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ORIGINAL ARTICLE

Mental health difficulties in cerebral palsy: A qualitative study of young people's and parents' perspectives

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Abstract

Aim: To explore the experiences of mental health difficulties and access to mental health support among young people with cerebral palsy (CP).

Method: We used a qualitative descriptive design. Participants were young people with CP aged 13 to 25 years and parents of children with CP (6–25 years). Nineteen semi-structured interviews were conducted. A narrative thematic analysis was conducted to identify themes related to their mental health experiences.

Results: Four themes were identified from the data: (1) understanding manifestations of mental health, triggers, and the importance of early intervention; (2) structural and human challenges in accessing mental health services; (3) the interplay between mental health and personal, social, educational, and familial challenges; (4) navigating future aspirations and holistic mental health support.

Interpretation: People with CP face complex, interconnected challenges to their mental health, influenced by personal, family, social, and systemic factors. Mental health difficulties often go unrecognized or are inadequately addressed, highlighting the need for early identification, integrated service provision, and holistic, person-centred interventions that support young people and their families.

Cerebral palsy (CP) is a lifelong neurodevelopmental condition that primarily affects motor function.[1] In addition to movement disorders, people with CP may experience epilepsy or impairments of cognition, speech, hearing, and vision.[2,3] While the World Health Organization's definition of health encapsulates the physical, mental, and social well-being,[4] most research into the health of people with CP focuses on motor function and co-occurring physical conditions.[2,5] This focus often overlooks the significant impact that mental health difficulties can have on the lives of people with CP, potentially exacerbating social and health disparities.[6]

People with CP are more likely to experience mental disorders than those without it.[7–9] A recent US study found a higher prevalence of depression (7.8% vs 2.7%) and anxiety (30.2% vs 6.2%) among children with CP than in those without it.[10] Adolescence is a critical period for the onset of mental disorders in the general population.[11] However, children with CP may experience mental health difficulties well before adolescence.[12,13] Mental health difficulties are defined as ‘a broad concept covering both less serious mental strain and more severe symptoms fulfilling criteria for a diagnosable mental illness or disorder’.[14] A higher prevalence of attention-deficit/hyperactivity disorder (ADHD) and autism[15,16] may contribute to the increased risk of mental disorders among people with CP. However, other factors such as discrimination, difficulties with peer

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Abbreviations: CAMHS, Child and Adolescent Mental Health Services; OCD, obsessive-compulsive disorder; PPI, public and patient involvement.

*Members of the RELATE-CP study team are listed in the Acknowledgements.

interactions and family dynamics, bullying, and the progression of musculoskeletal deformities may also affect mental health.[10,17–21] Furthermore, environmental barriers and physical health complications restricting activities and participation at a young age may negatively affect mental health.[10,19]

Emerging evidence suggests that formative experiences in childhood and adolescence can significantly shape mental health outcomes later in life. Studies in the general population have shown that early mental health symptoms predict later mental health disorders,[22] and that adolescent mental disorders are associated with long-term social and economic challenges.[23,24] For young people with CP, these early mental health difficulties may be compounded by additional neurodevelopmental, environmental, and social barriers to participation in life and achieving their goals.[19,25–27] These patterns highlight the importance of early identification and intervention principles that address both psychological and environmental challenges faced by this population.

Three case studies have reported on access, use, and experience of mental health services among young people with CP.[28–30] One qualitative study explored the broader lived experiences and overall well-being of young people with CP, within which mental health represented only one component.[31] However, no qualitative study has explored the experience of mental health difficulties among children and young adults with CP, including perceived factors that contribute to the development of difficulties during childhood and the experience of seeking support. Understanding this is vital for developing effective, person-centred interventions and support services for people with CP. Therefore, this study aimed to explore the experiences of mental health difficulties among young people with CP. It focused on how these difficulties present and progress, as well as the factors influencing mental health. Perspectives were gathered from adolescents and young adults with CP, and from parents of children and adolescents with CP.

What this paper adds

- Young people with cerebral palsy (CP) experience various challenges in relation to their mental health.
- These challenges include difficulties in understanding their emotions and accessing early support to promote mental well-being.
- Many with CP struggle to access mental health services because of structural barriers and a lack of tailored support.
- Mental health is closely linked to personal, social, and family challenges.
- A critical shift is needed towards a more holistic and person-centred approach to care.

METHOD

Design

We used a qualitative descriptive design in this study.[32,33] The study adhered to the Consolidated criteria for Reporting Qualitative research (COREQ) guideline.[34]

Participants

Participants were adolescents and young adults with CP aged 13 to 25 years, who had experienced mental health difficulties. In addition, parents of children, adolescents, and young adults with CP aged 6 to 25 years, whose child has experienced mental health difficulties, were included. Although the study focused on young people's experiences of mental health difficulties, parents' perspectives were included to reflect the family context in which these experiences occurred and to enhance the understanding of factors influencing well-being and access to services. All participants were recruited in Ireland. Mental health difficulties were either (1) self-reported by the person with CP or their parent, or (2) diagnosed by health professionals.

All people with CP in the specified age range were eligible to be included regardless of their functional mobility, as indicated on the Gross Motor Function Classification System (GMFCS), or the presence of other associated impairments.

Recruitment

Participants were recruited between October 2023 and January 2024. Potential participants were identified by health professionals working in a national specialist disability organization, who provided them with a participant information leaflet. Individuals who expressed an interest in participating were contacted by the researcher to provide additional information about the study and arrange a suitable time for the interview.

We used a purposive sampling strategy to understand experience of mental health difficulties.[35] On the basis of input from our public and patient involvement (PPI) contributors, both young people and parents were recruited to obtain a comprehensive understanding of the mental health experience. Young people were sampled according to their age, sex, and mobility level; parents were sampled according to sex and their child's mobility level. Before the interview, the researcher asked brief questions to gather demographic information, including age, area and county of residence, ethnicity, and functional mobility indicated by the young person's GMFCS level.

We did not use an a priori sample size or saturation as a strict criterion.[36] Instead, we drew on information power, PPI input, and pragmatic considerations to ensure a diverse and informative sample, consistent with our narrative thematic approach and social constructionist stance.[37,38]

Data collection

Semi-structured interviews were conducted by the researcher (MM), in person, online, or by telephone, depending on the participant's preference. To facilitate participation, several accommodations were used, particularly for participants with mild-to-moderate intellectual disability. For example, interviews divided into two sessions to reduce fatigue and accommodate alternative communication methods, such as communication devices and easy-read materials, were used where required. Participants were provided with an overview of the topic guide in advance, and joint interviews with a parent or family member were offered when additional support was needed. Adolescents and young adults were encouraged to share their perspectives independently, but support was provided where necessary.

The topic guide for young people and parents was developed using a narrative approach with open questions, allowing participants to share their mental health experiences. This approach encouraged participants to discuss events they perceived as important, explain why these events were relevant, and describe how they might be interconnected and had influenced subsequent behaviours.[39] The topic guides were initially piloted with a parent and young adult with CP; and were refined throughout the interview process (Appendix S1).

The interviews began by asking participants to share their experiences with mental health difficulties from early signs of difficulties to the present. For some in-person interviews with parents, the researcher and participant collaboratively created a timeline on paper to facilitate discussion.[40,41] In interviews with young people who had speech impairments or when interviews were conducted by video or telephone, the researcher used a timeline on paper to facilitate discussion. For some young adults, engaging with the timeline was emotionally challenging because they recalled distressing experiences. As participants shared their stories, the researcher asked follow-up questions to elaborate on key events in their experiences. These key events included early signs of mental health difficulties, decisions to seek support or not, visits to health professionals, receiving a diagnosis, and being referred to health services. The interviewer transitioned between events using bridging questions, aiming to explore participants' narratives in depth and to obtain a comprehensive understanding of their mental health experiences.

All interviews were transcribed verbatim. After each interview, the researcher reflected on the interview process and their memos were referred to later in the analysis phase.

Ethics

The study adhered to ethical guidelines from Resolution 196/1996 of the National Health Council and the Declaration of Helsinki, with approval from the Royal College of Surgeons in Ireland (REC202303034) and the Central Remedial Clinic (REC reference: 12122). Written informed consent was obtained from participants aged 18 years and older, and assent with parental consent for those aged 13 to 17 years. Safeguarding measures included distress and risk management protocols developed with mental health experts, and provision of support resources post-interview. The researcher received training to handle sensitive topics such as self-harm or suicide, and procedures were in place to address any safeguarding concerns in line with legal and ethical standards.

Data analysis

Descriptive statistics (frequencies and percentages) were used to summarize the demographics, including sex, living area, ethnicity, GMFCS level, and parent relationship. Age was summarized using mean and standard deviation. A narrative thematic approach, conducted from a contextualist perspective, was adopted to analyse participants' mental health narratives.[42] This approach acknowledges that participants' accounts reflect both individual experiences and broader social context, while the researcher's interpretation contributes to meaning-making.[42,43] This method focuses on identifying themes across different narratives, allowing a deeper understanding of the factors shaping participants' experiences.[42]

To ensure consistency, two researchers (MM and AW) independently read and coded 16% of the transcripts. The codes were then compared and discussed to develop a shared coding framework across all narratives. Following this, the primary researcher (MM) coded the remaining transcripts, updating the codebook and code descriptions as needed. These updates were then discussed with the research team (MM, AW, JMR, JF, and MN) to refine the analysis.

The initial codes were reviewed and categorized on the basis of the underlying meanings in each narrative, with further discussion held with the research team. The first-level categories were then grouped into second-level categories, based on similarities in meaning. A descriptive memo was developed for each category by the primary researcher (MM) and discussed with the research team (MM, AW, JMR, and MN). The team collaboratively derived and agreed on overarching themes from these categories, and themes were refined through discussion until consensus was reached. NVivo 12 Pro (Lumivero, Denver, CO, USA) was used to facilitate the analysis.

A composite narrative approach was used to develop two case studies focusing on the experience of people with CP, to enhance the understanding of mental health experiences when presented alongside the themes. This method was chosen because, while themes provide a broad view of shared experience across participants, the composite narrative adds a crucial element: a trajectory over time. The composite narrative approach effectively captures key events from the participants' mental health experiences,[44] weaving together stories from multiple interviews into a cohesive narratives.[44] The composite approach ensures participants' confidentiality compared with presenting individual case studies.[44] To create these narratives, individual case studies were first written for each participant, illustrating their experiences from early identification to the present. These narratives were then mapped to the four final themes identified through the narrative thematic analysis. Finally, the individual stories were merged into a single cohesive narrative, ensuring a unified and insightful representation of mental health experiences.

Preliminary findings were shared with experts in the field of mental health and CP, and with one person with CP for their interpretations. To ensure rigor and trustworthiness, the analysis process incorporated robust techniques, including collaborative team analysis, sharing preliminary findings, and maintaining a reflexive diary with a clear description of the analysis process throughout. Credibility was strengthened through triangulation of data sources and perspectives. This involved collecting and comparing insights both from young people and from parents, and engaging multiple researchers in the interpretation of the data. By integrating these diverse perspectives and collaborative analysis, we ensured a more balanced and trustworthy understanding of the findings.

Public and patient involvement

A young adult with CP identified the importance of conducting this qualitative study, was a PPI co-applicant, and contributed from the outset, helping to refine the research question, and the design, on the basis of lived experience. She also supported development of project materials and guided research processes as part of the project management group.

Two young people with CP and two parents of young people with CP formed PPI panels that reviewed study materials, advised on recruitment and accessibility, interpreted findings, and supported dissemination. Their input ensured the research remained relevant, inclusive, and grounded in lived experience.

Reflexivity

Reflexivity was embedded throughout the research process, consistent with a social constructionist perspective, where researchers' experience and assumptions are acknowledged as shaping interpretations rather than being 'eliminated'.[43] The lead researcher (MM), a physiotherapist experienced in working with young people with CP, maintained reflective memos and an audit trail to document assumptions and analytical decisions. Researchers' perspectives and interpretations were discussed regularly in the project management group to enhance reflexive awareness and ensure findings remained grounded in participants' accounts.

TABLE 1 Participants' characteristics (*n* = 19).

		Young people with CP (*n* = 9), *n* (%)	**Parents (*n* = 10), *n* (%)**
Mean age (SD), years:months		18:3 (4:4)	
Sex	Male	4 (44.4)	1 (10.0)
	Female	5 (55.6)	9 (90.0)
Living area	Urban	8 (88.9)	8 (80.0)
	Rural	1 (11.1)	2 (20.0)
Ethnicity	White	7 (77.8)	10 (100.0)
	Black	2 (22.2)	0 (0.0)
Gross Motor Function Classification System level	I	3 (33.3)	Not applicable
	II	2 (22.2)	
	III	1 (11.1)	
	IV	1 (11.1)	
	V	2 (22.2)	
Parent relationship	Mother	Not applicable	9 (90.0)
	Father	Not applicable	1 (10.0)

RESULTS

We interviewed 19 participants, consisting of two adolescents with CP (aged 14–15 years), seven young adults with CP (aged 18–24 years), and 10 parents of children (*n* = 2, aged 10 years), adolescents (*n* = 2, aged 14–15 years), and young adults with CP (*n* = 6, aged 18–24 years). Of the seven young adults interviewed, two had a parent present during the interview, either to provide technical support or because they preferred their parent's presence. Among the 19 interviews, six involved both a parent and a young person or young adult from the same family, resulting in a total of 13 unique mental health experiences. Participants represented all GMFCS levels (see Table 1). Three young adults had mild to moderate speech impairments, and one used a communication device. The interviews ranged from 25 to 101 minutes in duration.

Four themes were generated from the data: (1) understanding manifestations of mental health, triggers, and the importance of early intervention; (2) structural and human challenges in accessing mental health services; (3) the interplay between mental health and personal, social, educational, and familial challenges; and (4) navigating future aspirations and holistic mental health treatment.

Understanding manifestations of mental health difficulties, triggers, and the importance of early intervention

This theme captures diverse aspects of how young people with CP and their parents understand how mental health difficulties manifest and are triggered. Linked with this were challenges in recognizing and diagnosing mental health difficulties, resulting in delays in early intervention.

Narratives highlighted a range of physical and social difficulties which contributed to and compounded mental health difficulties. Most parents and young people reported that the physical aspects of CP, including visible differences and mobility issues, frequently contributed to heightened mental health difficulties. Some young adults reported that body image issues related to CP and academic pressures affected their self-esteem and social anxiety.

> … My self image has never been great. You know I would always be aware of my walker; will it fit in this door. Is it being ridiculously loud when I'm walking? That will always be there, that won't ever go for me. Unfortunately I don't think I will ever be one of those people that will be 100% comfortable in my own skin …
> (Female, wheelchair user, >18 years)

Some parents also highlighted the impact that physical pain and exhaustion associated with CP had on their child's mental health. They noted that the strain from managing co-occurring physical impairments and conditions contributed to increased frustration and emotional distress.

> … He's in a lot of pain at the moment, which is making … everything very uncomfortable and doing anything very bad. he told the doctor, he was feeling really low and certainly at times he doesn't want to be here … and in my own head I did think if he gets out of the pain, I think that'll be half the battle …
> (Parent of a male wheelchair user, >18 years)

Alongside the impact that physical difficulties had on mental health, young people also spoke about formative experiences in their school years. One of the most salient of these was experiences of bullying linked to their visible differences added another layer of emotional strain.

> And like they'd be like, oh why does your arm look like a T-Rex and I'd be like well I love T-Rex's … but deep down like it did affect me …
> (Female, non-wheelchair user, >18 years)

These types of hurtful comments, alongside feelings of exclusion, led to lasting impacts on young people's self-esteem and mental health. Even when individuals outwardly dismissed the remarks, they often internalized the negativity, reinforcing a sense of difference and vulnerability during a critical stage of identity development.

Some young adults with CP reported that major life changes, such as relocating to a new country, experiencing grief, or transitioning between educational stages, intensified their underlying mental health difficulties, triggering symptoms such as panic attacks and violent behaviour. Grief, particularly from the loss of a close friend or a beloved teacher, was described by a small number of young people and their parents as a profound emotional challenge, often compounded by the stress of adjusting to new environments or navigating adolescence. Furthermore, some parents noted that the COVID-19 pandemic intensified feelings of invisibility, deepening existing mental health difficulties.

Most parents highlighted that a significant challenge in addressing mental health concerns for young people with CP was the early identification and intervention of these issues. Some parents reported that communication difficulties associated with CP made it hard to recognize mental health difficulties. Young people and their parents noted that the progression of mental health difficulties often involved unpredictable mood fluctuations and symptoms, complicating efforts to identify clear triggers.

> This is like … you were walking on eggshells around my child … And it was just horrific to live with at that moment.
> (Parent of a male wheelchair user, >18 years)

Some parents also described how symptoms such as agitation, aggression, or heightened anxiety were sometimes misunderstood or overlooked, leading to delays in receiving appropriate support. Additionally, some young adults reported that cultural factors preventing them from seeking mental health support further delayed the diagnostic process. Moreover, some parents reported the limitations of standard assessment tools, which did not fully accommodate the needs of individuals with physical disabilities, added to the complexities of diagnosis. Alongside the direct and immediate impact on a young person with CP, anxiety was mentioned as a precipitator of additional mental health difficulties such as obsessive-compulsive disorder (OCD), self-harm, or suicidal thoughts.

Most parents and young adults stressed the importance of early intervention to address mental health difficulties effectively.

> I do think it would be really good if there was more psychology services or supports or people you could reach out to about the everyday difficulties of life, rather than only when something is really, really bad …
> (Parent of a male non-wheelchair user, <18 years)

Other suggested strategies included regular check-ins, multidisciplinary collaboration, and the use of interventions such as speech therapy and technological aids to improve communication and support. However, some parents reported challenges in obtaining a formal diagnosis of a mental disorder, often because of a focus on behavioural aspects rather than addressing underlying psychological issues.

Structural and human challenges in accessing mental health services

Young people with CP often encountered challenges when trying to access mental health services, largely because of systemic and service delivery issues. Most parents and young adults with CP reported that navigating these services proved challenging because of irregularities in the frequency and availability of appointments with professionals. For some young people, this inconsistency in psychiatric support led to gaps that hindered effective mental health management.

> Yeah the gaps in the mental health services for children … are dreadful, they seriously need to close the gaps …
>
> (Parent of a female non-wheelchair user, >18 years)

Most parents and young people reported that the quality of statutory mental health services varied considerably. Some individuals experienced effective care, while others faced long wait times and fragmented treatment plans. They reported that this variability was evident in experiences with Child and Adolescent Mental Health Services (CAMHS), where individuals often remained on waiting lists without receiving timely initial and follow-up appointments. Additionally, some young people with CP were frustrated when CAMHS discharged them to disability services, using their CP diagnosis as a reason for not accepting them into the service.

> So, we're waiting. I only phoned CAMHS two weeks ago to say, that my child has really escalated now back to this like, the OCD has really peaked, her hands are falling off her and I don't know what to do and so the girl just told me that … we're really, busy and she's kind of saying to me, I don't know why the [specialist disability services] are referring your child back here, She has the diagnosis of cerebral palsy but I said the cerebral palsy is not the issue, it's her mental health and the OCD that's the issue and they can't give her the service that she needs …
> (Parent of female non-wheelchair user, <18 years)

Some parents also noted that changes in the national structure of children's disability services and difficulties identifying a key contact person further complicated families' efforts to secure consistent support and navigate the system. Some parents also reported that transitions from paediatric disability services to the adult healthcare system exacerbated these issues. This critical stage was marked by bureaucratic obstacles and the need for reapplication to community disability services after 18 years, which led to feelings of being overlooked or unsupported.

> So this social worker says to me, before he was eighteen, you need to get this form in … I filled it in. They sent the form back to me; we can't accept the form until he's eighteen … So I had to wait until he's eighteen. Then to apply for all these services he needs, he's eighteen … but sure now we're still waiting on everything …
> (Parent of male wheelchair user, >18 years)

Parents and young adults reported that this uncertain transition period highlighted the need for a more seamless process and comprehensive support frameworks to ensure continuity of care and prevent young people from ‘falling through the cracks’.

Some young adults with CP also reported that the fragmented nature of mental health services and frequent changes in providers disrupted continuity of care, making it difficult to build trust and rapport, which were crucial for effective mental health support. As young people, they often faced difficulties forming meaningful connections with mental health professionals, feeling unheard or misunderstood during therapy. In addition, a small number of young people reported experiencing stereotypes and biases related from health professionals, such as misjudgements about their intelligence based on their physical appearance and speech.

> Certain people talked to me as if I'm a baby, I don't need the baby talking, I'm grown up and I feel … that just discourages them [people with CP] to just even do the things in general because they're just treated like a child, because you're disabled …
> (Female non-wheelchair user, >18 years)

Most parents and young people with CP reported that, in response to the deficiency in public services, they turned to alternative support sources, such as charities and private sector services. They reported that charitable organizations and the private sector provided valuable assistance. However, these solutions were often short term and came with their own set of challenges, including financial and logistical constraints.

> Because the waiting lists were huge and at that time … we were told that you could be like … years waiting, the waiting lists were mega for assessments … So kind of we had no choice [to seek a private psychologist] or else she would

> have had to just keep going to school with no support, you know, no supports for anything …
> (Parent of female non-wheelchair user, <18 years)

The interplay between mental health and personal, social, educational, and familial challenges

Navigating mental health dynamics involves a complex interplay of personal, social, educational, and familial factors that shape an individual's well-being and development. Some young people reported that the experience of managing their mental health was marked by a continual effort to balance self-management with the acceptance of their own identity and impairments.

> But like yeah acceptance is difficult for me. Like I tolerate my disability but am I okay with it, or do I embrace it, no. Unfortunately I don't …
> (Female wheelchair user, >18 years)

A change in environment, such as transferring from specialized to mainstream educational settings, often revealed barriers to participation imposed by their environments compared with peers. This led them to question their identity and experience increased stress, self-consciousness, and a sense of social exclusion, particularly when the visibility of their physical disability became newly apparent in mainstream contexts.

> But actually, the transition from schooling in the [special school] to mainstream was difficult … I actually didn't realise I was physically disabled until I went to a mainstream school …
> (Female wheelchair user, >18 years)

Some young adults reported that their struggle to accept their disability was compounded by societal judgements, which affected their self-confidence and emotional health. When personal expectations, such as achieving independence, clashed with societal structures and attitudes that emphasized restrictions and prevented people with CP meeting their own expectations, they were left feeling frustrated, inadequate, and entrapped.

Some young adults reported that social dynamics played a critical role in their mental health experience, with positive peer interactions and supportive relationships being vital for overall well-being. Difficulties in forming meaningful connections because of ethnicity, disability, or cultural differences were reported by a small number of young people and their parents as contributors to isolation and exacerbated mental health struggles. Conversely, some parents and young adults reported that a supportive and inclusive social environment mitigated these challenges, emphasizing the importance of fostering positive peer interactions and creating spaces where individuals felt accepted and valued. In a few cases, where young people had understanding peers and a supportive social network, they reported this significantly enhanced their resilience and emotional health.

> Very upset, very upset because I had all the friends on that [football] team … I just felt left out, you know.
> (Male non-wheelchair user <18 years)

Later, after joining a disability-specific sports team, they reflected,

> I've made good friends from there [CP football team] … it's great to see, interact with a load of boys that have what I have … and great to play the sport that I love in some shape or form.
> (Male non-wheelchair user <18 years)

Some young people with CP reported that inadequate mental health support from school counsellors, insufficient academic assistance, and the transition to higher education revealed additional challenges, including inconsistent support services and unclear disability accommodations. These accommodations, such as timely class schedule updates, flexible assignment deadlines, access to assistive technology, and guidance from disability officers, were often lacking, leading to heightened stress and isolation. The difficulty or inability to ensure these necessary physical adaptations and supports further exacerbated mental health stresses for these young people.

Most parents reported that family dynamics were deeply affected by mental health difficulties of their child with CP, creating a complex web of challenges both for parents and for siblings.

> His outbursts were always at home … it was so awful what we went through. And then seeing poor little sister terrified as well, the 6-year-old … Because he could just make this face sometimes and his younger sister is even afraid of that face …
> (Parent of male wheelchair user, >18 years)

Most parents reported that the strain of managing a child's mental health needs led to significant stress and feelings of isolation for parents, who were balancing caregiving responsibilities with other family duties. Some parents reported that financial strain and inadequate support services further complicated this balancing act, affecting the entire family.

> No one's asking me are you okay? I can't get respite. I'd love a week where he was in somewhere that I could go away and not worry.
> (Parent of male non-wheelchair user, >18 years)

Most parents also emphasized the importance of their own well-being in this dynamic. Some parents reported that they often sought their own counselling and support to manage the stress associated with caregiving and to maintain their own mental health. Some parents noted that individual or couples therapy, along with practices such as mindfulness meditation, played a critical role in helping them reduce stress and sustain their well-being. This, in turn enhanced their ability to support their child more effectively.

> I now see a therapist every 2 weeks. So, I've been doing that for 2 years, in a private capacity and I find that that's really helpful … And I will continue that because I think that keeps me strong and then I'm able to manage the family …
> (Parent of male non-wheelchair user, <18 years)

A small number of young adults reported that gaps in understanding or awareness of mental health struggles among their parents strained the parent–child relationship, which led to further emotional difficulties and reluctance to seek professional help.

Navigating future aspirations and holistic mental health treatment

For people with CP, their future was often marked with uncertainty and complexity. Some parents and young adults highlighted that forming lasting relationships and establishing a family was a fundamental aspiration. However, this desire was often complicated by financial instability, unstable employment, and lack of appropriate support.

Some young adults reported that the absence of clear academic or career goals often led to profound feelings of emptiness and sadness, exacerbating their struggle to find motivation and purpose in daily life. The uncertainty in their future created a sense of despair, particularly during solitary moments.

> Just feeling like depressed, like, what's the point of even being here if I don't have a purpose, like I don't know what I want to do in the future …
> (Female non-wheelchair user, >18 years)

Most parents and young adults agreed on the importance of a holistic approach to mental health treatment in addressing the intertwined challenges they faced to achieving their future aspirations. Some parents reported that effective care must integrate management of mental well-being with management of all associated impairments of CP, including behavioural impairments, sensory impairments, and physical impairments.

> You need to look at the links between cerebral palsy and other neurological things like ASD and ADHD and all of the other diagnoses in between those two things … like your susceptibility to depression, and all of that needs to be treated in a more holistic way …
> (Parent of male wheelchair user, >18 years)

Some parents and young people recommended that this holistic approach should combine medication management with therapeutic interventions to ensure a comprehensive strategy for promoting mental well-being.

Some young adults noted that personal assistants played a crucial role in facilitating independence by providing essential assistance. When available, support from a personal assistant provided both the necessary assistance and a stable, understanding presence, which allowed them to manage their academic responsibilities and participate more fully in social activities.

> Because like some of the happiest times were those few weeks … when I had [personal assistant] support and I was able to function as a 20-year-old away from my parents and being able to do things …
> (Male wheelchair user, >18 years)

However, support from a personal assistant was often inconsistent and difficult to find, which significantly affected young adults' abilities to engage effectively in society and created an uncertain future.

Case studies

The two composite narratives of case studies are presented in Tables 2 and 3, which highlight the overarching themes and key events in the mental health experiences.

DISCUSSION

This study explored the mental health experiences of young people with CP and their parents in Ireland, identifying several barriers to accessing appropriate mental health services. The mental health of young people involves interactions across different levels including individual, relationships, and broader social systems. Bronfenbrenner's ecological systems theory, which recognizes the dynamic interactions, is highly relevant for understanding the mental health experiences of people with CP.[45] This theory explains how development is shaped by interacting layers of influence—including the individual, their immediate relationships (microsystem), the connections between these settings (mesosystem), and the broader social and service structures surrounding them (exosystem). Using the socio-ecological model as a framework, we discuss the individual, microsystem, mesosystem, and exosystem factors influencing mental health outcomes and access to services for young people with CP.

TABLE 2 Composite narrative case study of Chris, non-wheelchair user.

1. **Understanding manifestations of mental health, triggers, and the importance of early intervention**

Chris's experience through adolescence and into young adulthood was marked by significant mental health struggles closely linked to living with cerebral palsy. Chris experienced signs of anxiety and depression in his mid-teens, such as persistent feelings of loneliness and isolation, particularly during stressful periods such as school examinations and personal losses. As time progressed, these feelings intensified, leading to obsessive-compulsive disorder and panic attacks. Compulsive behaviours offered temporary relief but added to Chris's emotional burden. Despite seeking help through counselling services, the support often felt inadequate, failing to address deeper emotional turmoil stemming from bullying, social exclusion, and a lack of peer support. These unresolved issues escalated in late adolescence, leading to self-harm and suicidal thoughts.

2. **Structural and human challenges in accessing mental health services**

Chris faced considerable challenges in accessing suitable mental health care. After experiencing a crisis involving self-harm, Chris received immediate support through GP referral, including counselling from charities for young person's mental health and antidepressants through specialist disability support, but care following this was inconsistent. After a long waiting period, Chris was eventually able to access state-funded mental health services, but was discharged after a major setback. The reason for discharge was his cerebral palsy diagnosis, and his care was transferred to disability services, which prioritized physical therapy over mental health needs. Although Chris was entitled to psychiatric care, visits were infrequent and insufficient, leading to unmet mental health needs. Additionally, frequent changes in staff in mental health services created a fragmented system of care, contributing to a lack of continuity that left Chris feeling vulnerable and unsupported. Over time, Chris found private online therapy more beneficial because of its flexibility and being able to relate to the health professionals; however, the high cost posed a significant barrier to him availing of it in the long term.

3. **The interplay of mental health and personal, social, educational, and familial challenges**

Chris struggled with anxiety and depression, which manifested in withdrawing from social interactions and feeling like a burden to others. This lack of peer support exacerbated his feelings of isolation. The transition from specialist disability services to mainstream education was particularly challenging, with inconsistent school support that failed to address Chris's emotional and academic needs. Frustration over his physical limitations often led to frequent absences from school, ultimately prompting Chris to take a break from school to focus on his mental health.

The constant need to manage both the physical and emotional aspects of Chris's care placed considerable strain on family dynamics. Chris's emotional outbursts, often triggered by anxiety or frustration, led to tension at home, particularly with siblings who sometimes resented the attention Chris received. Although his parents made efforts to encourage open communication and understanding, the emotional toll of managing Chris's mental health difficulties alongside his physical impairments associated with cerebral palsy weighed heavily on everyone, leading to periods of conflict and stress.

4. **Navigating future aspirations and holistic mental health treatment**

As Chris entered early adulthood, he realized the importance of supportive therapeutic relationships, finding comfort in therapy that emphasized understanding of his cerebral palsy. However, Chris faced persistent gaps in integrated care, where mental health support was often overshadowed by physical therapies. This lack of comprehensive mental health care left Chris feeling frustrated at times, but he remained committed to personal development, actively seeking better strategies for self-care and resilience.

Chris and his family have become vocal advocates for a holistic approach to mental health treatment, emphasizing the need for cohesive care that addresses both physical and emotional health. They stress the importance of family support for individuals with cerebral palsy, recognizing that open dialogue and understanding in the family can significantly enhance coping strategies and overall well-being. Together, they remain hopeful for a future where mental health services are more accessible, integrated, and tailored to the unique needs of people with cerebral palsy.

Previous studies have shown that mental health difficulties in individuals with CP are often exacerbated by individual factors such as pain, sleep disturbances, and intellectual disability.[10,19,46] Children with CP report a higher prevalence of pain and are at greater risk of developing mental health conditions than their peers without CP.[10,47] Pain has been found to interfere with sleep and reduce physical activity, further affecting mental well-being.[48,49] Our findings support this body of evidence, demonstrating how unmanaged pain can significantly affect mental health. This highlights the importance of early identification and intervention in pain management to enhance both quality of life and emotional well-being in children with CP.

In addition to physical symptoms, children with CP often present with co-occurring conditions such as autism and ADHD, which are known to increase the risk of developing anxiety and depression.[15,46] Our findings reveal that children with CP and these co-occurring conditions experience particular challenges in accessing mental health services such as CAMHS. This is often due to exclusionary eligibility criteria or a lack of professional expertise in managing physical and neurodevelopmental conditions simultaneously. These systemic gaps highlight the need for early and comprehensive support strategies initiated at the time of CP diagnosis, with the aim of fostering coping skills and resilience to prevent mental health deterioration in adolescence.[23,50]

Furthermore, the study reinforces that mental health symptoms in individuals with CP are often overlooked or misattributed solely to the physical disability, delaying appropriate interventions.[8] A critical shift is needed towards a more holistic model of care, which acknowledges the interconnectedness of physical and mental health rather than focusing predominantly on physical rehabilitation.

Family dynamics play a crucial role in shaping mental health of young people with CP. Our findings highlight the significant emotional burden carried by parents, who often serve as both the primary caregivers and advocates for their children. Providing targeted support including access to mental health resources, peer support networks, and psycho-education programmes for parents can empower parents with strategies to better manage these demands and support their children more effectively.[51]

Siblings of children with CP are also affected, sometimes experiencing emotional distress due to perceived neglect or increased caregiving responsibilities, creating additional stress in the family. Previous research emphasized the importance of mental health services that include family-based support interventions to strengthen overall family functioning and resilience.[29] Strengthening familial support structures through tailored interventions can contribute to better mental health outcomes not only for children with CP but for their families as a whole.

Social and educational environments in which young people live significantly influence mental health outcomes.[52] For children with CP, these settings often present additional challenges that can adversely affect psychological well-being. Consistent with previous research, our findings indicate that experiences of social isolation, exclusion, and bullying are common among this population and contribute significantly to mental health difficulties.[19,53]

TABLE 3 Composite narrative case study of Sumi, wheelchair user with cerebral palsy.

1. **Understanding manifestations of mental health, triggers, and the importance of early intervention**

Sumi's experience with mental health began at an early age, characterized by anxiety and emotional distress. As she entered adolescence, she experienced symptoms such as a volatile temper, chronic fatigue, and persistent sleep problems, which significantly affected her emotional stability. The fatigue and sleep disturbances created a cycle of frustration and instability, making it challenging for her to cope.

Triggers such as sadness, isolation, and a lack of support from special needs assistants exacerbated her struggles. Physical pain also served as a significant trigger, compounding her emotional challenges. Often, misunderstood behavioural issues masked deeper emotional turmoil. However, Sumi was linked to a team in specialist disability services providing early intervention for cerebral palsy which addressed the physical needs of cerebral palsy with a comprehensive assessment and personalized intervention plan for her unique physical challenges.

2. **Structural and human challenges in accessing mental health services**

Initially, Sumi received essential counselling and coping strategies through specialist disability services tailored for children with cerebral palsy. This supportive environment helped her address anxiety and develop resilience specific to her physical needs. However, as she transitioned from specialized care to broader community services, she encountered considerable difficulties. This shift left her feeling unsupported, with many of her needs going unaddressed. The absence of tailored support in mainstream educational settings, such as understanding the nuances of challenges related to cerebral palsy, further exacerbated her feelings of isolation and frustration, making it increasingly difficult for her to navigate new environments and access necessary resources.

Despite positive experiences with the specialist disability services, Sumi's inconsistent access to continuing psychiatric support presented additional hurdles. Frequent therapist turnover and a lack of continuity of care complicated her ability to receive effective mental health services. Logistical challenges such as transportation created further barriers to obtaining necessary help.

3. **The interplay of mental health and personal, social, educational, and familial challenges**

Sumi struggled with accepting her disability, grappling with feelings of difference and isolation that initially made it difficult to embrace her identity. Over time, supportive environments and connections with understanding individuals helped her view her cerebral palsy not as a defining barrier but as part of her unique identity.

While receiving professional support in specialized disability services offered Sumi a sense of safety and validation, transitioning to a mainstream school revealed significant obstacles. The less accommodating environment heightened her awareness of her disability and intensified feelings of isolation and anxiety. The physical limitations imposed by her environment prevented her from participating in activities with her peers, deepening her sense of exclusion. Inadequate support from education professionals, including ineffective assessments that did not account for her communication device or specific learning needs, further complicated her access to necessary resources, undermining her mental well-being.

Emotional volatility and outbursts, often linked to her frustration over her physical limitations, created stress for family members, leading to feelings of fear and anxiety, particularly for her younger sibling. Her parents worked hard to provide reassurance and maintain a supportive atmosphere at home, striving to ensure that all family members felt safe and understood. Balancing the demands of supporting Sumi with the needs of the family required tremendous effort, as her parents advocated for better resources and support services.

4. **Navigating future aspirations and holistic mental health treatment**

As Sumi grew older, engaging in creative outlets and connecting with peers had a positive impact on her mental well-being. Despite experiencing recurring anxiety, Sumi developed coping skills that allowed her to address these anxieties through problem-solving and maintaining a positive outlook. Her family, while navigating systemic barriers, advocated for better educational practices and consistent mental health support, which helped Sumi make gradual improvements. As Sumi continued her experience, the need for tailored support services, such as personal assistants, became evident, especially as she sought independence. Her experience also emphasized the importance of early, integrated mental health support that addresses the complex interplay of cerebral palsy with other conditions such as autism or attention-deficit/hyperactivity disorder. The family's continuing advocacy for a more inclusive and supportive mental health system highlighted the necessity of community-driven solutions and systemic changes to ensure that young people with cerebral palsy have access to the resources and care needed to achieve their aspirations.

Physical impairments and social stigma may increase vulnerability to peer victimization and limit opportunities for inclusion.

Young people with CP in this study reported challenges in school settings, including bullying, social exclusion, and difficulties meeting academic demands owing to insufficient accommodations. These issues negatively affect emotional health, self-esteem, and participation. Importantly, in the general population, bullying during childhood has been associated with long-term mental health consequences, including depression, anxiety, and increased risk of self-harm in adulthood.[54] The compounded effects of bullying and marginalization may place young people with CP at even greater risk for poor mental health outcomes.

This study also found that anxiety about the transition to adulthood, including employment and independent living, is a significant concern. Gannotti et al. identified that unclear pathways to employment and autonomy contribute to long-term mental health challenges in individuals with CP.[18] Addressing these concerns through structured, early interventions including career guidance, mentorship programmes, and self-advocacy training may improve long-term mental health outcomes.

Moreover, broader social determinants of health must be considered when designing interventions. As Emerson et al. highlight, access to inclusive education, equitable social resources, and supportive peer networks is essential for fostering mental health and well-being.[55] A holistic approach that incorporates these elements and promotes community engagement is critical to improving mental health trajectories for young people with CP.

Participants in this study identified systemic barriers in accessing mental health services. These included prolonged waiting times, a shortage of mental health professionals with expertise in CP, and unsuitable discharge protocols that failed to accommodate continuing support needs. These findings are consistent with existing literature that highlights the underdiagnosis of mental health difficulties in individuals with CP, often because of diagnostic overshadowing and communication barriers.[20]

One particular issue of concern was the inadequacy of mental health assessment tools for young people with CP, particularly those with complex communication needs. To address this, there is a pressing need to develop and implement adapted screening tools and targeted training programmes for mental health professionals. Such measures would better equip providers to identify and respond to the unique mental health presentations in this population.

The recent restructuring of children's disability services in Ireland through a targeted service improvement programme (Progressing Disability Services) aimed to create integrated regional models of care.[56] However, our findings suggest that, despite these reforms, significant gaps remain in the coordination between disability and mental health services. This lack of integration continues to result in fragmented care and inconsistent access to support.

This study was co-designed with input from PPI contributors and guided by a multidisciplinary team of researchers and clinicians. The use of robust qualitative methods and the incorporation of a composite case study approach provided rich, in-depth insights into the mental health experiences of young people with CP. Credibility was strengthened through triangulation of data sources and perspectives—drawing on input from young people and parents, and involving multiple researchers in data interpretation to ensure balanced and trustworthy findings.

However, certain limitations must be acknowledged. For two participants under 18 years, interviews were conducted with a parent present at the young person's request. This may have influenced disclosure or expression; however, researchers emphasized that the interview focused on the young person's views and encouraged independent responses. While the sample was heterogeneous, this diversity was an intentional qualitative strength, supporting exploration of a wide range of experiences and enhancing the richness and transferability of the findings.

In light of these findings, we propose several key areas for future research, policy, and service development. First, the expansion of community-based mental health programmes tailored to the needs of young people with CP and their families is essential. This is recommended in the literature for children and families in general as an important step for promoting mental health.[57] Sustained support at the community level can help address current service gaps and improve long-term outcomes.

Second, stronger integration between disability services, educational settings, and mental health care systems is critical to ensuring seamless, continuous care. Schools, in particular, represent an important setting for mental health support. The implementation of school-based mental health interventions can foster more inclusive and responsive learning environments.[52]

Third, investment in specialized mental health training for professionals working with individuals with CP is necessary. This includes both clinical training in neurodevelopmental and disability-specific mental health care, as well as broader training in disability awareness.[58] Such initiatives would help to address misdiagnosis, improve provider confidence, and ultimately lead to more effective and equitable mental health support for this population.

CONCLUSION

This study emphasizes the urgent need for integrated, person-centred mental health services for young people with CP. Addressing these barriers requires a coordinated effort between families, educators, healthcare professionals, and policymakers to ensure that young people with CP receive timely, appropriate, and holistic mental health support.

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CONFLICT OF INTEREST STATEMENT

The authors have stated that they had no interests that might be perceived as posing a conflict or bias.

DATA AVAILABILITY STATEMENT

Data from interviews with participants cannot be sufficiently de-identified and participants did not give written consent for future use of their data. Therefore, supporting data are not available on request.

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SUPPORTING INFORMATION

The following additional material may be found online:
Appendix S1. Topic guide.

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