ORIGINAL ARTICLE

Transition from child to adult services for young people with cerebral palsy in Ireland: Influencing factors at multiple ecological levels

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Abstract

Aim: To explore the factors that influence the process of transitioning from child to adult services in Ireland among young people with cerebral palsy, their parents, and service providers.

Method: This study followed a qualitative descriptive approach. Semi-structured interviews were conducted with 54 participants, including young people with cerebral palsy aged 16 to 22 years ($n = 13$), their parents ($n = 14$), and service providers ($n = 27$). Data were analysed using the Framework Method. Findings were categorized using an ecological model across four levels: individual, microsystem, mesosystem, and exosystem.

Results: Limited awareness, preparation, and access to information hindered successful transition. Microsystem factors such as family knowledge, readiness, resilience, and health professional expertise influenced transition experience. Mesosystem factors encompassed provider–family interaction, interprofessional partnerships, and interagency collaboration between child and adult services. Exosystem factors included inadequate availability and distribution of adult services, limited referral options, coordination challenges, absence of transition policies, staffing issues, and funding allocation challenges.

Interpretation: Transition is influenced by diverse factors at multiple ecological levels, including interactions within families, between health professionals, and larger systemic factors. Given the complexity of transition, a comprehensive multi-level response is required, taking into account the interactions among individuals, services, and systems.

Most young people with cerebral palsy (CP) survive into adulthood[1] and will move from paediatric to adult services. Transition is more than the transfer of care to adult services; it describes the process by which young people are prepared to take charge of their lives and their health in adulthood.[2] Poor management of transition may contribute to poor health outcomes, decreased opportunities to participate in the community, and decreased quality of life.[3–5] National policy and strategy documents in Ireland emphasize the importance of supporting the transition from child to adult services.[6–9] However, there is a dearth of information on current organizational approaches for facilitating transition and no formal guideline on how this transition should be provided for young people with CP. Existing transition pathways in Ireland tend to focus on specific diseases and are limited to specific institutions.[10]

Internationally, transitional care interventions for young people with childhood-onset neurological disabilities often target individual-level behaviours, attitudes, and skills.[11] The transition process is complex and involves multiple

stakeholders, levels, and peripheral systems shaped by larger social contexts.[12] Therefore, developing effective interventions requires a comprehensive understanding of the interaction between the young person and their environment.[12] Bronfenbrenner's Ecological Systems Theory,[13] which recognizes these dynamic interactions, is highly relevant for understanding the transition process in people with disabilities.[14,15] This theory identifies distinct systems (microsystem, mesosystem, exosystem) surrounding the individual, highlighting the influence of immediate environments, connections between members of those environments, and external contexts that indirectly influence the individual and their transition.

The data presented were collected as part of a larger investigation into transition care for young people with CP in Ireland.[16] The study employed a convergent parallel mixed-methods design to examine how transition care is provided to and experienced by young people with CP in Ireland. The quantitative component involved questionnaires completed by young people with CP, their parents, and health professionals to assess the experience and provision of key transition practices.[17] Simultaneously, the qualitative component gathered perspectives on transition. This article presents an analysis from the qualitative component utilizing an ecological model to explore the multi-level, interactive factors that influence the transition to adult services, as expressed by young people with CP, their parents, and health professionals.

METHOD

The principles of qualitative description guided sampling, data collection, and analysis decisions. Qualitative description aims to capture participants' perspectives, meanings, and interpretations to provide a detailed and comprehensive description of a phenomenon or experience.[18] The reporting of this study adhered to the Consolidated Criteria for Reporting Qualitative Research (COREQ).

Participants and recruitment

We purposefully sampled three data sources: young people, parents, and health professionals. We aimed to recruit 25 service users, where 'service user' encompassed young people with CP, aged 16 to 22 years in all Gross Motor Function Classification System (GMFCS) levels[19] and residing in Ireland, and their parents. We included people with mild-to-moderate intellectual disability, excluding those with severe intellectual disability where adaptations to gather their perspectives were not feasible. Parents of young people with all severities of physical and intellectual disability were included. Service users were selected using a sampling frame that considered relevant characteristics identified in the literature, such as gender,[20] GMFCS level,[21,22] geographical location, and stage of transition.[21,22] We aimed to recruit 20 service providers encompassing health professionals and managers from child

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What this paper adds

- Transition was characterized by a lack of information, preparation, and continuity.
- Interpersonal interactions with family, peers, and health professionals supported knowledge development and preparation.
- Coordination and communication challenges between services and agencies affected continuity.
- Limited access to adult services, unclear pathways, and coordination gaps created care discontinuity.
- Policy gaps, staffing challenges, time constraints, funding, and service distribution impacted transition.

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and adult services who provide care for young people with CP in Ireland. Health professionals were purposively sampled based on their profession, sector, cohort (paediatric or adult), and geographical region.

Information about the questionnaires and interviews for the mixed-method study was shared with young people and parents through national organizations that provided services to people with CP, disability officers in higher education, special education needs schools, and social media. Service providers were recruited through national organizations that provided services to people with CP, professional bodies, and social media. Participants had the choice to complete an interview, questionnaire, or both. After completing the questionnaire, individuals were asked if they were interested in participating in an interview. The first author contacted those who expressed interest through their preferred contact method. Snowball sampling[23] expanded the health professional participant pool by utilizing existing participants' networks to identify health professionals like nurses and paediatricians who were identified as missing from the sampling frame. Seven people who indicated interest in participating in an interview could not be contacted or declined to participate. Participants were recruited between September 2020 and June 2021.

Data collection

Topic guides for semi-structured interviews were developed based on a framework of key transition practices.[16] Topic guides were created for and piloted by young people, parents, and health professionals (Table S1). Because of the COVID-19 pandemic, interviews were conducted by the first author, an experienced qualitative data collector, through participant-chosen phone or video calls. For video calls, significant gestures and expressions were noted in field notes. The interviews were organized based on the young person's preference for individual or joint interviews with a parent.

Dyadic joint interviews consisted of simultaneous conversations with the young person and parent, aiming to establish a shared frame of reference and gather both joint accounts and individual perspectives on the transition.[24,25] The majority of interviews involved verbal conversations, while one young person used eye gaze technology for communication. To enhance accessibility, adaptations were made, such as providing easy-read documentation, sharing the topic guide in advance, using more closed-ended questions, and allowing a communication partner of their choice. Participants were informed of the option to complete the interview over multiple sessions and review and amend transcripts, but no participants requested these options. Written or verbal informed consent was obtained from young people, parents, and health professionals in accordance with ethical and GDPR requirements. For participants aged 16 to 18 years old, consent was additionally provided by their parent.

Data analysis

Verbatim audio recordings were transcribed, pseudonymized, and imported into NVivo V.12: (Lumivero, Denver, CO, USA). Interviews were analysed using the Framework Method,[26] which incorporates both deductive and inductive data analysis. This method accommodated our predefined topics based on key transition practices while remaining open to the emergence of additional inductive themes.

The Framework Method involves five iterative stages: familiarization, thematic framework identification, labelling, charting, and mapping and interpretation.[26] The research team (JF, JR, AW, MN) read and independently coded six transcripts (three service user and three service provider). An initial framework of 116 codes was established through comparison and grouping of similar codes. The research fellow (JF) applied the initial framework to all transcripts. A co-author (JR) checked a proportion (20%) of coded transcripts. Modifications were made to the framework as new issues emerged through discussions with co-authors. Data was organized into charts summarizing themes, issues, and individual responses. Categories were merged where possible, and themes were discussed until consensus was reached in additional meetings with co-authors (Table S2). Preliminary results and interpretations were shared with the project management group and young person and parent advisory group for their reflections and interpretations. The research fellow analysed participant data and identified emergent categories that aligned with the ecological model (Figure 1). The data were categorized based on the ecological systems in which they occurred. To ensure trustworthiness, the analytical process involved collaborative team analysis, reflexive diary maintenance, and consideration of negative case analysis to identify data elements that challenged identified patterns.

Ethical approval

This study obtained approval from the Research Ethics Committees of the Royal College of Surgeons in Ireland, the Central Remedial Clinic, and Enable Ireland.

RESULTS

Fifty-four participants shared their perceptions and experiences of transition. Twenty-one service user interviews were conducted with 13 young people and 14 parents. Seven young people were interviewed alone, eight parents were
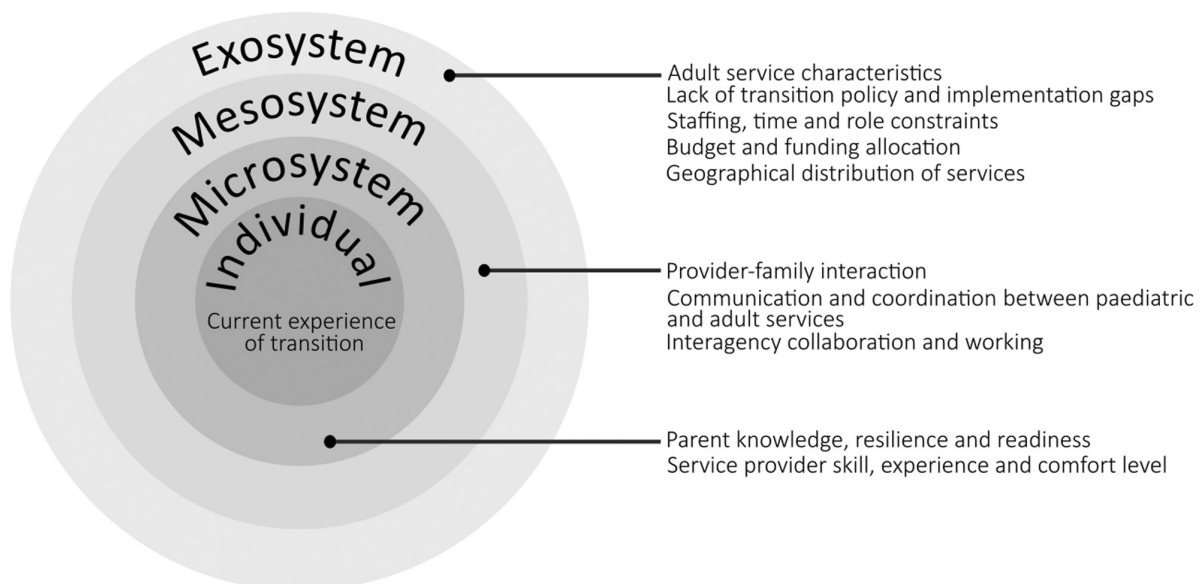
FIGURE 1 Categories at each ecological level.

interviewed alone, and six parents and young people took part in a joint interview (mean duration: 67 minutes; range: 37–112 minutes). Twenty-seven health professionals or managers (i.e. service providers) took part in interviews (mean duration: 64 minutes; range: 18–100 minutes).

The majority of young people were female (*n* = 14) with a mean (SD) age of 18 years (2 years 5 months; range 16–22 years). Twelve were in GMFCS levels I to III. Ten were still in paediatric services (Table 1). Nine health professionals were physiotherapists. Most worked in paediatric services (*n* = 20), in Dublin (*n* = 18), and in the voluntary sector (*n* = 19) (Table 2). Illustrative quotations are provided in text.

Individual

The individual level included the young person's knowledge, attitudes, beliefs, and experience of transition.

Current experience of transition

At the centre of the model, young people pre- and post-discharge described a lack of knowledge and awareness about transition and transfer of care, including uncertainty about who would take over their care, how to contact them, referral options, and the differences between child and adult services. Limited access to reliable information amplified uncertainty about the future, stress, and apprehension. Those in GMFCS levels I and II reported a complete absence of information and uncertainty about transitioning to adult services. They hypothesized that this may be because of more limited contact with services, the stability of their condition, or not actively seeking

TABLE 1 Young person characteristics.

	Mean	SD
Age, years:months	18:3	2:5
	n	(%)
Female	14	67
GMFCS level		
I	7	33
II	2	10
III	3	14
IV	1	5
V	8	38
Transition stage		
Pretransfer	10	48
Post-transfer	11	52
Location		
Dublin	10	48
Outside Dublin	11	52

TABLE 2 Service provider characteristics.

	n (%)
Profession	
Physiotherapist	9 (33)
Occupational therapist	3 (11)
Speech and language therapist	1 (4)
Social worker	2 (7)
Nurse	6 (22)
Manager	3 (11)
Psychologist	1 (4)
Paediatrician	2 (7)
Setting	
Adult services	7 (26)
Paediatric services	20 (74)
Service type(s)	
Statutory	8 (30)
Voluntary	19 (70)
Location	
Dublin	18 (67)
Outside Dublin	9 (33)

information. Nevertheless, they expressed concerns about the transition process and their future management. Limited knowledge and awareness hindered engagement, preparation, and planning for transition, and many young people did not know where to seek help or what they were entitled to. Discharged young people expressed regret over their inability to engage in the process because of a lack of awareness. Insufficient preparation made transfer feel sudden and abrupt, even if they had some prior knowledge of it. As one 19-year-old participant explained, discharge appointments happened without notice, resulting in important questions being overlooked:

> I didn't even realize that a meeting was something that you did. I was being asked did I have any questions at this team meeting. I think it was just a bit of a shock to see them [paediatric health professionals]. Because I hadn't seen them in a bit. I didn't have time to think of any questions that I might have now.
> (service user [SU]18, young person)

Service users emphasized the importance of introducing the transition process at a defined age, enabling early planning for their needs and preferences, sourcing service options and information, and establishing connections with onward services. Young people wanted a cohesive transfer review involving all departments to review therapy needs, make relevant referrals, and provide guidance on locating adult support in each specialty. Advance awareness of their discharge meeting would assist young people to plan their questions and enhance their engagement.

Microsystem

The microsystem included interpersonal interactions between young people and others in their immediate environments (e.g. exchanges with parents or health professionals).

Parent knowledge, resilience, and readiness

Parents played a crucial role in gathering and interpreting transition information for young people; however, their effectiveness was influenced by their understanding, experiences, and family circumstances. Even parents with expertise in navigating health systems acknowledged knowledge gaps in adult service provision, funding, and accessing information and support. Parents of discharged young people relied on insights from other parents who had transferred, valuing their transparent experiences. While service providers and parents recognized the potential of peer information to bridge knowledge gaps, concerns were raised about its inconsistency when obtained through word-of-mouth and personal connections as the mother of a 19-year old adult explained:

> even lately, because of her vision impairment, she's actually entitled to the blind allowance. But I had to by chance research it. And another Mammy in the same position, said, 'no one ever told me that'. So she's got it as well because we happen to hear somebody talking about it.
>
> (SU02, parent)

Service providers highlighted that some parents were confident in supporting their child's transition, while many others experienced burnout. Parents and service providers recognized years of fighting and constantly staying ahead took a toll, leaving parents with limited capacity to handle additional responsibilities during transition. Alongside supporting their child, parents also had work and family obligations. Service providers felt that families may delay the transfer from child services when possible because the paediatric system provided more support to their young person, as a nurse working in children's services highlighted:

> a lot of our young adults would probably stay til they're 19. It used to be 18 but now they can apply for an extra year. For some that's really beneficial because it gives them an opportunity to do a little tester in certain areas and see if that's where they would like to access, but for some it is that the family would like them to stay cosseted and supported in the world that they know and not like them to move on.
>
> (service provide [SP]05, nurse)

Service provider skill, experience, and comfort level

Service providers noted that clinician experience and comfort level can influence transition. Experienced clinicians who transparently present available services and ask the right questions facilitate better knowledge transfer. Young people and parents stressed the need for transparent, developmentally appropriate information and reassurance of service continuation. They preferred information from trusted health professionals and expressed frustration when they had to actively seek information rather than it being provided to them. Service users felt service providers lacked transparency and openness when discussing available services in adulthood, leading to frustration. However, health professionals faced limitations in providing information, advocating for adult services, and offering reassurance because of their limited awareness of existing services, uncertainty in the process, and difficulty sourcing information. As a result, they approached the topic cautiously and may unintentionally trail off instead of making promises they could not fulfil. The lack of support or reassurance from staff had a demoralizing effect, as noted by a parent of a 21-year-old adult:

> sometimes in [service name] people couldn't look me in the eye, cause the psychologist, the teams, the physio, the nurses know that there's nothing. I'm watching not just my family but families for years before me, for years after me experiencing the same thing they're so embarrassed, they're demoralized and they're sitting there going 'Oh my God'.
>
> (SU13, parent)

Paediatric service providers acknowledged their discomfort with the void young people face upon discharge. Needs may arise when young people enter the next phase of life without the familiar support of the paediatric environment. Some providers addressed this discomfort by delaying the final appointment, keeping young people longer, or remaining available for queries after transfer. However, this approach was unsustainable within the capacity of child services, and the informal nature of this workaround left young people uncertain how they could interact with paediatrics services as an adult. A comprehensive directory, detailing health professional roles, service structure, available services, and key contact information was seen as beneficial for facilitating information exchange by both service users and providers. Service providers stressed flexible timing of transfer to accommodate the maturity and developmental level of young people, ensuring ongoing support until they are successfully settled in their next phase.

Mesosystem

The mesosystem involved interactions between members of the microsystem (for example interactions between health

professionals or interactions between health professionals and parents). Although these interactions did not involve the young person directly, they influenced their transition.

Provider–family interaction

Parent–professional interactions influenced transition. Service providers approached future planning conversations cautiously, particularly for young people with life-limiting conditions, and refrained from initiating discussions if they believed families were not ready to have them. Parents, however, often struggled with contemplating the future as they had grown accustomed to living in the present after their child's diagnosis. A parent of a 17-year-old highlighted this challenge:

> I have to say I don't think too far ahead. Because if I did, I'd drive myself crazy. I stopped that a couple of weeks after she was diagnosed. I stopped thinking too far ahead, because my head was just. I thought I was going to just think of it a little bit down the line, but not too far. So I don't really know a lot about the adult services, to be honest with you I don't know anything.
>
> (SU14, parent)

Although health professionals hesitated to initiate early discussions to prevent anxiety, parents often welcomed such conversations when initiated by professionals. Unsupported parents felt responsible for driving transition to maximize the likelihood of a successful transfer. However, health professionals perceived parents who independently sought information as resourceful and less in need of support, perpetuating the cycle of parents reluctantly taking charge of the process.

Communication and coordination between paediatric and adult services

Paediatric and adult service providers recognized the need for collaboration but faced challenges due to physical separation and limited formal contact. There was friction between the two services, with paediatric providers often feeling responsible for young people's transition into adulthood. Inadequate follow-up from adult services made the preparation by paediatric providers seem futile. Adult service providers felt ill-equipped to manage young people immediately after the transfer and suggested that paediatric providers could improve transition by providing appropriate referral letters, preparing young people for adult responsibilities, and setting realistic expectations. A paediatric physiotherapist highlighted this issue:

> the reality is for a lot of these young people, they're entering a void. Because the services, it's the cliff edge they talk about … the children push

and adult pull is what we'd like to see. But what happens is from the children's service you can be pushing all you want. But like the adult services are so overwhelmed they're certainly not reaching the hand down to pull the children through.
>
> (SP11, physiotherapist)

Communication challenges between child and adult services impacted information transfer. Handover approaches varied from referral letters to comprehensive multidisciplinary team discussions. Uncertainty regarding the recipient of the referral in adult services hindered face-to-face handover between the teams. Parents of discharged young people often played a crucial role in bridging the communication and information gap between child and adult services as a parent of a 19-year-old adult highlighted:

> going into adult services, they were very much depending on me to tell them her list of equipment, arrange to transport her equipment from school to adult services. That should have all been done from the schools, they should have said 'there's [young person name], her list of issues and her list of whatever else, off you go'. But it doesn't seem to have been done.
>
> (SU02, parent)

While some paediatric service providers offered reports to young people or families upon discharge, many parents felt excluded from the process and desired copies of all correspondence. To improve continuity between child and adult services, the idea of a health passport summarizing pertinent information about the young person, with agreement from adult service providers to use it, was proposed.

Opportunities to become familiar with adult services were important to successful transition. When they occurred, meetings provided reassurance, reduced anxiety, and fostered new working relationships. Adult service providers also found it beneficial to introduce themselves, set boundaries, and gather information for optimal support. A parent of a 21-year-old shared the benefits:

> I do think the sample days made a huge difference to her. It just meant that she had an idea what to expect. They were able to tell her what the programme would have. They did similar things with the parents; they brought us all in for a one-day session to go through the programme and explain it to us. She came home on a very big high from the sample days and decided then she definitely wanted to go to the service. That it was going to be the right fit for her, because they'd made her feel very welcome and very grown up.
>
> (SU17, parent)

Although acknowledged as best practice, there were limited opportunities for orienting young people to adult

services, because of uncertainty regarding service provision and the responsible party in adult services. Service providers and parents emphasized the importance of a defined handover period with collaboration between paediatric and adult providers for an ideal transition. A gradual handover would enable nuanced information transfer, reassure families, and help young people connect with their adult team. In cases where a handover period is not feasible, a joint meeting would provide reassurance to paediatric service providers and families regarding the transfer of information to adult providers, while also allowing young people to familiarize themselves and ask questions to their new care provider.

Interagency collaboration and working

Interagency collaboration and partnerships between statutory services, voluntary services, health, education, and social care agencies involved in transition posed challenges, as noted by service providers. The lack of a cohesive vision and fragmented approach affected families. Parents highlighted difficulties with funding, information transfer, and obtaining assistive devices. Inconsistencies regarding the age of adulthood within and between sectors created logistical challenges, especially for young people with coexisting conditions who accessed multiple services. A nurse working with both adult and paediatric clients highlighted these issues:

> I straddle that daily because I'm Health Service Executive but some of the clients and some of the staff we work with, they're Department of Education and we tend to come at things very differently. So when you have a service user transitioning from one to the other, it can be a little bit hard because the Department of Education can fund a lot of supports. Whereas, the Health Service Executive are much slower. It's a much bigger machine
>
> (SP05, nurse)

Parents and service providers advocated for electronic patient records and technological tools to improve information continuity and knowledge sharing across agencies and sectors. Accessible and up-to-date electronic records would alleviate concerns about relaying information accurately, empower young people, and support interagency collaboration.

Exosystem

The exosystem involved contexts that were not immediately experienced by the young person but, rather, affected their immediate environment, for example larger systems and policies, and thereby indirectly influenced their transition.

Adult service characteristics

Service providers and users associated child services with higher care input and therapy frequency, benefiting from a functioning multidisciplinary team and established clinical pathways. Access to adult services was more challenging, with fewer options, unidisciplinary teams, and less frequent appointments. Eligibility criteria differed, leaving some young people ineligible for services they received in childhood. Young people in GMFCS levels IV and V had a higher likelihood of meeting eligibility criteria for available services. Those with intellectual disabilities or transitioning from special education needs schools were perceived to have more resources compared to mainstream school settings. Pathways were less clear for those with physical disabilities and no associated learning difficulties, especially outside of Dublin. Young people in GMFCS levels I or II faced challenges as they fell in between 'disabled' and 'able-bodied' categories and had lower priority for clinical services. A 16-year-old in GMFCS level I shared their perspective:

> When you have a certain level of disability you're just kind of left to your own devices. I wouldn't refer to myself as disabled, because I feel wrong saying it. Because I'm not disabled, I'm able to do things. I know that's not the definition of it, but that's how it feels. I'm kind of just left to work things out for myself. There's no resources available to me. I just don't have anything, I don't know where I'm going, or what I'm doing. Or how to do it. Which is a bit of a struggle
>
> (SU08, young person)

Without equivalent adult services, young people were referred to their general practitioner (GP), primary care, or disability services at higher education institutions. Reliance on higher education institutions to address the gap in disability services was common outside of Dublin. However, not everyone pursued higher education; some were uncomfortable registering with disability services in that setting. Furthermore, there was a lack of services available after graduation as one 19-year-old shared:

> we're still trying to figure out are there other services, instead of a GP, because we were just told the GP. And then the college services, which obviously won't be available to me when I leave college, thankfully, currently I don't really need them. But, if I do need them it's trying to make sure that I have them available. Or that they're easy for me to find.
>
> (SU18, young person)

While community services were theoretically available to all adults, service users post-transfer and service providers expressed difficulties with referral processes and eligibility

criteria for accessing these services, as well as uncertainty about the role and remit of health professionals working in the community services. An occupational therapist in adult services highlighted this issue:

> There's nobody to refer clients onto at the moment. Some primary care teams will take them on and some won't, and generally speaking, the primary care is they need to have a need at that time to be seen, so I'll make the referral, but they're not going to necessarily meet them unless they need something at that time
>
> (SP21, occupational therapist)

There was a lack of equivalent services and coordination in adult services. Without paediatrician oversight, care coordination became fragmented. Young people with multiple conditions were referred to various services and specialists in different locations. GPs were expected to fill the coordination gap, but they often lacked expertise in physical disability, making it unrealistic to expect equivalent coordination as provided by a paediatrician. Service users and providers had limited interaction with GPs during childhood, and without a paediatrician equivalent, young people and families had to navigate an unfamiliar and fragmented system to access services as the mother of a 21-year-old explained:

> being discharged from the paediatric services and suddenly your GP is in control of everything. Which is fine if you've got a really good GP, like we have. But the GPs don't always know the kids. Especially if they've been dealt with in services the whole time and they've had their paediatrician in the clinic looking after everything for them. And then you're suddenly going back to a GP who goes 'but I don't actually know your child. I don't really know how I'm supposed to help you here.' It's been a learning curve for us.
>
> (SU17, parent)

Paediatricians aimed to strengthen the bond between service users and GPs by maintaining open communication channels during childhood, promoting parent involvement, and avoiding micromanagement. Both service providers and parents emphasized the importance of having access to knowledgeable multidisciplinary adult teams to ensure comprehensive care for young people. They also stressed the need for community-centred general health care and therapy in adulthood, with referrals to specialists or hospitals as necessary.

Lack of transition policy and implementation gaps

While pockets of good practice existed, standardizing transition approaches across organizations without national consensus proved challenging. Service providers recognized the ad hoc nature of transition management due to the absence of formalized policies. This lack of a framework hindered consistent delivery of young people's needs in a uniform manner. Furthermore, service providers reported ambiguity between policy and implementation, which was echoed by a parent of a 21-year-old adult. Existing policies appeared sufficient on paper, but the actual procedures communicated to them fell short in practice:

> the Health Service Executive had come along and said what happens is we identify a service or place of education for [a] young person and then in the last year of their school life they go off for a day. They meet the staff, meet the other colleagues, and they see the environment and they slowly get to know that environment and they move away from their school life. And then, when they leave school, that service picks them up and they continue with their life. That didn't happen for anybody as far as I could see
>
> (SU13, parent)

Service providers stressed the need for a user-driven national framework outlining the yearly transition process and specifying eligible supports at each stage, aiming to improve navigation and ensure consistent delivery.

Staffing, time, and role constraints

Child and adult services faced high workloads, stretched resources, and long waiting lists. Paediatric service providers recognized the importance of a structured transition process but struggled to implement it because of limited resources and competing priorities. Limited time and staffing hindered attempts at transitional care interventions. Delayed access to adult services increased the risk of young people experiencing crises and falling through the gaps. Adult service providers, focused on urgent needs, had little time for transition support. Transition roles in most services were informal, causing uneven work distribution and a lack of clarity on responsibility. Some paediatric providers were highly engaged in transition, while others had minimal involvement. The process relied on dedicated individuals, which was unsustainable as a physiotherapist working in adult services explained:

> A good few years back, there was a little bit of a push. One of the paediatricians, since retired, had an interest and we started. We kind of started a type of a transition. Sort of. We got together anyway and we tried, but it kind of fell by the wayside after she retired.
>
> (SP10, physiotherapist)

TRANSITION FROM CHILD TO ADULT SERVICES FOR YOUNG PEOPLE WITH CEREBRAL PALSY IN
IRELAND: INFLUENCING FACTORS AT MULTIPLE ECOLOGICAL LEVELS

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Most service providers advocated for a dedicated transition coordinator role to enhance clarity and accountability in the transition process. This role would allow for proactive planning, ownership, and driving of the process. Additionally, providers emphasized the importance of an oversight role to bridge services, promote evidence-based practices, and advocate for effective transition within and between organizations.

Budget and funding allocation

Service users and providers expressed the need for more effective budget allocation in the disability sector. Discharged service users felt funding distribution favoured child services, while providers believed budget allocators lacked understanding and connection with on-the-ground providers. Service users also felt a lack of interest in establishing appropriate disability roles. Decisions made at the executive level did not align with service-level changes, limiting providers' autonomy and causing frustration with bureaucratic obstacles. A physiotherapist in paediatric services provided further insight:

> it is a constant coming up against that wall of administration nonsense that wall of barriers to do with funding and vacancy and roles … I really think just taking out that layer of bureaucracy and just shaping it a bit more accordingly based on what the child needs as opposed to what maybe the CHOs [community health care organizations] as a whole needs.
>
> (SP17, physiotherapist)

Insufficient funding prioritization for adult services and supports was a concern raised by providers and parents. Despite being aware of the transition timeline from school, funding for adult day services or training programmes was not allocated until the last minute, despite the need for these placements being evident several years in advance. Limited awareness of options and increased parental anxiety resulted from delayed funding and lack of proactive attitude in transition planning. Paediatric providers questioned the validity of early planning when staff recruitment and orientation to adult services were affected by funding inertia.

Geographical distribution of services

Transition care interventions varied in implementation and were regionally dependent. Service users and providers outside of Dublin highlighted lower awareness and understanding of transition. Contact between geographically dispersed young people and community teams was limited, hindering effective information sharing. Rural areas faced challenges in implementing group interventions because of limited participation numbers. Variability in service provision existed across regions because of different organizations delivering paediatric disability services. Service providers and parents reported inequitable distribution and lack of national coverage of services were more pronounced in adult services. Urban areas housed specialized centres and consultants, with narrow geographical referral criteria. Catchment-based 'postcode lotteries' were described, posing risks for service users transitioning from child to adult services. Limited adult services and training programmes contributed to a system that prioritized fitting individuals into existing services rather than providing choices. A nurse in Dublin working with both adult and paediatric clients provided further insights:

> Some of those services aren't right for some of these service users, and you can pigeonhole them and put a square peg into a round hole and it doesn't work … You hear families moving house to access services and that, to me, is mad as a concept. I don't think that your geography should determine what service you go into. In the disability sector we tend to just go it's just service A. We don't have a service B. This is the service that exists. If we don't take this we get nothing and that's back to that void.
>
> (SP05, nurse)

Existing adult services acted creatively to make available placements within catchment areas as individual as possible to service user needs. However, existing centres are constantly struggling for space, which raised concerns about the security and longevity of placements among parents.

DISCUSSION

Employing an ecological approach provided insight into the multi-level factors that influence transition to adult services from the perspectives of young people with CP, parents, and health professionals. Consistent with previous research, transition was characterized by a lack of information,[27] preparation, and continuity.[28] Microsystem interactions with family and health professionals facilitated knowledge acquisition. However, parents encountered difficulties in imparting information because of shared information gaps with young people.[27,29] Paediatric service providers recognized the significance of providing information but often lacked clarity on eligibility and availability of adult services. This uncertainty caused discomfort among providers, leading to reluctance in conveying the challenging reality of adult service provision and occasionally resulting in delayed discharge from child services. Inadequate knowledge and preparation, along with discontinuity between child and adult services, caused uncertainty, anxiety, and difficulties during the transition to adult services. The abrupt transfers experienced by young people left them feeling abandoned and unsupported as previously described.[28]

While improved coordination, communication, and collaboration in mesosystems are necessary for supporting continuity, many experiences of uncertainty, unpreparedness, discontinuity, and fragmentation stem from issues at the exosystem level. Staff shortages and heavy workloads in child and adult services result in long waiting lists. Limited formal dialogue between child and adult services leads to working practices lacking shared planning and formal support arrangements for transition. Because of limited resources and competing service needs, transition often gets deprioritized. In many services, there was a lack of dedicated roles and time to support the implementation and sustainability of transitional care interventions. Without a national framework, agreed-upon policies, dedicated transition support roles, and implementation oversight, transitions were unstructured, dependent on individuals, and highly varied across services. Limited service coverage, geographical accessibility challenges, and service fragmentation resulted in insufficient support in adulthood, in comparison to that provided in child services. Additionally, the incompatibility of information systems between organizations affected information sharing and cross-agency continuity of care.

While changes in the adult system are a necessary focus, system-level changes can be time consuming. Therefore, it is necessary to consider how to support equitable transition experiences within existing services and supports. Transition is a complex process consisting of interactions between people, services, and systems.[12] Examining these interactions across multiple levels highlights their interdependency and their direct and indirect impact on a young person's transition. Researchers, practitioners, and policymakers can leverage these conceptual relationships to develop interventions that address the complexity of person-environment interactions through multidimensional approaches, rather than targeting isolated factors. Complex interventions, comprising multiple interacting components, addressing various organizational levels, and necessitating behaviour change among participants and intervention providers, have proven beneficial for supporting transitions in young people with other long-term conditions,[30] and should be explored for young people with CP as well.

Service users recommended transparent, trustworthy, developmentally appropriate, and easily accessible information on the transition process. These findings align with international guidance, which suggest that early introduction and effective communication of practical information about transition, adult services, and available supports enhance engagement and preparedness for the transfer.[31,32] Knowledge acquisition can happen through individual efforts or interactions within the young person's immediate environment. Health professionals, leveraging their relationships with young people, are well positioned to provide information, but effective methods of delivery need to be identified to minimize burden on overwhelmed service providers. Structured yet flexible individual transition plans facilitate contextualized preparation, goal

identification, and holistic, patient-centred care.[33,34] Electronically available educational resources, such as checklists, leaflets, and digital peer transition stories, offer cost-effective solutions to improve knowledge and awareness.[11,35] Additionally, peer-support,[33] including parent peer-support during transition,[36] has shown promise in other populations, but careful consideration is needed to facilitate peer-support for people with CP because of their diverse needs and presentations.

Participants identified key factors for achieving optimal continuity during transition, including effective information transfer between services, opportunities to meet the adult team, establishing a relationship with a GP, and receiving support from a transition coordinator. Transitional care interventions such as portable health summaries,[37] joint working and opportunities for orientation to adult services,[33,38–40] and appointing a coordinator to oversee transition[33] have been shown to enhance information exchange, preparation, and confidence in interactions with adult services, and are considered core elements of a successful transition. Although these interventions align with international guidance and have measured success, many are considered time consuming and adherence to guidance can be challenging in light of workload and resource constraints.[41] There is ongoing debate regarding the capacity of GPs to coordinate the medical needs of young people with CP[42] and limited evidence exists on primary care interventions for improving transition outcomes in young people with chronic conditions.[43] Given that GPs may be the only consistent health professionals during transfer, there is a need to develop and evaluate interventions to facilitate relationship development and integrate primary care practitioners in the transition process. However successful implementation relies not only on individual health professionals but also on a system structure that allows dedicated time and staffing to support the transition process.

Strengths and limitations

Utilization of the ecological model is a strength, and triangulation of data sources (young people, parents, health professionals) enhances credibility. However, the study had underrepresentation of males and people in GMFCS levels II and III. Data on socioeconomic status and ethnicity were not collected, limiting the generalizability of the findings. People with negative experiences may have been more motivated to participate, possibly resulting in an overrepresentation of negative experiences and overestimation of transfer difficulties. During joint interviews, the researcher aimed to elucidate the young person's perspective. However, some young people may have been reluctant to speak freely in front of their parents, while others may have relied on their parent's support to express themselves. Additionally, because of the COVID-19 pandemic, interviews were conducted via phone or videocall, potentially excluding some participants.

Conclusion

This study emphasizes that transition is influenced by various factors at multiple levels, including interactions within and between families, health professionals, and broader systemic factors such as policies and funding priorities. Understanding the interplay between personal and environmental factors at different ecological levels can aid in planning and implementing transitional care interventions. Comprehensive changes across ecological levels are crucial for a holistic approach to support transition and alleviate feelings of abandonment, loss, and uncertainty. The complexity of transition calls for a sophisticated multi-level systemic response involving all relevant stakeholders.

CONFLICT OF INTEREST STATEMENT
We have no conflict of interest to declare.

DATA AVAILABILITY STATEMENT
Data available in article supplementary material.

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SUPPORTING INFORMATION

The following additional material may be found online:

Table S1: Description of key transition practices and indicative interview questions

Table S2: Coding tree