Received: 4 June 2024 | Accepted: 27 March 2026

DOI: 10.1111/dmcn.70310

ORIGINAL ARTICLE

# Transition to adulthood: Perspectives from young people with cerebral palsy, parents, and health professionals

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**Funding information**
Central Remedial Clinic, Grant/Award Number: APA-2019-004; HRB Clinical Research Facility Galway, Grant/Award Number: APA-2019-004

## Abstract

**Aim:** This descriptive qualitative study explored the transition to adulthood for young people with cerebral palsy (CP), gathering perspectives from young people, parents, and health professionals.

**Method:** Twenty-one semi-structured interviews were conducted with young people with CP aged 16 to 22 years, and their parents, and 27 interviews were conducted with health professionals. Data were analysed using the framework method.

**Results:** An overarching theme 'from passenger to pilot' depicts how young people gradually take on a more autonomous role during transition with four subthemes reflecting the multiple transitions young people navigate. System transitions describe the differences in expectations and care philosophies as young people move from a child-centred to adult-oriented health system. Power transitions highlight dynamics between young people, parents, and health professionals that hinder young people's autonomy in health management. Developmental transitions describe the development of young people's autonomy through enhanced personal capacities, facilitated or constrained by interactions with parents and health professionals. Social and educational transitions describe aspirations and barriers in broader life-course participation.

**Interpretation:** To empower young people with CP, transition support must extend beyond service coordination to address communication, power-sharing, and relational continuity. Holistic approaches that recognize transition as a negotiated process, shaped by interactions between young people, parents, and health professionals are needed to support autonomy, engagement, and preparedness for adult services.

Young people with cerebral palsy (CP) face unique challenges as they transition to adulthood, a developmental period marked by increasing social, emotional, and health-related demands. During this time, they must balance relationships, education, and employment, alongside managing their health and social care needs. Transition is defined as a purposeful, planned process that addresses the medical, psychosocial, and educational/vocational needs of adolescents and young adults as they move from child-centred to adult-oriented health care systems.[1] This transition is recognized as a critical stage in the life course for young people with CP, with the potential to shape long-term participation, wellbeing, and health outcomes.

The organizational shift involved in transition creates significant challenges. Children's services are typically family centred and multidisciplinary, providing coordinated support to both the young person and their family. In contrast, adult health care emphasizes autonomy, self-management,

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and individual responsibility, with care often fragmented across multiple providers. These differences mean that young people may leave a highly supported environment and encounter systems with fewer resources and higher expectations for independence. Without appropriate preparation, risks include disengagement from services, reduced quality of life, and poorer health outcomes.[2–4]

There is growing international interest in understanding how young people with CP experience this transition. Qualitative studies across diverse health systems have highlighted abrupt and poorly coordinated transitions, insufficient preparation, limited access to information about ageing with CP, and difficulties in education, employment, and social participation.[5–12] Parent-focused research similarly documents the emotional and practical burden of navigating fragmented systems, alongside concerns about future independence and their own evolving role.[6]

Despite the existence of guidance on the core components of effective health care transition, young people with CP continue to experience gaps in preparation, access to information, and coordination between child and adult services. This persistent mismatch between recommended practice and lived experience underscores the need to examine how transition unfolds within real-world service contexts and from multiple stakeholder perspectives.

While existing studies provide important insights, most focus on a single perspective, typically that of young people[5,7–13] or their parents.[6] As a result, the relational dynamics that shape the transition process, and the ways young people, parents, and professionals influence one another remain poorly understood. Transition is not merely an administrative handover between services; rather, it is a complex process influenced by individual characteristics, family relationships, service contexts, and broader societal expectations.[5,8,14,15] To develop effective transition pathways, it is therefore essential to examine how the experiences and expectations of young people, parents, and health professionals intersect.

The aim of this descriptive qualitative study was to explore how young people with CP experience the transition to adulthood, with particular attention to how interactions with parents and health professionals shape this process. Drawing on the perspectives of young people, parents, and health professionals within the Irish health context, the study sought to develop a multiperspective understanding of the relational dynamics that influence transition.

## METHOD

This article reports the qualitative findings from a broader mixed-methods study examining transition for young people with CP in Ireland.[16] The study employed a convergent parallel design to explore both how transition is delivered and experienced in the Irish context. In the quantitative strand, questionnaires were completed by young people with CP, their parents, and health professionals to evaluate the implementation and experience of key transition practices.[17] In parallel, the qualitative strand sought to provide deeper insight into the transition process.[15] Data strands were analysed independently and integrated during interpretation to develop a comprehensive understanding of transition. This manuscript presents findings from the qualitative component of the overarching mixed-methods study.

**What this paper adds**

- Transition for young people with cerebral palsy is a relational, negotiated process rather than a single service transfer.
- Loss of long-term paediatric relationships contributes to instability alongside structural service fragmentation.
- Power dynamics limit young people's participation when communication remains parent- or professional-led.
- Misalignment exists between professionals' self-management strategies and young people's perceptions of support.
- Gaps in condition-related knowledge undermine readiness for adult health care.

### Design

This study was guided by qualitative description, an applied approach that provides a comprehensive, low-inference account of participants' experiences in their own terms.[18] Qualitative description is well suited to questions about what and how phenomena are experienced, producing findings that are accessible, grounded in participants' language, and directly applicable to practice. This approach captures perspectives with minimal interpretive inference, making it appropriate for representing the views of young people with CP, their parents, and health professionals, and for informing practical recommendations to improve transition support.

### Participants and recruitment

Three stakeholder groups—young people with CP, their parents, and health professionals—were recruited to generate a comprehensive and holistic understanding of transition. Variation in sex, Gross Motor Function Classification System (GMFCS) level, transition stage, professional role, organizational sector (paediatric/adult), and geographical location was sought to capture a diversity of experience; however, participants were recruited using convenience sampling, with all eligible individuals who expressed interest invited to participate. Young people were eligible if they were aged 16 to 22 years, had a confirmed diagnosis of CP, and were living in Ireland. Those with mild-to-moderate intellectual disability were included, while young people with severe intellectual disability were excluded where participation could not be supported through reasonable adaptations. Parents were eligible if they were the parent or legal guardian of a young person with CP in this age range living in Ireland. Health professionals were eligible if they were clinicians or service managers providing paediatric or adult services for young people with CP in Ireland.

Given the iterative nature of qualitative description, no fixed a priori sample size was established; however, we anticipated recruiting approximately 15 to 25 participants per stakeholder group. Recruitment occurred through multiple channels including national organizations, disability officers, special education schools, health professional bodies, and social media. In addition, participants in the preceding national survey on transition were invited to indicate interest in being contacted for interview.[17] Seven individuals who expressed interest could not be contacted or declined to participate.

## Data collection

Data were generated through semi-structured interviews to explore the experiences and perspectives of young people with CP, their parents, and health professionals. Semi-structured interviews offer a flexible structure that enables participants to describe their experiences in their own terms while allowing researchers to probe for clarity and depth.

Young people were invited to choose between an individual interview or a dyadic interview conducted jointly with a parent. Dyadic interviews, defined as interviews involving two participants who share a relationship, are commonly used to support communication, provide emotional safety, and capture shared or negotiated perspectives.[19] To help mitigate potential power dynamics within dyads, the interviewer directed questions to the young person first and ensured space for independent responses before inviting parents to contribute. Adaptations were made to support accessibility, including easy-read documentation, lay language guides, close-ended prompts, and involving parents as communication partners where appropriate. Significant gestures and expressions were documented in field notes. Interviews were conducted between September 2020 and June 2021. Interviews with health professionals were carried out in parallel with those of young people and parents. Topic guides for each stakeholder group were developed a priori based on a shared framework of nine key transition practices informed by previous UK research, National Institute for Health and Care Excellence guidelines, and national strategies ensuring consistent exploration of core transition issues across groups.[20] Topic guides were piloted with one young person and one parent, resulting in minor wording adjustments to improve clarity and accessibility (Table S1). All interviews were conducted by the first author (JF), a physiotherapist experienced in qualitative health research, who was not previously known to participants. Interviews took place online or by telephone according to participant preference and lasted between 40 minutes and 75 minutes. Participants were offered the option of completing the interview in two sessions, and reviewing and amending their transcripts; no participant took up these options. Informed consent was obtained either in writing or through audio-recorded verbal consent for all participants. For participants aged 16 to 18 years, parental consent was also required. Demographic information was collected from all participants, including age, sex, GMFCS level (young people), and professional role (health professionals).

## Data analysis

Audio recordings were transcribed, pseudonymized, and imported into NVivo V12 (QSR International, Burlington, MA, USA). for analysis. Data were analysed using the framework method,[21] a systematic yet flexible approach suitable for both inductive insight and deductive exploration. Analysis followed five iterative stages: familiarization with the data, development of a thematic framework, indexing, charting, and mapping and interpretation to identify patterns and relationships across the data set. Four authors (JF, JR, AW, MN) independently coded several transcripts and collaboratively developed the initial framework. The framework was then applied to all transcripts by one author (JF), with approximately 20% independently reviewed by a second coder to ensure consistency. Through iterative comparison across stakeholder groups, four themes were identified and refined. Subsequent analytic discussions identified a unifying concept that captured the central process underlying participants' experiences; this is presented in ‘Results’ as the study's meta-theme.

Trustworthiness was strengthened through multiple strategies. Peer debriefing occurred throughout the analysis, and preliminary interpretations were discussed with the study's advisory group, which included young people with CP, parents, and clinicians. Collaborative coding and theme development enhanced analytic rigour: the first author (JF) led the analysis, and all stages were reviewed and refined through regular multidisciplinary team meetings to support reflexivity and consistency of interpretation. Transparent documentation of analytic decisions, codebook revisions, and framework matrices created an audit trail. Triangulation across the three stakeholder groups—young people, parents, and health professionals—enhanced credibility by providing a comprehensive and comparative understanding of transition experiences. Reflexivity was maintained through a reflexive diary and ongoing discussions within the research team.

## Ethical approval

This study obtained approval from the Research Ethics Committees of the RCSI University of Medicine and Health Sciences, University of Medicine and Health Sciences, the Central Remedial Clinic, and Enable Ireland.

**TABLE 1** Young person characteristics.

| | *n* | (%) |
|---|---|---|
| Age, years:months, mean (SD) | 18:4 | (2:6) |
| 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 |
| Posttransfer | 11 | 52 |
| Location | | |
| Dublin | 10 | 48 |
| Outside Dublin | 11 | 52 |

Abbreviation: GMFCS, Gross Motor Function Classification System.

**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) |

# RESULTS

In total, 54 stakeholders participated; 21 interviews were conducted with 13 young people and 14 parents. Seven young people were interviewed individually, eight parents were interviewed individually, and six dyadic interviews were conducted with a young person and parent together (mean duration = 67 minutes; range = 37–112 minutes). Twenty-seven health professionals participated in interviews (mean duration = 64 minutes; range = 18–100 minutes).

Most young people were female (67%), with a mean (SD) age of 18 years (2 years 4 months) (range 16–22 years). Over half (57%) were classified within GMFCS levels I to III, and 48% were still engaged with paediatric services (Table 1). Most health professionals were physiotherapists working in paediatric services within the voluntary sector in Dublin (Table 2).

## Overview

Analysis generated one overarching meta-theme ‘From passenger to pilot’ supported by four interrelated themes. Each theme reflects contributions from young people, parents, and health professionals. The meta-theme captures a central process across participants' accounts: the gradual shift towards greater autonomy as young people with CP assume increasing responsibility for their health and life decisions, alongside evolving roles and expectation among parents and health professionals.

In childhood, young people often rely on parents and health care providers for decision-making, much like a passenger trusts a pilot to guide a journey. During the transition to adulthood, however, they begin to move from a passenger to a copilot and, where possible, towards piloting their own lives. Navigating adult health care takes time and practice. Just as pilots understand their aircraft, young people must understand their CP, its health impacts, how to communicate effectively with health care providers, and make informed decisions. Some young people may continue to need a copilot but supporting them to gradually take more control remains essential. This shift is shaped by ongoing interactions with health professionals, who must balance support with gradual transfer of responsibility. Empowering young people to take the pilot seat can increase their confidence, independence, and autonomy, enabling them to successfully navigate the transition to adulthood and chart their own course for the future. The four themes—system transitions, power transitions, developmental transitions, and social and educational transitions—capture distinct but interconnected dimensions of this process.

System transitions capture the shift from a coordinated, family-centred paediatric system to an adult-oriented model with different expectations, philosophies, and service structures. Power transitions reflect how evolving dynamics between young people, parents, and health professionals can both constrain and enable young people's autonomy in health management. Developmental transitions describe the growth of young people's knowledge, skills, and confidence in managing their health and how these were facilitated or hindered by interactions with parents and professionals. Social and educational transitions encompass young people's aspirations for adulthood including education, employment, independent living, and community participation, alongside the barriers they encountered.

Together, the meta-theme and four themes provide an integrated account of how transition unfolds across personal, relational, and systemic levels. Illustrative quotations are presented within the text.

## System transitions

The perspectives of young people, parents, and health professionals revealed a clear contrast between child-centred and adult-oriented health care philosophies. Children's services were described as family-centred with parents routinely involved in care and decision-making, often alongside or on behalf of the young person. In contrast, adult services focused primarily on the individual, with considerably less routine involvement of families. After transfer, young people reflected on the differing expectations, relational styles, and structures of paediatric and adult care, identifying both benefits and challenges. Many described a shift in how they were positioned within the system, noting marked differences in the warmth, familiarity, and interpersonal tone of care. Child-centred services were characterized by automatic appointment scheduling, easier access to health professionals, emotional support, therapy input, advocacy, and the provision of simplified accessible information. In adult services, however, young people encountered expectations for greater autonomy, more complex information, and less frequent contact with professionals. Establishing relationships with unfamiliar teams contributed to feelings of discontinuity, uncertainty, and reduced trust. As one young person described:

> before it was always child talk and just sweet-talking me into it and a lot of easy simple language. But now, everything's in detail, no sugar coating it in any way, shape, or form. You're given this and you're just going to have to work with it.
>
> (service user [SU]15, young person)

Young people had trusting relationships with paediatric health professionals who were knowledgeable about their medical history. In contrast, transfer to adult services often involved separation from their usual support mechanisms and raised concerns about unmet needs. Encounters with unfamiliar health care teams and limited continuity, often seeing different professionals at each visit, left many feeling like novices navigating a new system.

> take everything you can while you're in paediatric services. Because once you turn 16 or 18, you're gone from your paediatrician who was like, gold … and then you're thrown into the big bad world … all these services that you need are like ‘No, you're an adult now, tough’, ‘off you go’.
>
> (SU04, young person)

Most young people felt overwhelmed by the transfer to adult services, unsure of navigating the new environment. However, some embraced it positively, likening it to going to university, and valued being treated as adults, actively involved in their care.

## Power transitions

As young people transition to adulthood, responsibility for health care decisions and management gradually shifts from parents to them. Many young people recognized and valued their parents' significant role in decision-making within children's services and appreciated the support and objectivity parents provided. However, some struggled when parental views clashed with their own and expressed a desire for greater autonomy in communicating with health professionals. Although long-term relationships with health professionals fostered rapport and comfort, continued patterns of interaction established in childhood sometimes failed to adapt to young people's evolving developmental needs. When health professionals prioritized parental communication, young people reported feeling overlooked, disempowered, and excluded from important health decisions as they entered adolescence and adulthood.

> there's certain people in [service] that still treat me like I'm a young child. I'm not being bad, but they'll be like, ‘oh if you want to sit at that table over there and I'll talk to your mam and dad’. I can still hear what they're talking about. I'm right in the room ‘she's real good at this, or she's real bad at that’. I am sat here, you can say it to me. They're treating me as if I'm some kind of simpleton for lack of a better word … it feels kind of infantilizing … they haven't really changed their approach with me as I've gotten older.
>
> (SU08, young person)

Some young people felt frustrated and disengaged when their knowledge and opinions were disregarded. They described feeling dehumanized, when information and explanations were directed primarily to parents, rather than to them and emphasized the importance of trust, transparency, and being treated as capable partners in their care rather than sheltered as children. In adult services, communication and information were typically directed towards the young person, often without parental involvement. However, despite valuing increased autonomy, many young people continued to see parental presence in adult services for support with information interpretation, advocacy, and emotional support. They felt more respected by health professionals when accompanied by parents and experienced discomfort when parents were absent.

> if your Mam's not there to fight your corner, they just bully you … if Mam wasn't there I'd get a 20-minute appointment. If Mam's there I

> get 45 minutes. That's why I make her come because I get more out of the session.
>
> (SU04, young person)

Shifts in autonomy expectations, alongside cultural and legal shifts within adult health care systems, significantly altered parents' roles. In children's services, parents were active decision-makers; in the adult system, their role became supportive and consultative. Many parents found this shift distressing and felt disempowered. Some struggled with the transfer of decision-making authority to the young person, particularly when they felt their child's developmental age did not align with the expectations of adult services. Despite forewarnings, some parents felt unprepared for reduced involvement. They had concerns ranging from their child's wishes being disregarded to their choices not being questioned when parents perceived them as against the child's best interests.

> they tell you you're not going to be involved as much. But that doesn't prepare you for what that actually means. You go from being in control of the situation, being able to provide everything for your child and do everything that they need and be their advocate. To suddenly being told you're not allowed speak for them anymore. They have to do it themselves. And you're going; she doesn't understand what you're asking. And they're going; well she's just going to have to learn.
>
> (SU17, parent)

Although parents valued empowerment and increasing autonomy for their young person, many struggled to relinquish control because of concerns about their child's ability to manage their own care. These concerns included recalling and communicating information, accurately representing themselves, and discussing their needs confidently with professionals. Within this shifting power dynamic, some parents and young people acknowledged that capability for autonomy varies, and some individuals will always require some level of support. Consequently, parents often spoke on behalf of their child to maximize limited time with professionals and ensure key information was conveyed. Parents of young people in GMFCS levels IV and V described particular difficulty stepping back, as a successful transition heavily relied on their sustained involvement and advocacy. They described having to fight, beg, and even resort to political intervention to obtain health services in adulthood.

> we had to be involved too much … when [young person] was 16. I wrote to the Health Service Executive and I said to them. I have watched absolute carnage. Friends of mine. Pupils in the school, friends of [young person] leaving school to a big blank nothing.
>
> (SU13, parent)

Health professionals acknowledged parents' significant role in decision-making, planning, and goal setting. However, some described parent–young person relationships as overprotective or closely enmeshed, particularly when responsibility for care was expected to shift to the young person. To support this transition, professionals described working collaboratively with parents to foster positive communication, provide reassurance, and strengthen confidence in the young person's capabilities, thereby reducing feelings of exclusion and disempowerment. While empathizing with parents' challenges and anxieties as decision-making moved towards the young adult, health professionals emphasized the importance of shifting the locus of control to the young person and supporting parents to step back into a more facilitative role.

> I don't want to say they [parents] disable them but they don't enable them, so you need them to step back when all they want to do is protect them all the time. But they're only small for a short period, for the next 50 years you're not going to come in every evening and stretch his arm, so you have to start to look at the long-term picture.
>
> (service provider [SP] 2, physiotherapist)

However, before transfer, most health professionals reported that they rarely sought young people's views on parental involvement and were unable to recall instances of young people requesting independent appointments. Health professionals acknowledged power imbalances within child-oriented health care settings, where clinicians are positioned as experts, and young people are often cast in passive roles. At the same time professionals across child and adult health care settings recognized the practical benefits of parental attendance at appointments as communication partners who could provide comprehensive medical histories and support shared goal setting. Considering these advantages, some health care professionals expressed caution about suggesting that young people attend appointments without parental support.

## Developmental transitions

In childhood, young people had varying levels of engagement in their health care, with parents primarily responsible for decision-making and management. As they neared adulthood, many started taking on more responsibility, managing exercise routines and daily tasks.

> not as much with booking appointments and stuff. But I would be very confident in being able to maintain my stretches. I feel I'm mature enough now to realize the benefits and the negatives of it. I'd be mature enough to do them myself, if something doesn't feel right, then obviously I'm not just going to let it slide.
>
> (SU12, young person)

Post-transfer, young people aimed to gain control and experience managing their CP. However, limited understanding of their condition posed challenges. Those in GMFCS levels I to III reported limited knowledge about their CP and ageing with CP, which hindered their ability to communicate their medical history and seek appropriate support. Understanding their diagnosis and its future implications was particularly challenging, for those in GMFCS level I who often learned about their diagnosis later in life. Incomplete explanations and personal family narratives compounded this lack of understanding restricting meaningful participation in health care, especially during the transition to adulthood.

> I'm uneducated about my own disability. I don't know anything, I only found out that I was actually properly disabled when I was nine. My parents didn't want to tell me because they didn't want me to think I was different.
>
> (SU08, young person)

Young people found support in person-centred providers who tailored therapies to their interests and strengths. Those who viewed self-management as a natural progression often described growing up in empowering environments that fostered autonomy and encouraged active involvement in managing their condition. Equal opportunities within their households to try new things and learn diverse skills were seen as key facilitators of confidence and self-management.

> I come from a big family, there's six children in my household including myself and I feel like they didn't … like if I wanted, if my sisters or anything were doing something I got an opportunity to do it too, it wasn't kind of 'you can't do that' or 'you can't go do this'. I was allowed to try everything and practice and I learned how to do many things with that mindset.
>
> (SU10, young person)

For some young people, developing self-management skills involved testing boundaries and learning from experience. Physical consequences, such as fatigue or pain, prompted behavioural adjustments, help-seeking, and the adoption of healthier routines. For others, transitioning to adult health care services introduced unfamiliar professionals, requiring adaptation to new self-management roles. While some became proficient in self-advocacy to regain control and have their needs met, others struggled because of low confidence in communicating and advocating for themselves within the new health care teams.

> obviously I act, really confident here, I'm really good in the email but when I'm on the phone like even face-to-face, I'm not good with that confrontation, like that kills me but it has to be done but I hate it.
>
> (SU04, young person)

The extent to which communication responsibility shifted from parent to young person before transfer had positive implications for participation. Adopting a phased approach, where young people attended parts of appointments independently while parents remained available for support, increased their confidence and facilitated adjustment to the adult system.

> I did my own thing from about 14, 15 … if I had any issues or if my mam or dad had noticed anything, that would be at the start of the appointment and then they'd go get a coffee and I'd do my appointment I think it did prepare me for getting older.
>
> (SU10, young person)

Young people and parents highlighted the importance of having adequate time and space to express themselves during clinical encounters. Young people emphasized that participation was enhanced when health professionals directed questions towards them, offered choices, involved them in decision-making, and actively supported communication. To engage young people with low confidence, suggested strategies included providing structured opportunities to ask questions, dividing questions between young people and parents, or supporting young people to prepare questions in advance.

While young people made progress towards self-management, parents acknowledged that complete autonomy was not always achievable. During childhood, many parents described gradually transferring responsibility for basic therapy and health-related tasks, supporting the development of self-management skills in a scaffolded and reassuring manner. They encouraged independence and sought to avoid over-protectiveness even when it challenged their own comfort. However, both before and after transfer, parents continued to provide practical and emotional support, recognizing their ongoing role in facilitating self-management. For young people in GMFCS levels I to III, parental support commonly included assistance with appointment management, encouragement of adherence to interventions, and emotional reassurance. Parents of young people in GMFCS levels IV and V remained heavily involved, working in tandem with both health professionals and their young person to support ongoing care. Parents appreciated the support of health professionals in fostering self-management and independence through tailored treatment sessions that gave young people a sense of control over their health care journey. At the same time, some parents reflected that excessive support in childhood might unintentionally hinder the development of independent self-management skills.

> the schools are fabulous, but they [young people] are treated in a certain way. And everything is done for them, everything. From cutting their foods to everything.
>
> (SU01, parent)

Health professionals acknowledged that the protected environment of paediatric care can inadvertently limit opportunities for young people to develop autonomy. They recognized autonomy development as a gradual process. To guide self-management, they described personalizing treatment, actively involving young people in decision-making and referral processes, promoting positive body awareness, and encouraging ownership of care through collaborative goal setting. They emphasized the importance of empowering young people to problem-solve and viewed their role as coaches, supporters, and providers of knowledge rather than decision-makers. Professionals also highlighted the importance of respecting young people's choices, even when these were not considered optimal, as such experiences were seen as valuable opportunities for learning through consequence and reflection.

Health professionals observed that the most autonomous young people often came from home environments where expectations were similar for young people with CP and their siblings, and where independent care coordination was encouraged. However, they echoed the young person's view that parents frequently found it emotionally difficult to discuss CP and its implications, which limited opportunities for knowledge-sharing. Adult health professionals, in particular, expressed surprise at how little some young people understood about their condition and about ageing with CP.

> it's kind of getting ownership, I do encourage people to look online. I often ask them when I see them. Have you ever looked up any research around your condition? They usually say no, they haven't.
>
> (SP10, physiotherapist)

They emphasized that condition-specific knowledge is central to effective self-management, enabling early recognition of change and timely, appropriate responses.

## Social and education transitions

Alongside changes in health care, young people were navigating broader transitions into adulthood, including building social networks, pursuing education, seeking meaningful vocational roles, and working towards independent living and future career goals. However, these aspirations were often constrained by structural barriers such as limited access to suitable housing, employment opportunities, assistive technology, personal assistants, and physically accessible environments. Many young people described low confidence and heightened anxiety during this period, linked to perceived differences from peers, uncertainty about the future, and a lack of visible role models or representation of people with CP in adult life. As a result, young people expressed a strong desire for support in developing skills to enhance participation. While formal life-skills programmes were typically located within specialist disability services, young people more frequently emphasized the need for capacity-building in areas such as confidence, interpersonal skills, self-acceptance, self-esteem, and emotional wellbeing. Most young people and parents, particularly those in GMFCS level I, desired opportunities to connect with others with CP, valuing peer support as a source of reassurance, shared understanding, and practical strategies for navigating adulthood. Young people, especially those attending mainstream schools, also reported significant gaps in information about supports and opportunities relevant to their physical disability. They sought guidance from knowledgeable professionals who could help them pursue their goals within the context of living with CP and expressed frustration at the limited availability of tailored support and clear direction.

> … it would have been great if she [health professional] could give me a few suggestions. If she would say ‘do you know, I think this would be good for you’ because they know me for years, they know what type of person I am … But it was always … ‘oh just follow your gut and dream big’. It was really inspirational and all, but it's not practical.
>
> (SU05, young person)

They appreciated professionals who offered guidance on education, training, work/life balance, managing CP in further education, and selecting supportive courses and living arrangements. However, at times they perceived insufficient attention was paid to what mattered most to them and they were dissuaded from pursuing their aspirations.

> they asked me what I wanted to do when I left school. I always had an interest in medicine, from a young age, so I said that. And they were like, oh maybe don't do that … you're not able for that. And now I've kind of steered away from that because I don't want to do something I'm not able for. My mam's like ‘you shouldn't let them limit you’, well they're not necessarily the ones limiting me, they're just advising me that there's a limit.
>
> (SU08, young person)

Health professionals agreed that less confident or experienced health and education professionals may inadvertently pigeonhole disabled young people to a single path that does not align with their strengths or interests. They also highlighted challenges that arise when parents' expectations for future trajectories differ from those of young people. In response, professionals described their role as facilitative rather than prescriptive, aiming to support young people to make informed decisions and chart their own course towards achieving personally meaningful goals.

> some teenagers have very, very different ideas to what their parents want or think. And very, very different ideas to what maybe we would think is

> suitable for them. Our aim always is to try and make sure that the child gets the chance, and is facilitated to make up their own mind. Because at that age that's what's really important, it's what they think they want for themselves and to lay out some sort of supported pathway for them to be able to achieve that.
>
> (SP27, manager)

This work often involved expanding young people's perspectives and fostering higher self-expectations. Health professionals utilized diverse strategies like coaching, self-esteem courses, resilience building approaches, and strengths-based practice to support the development of skills and confidence. They also recognized peers' significance in providing empathy, support, and modelling independent behaviours. Many professionals found success in inviting former service users to share their adult journeys and achievements, which helped validate young people's aspirations and provide realistic role models.

> getting some of the young adults or just the adults who had moved to a service to come back was really very empowering to share their experience, they're saying they were anxious, they weren't sure, this is how it is and it helps them just take away some of the fear factor you know.
>
> (SP20, physiotherapist)

Parents and health professionals acknowledged the value of immersive environments, like overnight trips and respite opportunities, in supporting the development of practical and social life skills. However, they noted that skills such as advocacy and resilience were often given less priority compared to conventional life-skills training. Providing immersive experiences for practising these skills were perceived as resource-intensive and challenging to evaluate. Both young people and health professionals advocated for increased psychological support to facilitate the transition to adulthood and promote self-acceptance.

## DISCUSSION

The transition to adulthood for young people with CP is a complex and multidimensional process that extends beyond the transfer of health care. In this study, the overarching meta-theme 'From passenger to pilot' captured how young people gradually assumed greater responsibility for their health and life decisions while parents and health professionals adjusted to shifting roles. The four interrelated themes of system, power, developmental, and social transitions illustrate that transition is more than crossing service boundaries. Rather, it is a broader developmental journey marked by the redefinition of identity, autonomy, and relationships across personal, familial, and systemic levels. By integrating perspectives from young people, parents, and professionals, this study contributes a nuanced, relational understanding of transition as a shared process of negotiation rather than an individual event.

Previous research has described the challenges faced by young people leaving paediatric services, including fragmented care, poor coordination, and the abrupt withdrawal of support.[8,11,22] Consistent with these findings, our participants experienced disorientation and uncertainty as they navigated a less responsive and more fragmented adult health care system. Our study extends existing work by demonstrating that instability during transition reflects not only structural fragmentation but also disrupted relational continuity. While feelings of abandonment have been previously described,[7,23] participants in our study located these emotions in the loss of trusted, long-term paediatric relationships, underscoring the stabilizing role of relational continuity.

Transition also involved continuous negotiation of power and responsibility among young people, parents, and health professionals. Adolescent–parent dynamics reflected a delicate balance between parental protectiveness and the young person's desire for autonomy.[5,11,12] When communication from health professionals was directed primarily towards parents, young people felt their competence was underestimated, limiting their participation and sense of agency.[7,22,24–26] At the same time parental guidance, combined with clear communication and information sharing by professionals, supported emerging self-management and confidence. [5,26,27] However, when parents struggled to relinquish control or when professional support remained overly directive, young people felt unprepared for adult responsibilities.[5,26,27] Our findings build on this work by conceptualizing autonomy development as a relational process, shaped by how adults share power, adapt communication, and create opportunities for participation over time.

The multi-perspective design highlighted how autonomy and self-management are influenced not only by individual capacity, but by patterns of interaction across stakeholder groups. Young people often lacked sufficient condition-related knowledge to participate fully in their health care, while parents faced emotional barriers when educating their children about their CP. Although health professionals recognized these knowledge gaps in adulthood, they did not always address them directly, sometimes assuming that young people or families would independently seek information, an approach that may disadvantage those with lower health literacy. At the same time health professionals expressed concerns about parent reluctance to transfer responsibility, while parents feel their challenges in relinquishing control were underappreciated in line with previous research.[28] Young people, positioned between these power struggles, often reported feeling disempowered and disengaged. Together, these relational tensions suggest that existing patterns of interaction may inadequately prepare young people for the changing dynamics and expectations of the adult health care system.

Effective empowerment therefore requires shared responsibility across young people, parents, and professionals. Clear communication, collaborative goal setting, and explicit acknowledgement of each group's challenges are central to this process.[29] Health professionals have a key role in supporting families to navigate young people's evolving independence, ongoing dependencies, and interdependencies by providing appropriate guidance and resources.[30] Effective communication between young people and health professionals is associated with greater readiness for adulthood[31] and improved transition outcomes, including adherence and self-care.[32] These benefits are further reinforced when parents support communication by gradually enabling independence and fostering networks that build health care knowledge and confidence.[33] A key challenge in promoting self-management was the disconnect between health professionals' intentions and young people's perceptions of support. Professionals described using evidence-based approaches, such as encouraging self-directed research, respecting choices, and promoting ownership, yet many young people did not recognize these practices as forms of support. Instead, they sometimes interpreted the shift from directive to facilitative practices as withdrawal. This divergence may stem from differing understandings of autonomy development. Health professionals viewed autonomy development as a gradual trajectory embedded in ongoing therapeutic encounters, whereas young people experienced transition as a discrete moment when explicit guidance was most needed. Bridging this perceptual gap requires clear, intentional communication, including signposting the purpose of facilitative strategies, explicitly labelling shared decision-making moments, and explaining how these approaches support long-term independence. Structured assessments of transition readiness may further align expectations and clarify roles.[2]

Young people with CP expressed diverse aspirations for adulthood, including meaningful employment, independent living, relationships, and active participation in their communities. Achieving these ambitions required navigating interlocking barriers across health, education, and social systems. Consistent with previous research, young people reported difficulties forming social connections,[5] navigating stereotypes and prejudice,[7] and encountering environmental barriers such as inaccessible physical spaces.[9] Societal expectations around education and employment further constrained opportunities.[7,10,12,24] These findings show that transition is not solely a health care process but a broader developmental and social journey in which confidence, knowledge, and autonomy acquired within clinical settings shape young people's capacity to pursue adult roles.

Person-centred transition programmes tailored to young people's needs and aspirations may therefore play a critical role in supporting autonomy and participation. Evidence from young people with neurodisability and other long-term conditions suggests that such programmes can strengthen self-management, enhance continuity between paediatric and adult services, and provide opportunities for peer support and shared learning.[34] By offering structured education about CP, fostering self-acceptance, and supporting goal articulation, these approaches may address the knowledge and confidence gaps identified in this study and enhance transition readiness.[35]

## Strengths and limitations

A key strength of this study is the integration of perspectives from young people with CP, their parents, and health professionals, which enabled a rich and nuanced understanding of transition as a relational and negotiated process. Use of the framework method and adherence to trustworthiness strategies such as reflexivity and peer debriefing strengthened the analysis.

Several limitations should be considered. Participants were self-selected, potentially overrepresenting individuals with particularly strong views or experiences of transition. Males and participants classified in GMFCS levels II and III were underrepresented, which may limit the breadth of perspectives captured. Socioeconomic and ethnicity data were not collected, restricting examination of social determinants of transition experiences. In six interviews, young people and parents participated together, which may have influenced disclosure despite efforts to centre young people's voices. These factors should be considered when assessing the transferability of the findings.

## Conclusions

The transition to adulthood for young people with CP involves far more than the transfer of care; it reflects a broader developmental and relational shift in which young people move from ‘passenger to pilot’. Disruptions in relational continuity, evolving parent–child dynamics, and limited condition-related knowledge shaped young people's confidence and preparedness for adult services. Transition support must therefore extend beyond structural coordination to include clear communication, shared decision-making, and intentional scaffolding of autonomy. Young people benefit from early opportunities to participate in health care discussions, while parents and professionals require guidance to recalibrate their roles and responsibilities.

While grounded in the Irish context, these relational processes are likely relevant across health care systems and conditions. Strengthening person-centred, multi-sector transition support has the potential to enhance autonomy, continuity, and participation as young people assume greater responsibility for their health and adult lives.

## ACKNOWLEDGEMENTS

We thank Dr Michael Byrne, member of the project management team, for his valuable contributions, expertise, and advice throughout this project. We thank the members of the Young Person Advisory Group and the Parent Advisory

Group for their work throughout the study and interpretation of interview findings. We thank Amanda Breen from the Central Remedial Clinic and Sebastian Koppe from Enable Ireland for their support with interpreting study findings. We also thank the following people who helped us recruit to this study: Alison McCallion, Rory O'Sullivan, and Trish MacKeogh from the Central Remedial Clinic; Helen McDaid from the Health Service Executive; and Sonia Somers from Enable Ireland.

## DATA AVAILABILITY STATEMENT

Data available in article supporting information.

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## REFERENCES

1. Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, Slap GB. 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.
2. Donkervoort M, Wiegerink DJHG, Van Meeteren J, Stam HJ, Roebroeck ME, Transition Research Group South West N. Transition to adulthood: validation of the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence. Developmental Medicine & Child Neurology. 2009;51(1):53–62.
3. Roebroeck ME, Jahnsen R, Carona C, Kent RM, Chamberlain MA. Adult outcomes and lifespan issues for people with childhood-onset physical disability. Developmental medicine and child neurology. 2009;51(8):670–8.
4. van Gorp M, Dallmeijer AJ, van Wely L, de Groot V, Terwee CB, Flens G, et al. Pain, fatigue, depressive symptoms and sleep disturbance in young adults with cerebral palsy. Disabil Rehabil. 2021;43(15):2164–71.
5. Björquist E, Nordmark E, Hallström I. Living in transition - experiences of health and well-being and the needs of adolescents with cerebral palsy. Child Care Health Dev. 2015;41(2):258–65.
6. Björquist E, Nordmark E, Hallström I. Parents' Experiences of Health and Needs When Supporting Their Adolescents With Cerebral Palsy During Transition to Adulthood. Physical & occupational therapy in pediatrics. 2016;36(2):204–16.
7. Bagatell N, Chan D, Rauch KK, Thorpe D. 'Thrust into adulthood': Transition experiences of young adults with cerebral palsy. Disability and health journal. 2017;10(1):80–6.
8. Larivière-Bastien D, Bell E, Majnemer A, Shevell M, Racine E. Perspectives of young adults with cerebral palsy on transitioning from pediatric to adult healthcare systems. Seminars in pediatric neurology. 2013;20(2):154–9.
9. Racine E, Larivière-Bastien D, Bell E, Majnemer A, Shevell M. Respect for autonomy in the healthcare context: observations from a qualitative study of young adults with cerebral palsy. Child: care, health and development. 2013;39(6):873–9.
10. 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 and development. 2018;44(5):689–96.
11. Carroll EM. Health Care Transition Experiences of Young Adults With Cerebral Palsy. Journal of pediatric nursing. 2015;30(5):e157-64.
12. Brandão MB, Bueno KMP, Silvério APM, Antunes FIT, Feitosa AM, Figueiredo PRP, Mancini MC. 'Listen to us!'A qualitative study of adolescents with disabilities to help plan a transition service. Child Care Health Dev. 2022;48(5):833–41.
13. Palisano RJ, Di Rezze B, Stewart D, Freeman M, Rosenbaum PL, Hlyva O, et al. Promoting capacities for future adult roles and healthy living using a lifecourse health development approach. Disability and Rehabilitation. 2020;42(14):2002–11.
14. Stewart DA, Law MC, Rosenbaum P, Willms DG. A qualitative study of the transition to adulthood for youth with physical disabilities. Phys Occup Ther Pediatr. 2001;21(4):3–21.
15. Fortune J, Ryan JM, Walsh A, Walsh M, Kerr C, Kroll T, et al. Transition from child to adult services for young people with cerebral palsy in Ireland: Influencing factors at multiple ecological levels. Dev Med Child Neurol. 2024;66(5):623–34.
16. Ryan JM, Norris M, Walsh A, Breen A, Hensey O, Kerr C, et al. Transition from child to adult health services for young people with cerebral palsy in Ireland; implications from a mixed-methods study. HRB Open Res. 2024;7:47.
17. Ryan JM, Walsh M, Owens M, Byrne M, Kroll T, Hensey O, et al. Transition to adult services experienced by young people with cerebral palsy: A cross-sectional study. Dev Med Child Neurol 2022;00:1–9.
18. Sandelowski M. Whatever happened to qualitative description? Res Nurs Health. 2000;23(4):334–40.
19. Morris SM. Joint and individual interviewing in the context of cancer. Qual Health Res. 2001;11(4):553–67.
20. 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. 2020;10(12):e041425.
21. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Methodol. 2013;13:117.
22. Okumura MJ, Saunders M, Rehm RS. The Role of Health Advocacy in Transitions from Pediatric to Adult Care for Children with Special Health Care Needs: Bridging Families, Provider and Community Services. Journal of pediatric nursing. 2015;30(5):714–23.
23. DiFazio RL, Harris M, Vessey JA, Glader L, Shanske S. Opportunities lost and found: experiences of patients with cerebral palsy and their parents transitioning from pediatric to adult healthcare. Journal of pediatric rehabilitation medicine. 2014;7(1):17–31.
24. Boyle P, Galvin KT, Vuoskoski P, Stew G. The Experience of Living through the Transition from Adolescence to Adulthood for Young People with Cerebral Palsy. Occup Ther Health Care. 2023:1–20.
25. O'Connell B, Bailey S, Pearce J. STRADDLING THE PATHWAY FROM PAEDIATRICIAN TO MAINSTREAM HEALTH CARE: TRANSITION ISSUES EXPERIENCED IN DISABILITY CARE. 2003;11(2):57–63.
26. Racine E, Bell E, Yan A, Andrew G, Bell LE, Clarke M, et al. Ethics challenges of transition from paediatric to adult health care services for young adults with neurodevelopmental disabilities. Paediatrics & child health. 2014;19(2):65–8.
27. Magill-Evans J, Wiart L, Darrah J, Kratochvil M. Beginning the Transition to Adulthood. Physical & occupational therapy in pediatrics. 2005;25(3):19–36.27.
28. Betz CL, Nehring WM, Lobo ML. Transition Needs of Parents of Adolescents and Emerging Adults With Special Health Care Needs and Disabilities. Journal of family nursing. 2015;21(3):362–412.
29. O'Connor B, Kerr C, Shields N, Adair B, Imms C. Steering towards collaborative assessment: a qualitative study of parents' experiences of evidence-based assessment practices for their child with cerebral palsy. Disabil Rehabil. 2021 Feb;43(4):458–67.
30. Kaufman H, Horricks L, Kaufman M. Ethical considerations in transition. Int J Adolesc Med Health. 2010;22(4):453–9.
31. van Staa A, Sattoe JN, Strating MM. Experiences with and Outcomes of Two Interventions to Maximize Engagement of Chronically Ill Adolescents During Hospital Consultations: A Mixed Methods Study. J Pediatr Nurs. 2015;30(5):757–75.
32. Street RL, Jr., Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician-patient communication to health outcomes. Patient Educ Couns. 2009;74(3):295–301.

33. Nguyen T, Henderson D, Stewart D, Hlyva O, Punthakee Z, Gorter JW. You never transition alone! Exploring the experiences of youth with chronic health conditions, parents and healthcare providers on self-management. Child Care Health Dev. 2016;42(4):464–72.
34. 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 and development. 2018;44(1):83–8.
35. Levy BB, Song JZ, Luong D, Perrier L, Bayley MT, Andrew G, et al. Transitional Care Interventions for Youth With Disabilities: A Systematic Review. Pediatrics. 2020;146(5):1–12.

## SUPPORTING INFORMATION

The following additional material may be found online:
**Data S1** Supporting Information

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

**How to cite this article:** Fortune J, Ryan JM, Walsh A, Walsh M, Kerr C, Kroll T, et al. Transition to adulthood: Perspectives from young people with cerebral palsy, parents, and health professionals. Dev Med Child Neurol. 2026;00:1–12. https://doi.org/10.1111/dmcn.70310