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Families' perspectives of transitioning young adults with cerebral palsy to independent living

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ABSTRACT

Purpose: Adolescents and Young Adults (AYAs) with cerebral palsy (CP) face health and social inequities when transitioning to independent living. This study aimed to 1) understand the meaning of the transition to independent living for family members, and 2) identify barriers and enablers within family, community and service systems that may impact on this transition.

Materials and methods: Exploratory research design. Family members of AYAs with CP were surveyed through two health services. Responses were analysed using reflexive thematic and inductive content analysis and descriptive statistics.

Results: Thirty-two family members of 31 AYAs with CP took part in the study. Four themes were identified in relation to the meaning of the transition to independent living: 1) the opportunity for AYAs to experience adult life, 2) freedom for all parties, 3) uncertainty and worry about safely transferring care, and 4) future planning for ageing family members. Six themes related to barriers and enablers were [1]: AYAs health and wellbeing [2]; proximity to the AYA [3]; navigating complex service systems [4] timely access to funding and equipment [5], finding suitable accommodation and [6] confidence in care quality.

Conclusions: Findings provide insights for health and disability services supporting AYAs and families transitioning to independent living.

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Family; parents; young people; adolescents; disability; cerebral palsy; transition; independence; independent living

> IMPLICATIONS FOR REHABILITATION

- Understanding family members' perspectives on the meaning of the transition to independent living for young people living with cerebral palsy is needed to support the transition process.
- Although transition is desired, family members' experience of being overwhelmed by the structural inequalities that impede their young person's transition, needs to be addressed.
- Health professionals require a dual focus approach: simultaneously supporting a young person's independence goals, whilst incrementally building the skills and confidence of families to address their needs and concerns throughout the transition process.
- Health professionals should develop and maintain a thorough understanding of structural barriers and systemic challenges affecting independent living, enabling them to effectively guide families through the complex transition process with informed, tailored support.

Introduction

Cerebral palsy (CP) is a heterogeneous condition that may result in diverse levels of impairment and varied combinations of physical, communication, vision, or hearing difficulties, along with other health issues [1,2] often requiring additional support and care. As they get older, adolescents and young adults

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(AYAs) with CP can experience a decline in health and functioning, increased pain, reduced quality-of-life, and poorer social outcomes compared to their peers [3–10]. As a result, AYAs with CP can experience significant social and health inequalities as they prepare for and transition to adulthood compared with their peers without CP [11]. These additional challenges at a crucial life stage can mean that AYAs with CP and their families require additional supports, and/or experience significant delays or disruptions to usual life-course transitions.

As with all young adults in high resourced countries, evidence highlights that AYAs begin to focus on a range of goals and activities that increase their independence [12]. One significant marker of this independence is the transition to independent living. Despite a willingness to engage with goals for increasing independence, AYAs with CP have reported that the transition from adolescence to adulthood can be challenging, with insufficient support for their adjustment and adaptation to the expectations of adult life from within their family, community and multisectoral systems of support [5,13–18].

Given these challenges, research has focused on topics related to independence versus dependence, independence and inclusion, and rights-based advocacy and self-advocacy [19–22]. Types of housing, living arrangements available, the skills needed to live independently, and the challenges and benefits each of these factors pose to accessing appropriate housing in adulthood, have also been examined [23–28]. When exploring living conditions and social outcomes for adults living with CP, the importance of access to personal assistance and support across the lifespan to achieve successful independent living outcomes has been highlighted [29,30]. Research has also explored the role of independent living in strengthening a AYA with disability's social connections and relationships, increasing their capability to engage in informed decision-making, and in providing greater opportunities for choice and autonomy [5,26,31].

Using the life course perspective [32–34], the interdependence of an AYA with disability and their family shapes the transition to independent living outcomes. The factors that influence these outcomes include family support and resources [35,36], family adaptiveness to social changes, and family expectations of independence markers (e.g. education, employment) [35–37]. Broad social changes related to shifting policy may affect how and when families and young people living with disability engage with the transition to and remain living independently. In addition, the family's interface with, and adaptiveness to, structural opportunities required for independence can promote or limit choice for the young person [31,34,38]. While some of this existing evidence helps clinicians to understand the young person in their context, there is no research that explores the family processes related to the transition to independent living of their AYA, and what it means for families when preparing for and contemplating this important marker in a young person's life.

There is emerging evidence about the role of family processes in the context of the transition for AYAs from paediatric to adult healthcare [39–45]. As a result, there is increasing recognition that more needs to be done in understanding family processes [46] as part of a holistic healthcare approach for people with disability [47–50]. Despite this emerging research evidence and the likelihood that AYAs and their families may be considering a transition to independent living around the same time as the transition in healthcare, there is currently little research to inform health services or provide advice about the role health professionals can play, to support a young person with disability and their family preparing or undertaking the transition to independent living.

The primary aim of this study, therefore, was to explore the family processes by which AYAs with CP (aged 15–30years) and family members prepare for the transition to independent living. The secondary aim was to understand AYA and family members' perceptions of the barriers and enablers within families, communities and service systems that impacted this transition process. This paper reports family members' perspectives.

Material and methods

Study design

The overall study used an exploratory, sequential mixed-methods research design using survey methods followed by interviews, guided by what was learned in the survey responses. This paper reports on Stage

1 of the study which focused on family members' perspectives on the transition to independent living gathered through surveys.

Ethical approval was received from The Royal Children's Hospital Human Research Ethics Committee (Research Governance) (HREC/89714/RCHM-2022) and St Vincent's Hospital Human Research Ethics Committee (SSA ERM/89714).

Procedure

Participants

Eligible participants were adult (18+ years) family members of AYA aged 15–30 years diagnosed with CP and receiving treatment from the Transition Support Service (TSS) at a tertiary care paediatric hospital and/or at the Young Adult Complex Disability Service (YACDS), a complex disability clinic for young adults in Melbourne, Australia. The TSS assists young people with chronic medical conditions and/or disabilities and their parents/carers to transition to adult care. The TSS partners with adult services such as the YACDS clinic to transition healthcare of AYA with CP. The YACDS clinic provides a multi-disciplinary, statewide service for young people aged 18–40 years with complex disabilities, predominantly CP. Site investigators also conferred, if needed, with health clinicians to confirm the eligibility.

Participants were ineligible if there were known pre-existing risk issues such as significant family conflict, family violence, and housing insecurity that may be exacerbated by participating in this study. Family members who needed an interpreter were also ineligible due to a lack of funding to support their participation.

Recruitment

Family members were recruited between May 2023 and September 2023 from the two health services. The two site investigators (EC & VS) screened patient records *via* their clinical and electronic medical record databases. As some AYAs were attending both clinics, site investigators determined who would approach eligible participants about the study to avoid duplication. Following screening, a list of eligible participants and their email contact details was collated at each site (TSS $n=61$; YACDS $n=128$), and emails were sent to eligible participants with study information and a link to the online survey with embedded participant information and consent details. An initial email in May 2023, followed by three rounds of reminder emails (June – September 2023) were sent to family members to invite participation. In addition to email invitations, a printed study information flyer with a QR link to the survey was handed out by the site investigators and health clinicians to eligible participants at both clinics.

Family Member Survey development

The 'Transition to Independent Living – Family Member Survey' was developed for this study by the research team in consultation with consumer advisors. The purpose was to understand and explore 1) family member perspectives and meaning regarding their AYA's transition to independent living, and 2) family member perspectives on the barriers and enablers within families, communities and service systems that may impact this transition process.

Consumer Consultation. As this was an exploratory study, the research team consulted with three Consumer Advisory Groups from the Australian Centre for Health, Independence, Economic participation and Value Enhanced care for AYA with CP (CP-ACHIEVE): 1) Parent Advisory Group comprising ten parents and family members of young people with CP, 2) CP Unite Advisory Group comprising seven young adults aged 18–30 years with CP, and 3) CP Voice Advisory Group comprising six adolescents and young people aged 10–15 years with CP. The consumer consultations involved developing 'working definitions' for independence and independent living that resonated with young people living with CP and their families in an Australian context. The statements (see [Figures 1](#) and [2](#)) were crafted as a result of the consultations.

All content contained in the survey, including the common factors identified as important for an AYA's transition to independent living, were developed in consultation with the three advisory groups. Once developed, consumers tested the survey for accessibility of language and use of the online survey tool.

What is independence?

Independence means something different for each person. Independence could mean being involved in making your own decisions or being supported to have some independence, doing things you want to do so that you can reach your potential and live the way you choose. For example, making your own decisions about how you spend your time, what you do, where you go, who you see, weighing up options, taking positive risks, getting around in your community, taking responsibility, learning, and having new experiences of your choosing. Family members may have different views about independence to young people.

Figure 1. Definition for ‘What is independence?’.
Definition developed by the Research Team and CP-Achieve Advisory Groups.

What is independent living?

There are many ways to live independently in adulthood that can be different to the way you live as a child. You might be living (or aim to live) alone, with the support of paid workers or family members, or sharing your accommodation with other people. For example, this could include living in supported accommodation or living with family members in the same accommodation with choices and control in your everyday life. You could be living by yourself or with housemates. You may have services to support you, if needed.

Figure 2. Definition of ‘What is independent living?’
Definition developed by the Research Team and CP-Achieve Advisory Groups.

Family Member Survey. The Family Member survey comprised questions seeking demographic information for themselves and the AYA in their family including age, gender, country of birth, preferred language, Aboriginal or Torres Strait Islander identity status, and educational attainment. Family members were also asked to report on clinical descriptors of the AYA’s CP, according to the Gross Motor Function Classification System (GMFCS). The GMFCS is a five-level classification of gross motor function of people with cerebral palsy based on their self-initiated movements including sitting, walking and wheeled mobility [1]. Family members were also asked to provide other diagnoses, education, employment, and current and potential future living situation.

There were closed- and open-ended questions about independent living. For example, open-ended questions related to perspectives on the meaning of independent living and closed- and open-ended related to factors within their family, community and services system, that they thought were relevant to the AYA’s transition to independent living. This article reports on the findings about the meaning for families of the transition to independent living, and the barriers and enablers of the transition to independent living.

Data collection

The survey was delivered once using the online REDCap data electronic data capture tool hosted by the University of Melbourne, which was only accessible to the Principal Investigator (LCH). To ensure confidentiality, the site investigators did not receive any information regarding family members who decided to participate or not. Family members completed the survey at one timepoint only.

Data analysis

Family member and AYA demographic data, AYA characteristics (quantitative data) were summarised descriptively. Any missing data are indicated in results by reporting the sample size in responses.

Open-ended question responses (qualitative data) regarding the meaning of independent living were analysed using reflexive thematic analysis [51–53]. Data analysis drew on Braun and Clarke's six phase inductive approach to suit the nature of the enquiry and included 1) familiarisation with the data, 2) generating initial codes, 3) searching for themes, 4) reviewing the themes, 5) defining and naming themes, and 6) producing the report of the themes from the data. Two researchers (LCH & LKH) undertook phases 1–3 and all members of the research team discussed and reached consensus on the themes which described patterns in the data relevant to family members perspectives of the AYA's transition to independent living.

Factors reported as barriers or enablers for the AYA in their family to transition to independent living were analysed using Inductive Content Analysis (ICA) [54,55], using the following steps: 1) familiarisation with the data, 2) first-round coding – identifying big-picture meaning units, 3) second round coding – developing subcategories and fine-grained codes, 4) refining the fine-grained subcategories, and 5) synthesis and interpretation [55]. ICA was chosen to provide meaningful knowledge around the topic of the transition to independent living.

Results

Demographics of respondents

Of the 189 eligible patient families involved with the two services, 44 family members accessed the survey link, 41 family members provided consent and 32 (16.9% of those eligible) completed the survey. Most family members identified as parents (96.9%), and female (84.4%). The mean age of the family members was 55.26 years (SD 6.32 years) and 78% were born in Australia. All family members spoke English in their home environment (see Table 1).

Characteristics of AYA with CP in family

Most of AYA with CP were male (71.9%), with a mean age of 20 years (age range 15.7–28.9 years) and born in Australia (93.8%). Nearly two thirds (62.5%) of the young people in this sample were reported to be within GMFCS level IV or V, reflecting higher care needs. AYA engagement with health care services (40.6%) and paid carer support (38.7%) were common. AYA co-morbidities were reported to include epilepsy (64.3%) and intellectual disability (60.7%). Two AYAs had transitioned to independent living, 12 were contemplating transition and 17 had not yet considered it. AYA characteristics are displayed in Table 2.

The meaning of the transition to independent living

Analysis of qualitative data from 28 participants resulted in four major themes about the meaning of independent living. Two themes focused on desired positive outcomes, and two more strongly related

Table 1. Family member demographics.

Consent, n	41
Survey responses, n (range of responses, n)	32 (27–32)
Relationship to AYA n, % (32 responses)	
Parent	31 (96.9)
Paternal Aunt (guardian and administrator)	1 (3.1)
Gender of family member (32 responses)	
Woman or Female	27 (84.4)
Man or Male	5 (15.6)
Non-binary, I use another term, prefer not to say	
Age n, years (M, SD) (30 responses)	55.26 (6.32)
Country of birth of family member, n, (%) (32 responses)	
Australia	25 (78.1)
United States	4 (12.5)
Cambodia	1 (3.1)
New Zealand	1 (3.1)
United Kingdom	1 (3.1)
Main language spoken at home, n, (%) (26 Responses)	
English	26 (100)

Table 2. AYA demographics and characteristics.

Age Mean, SD, Range (31 responses) n, SD (%), range	20.02 (2.74) Age Range (15.7–28.9 yrs.)
Gender (32 responses*), n, (%)	
Male	23 (71.9)
Female	9 (28.1)
Non-binary, I use another term, prefer not to say	–
Country of birth, n, % (32 responses*)	
Australia	30 (93.8)
United States	2 (6.3)
GMFCS level (32 responses*), n, (%)	
Level I	3 (10.7)
Level II	3 (10.7)
Level III	3 (10.7)
Level IV	6 (18.75)
Level V	14 (43.8)
Not known	3 (10.7)
Other diagnosis (responses $n=28$), n, (%)	
Epilepsy	18 (64.3)
Intellectual disability	17 (60.7)
Gastrostomy feeds	12 (42.9)
Gastro-esophageal reflux	11 (39.3)
ASD	3 (10.7)
ABI	3 (10.7)
Dystonia	2 (7.1)
Diabetes	2 (7.1)
Recurrent chest infections	1 (3.6)
Anxiety	1 (3.6)
Hearing impairment	1 (3.6)
Scoliosis	1 (3.6)
Highest education level of AYA (responses $n=31$) n, (%)	
Year 12 or equivalent	14 (45.2)
Unsure	4 (12.9)
Year 11 or equivalent	3 (9.7)
Other registered training programs	3 (9.7)
Completed primary school but less than year 10 equivalent	2 (6.5)
Completed primary or less or equivalent	2 (6.5)
College/University	2 (6.5)
Did not do any school	1 (3.2)
Employment status (responses $n=31$) n, (%)	
Neither working nor looking for work	19 (61.2)
Studying full-time	4 (12.9)
In paid casual work	2 (6.4)
In paid full-time work	1 (3.2)
In paid part-time work	1 (3.2)
Unemployed and looking for casual work	1 (3.2)
Unemployed and looking for part-time work	1 (3.2)
Studying part-time	1 (3.2)
In unpaid (volunteer) full time work	1 (3.2)
Who does AYA live with? (32 responses*) n (%)	
Parents	31 (96.9)
Siblings	11 (34.4)
Step-parent	1 (3.1)
Carer	1 (3.1)
Paternal aunt and husband	1 (3.1)
What type of housing/living situation does the AYA live in now? (29 responses) n, (%)	
Private residence (privately owned/purchased)	24 (82.2)
Private residence (rental)	2 (6.9)
Supported disability accommodation/shared	2 (6.9)
Between two houses with family members	1 (3.4)
What type of housing/living would you consider appropriate for the AYA with CP in the future? (31 responses) n, (%)	
Private residence (privately owned/purchased)	22 (71.0)
Group home	14 (45.2)
Private residence (rental)	9 (30.0)
Share house	8 (25.8)
Housing co-operative	4 (12.9)
Not sure	4 (12.9)
Social housing (public and community housing)	3 (9.7)
Supported large residential accommodation (e.g. hostel, nursing home)	3 (9.7)
University residence	2 (6.5)
Supported disability accommodation/shared care	1 (3.3)
Other not specified	1 (3.3)
What service support systems does the AYA interact with? (32 responses*) n, (%)	
National Disability Insurance Scheme (NDIS)	32 (100)
Centrelink – Disability Support Pension (Income Support)	20 (62.5)

(Continued)

Table 2. Continued.

Rental Assistance	1 (3.1)
Healthcare	13 (40.6)
Paid carer support	12 (38.7)
Transport	10 (31.3)
Education	9 (28.1)
Bank	6 (18.8)
Specialist disability accommodation	4 (12.5)
Day program	3 (9.6)
Community Services (services that provide information, advice, practical help)	2 (6.3)
Employer organisations	2 (6.3)
Volunteer organisations	2 (6.3)
State Trustees (Guardianship and Administration)	1 (3.1)
Other – AYA not able to interact with services	1 (3.1)
Transition to independent living (32 responses*) n, (%)	
The AYA in my family has not considered a transition to independent living	17 (53.1)
The AYA in my family is considering a transition to independent living	12 (37.5)
The AYA in my family has transitioned	3** (9.4)

*32 family member responses relate to 31 AYA. ** 3 family member responses relate to 2 AYA.

to the fears and uncertainty experienced by family members as they considered transition. The themes were 1) the opportunity for AYA to experience adult life, 2) freedom for all parties, 3) uncertainty and worry about safely transferring care, and 4) future planning for ageing family members.

Theme 1a: Opportunity for AYA to experience adult life. Family members viewed the transition to independent living for the AYA as a positive step towards adult life, providing opportunity to live safely away from home with people they like spending time with, and to experience life and make independent decisions. Further independence and personal growth of the AYA were also attributed to the meaning of the transition to independent living.

Living out of home of the parents, with other people her age, in a shared environment with 1:1 support, accessing the community at her leisure, enabling friendships and decision making. AYA GMFCS IV and not yet considered TIL

For family members whose AYAs were not living independently, the opportunity to be part of the broader community and to connect socially beyond the immediate family were identified as a likely prompt for this transition.

Theme 1b: Freedom for all parties. Family members described benefits for the whole family related to the AYA's transition to independent living. The AYA living independently of family created changes that opened options for everyone, freeing up all parties to change roles and responsibilities within the family. In particular, the shift towards freedom was represented in the changing relational aspects of the parent and young person.

It meant for me that I could finally be just his father...a lovely experience. The personality change in [AYA] within a few months - [AYA] was the boss - and [AYA] ran the team - I could just be [AYA's] dad, and we still spent time together...Time and not as tired - so other family members could have time together - freedom and independence for us as well. AYA GMFCS V and has TIL

Family members whose AYA was still contemplating the move were starting to recognise the potential benefits for all members of the family.

Freedom for all parties. Still nurtured well...Lovingly cared for...flexible between independent living and home. AYA GMFCS V and not yet considered TIL

Less worry reduces workload for others [in family], makes everyone happier, including young adult. AYA GMFCS not reported and has TIL

Knowing our daughter will be able to expect a normal level of freedom in her life without having to care for her [sibling]. AYA GMFCS V is considering TIL

Theme 1c: Uncertainty and worry about safely transferring care. The transition to independent living meant a degree of uncertainty and worry for family members in this study. Several parents described the prospect of independent living for the AYA with CP in their family as a ‘challenging decision to face’ and/or ‘not possible.’ Other parents experienced the young person’s transition to independent living as raising feelings of ‘insecurity’ and ‘uncertainty’. Safely transferring care of the AYA to others was a key consideration for family members and one that could not easily be assured:

To have cared for [AYA] for 25 years mainly on my own. To have [AYA] set up somewhere he is safe, happy, and cared for would be a huge weight off my shoulder [but] now that I have seen [what] a lot of the [supported accommodation] providers are like I’m afraid for [AYA] for when I am not around. AYA GMFCS V, has TIL

This would provide us with reassurance and confidence that when we are no longer able to care for our AYA that he would be well cared for in a safe and happy environment. AYA GMFCS not reported and not yet considered TIL

Theme 1d: Future planning for ageing family members. For some family members, the meaning of independent living was focused on the future. For ageing family members, including the AYA, it meant that they needed to plan for when the living and care arrangements for the young person needed to change. Declining health in ageing parents was viewed as a trigger for planning to change the AYA’s living arrangements. Transition planning for older families was reliant on appropriate care, support and a living situation that suited the AYA’s needs. Some family members were more optimistic and confident than others that this transition could be a safe and positive experience.

Knowing [AYA] will be safe into the future without [AYA’s] parents being his carers... Knowing [AYA] won’t be left in a catastrophic situation if we die or our health declines. AYA GMFCS V is considering TIL

Family members’ perceived barriers and enablers to AYA transition to independent living

Ten family members provided qualitative descriptions of the perceived barriers (10 responses) and enablers (9 responses) to the AYA’s transition to independent living, synthesised into six themes (Table 3).

Theme 2a: Health and wellbeing of the AYA. Family members were concerned about the health and wellbeing of the AYA in a transitional living arrangement. If the transition did not go to plan, this could negatively impact the AYA’s health and wellbeing. Family members expressed their ‘worry and concerns’ about the risk to the AYA’s health if the level of care provided was not akin to what was provided within the family. Family members also identified the community’s attitudes towards disability, with concerns for the AYA’s safety and inclusion in their community when attitudes were negative. AYAs need opportunities and options to practice their independence skills in appropriate settings outside the family, with respite care and day programs viewed as appropriate and viable options considered. Having ‘people who know the AYA’ and ‘places to go’ would also enable the transition process.

Theme 2b: The ability to live close to the AYA to support, monitor and visit regularly. Finding a location that met this criterion as well as the AYAs’ other support needs could be challenging. Family members want to remain highly involved with the AYA, providing support to ensure their independence was maintained. They saw this as a necessary monitoring role, that was largely dependent on the families’ resources (time and energy).

Having [accommodation] suitable and available closer to where family members live to be able to assist them when needed. AYA GMFCS IV has not yet considered TIL

Family members described their own ‘resistance to change’ and that they found it challenging to trust that the AYA would be able to manage independent living. To overcome these concerns, family members reported that preparing for change was important for both the AYA and family members, as was having an expectation that increased independence could be achieved.

Theme 2c: Navigating complex service systems, information and knowledge. Navigating complex service

Table 3. Inductive content analysis – barriers and enablers to AYA transition to independent living.

Categories	Sub-categories: Barriers (Responses $n=10$)	Sub-categories: Enablers (Responses $n=9$)
a. Health and wellbeing of the AYA	<ul style="list-style-type: none"> Limited opportunities to practice independence. Individual needs vary and are not always considered. AYAs 'anxiety' will increase if transition does not go to plan. Risk to AYAs decline in health and safety. Negative community attitudes towards disability. 	<ul style="list-style-type: none"> Opportunities to practice independence in respite care and day programs. Having people who know AYA, places to visit and things to do. Changing community attitudes towards disability that are positive and inclusive of AYA
b. The ability to live close to the AYA to support, monitor and visit regularly.	<ul style="list-style-type: none"> Family members resistant to change. Challenging to trust that AYA will be safe. Family needs to live close to AYA to provide aid and support.. Parents need to be highly involved and monitoring the AYAs independence. Onus of responsibility on the family to manage transition for AYA. 	<ul style="list-style-type: none"> Preparing the AYA and family for increased independence Family live close to AYA to visit on a regular basis. Family that has the resources (time and energy) to remain connected and support AYA. Ability to navigate systems and research options that may be available to AYA. Family that can advocate effectively. Having sufficient financial resources that can supplement funding that is made available to AYA
c. Navigating complex service systems, information and knowledge	<ul style="list-style-type: none"> Lack of access to transport options that are appropriate and affordable for AYA. Lack of access to information about disability accommodation. Difficulty in accessing education and employment. Long distances to services such as supermarket, shops and health care services. 	<ul style="list-style-type: none"> Access to transport. Having knowledge of the service system. Access to study and employment opportunities. Access to buildings and services. Health services that go 'above and beyond' to support AYAs independence
d. Timely access to funding and equipment	<ul style="list-style-type: none"> Complex application process delays access to equipment needed for AYA's independence. Insufficient funding for specialist care workforce. 	<ul style="list-style-type: none"> Knowing how to apply and access funding. Sufficient funding to meet AYAs needs.
e. Identifying accommodation to suit the AYA's needs and wants for their adult life	<ul style="list-style-type: none"> Lack of trust in services that claim to be competent in managing complex care. Lack of accommodation options for AYA with high and complex needs 	<ul style="list-style-type: none"> Accommodation that matches AYAs level of independence. Accommodation that provides a safe and comfortable home for AYA and workplace for carers.
f. Confidence about the quality of care	<ul style="list-style-type: none"> Lack of confidence in the level of care the AYA will receive. Lack of adequate training and inadequate remuneration and retention support care workforce Lack of day programs that can support AYA with complex care needs. Lack of respite services and carers that support AYA socialisation. 	<ul style="list-style-type: none"> Confidence in the level of care matching AYA need Active involvement in the training of carers pportunities to take part in day programs

systems, information and knowledge to undertake the transition process influenced family members' views about the transition process. Information about disability accommodation is a necessity but not readily available to them or their AYA.

Family researching options, training staff in our [AYAs name] care requirements, applying for funding, being able to visit. AYA GMFCS V, is considering TIL

The living situation of the AYA needed to be close to accessible services, buildings and transport. Opportunities to access study and employment opportunities were also important. When this can be achieved, it is easier for an AYA to live independently in their community.

Theme 2d: Timely access to funding and equipment. To facilitate a transition to independent living, AYAs need timely access to funding and equipment. However, this frequently involved complex application processes, causing delays in receiving the funding or equipment needed to support the AYA's move towards independence and independent living. Family members reported that possessing the 'know-how'

to access funds would enable AYAs to be better prepared for their transition to independent living.

We're in the early stages of seeking additional funding to move to 24:7 formal supports at home. Time will tell whether this is approved. AYA GMFCS V, considering TIL

Funding was also identified as influencing the transition to independent living, with insufficient funding for AYAs requiring a specialist carer workforce being a challenge, and sufficient funding for AYAs' needs being an opportunity. Even when funding was available to AYA, family members reported they needed to supplement the funding to ensure successful independent living.

Theme 2e: Identifying accommodation to suit the AYA's needs and wants for their adult life. Identifying suitable accommodation was perceived as crucial to their transition to independent living. Family members reported the lack of accommodation options available for the AYA, particularly those with complex care needs, posing a barrier to their transition to independent living.

Finding a home with other participants who have similar interests. This home would have 24hr care support. It would enable our AYA to have choices in their day-to-day care. AYA GMFCS not reported, has TIL

Matching the accommodation to the AYA's level of independence would be an enabler for their transition to independent living, as would ensuring that the accommodation is a safe and comfortable home for the young person and a safe and comfortable workplace for the carer workforce.

Theme 2f: Confidence about the quality of care. Family members need to feel confident about the quality of care that their AYA would receive in their living situation. Family members reported lacking confidence in the level of care a young person would receive in an alternative setting to the family home. This lack of confidence was connected to a lack of trust in supported accommodation services that claimed to be competent in managing AYAs with complex care needs.

In today's current environment too many providers claim to be capable of servicing all types of disability. This results in families embarking on care arrangements in good faith only to discover that the provider is not adequate to the challenge after valuable time and tolerance has lapsed. If we handle this transition badly our AYA's anxiety levels may elevate to a level where the transition becomes unlikely/impossible. Transparent certification of services might allow families to select appropriate services the first time. AYA GMFCS V, considering TIL

Confidence in the care provided was greater when family members perceived care providers were suitably trained and appropriately remunerated.

Better qualified support workers to handle complex disabilities and ability to pay more to them for working at this level. AYA GMFCS V, considering TIL

When this was lacking, family members reported it resulted in poor retention of quality carers for the AYA. To alleviate their concerns about training, family members expressed a preference for being actively involved in the training program of their AYA's carer workforce. In addition to requiring confidence in a support care workforce, family members indicated that their AYA needs opportunities to take part in day programs, as well as access to respite and care services with qualified staff to support the socialisation of the AYA in settings other than their home. Typically, these opportunities were reported to be limited.

Discussion

This exploratory study provided important insights into family members' perspectives on the transition to independent living for AYA living with CP and complex care needs. Overall, the meaning attributed to the transition to independent living by family members in this study was positive – families reported TIL meant enabling greater independence, choice and opportunity for the young person and their family. However, the perspectives shared by family members also reflected that they felt overwhelmed and

uncertain about how to support the AYA to make this transition. The participants of this study weighed up a range of factors when contemplating their AYA transition to independent living, influenced by their meaning-making processes. Many of these factors highlight the duality that exists within families, service systems and communities that negatively (when absent) or positively (when present) influence this important transition for the AYA in their family. This is consistent with the fact that most environmental or contextual factors can act as barriers or enablers depending on the circumstances [56,57]. The findings emphasise the importance of families in being able to support AYA to reach the independent living milestone and the many challenges that need to be addressed for the young person to achieve health and social equity with their non-CP peers.

The family members' perspectives shared in this study highlighted that successful transition of the young person to independent living was based on starting the process early, privileging the expert knowledge family members have about the young person and creating opportunities for the young person to practice their independence safely. In addition, successful outcomes depended on structural factors that address the inequity experienced by young people with CP wanting to transition to independent living, through the provision of appropriate, accountable and sustainable care and accommodation within safe and inclusive communities. Structural factors similar to those found in previous studies [31,34,38] suggest that these barriers will persist without systemic policy changes.

These findings build on the broader literature related to family perspectives on the transition to independent living informed by life course theory [32–34,38], highlighting the interdependence between the AYA and the family's meaning-making. Family members in this study described a connection between the AYA's readiness, preparedness and confidence, and their own assurance or belief as family members that it was possible to 'let go' to support the transition. It also highlights the need for AYA to have opportunities to practice independence and exercise autonomy as identified in previous studies [5,26,31]. In applying the life course lens, we can also identify broad social changes and shifting policy in the Australian context where this study was based, that have shaped family members' perceptions of the AYA and what will promote or hinder their transition to independent living. Highlighted were many structural inequalities for the AYA and their family who are considering this transition in relation to accessing information, funding and resources, appropriate accommodation and quality care. Families were often relied upon to make up the shortfalls arising from these structural inequalities if their AYA's transition was to succeed.

This study identified that preparation for independent living of families and the AYA with CP needs to start early in the adolescent years. The survey findings suggest that family members supported the notion of an AYA's transition to independent living as an important marker for adult life. However, they were overwhelmed by the complex array of considerations for the AYA and the family to take this step, and may benefit from external support [50]. In addition to the structural considerations outlined above, family members described their own emotional readiness and preparedness to support the AYA as they embarked on this transition. Families expressed their fears and worries associated with the uncertainty surrounding this transition and the assurance needed to move forward in supporting the AYA with this planning process. An important part of this assurance for families was assessing the AYA's emotional readiness and preparedness for change, knowing them to be confident and resilient to attempt a transition without the guarantee of success. While the families in this study focused on the AYA's readiness for the transition, family member readiness and preparedness also needs to be explored further considering previous research on parent anxiety and concerns surrounding health transitions [58,59]. These emotional and meaning-making processes are complex and nuanced for each AYA and family, highlighting the need for formal and informal support as they navigate their way through this transition process.

By starting the transition process early and proactively with opportunities to practice independence and independent living, AYAs and their families may be better prepared to make decisions that consider the many facets to the process [58,59]. By starting early there is also the potential to reduce the risk of making decisions at a time of crisis, such as an unexpected change in family circumstances. Ageing family members in this study recognised that their future capacity to provide direct care to the AYA was time limited and this awareness was likely to prompt the need to begin the transition process.

The topic of independent living for the AYA may be raised during a period of other key transitions in the young person's life, such as moving between healthcare services and/or education or employment.

There is considerable research about the transition between paediatric and adult health care and about education and employment for young people with disability that could inform the process of supporting AYAs and family members to undertake the transition to independent living [39–44]. Given the interactions between the AYA, and their families, and health, education and disability services during these key transitions from paediatric to adult settings, there is an opportunity for these services to play a role in supporting families to explore independent living plans for the young person's future.

This study engaged with family members reporting on the AYA in their family, a high proportion of whom had been assessed as GMFCS level V with complex care needs. The findings therefore may be indicative of family members who care for a young person with complex care needs and who therefore have significant concerns about how to support their safe transition to independent living. Many of these families perceived the transition to independent living process as ongoing, with expectations of shared responsibility for the safety and wellbeing of the young person throughout their adult life. The transition process is also complex to navigate and potentially challenging for family members to contemplate.

The findings expand on the 'working definitions' of independence and independent living developed by the research team in consultation with the consumer advisory groups. The perspectives of family members in this study resonate with these definitions as outcomes for independence and independent living. The findings also provide a rich description of how families may begin to undertake this process and the many factors that need to be considered to achieve the desired outcomes for the AYA and family. Our understanding of these definitions can be expanded with the integration of AYA perspectives on this important life transition.

Given the significant disability reforms that have taken place in Australia, in the form of the National Disability Insurance Scheme (NDIS) [60,61], the need for greater knowledge regarding the TIL is critical. The aim of the NDIS is to support people living with disability to have choice and control over their lives. A recent review of the NDIS [62], found that people with disability were continuing to experience health and social inequity and that the NDIS needed to be more inclusive of families given their key role in supporting those living with disability. Supported Independent Living (SIL) is NDIS funded support to assist people with disability to live as independently as possible. SIL is offered to people with high support needs, including daily and overnight care, if needed [63], and is one option available to AYAs with more complex care needs. Together, the significant disability reform, the recognition for more holistic healthcare and the limited research evidence to inform how best to support AYA and family processes when contemplating the transition to independent living make this study timely and relevant.

Limitations

This study has several limitations. There were relatively low participation rates from families across the two health services. We recognise that the lower age limit of the AYA was 15 years which may have been considered too young for some family members to consider the transition to independent living. We made this decision based on the research evidence for health care transitions that supports early discussions with AYA and families and in consultation with the CP-ACHIEVE CP-Voice consumer advisory group, comprised of young people with CP aged between 10–18 years. Another reason for the low participation may be due to the inclusion criteria based on English literacy to complete the survey.

While both health services are statewide, data related to the family's location (rural or metropolitan) was not collected. The location of the AYA and family may have shaped their perspectives on the transition to independent living, particularly in relation to the barriers and enablers to this process. More detailed AYA and family characteristics, particularly in relation to cultural or other intersecting identities, and inclusion of families involved with disability services, could have also enhanced our understanding of how family members perceive this transition process. We also note that consistent with other childhood-onset disability research, most participants were mothers. The perspectives of those in fathering roles, or that of siblings are important to this topic, but included in a very limited manner.

Family member reports of the AYA, their level of functioning according to the GMFCS and other diagnoses provided some indication of the young person's care needs. While there was representation across

all AYA groups in relation to levels of functioning, there was a higher proportion of AYA with more complex needs (functioning within GMFCS level V), making it difficult to extend these findings to families with AYA with less complex care needs. Only two of the AYAs had transitioned to independent living and this also limits our understanding of the transition process in its entirety.

Implications for practice

There are many sectors that have the potential to interact with children, adolescents and young adults with disability and their families that could play a role in supporting them through the transition to independent living process. These may include, but are not limited to, health, disability, housing, education, and employment sectors. One of the key messages from families in this study was that they wanted the AYA with disability in their family to experience and succeed in this important life transition and yet they felt overwhelmed and unsure about how to support them through this process. Their perception was that the onus of responsibility to make this transition rested solely with the family. The services and professionals within these multiple sectors could assist the AYA and families to explore, plan and identify support options and opportunities for independent living. Ideally, this service and professional support would draw on specific expertise within a sector but also connect to other sectors, given the multitude of structural considerations raised by families in this study. Connecting families to practice wisdom across sectors could provide a more integrated and holistic approach to supporting the AYA with CP's transition to independent living. Bringing about collective and shared responsibility with the AYA will be needed to achieve an independent living outcome that is meaningful for their adult life and creates opportunities for all family members.

Implications for research

Given the many challenges faced by AYA with CP to transition to independent living, it is important that we understand their perspectives and consider how the family, service system and professional sectors and communities can respond and support a transition to independent living and adult living that is meaningful to them.

This paper reports on the first stage of a mixed methods study. The findings from this first stage will inform the focus of the second stage which will use in-depth semi-structured interviews to learn more about the how family resources, family coping processes and family problem-solving abilities can be employed to support the transition to independent living. In addition, family members will also explore services which could support them, the types of support needed and for whom, when these services could provide support and to what extent the location of the AYA and family impacts on accessing services needed to support the transition. The study includes the voices and perspectives of AYA, centring their perspectives on the transition process and what independent living means to them.

Conclusion

This exploratory study has advanced our understanding of what independent living means for families raising AYA with CP within the Australian context where there have been significant disability and social policy changes that impact on young people with disability as they approach adulthood. The findings inform our understanding of the factors within families, service systems and communities that have the potential to positively or negatively impact this process. Further research is needed to understand AYAs' perspectives about this important transition and how health and disability services can meaningfully respond when the topic of independence and independent living is raised.

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Author contributions

CRedit: **L. Hickey**: Conceptualization, Formal analysis, Investigation, Methodology, Project administration, Supervision, Writing – original draft, Writing – review & editing; **L. Harms**: Conceptualization, Formal analysis, Methodology, Writing – review & editing; **E. Culnane**: Conceptualization, Investigation, Methodology, Writing – review & editing; **V. Saunders**: Conceptualization, Investigation, Methodology, Writing – review & editing; **C. Imms**: Conceptualization, Methodology, Writing – review & editing; **M. Ball**: Writing – review & editing; **D. Reddihough**: Conceptualization, Methodology, Writing – review & editing.

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