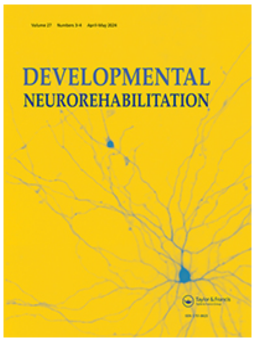

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# Reflections on Participation at Home, As Self-Reported by Young People with Cerebral Palsy

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**ABSTRACT**
This study explored the home-based participation of young people with cerebral palsy (CP) and described factors that make participation easier or harder. Fifteen young people with CP aged 15 to 26 years provided written reflections, photographs, or videos about their home-based participation experiences. Data were analyzed using reflexive thematic analysis. Self-reported reflections were grouped inductively into 129 codes, then 20 subthemes and 5 themes which emphasized CP characteristics, thoughts, emotions, equipment, environment, supports, and inclusion as important factors influencing home-based participation. Young people with CP largely described the home environment as an inclusive place to participate.

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Cerebral palsy; home; participation; qualitative thematic analysis; young people

## Introduction

During the late teenage years to early twenties, young people become more independent, take on increased responsibility, and explore new experiences in education, employment, independent living, and relationships.[1] However, many young people with disabilities such as cerebral palsy (CP) experience greater difficulties navigating these participation experiences when compared with their typically developing peers.[2,3] To provide appropriate support, accommodations, and funding, it is essential for health professionals to identify the challenges that young people with CP report about their everyday life that influence their participation.

*Participation* is defined by the World Health Organization as "involvement in a life situation." [4(p10)] Since involvement is a largely subjective construct, self-report is essential to capture the participation experiences and reflections of others.[5] However, there is a lack of studies documenting the self-reported participation experiences and perspectives of young people with CP.[6] In our recent Delphi study,[7] young people, their caregivers, and health professionals agreed that the "availability of appropriate activities and services" and the "acceptance and attitudes of others" were the most important factors influencing participation experiences of young people with CP. These findings highlighted *what* is important, but more research is needed to tell us *how* these factors make participation easier or harder. This detail should be gained by capturing self-report from young people with CP, when reflecting on their lived experiences in a variety of life situations and environments.[7]

This study focuses on participation at home. The home environment can vary across adolescence and young adulthood. Although many young people with CP live in their family home, some may have transitioned into their first independent or supported living arrangement. Some young people may also be living in alternate home environments, such as foster care, where living arrangements may change throughout adolescence and young adulthood. Participation is thus influenced by who the young people live with and their unique physical, social, and attitudinal environments at home. At the same time, young people are experiencing other changes, such as: evolving life roles, interests, and preferences; changing parental roles and the emergence of greater self-determination and autonomy; and changes to funding between pediatric and adult services.[1,8,9] Participation can be further influenced by these factors individually or collectively. The home is also a place that supports community participation. For example, a recent qualitative study using semi-structured interviews with adults who have mobility disabilities (aged 21 to 65 years) found that personal, social, and environmental factors in the home influenced their participation in the community.[10] Therefore, it is important to consider home as a place *for* participation and one that *supports* participation.

To date, research on the home-based participation experiences of young people with CP is mainly based on reports from caregivers.[7] Parents in a study by Law et al.[11] reported that their children with disabilities faced more challenges in home-based participation compared to their typically developing peers. They reported that participation was impacted by environmental barriers, lack of support at home, and inadequate funding, time, and information.[11] However, in a later study by Anaby et al.,[12] parents reported positive aspects of the home, namely that environmental and support barriers were experienced less frequently at home compared to in the community. This was attributed to parents having more control over the

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home environment and home-based routines.[12] Although parental reports provide valuable insights, they may not mirror the perceptions of young people, therefore research is needed to capture self-report on factors influencing home-based participation.

Several methodologies have been attempted to capture self-report of young people with CP. Bagatell et al.[1] used focus groups with young adults with CP (19 to 34 years) to explore self-reported experiences during the transition to adulthood, only including those who could communicate at a conversation level (verbally or using alternative communication). In three later studies, interviews were used to capture perspectives from young people with CP about rehabilitation,[13] or the transition to adulthood.[14,15] However, none reported on communication support needs (CSN) of their sample, nor whether non-verbal participants were included. Since communication function is one of the key determinants of social participation,[8] researchers must ensure research is designed to include contributions from the high number of young people with CP who have CSN.[16] Interviews and focus groups can be challenging for people with CSN as these methods can require rapid recall and may cause exertion and fatigue.[17] More inclusive methodologies include diary entries, photographs, or video-recordings,[18,19] where participants are provided with stimulus questions and self-paced reflection time to report their experiences and perspectives in more depth.

The aim of this study was to explore the home-based participation experiences of young people with CP in terms of the influencing factors that make participation easier or harder. The objective was to capture self-report directly from young people with CP with a diverse range of motor and communication abilities by using novel and accessible communication reflection options.

## Materials and Methods

### Research Design

This research involved a qualitative descriptive approach[20,21] to explore self-reported reflections of young people with CP regarding participation experiences and influencing factors. Data for this paper were collected as part of a broader study exploring the participation of young people with CP in everyday settings. This paper includes results for home-based participation experiences. A second paper focuses on community-based experiences. Data were analyzed using reflexive thematic analysis[22] and reported according to the COnsolidated criteria for REporting Qualitative research (COREQ) quality checklist (see Supplementary Appendix 1).[23] Ethical approval was granted by the Human Research Ethics Committees of the Cerebral Palsy League of Queensland (NHMRC EC00417) and The University of Queensland (NHMRC EC00456/7).

### Participants

Participants were recruited by population-based sampling via a state-wide CP register. Invitations were sent to all register members who were young people aged 15 to 26 years. The young people were eligible for the study if they were able to (i) communicate verbally, and/or using AAC, and/or with the support of a communication partner, and (ii) respond in English, with or without support from a translator. Young people were excluded if they had (i) a concomitant diagnosis that would confound the results (e.g., Autism Spectrum Disorder) or (ii) moderate to profound intellectual impairment (as documented on the register or provided by caregiver report). The CP characteristics of participants were classified using the Gross Motor Function Classification System (GMFCS),[24] Manual Abilities Classification System (MACS),[25] Viking Speech Scale (VSS),[26] Functional Communication Classification System (FCCS),[27] and the Primary Expressive Mode Group (PEMG).[28]

All participants over 18 years provided informed consent to participate in the research. Participants under 18 years and those with mild intellectual impairment were required to give assent and have consent from a caregiver. An accessible information sheet and consent form were provided. These documents used: (i) simplified language; (ii) enhanced text formatting (e.g., bolding of key words, increased font size, and line spacing)[29]; and (iii) Picture Communication Symbols (PCS) with permission from Tobii Dynavox LLC. Participants who submitted at least one reflection were offered a $50 gift card as a token of appreciation for their participation in the research.

### Development of a Home-Based Participation Framework and Self-Report Methodology

A customized data collection framework and methodology was needed to capture self-report on home-based participation experiences and influencing factors from a broad range of young people with CP. Development of the framework and methodology involved four phases: (i) home-based participation framework development; (ii) self-report method development; (iii) feedback from lived experience advisors; and (iv) pilot testing.

#### Home-Based Participation Framework Development

The first phase involved a systematic review[6] and an international Delphi consensus study[7] to identify appropriate participation constructs, frameworks, and profile measures relevant to young people with CP. From these findings, a participation profile tool was selected (described later in data collection section). Next, a set of stimulus questions were developed to guide young people to document *what* home-based participation experiences they were involved in. Then, a set of prompts were developed to elicit reflections from young people about *how* certain factors influenced participation, i.e., made participation easier or harder. Prompts were based on the *Environment* domains of the International Classification of Functioning, Disability, and Health Framework (ICF)[4] (see Supplementary Appendix 2).

#### Self-Report Methodology Development

A range of data collection options were offered to enable young people with all levels of motor and communication abilities to provide self-reported reflections. Each young person was able to respond using one, or a combination of: (i) written/typed reflections, (ii) images/photographs or artifacts, and/or (iii) video reflections (as described in data collection section). It was essential for this research to collect data over a sufficient period of time to capture a range of participation experiences that may occur daily, weekly, or less frequently. For this reason, 1 month was selected as this was a sufficient timeframe to capture routine and less common participation experiences. The timeframe was capped at approximately 1 month to ensure the feasibility of the study and minimize demand on participants. To support high-quality reporting, a 3-part training and support package was developed. First, participants were taught about the participation framework and how to engage in data collection. Tips were provided on what participants could and should not include within their video reflections and photographs, such as not capturing anyone without permission. Next, education resources were developed to support data submissions in each of the data formats. Finally, regular check-in sessions were designed to support ongoing engagement and troubleshooting during the reflection period.

### Feedback from Lived Experience Advisors

Feedback on the proposed data collection method was sought from consumer advisors with lived experience. Two consumer advisors worked with the researchers throughout the research project. These advisors were a young person with CP (28 years of age, GMFCS Level V, MACS Level V, VSS Level IV, FCCS III, and PEMG IV) and a primary caregiver of a young person with CP who had expertise in AAC resource development for young people with CSN. Advisors provided valuable input guiding the: (i) options and processes offered for data collection (e.g., written, photographs, video); (ii) phrasing of prompt questions to address research aims; (iii) information given to participants to ensure clarity and appropriate terminology; (iv) wording of research documents to increase readability for participants; and (v) choice of symbols used in the accessible documents. The researcher (JQ) met with advisors during the development of the study and after data collection and analysis. Advisors were remunerated for their time.

### Pilot Testing

To test the information provided to participants and refine the data collection methodology, an additional young person with CP (28 years of age) read the participant information, consent, and data collection documents and trialed the data collection process (see data collection section). Outcomes of this pilot testing were improvements to (i) descriptions of the study process and (ii) methods for gathering demographic information from participants.

## Data Collection

Data collection with each participant involved three steps: (i) orientation to study methodology; (ii) documentation of participant characteristics and participation profiles; and (iii) recording of self-reported participation experiences and factors influencing participation.

### Orientation to Study Methodology

Participants were oriented to data collection procedures via a meeting over Zoom with the principal researcher (JQ), which lasted approximately 1 hour. During the meeting, the researcher described: (i) the range of participation experiences and influencing factors they may want to discuss in their reflections; (ii) the types of reflection modes available; (iii) how to upload data; and (iv) how to seek help if needed. The researcher did not know any participants prior to this research.

### Participant Characteristics and Participation Profiles

During the initial orientation meeting, the researcher (i) collected self-reported demographic information and classification ratings and (ii) assisted the participant to complete the Picture my Participation (PMP) measure.[30] The PMP measure[30] was used to establish an overall understanding of the participation profile of the study participants. The PMP is designed to measure *Attendance* and *Involvement* of youth aged 5 to 21 years with disabilities across 20 everyday activities (9 in the home and 11 in the community).[30] *Attendance* is measured by how often the individual takes part in various life situations, as measured on a 4-point scale from 1: Never to 4: Always. *Involvement* is measured as the extent to which they show interest, are attentive and engaged in an activity, as measured on a 3-point scale from 1: Not involved to 3: Very involved. The PMP can be administered as a self-reported participation measure, using PCS[31] to enable engagement from participants with a range of communication abilities. The PMP was initially designed for use in low- and middle-income communities and has now been validated across several countries (Uganda, South Africa, and Sweden).[30,32] Permission was obtained from the authors of the PMP to complete the measure over Zoom (C. Imms, personal communication).

### Recording of Self-Reported Participation Experiences and Factors Influencing Participation

Each young person was asked to complete regular reflections in a self-paced manner over approximately 1 month on their home-based participation experiences and influencing factors. Participants chose the medium in which they provided self-report by video or written diary reflections, with or without photographs. At the start of every reflection, each young person provided contextual information about the type of participation experience to identify the setting of the reflection (e.g., cooking dinner in the kitchen or exercising in the garage). Participants could also submit other artifacts to provide additional contextual information such as an e-mail they were writing or the activity advertisement. Next, participants reflected on their experience, providing details on their perceptions of what occurred and describing how factors made their participation experience easier or harder, guided by the prompt questions when required (see Supplementary Appendix 2). This method enabled participants to represent and frame their own lives (their experiences) and allowed for collecting rich data in what they believed to help or hinder these experiences (their perspectives) similar to methods used in previous research (e.g., see refs).[33,34]

Each young person with CP recorded their reflections at a time that suited them in their typical setting. They were each given a unique URL to a secure data storage website where they uploaded their reflections. During data collection, the principal researcher (JQ) provided weekly opportunities for each participant to check-in via phone, Zoom, or e-mail to answer questions or provide technical support. Multiple supported communication options were available during meetings to assist people with CSN, such as using both written and spoken language (i.e., multi-modal communication), repeating information, paraphrasing, and rewording as recommended by Sellwood et al.[35] Caregivers could also attend as needed to support exchange and/or interpretation of communication between the young people with CP and the researcher.

### Raw Data Extraction

Raw data reflections were received from participants in three forms: (i) written/typed reflections (15 participants); (ii) photographs (9 participants); and (iii) video reflections (6 participants). Data from all three sources were extracted into a common written format for analysis. The first author (JQ) transcribed each video reflection verbatim and carefully checked transcriptions against recordings to ensure accuracy. Written reflections were entered verbatim. All photographs provided by participants visually presented content that was congruently provided in a written reflection. Written information was therefore used to translate the content of the photograph into written data form. For example, one participant submitted a photograph of themselves stirring mixture in a bowl using a specialized wooden spoon, accompanied with a written reflection which stated, "*I used equipment that has grip on the bottom of the bowl that way it won't move when I'm preparing the ingredients. Using equipment with longer handles helps me hold them easier …* " (YP6). Both the written text and the photograph were coded as *Using assistive equipment to help me cook*. Both codes were subsequently sorted into the subtheme *Using assistive aids and equipment* within Theme 3.

### Data Analysis

All reflections (written, photographs, and video) were deidentified using a participant number, then entered and coded using NVivo 12 (QSR International). All data were analyzed using reflexive thematic analysis as described by Braun et al.[22] Reflexive thematic analysis is a robust qualitative descriptive method used to systematically code qualitative data and then develop themes by identifying recurring and central patterns concerning the research question.[18,36] This reflexivity method was appropriate as the research team have clinical and research experience working as speech pathologists or physiotherapists with a range of clinical populations, including young people with CP in a wide range of settings. Any potential biases that may have been introduced to the data analysis and interpretations due to these clinical backgrounds were reduced by regular meetings and discussions on the data, findings, and implications.

To establish a valid and reliable coding process, the first author independently coded all reflections from three participants and then met with two members of the research team who reviewed, discussed, refined, and agreed on the coding in each reflection. This process continued for the next 12 participants. After 15 participants' reflections were coded, data were reviewed by all authors, and it was agreed that a theoretical saturation point had been reached. Recruitment was then concluded. Using this data, the first author then inductively sorted codes into subthemes. All authors met regularly during this stage to agree on the process, monitor code clustering, and to ensure consistency and dependability of the process for thematic analysis. This sorting and review process was repeated to cluster subthemes into major themes.

Strategies to ensure rigor were embedded into the research study design to enhance trustworthiness of the findings,[37] for example frequent peer reviewing and debriefing, use of reflective commentary, and participant checking. During participant checking, each young person was provided with a summary of the major themes with examples and asked if they agreed that each theme accurately captured the perspectives of people with CP. Ten of the 15 participants (66.7%) responded to the participant checking survey. All 10 participants agreed that the subthemes and themes were relevant and accurately represented their perceptions. No additional subthemes were generated as a result of the participant checking process.

## Results

### Participants

Fifteen young people with CP participated in this research (Table 1), including five adolescents (aged 15 to 17 years) and ten young adults (aged 18 to 26 years). An additional five young people with CP provided initial consent to participate but then did not complete the study due to becoming unwell ($n = 3$), not responding to contact attempts ($n = 1$), or not having the time to participate ($n = 1$). Participants represented a range of motor abilities across all levels of the GMFCS and the MACS. They also had a range of communication abilities, including those who communicated verbally and those with CSN who utilized AAC. Participants ranged across the four VSS levels and across the first four levels of both the FCCS and the PEMG. Participants had various education and employment levels and living arrangements, with 12 participants (80%) living in their family homes. All participants were assigned a pseudonym for reporting.

### Participant Profiles

Results from the PMP measure for participation at home are presented in Table 2. Ratings from the PMP showed high overall *Attendance* and *Involvement* in activities occurring in the home. Of the nine activities, five had a median score of 4/4 "Always" for *Attendance*, including: (i) personal care; (ii) family mealtime; (iii) my own health; (iv) family time; and (v) quiet leisure. The lowest median rating of *Attendance* was

**Table 1.** Characteristics of young people with CP.

|  | Age | Gender | CP Type | GMFCS | MACS | VSS | FCCS | PEMG | II | AI | Education | Employment | Living |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| YP1 | 17 | Non-Binary | Left Spastic Hemiplegia | II | II | I | I | I | No | None | Currently in high school and higher education (University) head start program | Casual paid employment | Living in parents'/family home |
| YP2 | 20 | Non-Binary | Left Spastic Hemiplegia | II | I | I | I | I | No | None | Completed all years of high school (including Year 12) | No employment/ volunteering | Living in parents'/family home |
| YP3 | 23 | Male | Spastic Triplegia | IV | II | II | I | I | No | Epilepsy (resolved by age 5), Some hearing impairment (includes conductive hearing loss), Scoliosis, Stutter | Currently enrolled in higher education (University/TAFE) | Casual unpaid volunteering | Living in parents'/family home |
| YP4 | 16 | Female | Spastic Diplegia | IV | I | I | I | I | No | Some visual impairment (wears glasses) | Currently in high school | No employment/ volunteering | Living in parents'/family home |
| YP5 | 25 | Female | Right Spastic Hemiplegia | I | I | I | I | I | No | Some visual impairment (wears glasses) | Completed higher education (University) | Full-time paid employment | Living in own home with partner |
| YP6 | 24 | Female | Spastic Quadriplegia | V | IV | II | II | I | No | Some visual impairment (wears glasses) | Completed higher education (TAFE) | No employment/ volunteering | Living in parents'/family home |
| YP7 | 17 | Male | Left Spastic Hemiplegia | I | II | I | I | I | No | None | Currently in high school | No employment/ volunteering | Living in parents'/family home |
| YP8 | 24 | Male | Left Spastic Hemiplegia | I | II | I | I | I | Mild | Some visual impairment (wears glasses) | Completed higher education (TAFE) | Part-time paid employment | Living in parents'/family home |
| YP9 | 22 | Female | Spastic Quadriplegia | III | II | III | II | II* | No | None | Currently enrolled in higher education (University) | Casual paid employment | Living in parents'/family home |
| YP10 | 17 | Male | Spastic Quadriplegia | IV | III | II | I | I | Mild | Some visual impairment (wears glasses) | Currently in high school | Casual paid employment | Living in parents'/family home |
| YP11 | 24 | Female | Ataxia | II | II | IV | IV | IV* | Mild | Some visual impairment (wears glasses) | Completed all years of high school (including Year 12) | No employment/ volunteering | Living in parents'/family home |
| YP12 | 20 | Female | Hypotonia | II | II | III | IV | III* | Mild | None | Completed all years of high school (including Year 12) | No employment/ volunteering | Living in parents'/family home |
| YP13 | 26 | Male | Left Spastic Hemiplegia | II | II | III | IV | IV* | Mild | Some visual impairment (wears glasses) | Completed some years of high school (left before Year 12) | Casual unpaid volunteering | Living away from parents'/ family home, with support |
| YP14 | 25 | Female | Right Spastic Hemiplegia | II | II | I | I | I | No | Some visual impairment (wears glasses) | Completed higher education (University) | Full-time paid employment | Living away from parents'/ family home, independently |
| YP15 | 15 | Female | Right Spastic Hemiplegia | I | II | II | I | I | No | Stutter | Currently in high school | No employment/ volunteering | Living in parents'/family home |

YP (Young Person); GMFCS (Gross Motor Function Classification System); MACS (Manual Ability Classification System); VSS (Viking Speech Scale); FCCS (Functional Communication Classification System); PEMG (Primary Expressive Mode Group); AAC (Augmentative and Alternative Communication); II (Intellectual Impairment); AI (Associated Impairments).

*Type of AAC used: YP9= Gesture; Typing; YP11= ProLoQuo2Go, Makaton signing, Typing, Writing; YP12= ProLoQuo2Go; and YP13= ProLoQuo2Go, Gesture.

**Table 2.** Picture my participation (PMP) measure for the level of *attendance* (A) and *involvement* (I) in activities in the home[30].

| | Personal Care | | Family mealtime | | My own health | | Meal preparation | | Cleaning at home | | Caring for family | | Caring for animals/ pets | | Family time | | Quiet Leisure | | Total | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | A | I | A | I | A | I | A | I | A | I | A | I | A | I | A | I | A | I | A/36 | I/27 |
| YP1 | 4 | 3 | 4 | 2 | 3 | 3 | 3 | 2 | 2 | 2 | 3 | 2 | 3 | 2 | 3 | 2 | 4 | 3 | 29 | 20 |
| YP2 | 4 | 3 | 3 | 2 | 3 | 2 | 2 | 2 | 3 | 2 | 2 | 3 | 4 | 3 | 3 | 2 | 3 | 3 | 27 | 22 |
| YP3 | 4 | 2 | 2 | 2 | 4 | 3 | 2 | 2 | 1 | 1 | 1 | 1 | 4 | 3 | 4 | 2 | 4 | 3 | 26 | 19 |
| YP4 | 4 | 3 | 4 | 3 | 3 | 3 | 3 | 2 | 3 | 2 | 2 | 2 | 1 | 1 | 4 | 3 | 3 | 3 | 27 | 22 |
| YP5 | 4 | 3 | 4 | 3 | 3 | 3 | 4 | 3 | 4 | 2 | 2 | 3 | 4 | 2 | 4 | 3 | 4 | 3 | 33 | 25 |
| YP6 | 4 | 2 | 4 | 2 | 4 | 3 | 3 | 2 | 1 | 1 | 1 | 1 | 1 | 1 | 4 | 3 | 4 | 3 | 26 | 18 |
| YP7 | 4 | 3 | 4 | 3 | 3 | 2 | 1 | 1 | 1 | 1 | 1 | 1 | 2 | 2 | 3 | 3 | 4 | 3 | 23 | 19 |
| YP8 | 4 | 2 | 4 | 3 | 4 | 3 | 1 | 1 | 3 | 3 | 1 | 1 | 3 | 2 | 4 | 3 | 4 | 3 | 28 | 21 |
| YP9 | 4 | 3 | 2 | 2 | 4 | 3 | 1 | 1 | 3 | 3 | 3 | 3 | 3 | 2 | 2 | 3 | 1 | 1 | 23 | 21 |
| YP10 | 4 | 2 | 4 | 3 | 4 | 1 | 3 | 3 | 3 | 1 | 4 | 3 | 2 | 2 | 4 | 3 | 4 | 3 | 32 | 21 |
| YP11 | 4 | 3 | 3 | 3 | 4 | 3 | 3 | 3 | 4 | 3 | 3 | 3 | 3 | 3 | 3 | 3 | 4 | 3 | 31 | 27 |
| YP12 | 4 | 3 | 4 | 3 | 3 | 3 | 2 | 2 | 3 | 3 | 3 | 3 | 4 | 3 | 3 | 3 | 4 | 3 | 30 | 26 |
| YP13 | 4 | 2 | 4 | 2 | 4 | 3 | 3 | 3 | 3 | 3 | 1 | 1 | 2 | 2 | 3 | 2 | 4 | 3 | 28 | 26 |
| YP14 | 4 | 3 | 2 | 3 | 3 | 3 | 4 | 3 | 4 | 3 | 2 | 3 | 2 | 3 | 4 | 3 | 4 | 3 | 29 | 27 |
| YP15 | 4 | 3 | 4 | 3 | 4 | 3 | 3 | 2 | 3 | 2 | 3 | 3 | 2 | 1 | 4 | 2 | 3 | 3 | 30 | 22 |
| Median | 4 | 3 | 4 | 3 | 4 | 3 | 3 | 2 | 3 | 2 | 2 | 3 | 3 | 2 | 4 | 3 | 4 | 3 | | |
| IQR | 0 | 1 | 1 | 1 | 1 | 0 | 1 | 1 | 0.5 | 1.5 | 2 | 2 | 1.5 | 1 | 1 | 1 | 0.5 | 0 | | |

A= Attendance: 4- Always, 3-Sometimes, 2-Not really, 1- Never.
I= Involvement: 3-Very, 2-Somewhat, 1- Not.
IQR= Interquartile range.

caring for family, which had a median score of 2/4 "Not really." Six home activities had median ratings of 3/3 "Very" for *Involvement*, including: (i) personal care; (ii) family mealtime; (iii) my own health; (iv) caring for family; (v) family time; and (vi) quiet leisure. The remaining three activities had a median rating of 2/3 "Somewhat" for *Involvement*.

## Reflection Data

A total of 15 young people (aged 15 to 26 years) provided 392 reflections, including 367 written reflections (15 participants), 90 photographs (9 participants), and 25 video reflections (6 participants). Thematic analysis resulted in 129 codes about home-based participation that were grouped inductively into 20 subthemes and five themes (Table 3). The five themes were: (i) My CP characteristics can make doing everyday activities at home more difficult; (ii) My own thoughts, emotions, and sense of achievement influence the things I do at home; (iii) Having the right equipment and environment enables me to do the things I want to do at home; (iv) Having the right caregiver supports helps me to do the things I want to do at home; and (v) Being accepted, included, and supported by the people in my home influences the things I do (Table 3). Each of the five themes are outlined in detail below and participant quotes are used as examples for each subtheme.[38]

### Theme 1: My CP Characteristics Can Make Doing Everyday Activities at Home More Difficult

This theme included seven subthemes that represented how CP characteristics influenced participation at home: (i) Having difficulty moving my body; (ii) Having difficulty moving my hands; (iii) Having difficulty speaking and communicating; (iv) Having difficulty managing sensory information; (v) Having a chronic level of pain that can be exacerbated by doing activities; (vi) Feeling fatigued; and (vii) Needing to

**Table 3.** Themes and subthemes.

| Themes | Subthemes |
|---|---|
| (1) My CP characteristics can make doing everyday activities at home more difficult | Having difficulty moving my body |
| | Having difficulty moving my hands |
| | Having difficulty speaking and communicating |
| | Having difficulty managing sensory information |
| | Having a chronic level of pain that can be exacerbated by doing activities |
| | Feeling fatigued |
| | Needing to use regular techniques to manage my pain, muscle tension, and build strength |
| (2) My own thoughts, emotions, and sense of achievement influence the things I do at home | My own opinions and attitudes |
| | My level of motivation, persistence, and productivity |
| | My own emotions and mental health |
| (3) Having the right equipment and environment enables me to do the things I want to do at home | Being at home in an accessible environment |
| | Having a quiet and peaceful home environment |
| | Using assistive aids and equipment |
| | Being able to use technology |
| (4) Having the right caregiver supports helps me to do the things I want to do at home | Having formal supports and services available at home |
| | Having informal help and support from people at home |
| | Having funding available for supports at home |
| (5) Being accepted, included, and supported by the people in my home influences the things I do | Building and maintaining relationships with the people around me |
| | Being included and interacting with the people around me |
| | Feeling accepted and emotionally supported |

use regular techniques to manage my pain, muscle tension, and build strength.

### Having Difficulty Moving My Body

Participants described how difficulties with mobilizing and moving their body made it harder to do the everyday things that they wanted to do in their home. This impacted a wide range of functional tasks, such as getting dressed, vacuuming the floor, unloading the dishwasher, washing dishes, moving boxes, or completing personal care.

> Harder: Physical ability when vacuuming. (YP4)

> To get ready for the day . . . having a support worker . . . Take pyjama pants off and replace with shorts or long pants. Place each leg in pant leg, pull pants half up and wedge in between my legs, ensure feet are placed on footrest. Stand up and pull pants up . . . (YP6)

It also impacted the ability to move from place to place around the home, and/or to transfer their body to and from different positions or pieces of equipment.

> Our floor hoist can hoist me out of my chair to the floor to do some stretching and exercise. (YP10)

### Having Difficulty Moving My Hands

Fine motor movements were consistently described as making activities in the home harder, such as doing chores (using pegs to hang out washing, tearing paper towels to wipe benches), cooking (cutting, peeling, grating, stirring, opening lids, cracking eggs), typing on the computer, holding a camera, and doing art.

> My left hand struggled and strained when having to do all the fine motor skills one handed. Opening a lid, unwrapping and tearing paper towels, would've been a lot simpler with two hands . . . (YP9)

> I enjoy cooking, however I am generally slower than able bodied people. Cutting is the thing that takes me the longest. As a result I tend to enjoy baking more than cooking. (YP14)

### Having Difficulty Speaking and Communicating

Participants had a range of communication abilities as determined by the VSS, FCCS, and PEMG tools. Their reflections highlighted that communication influenced participation in home activities for those with both mild (VSS II) and more severe (VSS III and IV) motor speech difficulties. The ability to communicate influenced their participation in a variety of home activities such as making phone calls, posting on social media, and talking with others.

> I asked mum to make an appointment for a haircut because people don't understand me on the phone. (YP12)

> I found that I had to focus more on my speech when I spoke to my siblings. . .Having communication issues is often a daily challenge . . . (YP15)

### Having Difficulty Managing Sensory Information

Some participants reflected on being hypersensitive to sensory information, specifically sounds, and shared how this can make their experiences more difficult. The experience of loud noise in the home, such as background TV sounds, barking dogs, or their family being loud in the kitchen, were described as "overwhelming," "annoying," or "disorienting."

> Having hypersensitivity makes it difficult to rise [rinse] my mouth out after brushing my teeth as I struggle to drink from the cup as I jolt when taking a sip. (YP6)

> . . . my senses started getting really overwhelmed and disoriented from just how loud it was. (YP3)

### Having a Chronic Level of Pain That Can Be Exacerbated by Doing Activities

The influence of pain and physical symptoms such as muscle tightness were consistently described as a chronic and ongoing factor impacting daily experiences in the home.

> [My] Pain was pretty bad when walking around the house today, so that was where most of the difficulties I had today came from. (YP2)

A range of activities in the home were made more challenging and were even avoided due to pain, such as walking, standing, cleaning, exercising, cooking, baking, and doing personal care.

> My foot increased in pain while cooking. By the time dinner was ready, it had gotten pretty unbearable to stand and walk much longer. (YP2)

> It may also have to wait until my arm is less reactive as cake decorating is very much a luxury and not a necessity. (YP14)

### Feeling Fatigued

Fatigue was described as a factor that worsened CP symptoms and made it more difficult for participants to do what they wanted to do, such as completing art projects and working on the computer.

> . . . I do get tired a lot more than other people. Often a lack of sleep means a lack of focus and concentration for me which means that it becomes even more difficult for me to control some of my movements especially on my right side (leg and arm); CP side which more often than not leads to more trips throughout the day. (YP15)

> Depending on my energy levels and how my body is feeling limits the amount of time I can be on the computer. (YP6)

In addition, prolonged periods of concentration or taking time to communicate at home were identified as factors that further increased fatigue levels.

> It takes a lot of physical and mental effort to communicate with hew [new] support workers to help them understand and when having to do this frequently it is very tiring and frustrating. (YP6)

> I was tired on Sunday because concentrating on all the conversations . . . (YP11)

### Needing to Use Regular Techniques to Manage My Pain, Muscle Tension, and Build Strength

Due to the chronic pain and physical symptoms experienced by participants, they reflected that regular management was an essential part of their daily routine. Participants described multiple strategies used to manage pain and reduce muscle tension, such as self-massage, stretches, exercise, rest, using hot/cold packs, and removal of painful orthotics which were all often done in the evening before sleep.

> I did some stretches before bed. My left foot was hurting more than usual so I didn't do as much as previous nights. There's not much I can do to relieve the pain other than avoiding pressure. The exercises I did do were okay though. (YP2)

> I do utilise stretches and exercises to assist in relaxing my muscles. . . (YP14)

Participants reflected on using a range of exercises and activities routinely at home to target improving their strength and motor function such as exercises (planking, push-ups, walking, standing, boxing, sit-ups, squats) and other creative ways to target motor function such as cooking and art.

> I want to build up upper body strength again, so I've added planking and push-ups to my nightly routine. (YP2)

## Theme 2: My Own Thoughts, Emotions, and Sense of Achievement Influence the Things I Do at Home

This theme included three subthemes: (i) My own opinions and attitudes; (ii) My level of motivation, persistence, and productivity; and (iii) My own emotions and mental health.

### My Own Opinions and Attitudes

Almost all participants reflected on how their own opinions about certain activities influenced their experiences. When sharing about activities that they enjoyed doing at home, their reflections highlighted that having fun helped them to have more positive experiences, such as when baking, watching movies, spending time with family and friends, having meals, looking after their home, exercising, relaxing, or caring for pets. In contrast, participants found that needing to do activities they did not enjoy made their experiences harder, such as doing their studies or cooking. Therefore, their own positive or negative opinions and attitudes toward each activity influenced their experiences and perceptions during the activities.

> I enjoy my home and being able to look after it, and I do enjoy these days, we like to watch some movies on Netflix. (YP11)

> I'm not a happy camper when it comes to cooking. (YP8)

Some reflections focused on improving their own acceptance toward changes in their own function.

> If anything needs changing, it would be my acceptance towards my decreased mobility. (YP2)

### My Level of Motivation, Persistence, and Productivity

Many participants reflected on the influence their levels of motivation and persistence to achieve their goals and be productive had on their daily experiences at home. They associated this with providing a sense of purpose and feeling fulfilled.

> I got over that initial hurdle of starting, and now I'm eager to progress. (YP2)

> . . . my perseverance to continue allowed for a fun learning experience! (YP1)

Goals were variable among participants but included things such as wanting to: learn a new language, create drawings and artworks, start their own business, improve their fitness, become more independent, live independently, and create a podcast to advocate for disability access and rights. The sources of motivation for these goals varied, but passion, excitement, and inspiration for personally chosen goals were shared among participants.

> . . . my brain was flowing with potential ideas and ways to make it happen and create a vision. (YP4)

> I like the fact I can achieve more than I thought possible with my artworks. (YP6)

### My Own Emotions and Mental Health

Data showed that when young people with CP had periods of downtime at home, they could be drawn into more self-reflection, resulting in the need to manage arising emotions or mental health difficulties. Some participants shared how having experienced anxiety, depression, or grief from losing a loved one and/or feeling strong emotions such as stress, frustration, humiliation, or sadness often arose and influenced their experiences at home.

> I felt humiliated, my nerves were running rampant and I was shaking by this point (I don't do well with phone calls, especially when they go awry). (YP2)

> I've always felt like I've had to make as many connections as possible, particularly deep ones to combat the feeling of rejection and loss that came with losing [sibling]. (YP3)

Participants shared about strategies they used to manage these emotions from home, such as talking with support people, reflecting, expressing emotions, or channeling these feelings into other outlets such as exercise and art.

> I love that sort of challenge where I push my body to the absolute limit and potentially break down barriers and boundaries. After the standing I did some boxing, which I love to do as it gives me a really good focus point to channel my emotions and use them in a positive way. (YP3)

> I work [woke] up, feeling just sad . . . However, I have learnt to self-reflect, to break myself down to build myself back up again. (YP9)

### Theme 3: Having the Right Equipment and Environment Enables Me to Do the Things I Want Do at Home

This theme included four subthemes: (i) Being at home in an accessible environment; (ii) Having a quiet and peaceful home environment; (iii) Using assistive aids and equipment; and (iv) Being able to use technology.

#### Being at Home in an Accessible Environment

Several participants described their homes as being an environment that is individualized and accessible. The home environment facilitated participation, with personalized physical adjustments that allowed participants to feel more independent.

> I felt like my participation in the day was made easier by . . . the environment. (YP1)

> Being at home in a highly accessible environment . . . made this time easier and more enjoyable as I felt I could relax and have a great time without worrying about accessibility of the environment and not being able to participate. (YP4)

A participant also reported the positive benefits of using a smart home device in their home to improve the accessibility of actions, for example adjusting the lights due to having difficulty reaching the wall switches from their wheelchair.

> . . . I use my Google Home to change the lights on my light bulb . . . they make it so much easier than to just flick this switch. . . (YP3)

#### Having a Quiet and Peaceful Home Environment

Participants described their home as a quiet and peaceful place that enabled them to do the relaxing things they wanted, such as rest, listen to music, do art projects, watch shows and movies, or recover from illness.

> I went home and relaxed and rested, trying to make sure my ear got better. (YP1)

> We then had a nice relaxing afternoon at home waiting [watching] movies and enjoying time together. (YP5)

> I prefer to do art at home individually as its [it is] a quieter environment meaning less likely for me to startle. (YP6)

#### Using Assistive Aids and Equipment

Having the right assistive aids and equipment at home were described as greatly facilitating participation in the home, mainly to help with physical symptoms and mobility during activities. Interestingly, participants did not discuss using their assistive equipment for communication in the home. Participants described using floor hoists, walkers, wheelchairs, crutches, ankle-foot orthoses (AFO), compression socks, a hearing aid, a small mechanical keyboard, an adjustable table, adapted cooking equipment, and a food processor.

> Being in my own environment that was fully accessible so that I can be fully independent also assistive technology such as my wheelchair. (YP4)

> I used equipment that has grip on the bottom of the bowl that way it won't move when I'm preparing the ingredients. Using equipment with longer handles helps me hold them easier and range of movement. (YP6)

However, participants also reflected on times when the assistive equipment they needed at home was damaged, not working, unavailable, or painful. Examples of times when assistive equipment was not helping participation at home were when a participant's AFO was damaged and causing pain, or a hearing aid was damaged, or due to not having wheelchair-accessible clothes available.

> I wore my AFO all afternoon. Just walking around the house . . . The tightness in the shoe only affects the other four toes . . . today, it felt more numb. (YP2)

> It would make it [getting dressed] easier if there was wheelchair accessible clothing, such as button up shirts, that button from the sides or back. (YP6)

#### Being Able to Use Technology

Many participants reflected on being able to participate in activities from home due to having access to technology (i.e., computer, laptop, mobile phone, and internet). A participant who is non-verbal highlighted how "*Technology makes it easier for me, as I can do things online*" (YP11), providing an alternative to needing to communicate with people on the phone or in person.

Reflections emphasized that technology helped participants complete many activities from home, such as schoolwork and assignments, attending virtual classes and lectures, working from home, having meetings and social catchups via video chat, shopping online, ordering food to be delivered, developing podcasts to advocate for disability awareness, sending e-mails, and playing games online with friends.

> I like that [the] fact I can use the laptop [at home] and it gives me independence . . .. (YP6)

This subtheme was particularly relevant for times during the COVID-19 pandemic, when people spent more time at home.

> While I have been in isolation, I have been doing lots on my computer and phone. Lucky for tech! (YP13)

One participant reflected on having difficulty when they did not have access to functional technology to work and study from home, as their speech-to-text software was not compatible with attending classes on Zoom.

> I have no issue with zoom classes [at home], however I do not love the fact that they prevent me from using speech to text software. Taking notes is one of the primary things I use dragon for and to not be able to effectively access it is difficult. *(YP14)*

### Theme 4: Having the Right Caregiver Supports Helps Me to Do the Things I Want to Do at Home

This theme included three subthemes: (i) Having formal supports and services available at home; (ii) Having informal help and support from people at home; and (iii) Having funding available for supports at home.

### Having Formal Supports and Services Available at Home

Formal supports included both health supports and other types of supports. Access to health supports at home included having health professional appointments in the home and those delivered via telehealth. Participants described how helpful these flexible service options were in assisting with regular access to their medical health professionals.

> I also had a telehealth appointment and got a script for antibiotics. I found the EScript [E-Script] system very easy to use and it makes so much sense to have electronic scripts when so many appointments are done virtually. (YP14)

Community-based allied health professionals who provided sessions within the home were also described as helpful by participants.

> At 11 o'clock this morning my physio … came to my house and did an hour long session with me. During the session I completed standing, sit to stands, boxing and used an arm crank machine. I felt extremely good doing boxing and standing. Due to having to put all my effort into them, particularly boxing. (YP3)

> I was able to explain [to my Physiotherapist] where my body was hurting, so [they] had helped me by stretching and massaging. (YP10)

However, the need for more supports to manage pain and physical symptoms from home was also reflected. Participants shared that they wish they knew more techniques and strategies to be able to manage their symptoms themselves from home, particularly in the evening to help relax their muscles before sleep.

> … I couldn't think of any stretches that doesn't put massive amounts of pressure on the foot of the leg you want stretched. (YP2)

> This has impacted me majorly because yesterday and today I sensed really bad stiffness and tightness in my legs. To combat this and with minimal options, I am attempting to stretch and walk around my house as much as possible but I wish I knew other techniques… (YP15)

Other types of formal supports were accessed by participants and increased participation at home. A participant had an art teacher who attended their home regularly to provide accessible art classes within their environment.

> My art teacher works with me to reach my art goals by thinking outside the box and creating/adapting ways to achieve the outcome I want by using different techniques designed around what I am capable of. (YP6)

Participants who required regular support worker services within the home typically had higher mobility needs and CSN. These participants emphasized the influential impact of regular access to these supports on their experiences. Reflections highlighted how support workers become an important part of their daily lives by providing necessary supports for personal care to get dressed and ready for the day, completing home duties and chores, food preparation and feeding at mealtimes, wheelchair transfers, and exercises.

> My support worker supported me/helped me with the tasks I struggled with. (YP4)

> Once home my support worker assisted me with preparing the food and feeding me. (YP6)

Participants who required regular in-home assistance from support workers reflected a significant impact on their daily experiences if their support workers changed or did not attend when expected. Having short-term workers who may not perceive their role as a long-term, or an ongoing career option, caused significant disruptions to their participation, leading to frustration.

> *Have had some long term support workers that finished and now finding it difficult to find people that understand me and my needs. A lot of time and effort is spent training people and they don't see this work as a career and I have to keep finding new people.* (YP6)

### Having Informal Help and Support from People at Home

At times, when formal supports were unavailable, some participants needed to rely on other informal support networks, such as a family, to fill the gaps in their support.

> … was at home by myself for some time and had to message Dad to come back when I needed something … Frustrated as didn't have a support worker and had to interrupt Dad while he was trying to get work done. (YP6)

Participants described how these informal supports in the home from parents, siblings, other family members, roommates, or friends helped their daily experiences.

> … I was grateful that I had relatives here and that I was in an atmosphere that allowed me to remain autonomous and comfortable. (YP4)

Informal support people assisted participants in completing daily activities such as cooking, personal care, making appointments, or providing financial support.

> I decided what goes where for the decoration of the cake, and my friend helped me place them in the position. (YP10)

> My family is amazing, and this support ensures that I am on the same level as my peers and that I am not constantly using my savings for medical treatments. I am lucky that I have this support. (YP14)

### Having Funding Available for Supports at Home

Some participants discussed their experiences accessing funding from the National Disability Insurance Scheme (NDIS) for formal supports at home, such as health professionals and support workers. The NDIS provides funding directly to individuals with disabilities and their families, who then have choice and control over their preferred services and providers.[39] Reflections captured how NDIS support allowed participants to be more independent and work toward their goals.

> . . . the NDIS which I have been lucky to be a part of since finishing high school. It has been helpful, with my goals of working towards independent living and cooking and also health and fitness. (YP11)

The NDIS provides peace of mind to participants that they will have access to ongoing support if their parents or family become unwell and cannot look after them.

> I know it is there if I need more help or if mum got sick. (YP11)

### *Theme 5: Being Accepted, Included, and Supported by the People in My Home Influences the Things I Do*

This theme included three subthemes: (i) Building and maintaining relationships with the people around me; (ii) Being included and interacting with the people around me; and (iii) Feeling accepted and emotionally supported.

### *Building and Maintaining Relationships with the People Around Me*

Participants described home as a familiar and inclusive social environment that facilitates quality time and relationship-building with others. Quality time with people in the home was spent talking, laughing, watching movies, celebrating birthdays, cooking, and sharing meals.

> . . . we learned a lot about each other, just trying to create a strong connection. (YP3)

> I was home and talked with my siblings that was heart-warming . . . After a long day, it's peaceful to come home to settle down and see people who are familiar. (YP9)

Most of the reflections on interactions in the home were positive, however, there were a few examples of negative experiences, such as having a disagreement or arguing with family.

> . . . one of my younger brothers was trying to tell me what I should be doing to make sure I don't make a mess and insisted on calling me names . . . (YP15)

### *Being Included and Interacting with the People Around Me*

Being included by people in the home was described throughout reflections, particularly by participants with CSN, who shared that communicating " *. . . is easy with my family . . .* " (YP11). Young people reflected on how their participation at home is supported by their family, who listen and include them when communicating, even when using alternative communication methods.

> I feel Included, I use signing the most with my family. (YP11)

> I liked having my cousins at my house. Everyone is really nice to me and talks to me. (YP12)

### *Feeling Accepted and Emotionally Supported*

People close to the young people with CP, such as family, friends, or support workers, were described as accepting, with positive attitudes such as being nice, patient, understanding, and "*Everyone was kind*" (YP9). These positive attitudes were a source of support that helped participation experiences at home. The people in their lives not only provided physical supports to help participation and meet their immediate needs, but also deep connections from their relationships, providing company, emotional support, acceptance, and comfort.

> He really helps me in life. We help each other. I treasure our friendship very much. (YP9)

Regular emotional support and company could be provided by a range of different people in the environment including support workers.

> I was extremely relieved and grateful to have that support and understanding from my carer . . . So we talked for about 3 hours and by the end of it, I felt like a great weight had been lifted off my shoulders. (YP3)

## Discussion

This study explored the home-based participation experiences and influencing factors of young people with CP and identified a range of self-reported factors that they perceived influenced their participation at home. This research is novel in that it has included the self-reported perspectives of young people with CP with a range of motor and communication abilities to provide a more representative understanding of how factors are influencing the home-based participation of this group. The innovative methods utilized in this research allowed young people to authentically represent their own experiences in context utilizing their preferred communication method. Their voices can inform future supports, accommodations, and funding allocation for services within the home, based on specific examples of activities that young people with CP find difficult to do in their homes and the types of support that they report they need to participate.

Participants reflected on the importance of having meaningful goals and a purpose (Theme 2). For young people to thrive and feel fulfilled, striving toward goals and having the autonomy to do things they enjoy doing in the home is important. Services providers are encouraged to consider the entire picture when working with young people with CP. This includes supporting physical, emotional, and social needs as well as helping young people to establish purpose, meaning, aspirations and have opportunities to explore their passions.[40]

Reflections suggested that young people with CP may struggle with emotions and mental health at home and may benefit from having access to more strategies and support (Theme 2). Participants shared how the home provides a place for them to relax and have downtime, with fewer external distractions than experiences in the community. Due to having quiet time at home, some participants reflected on how this made home a place to struggle with managing emotions or mental health. Reports of mental health struggles are common across studies.[41] A recent study with 42 adults with CP (aged 18 to 72 years) found that one-third experienced moderate to extremely severe depression, over half had symptoms of anxiety, and a significantly higher proportion experienced more difficulties with emotional regulation than the general population.[42] Therefore, young people with CP and their families should be empowered with strategies and tools for managing their emotions and mental health at home, including awareness of how to access services and supports from home when needed throughout the week.

The home environment was perceived as a haven of individualized adaptations and supports that help participation (Themes 3, 4, and 5). This finding was also reflected in the results from the PMP profile which had showed that participants' overall *Attendance* and *Involvement* in the home were high, with five activities scoring a median of "Always" attending and six activities with a median of "Very" involved. Although some activities, such as Meal Preparation, had variability among participants for both *Attendance* and *Involvement*. This was discussed by participants across the reflections as many young people described specific strategies they used to adapt the activity and cook in their own kitchen (Theme 3). These findings are similar to Anaby et al.[12] with participation barriers being less influential in the home than in other community environments, with home having less formal routines and more control over adaptations to manage their CP symptoms.

Participants shared about their ongoing struggles with managing and living with the functional impairments associated with CP (Theme 1). Symptoms of pain and muscle tightness made activities in the home more challenging and in turn these activities exacerbated symptoms. Chronic pain is common in young people with CP.[43,44] Participants described how managing their symptoms is a crucial part of their daily routine at home, which is a similar finding to other recent qualitative studies. Bagatell et al.[1] reported a key theme of *Understanding and managing my body* from young adults with CP (aged 19 to 34 years) and described how practitioners were sought to help manage symptoms. Ostojic et al.[45] found a central theme of *I know how to deal with it* [pain], highlighting how pain was important to young people with CP (aged 9 to 17 years). Participants in the current study shared a range of strategies that they utilized to manage their pain and that they wanted more support and education to manage their symptoms from home (Theme 4). Reflections showed that the at-home strategies utilized by participants were primarily performed in the evening before sleep, which was a difficult time for services to provide clinical support. Service providers could consider these reports to inform future service allocation, such as providing in-home support at later times or providing participants with training in skills for self-managing their symptoms at home after hours. This would empower young people with better health literacy, knowledge, and skills.

Most participants relied on the helpful support of people around them to assist their participation experiences (Theme 4). Formal and informal support people were mainly perceived as positively influencing experiences and being extremely helpful by participants in this study such as helping with home duties, chores, preparing food, feeding at mealtimes, providing wheelchair transfers, and support with exercises. However, some participants reflected on the variable availability of support workers as a factor that made participation harder, such as when support workers changed jobs or missed an appointment time. Support workers can often be in casual positions, such as tertiary students training for subsequent roles, which can contribute to the transient nature of some support worker positions. Service providers and funders need to continue to focus on how disability support workers can be better supported to stay in the career long-term and reduce the high turnover rate of employees.[46]

Participants described how *Feeling accepted and emotionally supported* by people in the home helped their experiences (i.e., family, friends, and support workers). The home allowed participants to establish deep and meaningful social relationships with others. Theme 5 explored how important *building and maintaining relationships* was to participants. Connection with others and building strong networks are critical to support mental health and happiness.[47] Research has found that simply living near people who we have a close connection with increases our longitudinal happiness.[47] In addition, as the current study included individuals with CSN, the subtheme *Being included by the people around me* emphasized the importance of being included and understood during interactions. This finding also reflects how most participants in this study were living with others, mainly with family. The level of acceptance and inclusion by others is an extremely important factor influencing participation.[7] Participants emphasized the high level of inclusion from others in their home, with people who know how to best communicate with them. This research has emphasized that young people with CP want meaningful social connection, acceptance, and inclusion, and that home is where these needs may be well addressed.[17]

## Strengths and Limitations

Strengths included having population-based recruitment, which resulted in a representative sample of young people with a range of presentations and perspectives self-reporting on their experiences. Consumer advisors with lived experience provided valuable support to this research. Utilizing regular self-reported reflections reduced the risk of recall bias as participants could reflect on their participation experiences and influencing factors as they occurred in context. A few limitations to this research can be considered. Participants were all living in Australia and their reflections represent experiences accessing disability supports and services within this context. Further studies in other countries could explore whether these findings translate into other contexts. Most of the young people with CP in this study lived in their family homes with their parents. This is a fairly typical living situation for this age group of participants in Australia, however future studies might focus on subgroups living out-of-home or in alternate home environments, such as foster care. Reflections from adolescents and young adults were combined in this study. Future research could investigate separate views for these ages. This research excluded individuals with moderate to profound intellectual impairment due to the requirement to self-report. Future research could use alternate data collection strategies such as caregiver provided photographs or artifacts to explore experiences of individuals with more severe intellectual impairments.

## Conclusion

This study provides findings from the self-reported perceptions of young people with CP on their home-based participation experiences and influencing factors. Data revealed five main themes influencing participation: (i) My CP characteristics can make doing everyday activities at home more difficult; (ii) My own thoughts, emotions, and sense of achievement influence the things I do at home; (iii) Having the right equipment and environment enables me to do the things I want to do at home; (iv) Having the right caregiver supports helps me to do the things I want to do at home; and (v) Being accepted, included, and supported by the people in my home influences the things I do. Participants largely described the home environment as an inclusive place where they have the equipment, accommodations, and support they need. They highlighted the importance of feeling accepted, included, and supported by people in the home environment to help their participation experiences. However, young people with CP expressed needing more help at home to manage their symptoms of pain and muscle tightness, to support their emotions and mental health, and to secure more long-term reliable carer support.

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## Data availability statement

Deidentified data supporting the findings of this research may be available on request from the corresponding author (JQ). Data are not publicly available because they include information that could compromise research participant privacy.

## References

1. Bagatell N, Chan D, Rauch KK, Thorpe D. “Thrust into adulthood”: transition experiences of young adults with cerebral palsy. Disabil Health J. 2017;10(1):80–86. doi:10.1016/j.dhjo.2016.09.008.
2. Donkervoort M, Roebroeck M, Wiegerink D, van der Heijden-Maessen H, Stam H. The Transition Research Group. Determinants of functioning of adolescents and young adults with cerebral palsy. Disabil Rehabil. 2007;29(6):453–63. doi:10.1080/09638280600836018.
3. Reddihough DS, Jiang B, Lanigan A, Reid SM, Walstab JE, Davis E. Social outcomes of young adults with cerebral palsy. J Intellect Dev Disabil. 2013;38(3):215–22. doi:10.3109/13668250.2013.788690.
4. World Health Organization. 2001. International classification of functioning, disability and health: ICF. Geneva: World Health Organization. https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health.
5. Imms C, Granlund M, Wilson PH, Steenbergen B, Rosenbaum PL, Gordon AM. Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. Dev Med Child Neurol. 2017;59(1):16–25. doi:10.1111/dmcn.13237.
6. Quartermaine JR, Rose TA, Auld ML, Johnston LM. Participation measures that evaluate attendance and involvement for young people aged 15 to 25 years with cerebral palsy: a systematic review. Disabil Rehabil. 2023;1–17. doi:10.1080/09638288.2023.2207042.
7. Quartermaine JR, Rose TA, Auld ML, Johnston LM. Factors impacting positive and negative participation of young people with cerebral palsy: a delphi study of consumers and health professionals. Disabil Rehabil. 2023;1–9. doi:10.1080/09638288.2023.2207042.
8. Jacobson D, Löwing K, Hjalmarsson E, Tedroff K. Exploring social participation in young adults with cerebral palsy. J Rehabil Med. 2019;51(3):167–74. doi:10.2340/16501977-2517.
9. Schmidt AK, van Gorp M, van Wely L, Ketelaar M, Hilberink SR, Roebroeck ME. Autonomy in participation in cerebral palsy from childhood to adulthood. Dev Med Child Neurol. 2020;62(3):363–71. doi:10.1111/dmcn.14366.
10. Greiman L, Koon L, Schulz JA, Nary D. A usable home: a qualitative investigation of the relationship between home usability and community participation for people with disabilities. Disabil Health J. 2022;15(1):101211. doi:10.1016/j.dhjo.2021.101211.
11. Law M, Anaby D, Teplicky R, Khetani MA, Coster W, Bedell G. Participation in the home environment among children and youth with and without disabilities. Br J Occup Ther. 2013;76(2):58–66. doi:10.4276/030802213X13603244419112.
12. Anaby D, Law M, Coster W, Bedell G, Khetani M, Avery L, Teplicky R. The mediating role of the environment in explaining participation of children and youth with and without disabilities across home, school, and community. Arch Phys Med Rehabil. 2014;95(5):908–17. doi:10.1016/j.apmr.2014.01.005.
13. Freeman M, Stewart D, Cunningham CE, Gorter JW. “If i had been given that information back then”: an interpretive description exploring the information needs of adults with cerebral palsy looking back on their transition to adulthood. Child Care Health Dev. 2018;44(5):689–96. doi:10.1111/cch.12579.
14. 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. Advance online publication. doi:10.1080/07380577.2023.2211669.
15. Normann G, Arntz Boisen K, Uldall P, Brodsgaard A. Navigating being a young adult with cerebral palsy: a qualitative study. Int J Adolesc Med Health. 2020;34(4):187–95. doi:10.1515/ijamh-2020-0039.
16. Australian Cerebral Palsy Register Group. 2023. Report of the Australian cerebral palsy register birth years 1995-2016. https://cpregister.com/wp-content/uploads/2023/01/2023-ACPR-Report.pdf.
17. Dee-Price B-J, Hallahan L, Nelson Bryen D, Watson JM. Every voice counts: exploring communication accessible research methods. Disabil Soc. 2020;36(2):240–64. doi:10.1080/09687599.2020.1715924.

18. Lyons R, McAllister L, Carroll C, Hersh D, Skeat J. Diving deep into qualitative data analysis in communication disorders research. Albury: J&R Press Ltd; 2022.
19. Pickering DM, Gill P, Reagon C. A kaleidoscope of well-being to authentically represent the voices of children and young people with complex cerebral palsy: a case study series. Disability And Rehabilitation. 2023;46(7):1339–53. Advance online publication. doi: 10.1080/09638288.2023.2194680.
20. Sandelowski M. What's in a name? Qualitative description revisited. Res Nurs Health. 2010;33(1):77–84. doi:10.1002/nur.20362.
21. Willis DG, Sullivan-Bolyai S, Knafl K, Cohen MZ. Distinguishing features and similarities between descriptive phenomenological and qualitative description research. West J Nurs Res. 2016;38(9):1185–204. doi:10.1177/0193945916645499.
22. Braun V, Clarke V. Reflecting on reflexive thematic analysis. Qual Res Sport Exerc Health. 2019;11(4):589–97. doi:10.1080/2159676X.2019.1628806.
23. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (coreq): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–57. doi:10.1093/intqhc/mzm042.
24. Rosenbaum PL, Palisano RJ, Bartlett DJ, Galuppi BE, Russell DJ. Development of the gross motor function classification system for cerebral palsy. Dev Med Child Neurol. 2008;50(4):249–53. doi:10.1111/j.1469-8749.2008.02045.x.
25. Eliasson AC, Krumlinde-Sundholm L, Rösblad B, Beckung E, Arner M, Öhrvall AM, Rosenbaum P. The manual ability classification system (macs) for children with cerebral palsy: scale development and evidence of validity and reliability. Dev Med Child Neurol. 2006;48(7):549–54. doi:10.1017/S0012162206001162.
26. Pennington L, Virella D, Mjoen T, Andrada MD, Murray J, Colver A, Himmelmann K, Rackauskaite G, Greitane A, Prasauskiene A. et al. Development of the Viking speech scale to classify the speech of children with cerebral palsy. Res Dev Disabil. 2013;34(10):3202–10. doi:10.1016/j.ridd.2013.06.035.
27. Barty E, Caynes K, Johnston LM. Development and reliability of the functional communication classification system for children with cerebral palsy. Dev Med Child Neurol. 2016;58(10):1036–41. doi:10.1111/dmcn.13124.
28. Caynes K, Rose TA, Burmester D, Ware RS, Johnston LM. Reproducibility and validity of the functional communication classification system for young children with cerebral palsy. Dev Med Child Neurol. 2021;63(7):866–73. doi:10.1111/dmcn.14844.
29. Scope's accessible information service: What is easy english. 2015. Scope; [accessed]. https://shop.scopeaust.org.au/wp-content/uploads/2015/01/what-is-easy-english.pdf.
30. Arvidsson P, Dada S, Granlund M, Imms C, Bornman J, Elliott C, Huus K. Content validity and usefulness of picture my participation for measuring participation in children with and without intellectual disability in South Africa and sweden. Scand J Occup Ther. 2020;27(5):336–48. doi:10.1080/11038128.2019.1645878.
31. Jonson R. Picture communication symbols. Solana Beach: Mayer-Johnson, Inc; 1985.
32. Andrews C, Namaganda LH, Imms C, Eliasson A-C, Asige E, Wanjala G, Kakooza-Mwesige A, Forssberg H. Participation of children and young people with cerebral palsy in activities of daily living in rural uganda. Dev Med Child Neurol. 2023;65(2):274–84. doi:10.1111/dmcn.15323.
33. Buchwald D, Schantz-Laursen B, Delmar C. Video diary data collection in research with children: an alternative method. Int J Qual Methods. 2009;8(1):12–20. doi:10.1177/160940690900800102.
34. Noyes A. Video diary: a method for exploring learning dispositions. Camb J Educ. 2004;34(2):193–209. doi:10.1080/03057640410001700561.
35. Sellwood D, Raghavendra P, Walker R. Facilitators and barriers to developing romantic and sexual relationships: lived experiences of people with complex communication needs. Augment Altern Commun. 2022;38(1):1–14. doi:10.1080/07434618.2022.2046852.
36. Braun V, Clarke V. What can "thematic analysis" offer health and wellbeing researchers? Int J Qual Stud Health Well-Being. 2014;9(1):26152–26152. doi:10.3402/qhw.v9.26152.
37. Lyons R, McAllister L. Qualitative research in communication disorders: an introduction for students and clinicians. Guildford: J&R Press Ltd; 2019.
38. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101. doi:10.1191/1478088706qp063oa.
39. Reddihough DS, Meehan E, Stott NS, Delacy MJ. Australian Cerebral Palsy Register Group. The national disability insurance scheme: a time for real change in australia. Dev Med Child Neurol. 2016;58(S2):66–70. doi:10.1111/dmcn.13007.
40. Cussen A, Howie L, Imms C. Looking to the future: adolescents with cerebral palsy talk about their aspirations - a narrative study. Disabil Rehabil. 2012;34(24):2103–10. doi:10.3109/09638288.2012.672540.
41. Whitney DG, Peterson MD, Warschausky SA. Mental health disorders, participation, and bullying in children with cerebral palsy. Dev Med Child Neurol. 2019;61(8):937–42. doi:10.1111/dmcn.14175.
42. Honan I, Waight E, Bratel J, Given F, Badawi N, McIntyre S, Smithers-Sheedy H. Emotion regulation is associated with anxiety, depression and stress in adults with cerebral palsy. J Clin Med. 2023;12(7):2527. doi:10.3390/jcm12072527.
43. Eriksson E, Hägglund G, Alriksson-Schmidt AI. Pain in children and adolescents with cerebral palsy - a cross-sectional register study of 3545 individuals. BMC Neurol. 2020;20(1):15. doi:10.1186/s12883-019-1597-7.
44. McKinnon CT, Meehan EM, Harvey AR, Antolovich GC, Morgan PE. Prevalence and characteristics of pain in children and young adults with cerebral palsy: a systematic review. Dev Med Child Neurol. 2019;61(3):305–14. doi:10.1111/dmcn.14111.
45. Ostojic K, Sharp NL, Paget SP, Morrow AM. Lived experiences of pain in children and young people with cerebral palsy. Dev Med Child Neurol. 2022;64(3):364–71. doi:10.1111/dmcn.15061.
46. Judd MJ, Dorozenko KP, Breen LJ. Workplace stress, burnout and coping: a qualitative study of the experiences of Australian disability support workers. Health Soc Care Community. 2017;25(3):1109–17. doi:10.1111/hsc.12409.
47. Fowler JH, Christakis NA. Dynamic spread of happiness in a large social network: longitudinal analysis over 20 years in the Framingham heart study. BMJ. 2008;337(7685):23–26. doi:10.1136/bmj.a2338.