{13,20} In this study, only 6% of young people who were pre-discharge received information compared to 40% of young people who were post-discharge, suggesting that when provided, information is provided immediately before transfer. The NICE guidelines on transition emphasize that information should be provided early enough to allow young people time to reflect and discuss with parents, carers, and professionals.¹¹ In addition to the timing of information, the format of information may be important to enhance young people's experience. While health professionals often provide information verbally and over a series of consultations,¹³ parents and young people may value written information outlining a roadmap of the process.¹³

Direct transfer from child to adult service was the predominant transition model reported by most professionals. However, a further 35% said no adult team was available. This may explain why only 30% of professionals reported that young people had the opportunity to meet the adult team and only 16% of young people had met the adult team. The lack of services for adults with CP likely contributes to the particularly poor experience of transition among people with CP compared to those with a long-term illness.¹³ In the absence of adult services, half of health professionals reported sending a discharge letter to the young person's GP. However, only 10% of young people were aware that their GP

had received a letter. Lack of involvement of GPs in transitional health care planning is common.¹⁴ Limited coordination between children's services, adult services, and primary care may contribute to young adults' feelings of being thrust into adulthood, of being abandoned, and of not knowing whom to talk to when attempting to access services.^{2,22}

Health self-efficacy and self-management are consistently highlighted as integral issues during transition, regardless of a young person's condition.^{11-13,23} Promoting health self-efficacy—defined as young people receiving enough help to increase their confidence in managing their condition—during transition is positively associated with future satisfaction with services.¹² Only 17% of young people received adequate support to maintain their mental health and emotional well-being compared to 36% who received support to self-manage their physical health. There is evidence that young people with CP are more likely to experience mental disorders than those without CP.²⁴ Providing appropriate support in adolescence is essential for reducing the development of mental disorders in adulthood.²⁵

Of all the transition practices we examined, health professionals most commonly reported promoting health self-efficacy and supporting self-management. Health professionals often promote health self-efficacy informally and at different times in consultations throughout the young person's attendance at children's services.¹³ This may result in young people not recognizing health professionals' attempts to promote self-efficacy. Lack of protocols for promoting health self-efficacy or supporting self-management in services may also lead to variation in provision within and between services. There was some evidence that young people in GMFCS levels III and V were less likely to experience promotion of health self-efficacy compared to those in GMFCS level I, regardless of intellectual disability. Health professionals may find it challenging to promote health self-efficacy among people with more severe impairment or may decide that it is not necessary or relevant to promote health self-efficacy based on a person's level of physical impairment. Given the importance of promoting self-efficacy and self-management during transition, health professionals need appropriate protocols and training to enable them to give all young people with CP the opportunity to improve self-efficacy and self-management.

Only 20% of health professionals reported that their service had a senior manager with responsibility for transition and 36% reported their service ensured that each young person had a named worker. Without identifying a person responsible for the coordination of transition in an organization, the approach to transition is likely to be incoherent regardless of the enthusiasm among staff to improve it.¹⁴ Introducing a consistent approach within and across organizations to support young people with CP to meet the adult team, promote health self-efficacy, and support appropriate parent involvement should be prioritized because these are associated with better outcomes in adulthood.¹²

Differences between the provision of transition practices and the experience of young people highlight the need to

involve young people and their families in service design, delivery, and evaluation related to the transition to ensure it meets their needs. Since young people have different views on what they require from transition and how they interact with the process,^{26,27} involving young people is essential to ensure their individual needs are met. This is an overarching principle of the NICE guidelines for transition¹¹ and has been highlighted in previous research.²³ Finally, focusing on developing specific services for young people is likely insufficient to improve transition. All aspects of health and social care that young people engage with need to be responsive to and aligned with the care of adolescents. Developmentally appropriate health care, which adapts to the biopsychosocial development of young people rather than age, needs to be implemented across settings.²⁸ However, this requires system-level strategies and guidelines for practical implementation to become a routine part of clinical practice.²⁸

Limitations of this study include response and recall biases. Data about young people's experience were collected from both young people and parents; parents' responses may not reflect the experience of young people. Young people or parents with poorer experience of transition may have been more likely to complete the questionnaire. Bias in reporting may be greater in young people or parents who are post-discharge compared to pre-discharge because they are likely recalling events over a longer period. An additional limitation of this study is that the results relating to factors associated with transition practices lack precision, as indicated by wide CIs. These findings should only be used to inform further evaluation of the factors that may predict young people's experience of transition. Furthermore, we only explored associations between factors relating to the young person and their experience of transition practices. Factors relating to the health professional and environment, such as the health professional's experience and interest in transition, geographical location of services, high staff turnover, and lack of time during consultations probably influence the experience of transition practices in young people with CP.^{13,14} Importantly, we cannot directly compare the experiences of young people and the responses of health professionals and therefore determine if their responses agree because health professionals may not work in the services attended by young people. A previous study found that less than half of young people received a written transition plan, life skills training, a named worker, or an opportunity to meet the adult team from services that stated they provided these.¹³ Further studies should directly compare the experiences of young people with CP against what services provide and explore the reasons for differences if they exist. The use of a questionnaire also prevents us commenting on the nuanced experience of transition from the perspectives of professionals and young people; further qualitative research is required to address this.

In conclusion, many young people with CP in Ireland do not experience practices that may improve the experience of transition and lead to better outcomes in young adulthood.

Although many health professionals provide transition practices, this is not consistent and several practices are not commonly provided. A coherent approach to implement transition within and across organizations is needed. Any approach to improve the transition experience should involve young people with CP and families to ensure it meets their needs.

ACKNOWLEDGMENTS

We thank the following people for their help with recruiting young people to this study: Alison McCallion, Rory O'Sullivan, and Trish MacKeogh from the Central Remedial Clinic; Sebastian Koppe and Sonia Somers from Enable Ireland; and Helen McDaid from the Health Service Executive. We also thank the members of the young person and parent advisory groups for their work throughout the study and the interpretation of the study findings. Open access funding provided by IREL.

This research was funded by the Health Research Board and the Central Remedial Clinic (no. APA-2019-004).

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are openly available in Zenodo at <http://doi.org/10.5281/zenodo.6636481>

ORCID

Jennifer M. Ryan  <https://orcid.org/0000-0003-3768-2132>

Claire Kerr  <https://orcid.org/0000-0003-2067-5091>

REFERENCES

- Blair E, Langdon K, McIntyre S, Lawrence D, Watson L. Survival and mortality in cerebral palsy: observations to the sixth decade from a data linkage study of a total population register and National Death Index. *BMC Neurol*. 2019;19(1):111.
- Bagatell N, Chan D, Rauch KK, Thorpe D. "Thrust into adulthood": Transition experiences of young adults with cerebral palsy. *Disabil Health J*. 2017;10(1):80–6.
- NCEPOD Each and Every Need. London 2018. Retrieved from: <https://www.ncepod.org.uk/2018cn.html>
- Roquet M, Garlantezec R, Remy-Neris O, Sacaze E, Gallien P, Ropars J, et al. From childhood to adulthood: health care use in individuals with cerebral palsy. *Dev Med Child Neurol*. 2018;60(12):1271–7.
- Solanke F, Colver A, McConachie H. Are the health needs of young people with cerebral palsy met during transition from child to adult health care? *Child Care Health Dev*. 2018;44(3):355–63.
- Ryan JM, Peterson MD, Matthews A, Ryan N, Smith KJ, O'Connell NE, et al. Noncommunicable disease among adults with cerebral palsy: A matched cohort study. *Neurology*. 2019;93(14):e1385–e96.
- Smith KJ, Peterson MD, O'Connell NE, Victor C, Liverani S, Anokye N, et al. Risk of Depression and Anxiety in Adults With Cerebral Palsy. *JAMA Neurol*. 2019;76(3):294–300.
- van Gorp M, Hilberink SR, Noten S, Benner JL, Stam HJ, van der Slot WMA, et al. Epidemiology of Cerebral Palsy in Adulthood: A Systematic Review and Meta-analysis of the Most Frequently Studied Outcomes. *Arch Phys Med Rehabil*. 2020;101(6):1041–52.
- Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health*. 1993;14(7):570–6.
- Cramm JM, Strating MM, Sonneveld HM, Nieboer AP. The Longitudinal Relationship Between Satisfaction with Transitional

- Care and Social and Emotional Quality of Life Among Chronically Ill Adolescents. *Appl Res Qual Life*. 2013;8(4):481–91.
- NICE. Transition from children's to adults' services for young people using health or social care services (NG43). 2016 Retrieved from www.nice.org.uk/guidance/ng43
 - Colver A, McConachie H, Le Couteur A, Dovey-Pearce G, Mann KD, McDonagh JE, et al. A longitudinal, observational study of the features of transitional healthcare associated with better outcomes for young people with long-term conditions. *BMC Med*. 2018;16(1):111.
 - Colver A, Pearse R, Watson RM, Fay M, Rapley T, Mann KD, et al. How well do services for young people with long term conditions deliver features proposed to improve transition? *BMC Health Serv Res*. 2018;18(1):337.
 - Colver A, Rapley T, Parr JR, McConachie H, Dovey-Pearce G, Couteur AL, et al. Facilitating transition of young people with long-term health conditions from children's to adults' healthcare services - implications of a 5-year research programme. *Clin Med*. 2020;20(1):74–80.
 - National Clinical Programme for Paediatrics and Neonatology. A national model of care for paediatric healthcare services in Ireland. Chapter 33: Neurodisability. Ireland: HSE. 2016 Retrieved from: <https://www.hse.ie/eng/services/publications/clinical-strategy-and-programmes/paediatricneurodisability.pdf>
 - Health Service Executive. National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland. From theory into action. Implementation Framework 2019–2021. 2019 Retrieved from: <https://www.hse.ie/eng/services/list/4/disability/neurorehabilitation/national-strategy-policy-for-the-provision-of-neuro-rehabilitation-services-in-ireland.pdf>
 - Ryan JM, Fortune J, Walsh A, Norris M, Kerr C, Hensey O, et al. Transition from child to adult health services for young people with cerebral palsy in Ireland: a mixed-methods study protocol. *BMJ Open*. 2020;10(12):e041425.
 - Coyne I, Malone H, Chubb E, While AE. Transition from paediatric to adult healthcare for young people with cystic fibrosis: Parents' information needs. *J Child Health Care*. 2018;22(4):646–57.
 - McNamara N, McNicholas F, Ford T, Paul M, Gavin B, Coyne I, et al. Transition from child and adolescent to adult mental health services in the Republic of Ireland: an investigation of process and operational practice. *Early Interv Psychiatry*. 2014;8(3):291–7.
 - Freeman M, Stewart D, Cunningham CE, Gorter JW. "If I had been given that information back then": An interpretive description exploring the information needs of adults with cerebral palsy looking back on their transition to adulthood. *Child Care Health Dev*. 2018;44(5):689–96.
 - Nieuwenhuisen C, van der Laar Y, Donkervoort M, Nieuwstraten W, Roebroek ME, Stam HJ. Unmet needs and health care utilization in young adults with cerebral palsy. *Disabil Rehabil*. 2008;30(17):1254–62.
 - Fegan L, Hall EO, Uhrenfeldt L, Aagaard H, Ludvigsen MS. Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis. *Int J Nurs Stud*. 2014;51(1):123–35.
 - Nguyen T, Stewart D, Gorter JW. Looking back to move forward: Reflections and lessons learned about transitions to adulthood for youth with disabilities. *Child Care Health Dev*. 2018;44(1):83–8.
 - Whitney DG, Peterson MD, Warschausky SA. Mental health disorders, participation, and bullying in children with cerebral palsy. *Dev Med Child Neurol*. 2019;61(8):937–42.
 - Mulraney M, Coghill D, Bishop C, Mehmed Y, Sciberras E, Sawyer M, et al. A systematic review of the persistence of childhood mental health problems into adulthood. *Neurosci Biobehav Rev*. 2021;129:182–205.
 - Hislop J, Mason H, Parr JR, Vale L, Colver A. Views of Young People With Chronic Conditions on Transition From Pediatric to Adult Health Services. *J Adolesc Health*. 2016;59(3):345–53.
 - Gorter JW, Stewart D, Cohen E, Hlyva O, Morrison A, Galuppi B, et al. Are two youth-focused interventions sufficient to empower youth with chronic health conditions in their transition to adult healthcare: a mixed-methods longitudinal prospective cohort study. *BMJ Open*. 2015;5(5):e007553.

28. Rapley T, Farre A, Parr JR, Wood VJ, Reape D, Dovey-Pearce G, et al. Can we normalise developmentally appropriate health care for young people in UK hospital settings? An ethnographic study. *BMJ Open*. 2019;9(9):e029107.

SUPPORTING INFORMATION

The following additional material may be found online.

Table S1: Description of key transition practices and related questions.

Table S2: Description of young people and transition practices experienced by young people according to discharge status.

Table S3: Results from the logistic regression analyses examining associations between GMFCS level, intellectual disability, discharge status, and transition practices.

How to cite this article: Ryan JM, Walsh M, Owens M, Byrne M, Kroll T, Hensey O, Transition to adult services experienced by young people with cerebral palsy: A cross-sectional study. *Dev Med Child Neurol*. 2023;65(2):285–293. <https://doi.org/10.1111/dmcn.15317>

Mac Keith Press

Principles and Practice of Child Neurology in Infancy


Colin Kennedy


Course 1: Principles of Child Neurology in Infancy


Course 2: Clinical Practice of Child Neurology in Infancy

EACCME® Accredited Online Courses

Mac Keith Press and the European Paediatric Neurology Society present two interactive online learning courses that provide authoritative advice on managing neurological disorders presenting in infancy.



Mac Keith Press 



EUROPEAN
PAEDIATRIC
NEUROLOGY
SOCIETY

January 2021 - £150 / €165 / \$195 USD (single course) or £200 / €220 / \$260 USD (both courses)
Visit www.mackeith.co.uk/courses to learn more and register for free trial access.