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Title:
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Date:
2021-10-01

Citation:
Gaskin, C. J., Imms, C., R. Dagley, G., Msall, M. E. & Reddihough, D. (2021). Successfully Negotiating Life Challenges: Learnings From Adults With Cerebral Palsy. Qualitative Health Research, 31 (12), pp.2176-2193. https://doi.org/10.1177/10497323211023449.

Persistent Link:
https://hdl.handle.net/11343/287010

SUCCESSFULLY NEGOTIATING LIFE CHALLENGES: LEARNINGS FROM ADULTS WITH CEREBRAL PALSY.

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Gaskin, C., J., Imms, C., Dagley, G., Msall, M.E., Reddihough, D. (2021). Successfully negotiating life challenges: Learnings from adults with cerebral palsy. *Qualitative Heath Research*, DOI: 10.1177/10497323211023449

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Key words

Cerebral palsy, adults, participation, qualitative

Abstract

Despite facing multidimensional inequalities, some adults with cerebral palsy achieve positive social outcomes (e.g., independent living, employment, and romantic relationships). We interviewed 23 adults (aged 23-47 years) about how they successfully negotiated the challenges of adulthood. Common to all life situations was *doing what others* (people without cerebral palsy) *do*. Origins of success lay in their *formative experiences* (e.g., typical parental expectations with commensurate support, and acceptance and supported involvement in school life). Their *present functioning* (e.g., positive self-concept, well-honed social skills, and physical fitness) combined with *present contexts* (e.g., expectations of involvement in adult activities, and accessible and accommodating environments) enabled them to find ways of negotiating challenges. *Finding a way* included drawing on knowledge and skills, gravitating towards those who are comfortable with difference, maintaining function, and using natural and paid supports. The findings suggest multiple avenues for supporting people with cerebral palsy to achieve positive social outcomes.

Introduction

Many people with cerebral palsy experience substantial difficulties with negotiating major challenges of adulthood, such as completing higher education, gaining employment, living independently from their parents, and attracting intimate partners (Frisch & Msall, 2013; Michelsen et al., 2006; Reddihough et al., 2013). With shifts in public policy towards protecting and promoting the human rights of people with disability and supporting their economic and social participation as equal citizens (Gaskin, 2015), there has never been a better time for adults with cerebral palsy to confront the multiple and systemic disadvantages they encounter. Through understanding how some adults with cerebral palsy find ways to negotiate the challenges of adulthood, we may be better placed to support others in making the most of opportunities available to them.

Cerebral palsy is a non-progressive, life-long neurological condition affecting movement and posture (Rosenbaum et al., 2007). Worldwide, one person in every 500 is diagnosed with cerebral palsy (Oskoui et al., 2013). In 2018 in Australia, an estimated 35,500 people had cerebral palsy, of whom 75% were aged 20 years or older (Deloitte Access Economics, 2020). The severity of cerebral palsy differs markedly between individuals, from being barely noticeable to experiencing no independent mobility, even with assistive technology (Palisano et al., 2008). Motor control difficulties commonly affect functional activities including walking (almost half of people with cerebral palsy cannot walk or need assistance to do so), handling objects (two-thirds experience challenges), and communicating (two-fifths have problems in this area) (Novak et al., 2012). Many people with cerebral palsy have additional challenges; for example, half have intellectual impairment, one in four have epilepsy, and the same proportion (one in four) may have a severe hearing impairment, visual impairment, and/or challenges impacting on anxiety, attention, and mood (Novak et al., 2012).

Focusing on the bodily manifestations of cerebral palsy only provides a narrow insight into the experience of this condition. As conceptualised in the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001), disability and functioning are not synonymous with the presence or absence of health conditions (diseases, disorders, and injuries), but are the outcomes of interactions among health conditions and contextual factors (environmental and personal) (World Health Organization, 2001). The ICF theoretical framework directs attention not only to body functions and structures, but also to the activities people are able to perform and their participation, defined as the extent of their involvement in life situations. The ICF framework can be usefully employed in the study of cerebral palsy (Andrade et al., 2012; Kembhavi et al., 2011) and is particularly valuable for understanding the dynamic interactions between people and their environments.

Although adults with cerebral palsy wish to engage fully with their communities (Yeung et al., 2008), they face participation restrictions in many typical adult activities (van Gorp et al., 2020), such as independent living (Alriksson-Schmidt et al., 2014; Donkervoort et al., 2007; Jacobson et al., 2019; Reddihough et al., 2013), education (Frisch & Msall, 2013; Michelsen et al., 2005; Reddihough et al., 2013), employment (Alriksson-Schmidt et al., 2014; Donkervoort et al., 2007; Michelsen et al., 2005; Reddihough et al., 2013; Verhoef et al., 2014), leisure activities (Boucher et al., 2010; Donkervoort et al., 2007) and interpersonal relationships (Reddihough et al., 2013; Wiegerink et al., 2011; Wiegerink et al., 2006). The findings from a large Australian study of young adults aged 20-30 years with cerebral palsy, for example, demonstrated that they experienced disadvantages in a range of social outcomes (Reddihough et al., 2013). A third of them (36%) had completed tertiary education compared with 53% of an age-matched sample of people without disability. Employment rates were much lower for the young adults with cerebral palsy (36% versus 80%). They were three times more likely to be living in their parents' homes (65% vs. 22%). By age 30, only 20% (versus 70%) of young adults with cerebral palsy had been married or partnered. Finally, nearly 80% of adults with cerebral palsy (versus 39%) had annual incomes of less than $20,000 Australian dollars.

Building on the consideration of people's involvement in life situations within the ICF, the outcomes of participation can be understood within to two domains: attendance (i.e., being in the same situations as others) and involvement (i.e., the experience of participating while attending, which might comprise elements of engagement in the activity, persistence, or social connection) (Imms et al., 2017). Research about adults with cerebral palsy has largely focused on the attendance aspect of participation; that is, the proportion who *attend*, for example, work or education programs (Alriksson-Schmidt et al., 2014; Donkervoort et al., 2007; Frisch & Msall, 2013; Reddihough et al., 2013; van Gorp et al., 2020; van Gorp et al., 2019). Factors that influence being able to attend a particular life situation include the availability, accessibility, and affordability (time, effort, cost) of the physical and social contexts (Maxwell et al., 2012). Less information is available about the involvement aspect of participation. Factors that influence this aspect of participation are more likely to be accommodations that are (or are not) made within specific contexts and the acceptability of those accommodations. Attendance is a necessary, but not sufficient, condition for involvement. Understanding both elements is important, because they likely offer different entry points for support or intervention.

Findings from interviews with adults who have cerebral palsy point strongly towards multidimensional inequalities as potential reasons for the differences in social participation outcomes, rather than the presence of cerebral palsy (Gaskin et al., 2009, 2010, 2011, 2012). Poor post-school educational attainment, for example, can be partially attributed to issues with access (e.g., not being able to physically access classes, and overt denial of educational opportunities) and accommodations (e.g., in assessment structure), rather than the potential of young adults with cerebral palsy. Equally, low rates of marriage and coupling can be attributed, in the most part, to the desexualisation of people with cerebral palsy (Dune, 2013). Just as these inequalities seem to produce participation restrictions, however, it is also the case that many adults with cerebral palsy manage to overcome such social disadvantages.

Demonstrating the potential of finding features of the lives of people with disabilities that promote success, researchers have identified six attributes/assets for adults with learning disabilities (self-awareness, proactivity, perseverance, appropriate goal setting, effective use of social support systems, and emotional stability/emotional coping strategies) (Goldberg et al., 2003; Raskind et al., 1999). These attributes explained substantial amounts of variance in outcomes (49-75%) for major life domains (e.g., employment, education, and independent living) (Raskind et al., 1999). Finding possible determinants of success in the lives of adults with cerebral palsy could inform initiatives to support individuals to reach their goals.

Living in an often inaccessible and unaccommodating society, then, makes life challenging for people with cerebral palsy. What is unclear, however, is how some people with cerebral palsy manage to navigate their worlds with a fair amount of success. In addition, it is unknown what supports have been useful (or would be useful) in assisting people with cerebral palsy to meet major life challenges. Learning from people with cerebral palsy about what has worked for them could help to build a strong evidence base that could be drawn upon to help others. Taking such an approach also assumes that the solutions to the challenges that people with cerebral palsy face lie within the knowledge and experiences of people with cerebral palsy themselves, rather than well-meaning others. Our main aim was to investigate how people with cerebral palsy have successfully negotiated major challenges of adulthood. We considered the major challenges of adulthood to comprise participation in adult life situations, which might include education, employment, living independently from parents, making and maintaining friendships and intimate relationships, family life, and obtaining quality health care. In doing so, we aimed to identify what factors may have contributed to successful outcomes and what supports were needed (or may have been useful) in achieving these outcomes. A secondary aim was to understand how stories of success differed from less favourable outcomes.

Methods

Our team comprised researchers with backgrounds in varied disciplines (psychology, occupational therapy, and developmental medicine), qualitative research expertise, and lived experience of cerebral palsy (an adult with cerebral palsy). In addition, we engaged with two adults with cerebral palsy as advisors to inform and shape the research design and assist with interpreting the results. We aimed to use our varied expertise and perspectives (Thorne, 2016) to support achieving a deep understanding of how success in varied life situations might be achieved, recognising that different patterns, and determinants, of success may be evident along with commonalities that could be usefully shared.

In this qualitative study, we used interpretative description methods to guide our approach (Thorne, 2016). Interpretative description assumes that knowledge is constructed though social interaction, experience, and context, with methods used to generate information that can be usefully applied. This perspective is based on the need to have enough contextual understanding to guide decisions about using the research findings.

Ethical approval was obtained from the University of Melbourne (ID: 1748721), and the study was registered at the Australian Catholic University (HREC: 2017-147R). Participants provided written informed consent to participate in the study. Given the (sometimes) sensitive nature of our enquiry, participants were provided with information about how to obtain psychological support if needed. All data were securely stored on password protected electronic platform that only the researchers could access.

Confidentiality of participants was supported through separation of identifying information from transcripts prior to analysis; unlinking key demographic information (e.g. sex) from the description of individual participants and quotes in the reporting of findings; and collapsing descriptive categories (i.e. age groups) that when combined with other information might serve to identify an individual (Morse & Coulehan, 2015).

Participant Recruitment

We conducted the research in Melbourne, Australia, and surrounding regions. Advertising about the study occurred through the Victorian Cerebral Palsy Register and relevant service providers. We sought participants who were (a) adults with cerebral palsy, (b) within two age ranges (18-30 years, 31-45 years), (c) from across the spectrum of gross motor functional impairment (levels I to V of the Gross Motor Function Classification System [GMFCS]) (Palisano et al., 2008), and (d) of the belief they could tell us about how they had successfully negotiated aspects of adult life. No exclusion criteria were applied, including in relation to difficulties with communication or intellectual functioning. We aimed to engage with individuals in each GMFCS level to obtain diversity of experience of cerebral palsy and its associated impairments in relation to our questions. We sought individuals across two broad age ranges as they could be seen to represent periods of the lifespan in which the life situations in focus can differ (e.g., those aged 18 to 30 years may be involved in moving out of home, gaining further education; those aged 31 to 45 years may be settled in employment and raising families).

Data Collection Methods

Data were collected using semi-structured interviews, conducted in locations convenient for the participants, and recorded digitally with participant permission. Interviews were chosen as the data collection method as it was anticipated that individual exploration of the questions would provide first-hand and detailed knowledge of our topic and allow flexibility in engagement with those with communication difficulties, a group who are frequently excluded from research (Lloyd et al., 2006). Three experienced interviewers conducted the interviews (CG, GD, and ED). One of the interviewers has cerebral palsy. At the beginning of each interview, the participant's age, gender, and GMFCS classification were confirmed. Researchers determined each participant's Communication Function Classification System (CFCS) level (Hidecker et al., 2011) following completion of the interviews as a way of describing communication ease.

The interview guide was developed based on (i) the major life areas as described in the ICF (World Health Organization, 2001); (ii) findings of prior research in the field of cerebral palsy that reported inequality of outcomes between those with and without cerebral palsy across varied life situations (Frisch & Msall, 2013; Reddihough et al., 2013; van Gorp et al., 2020); and (iii) the team's personal and professional experiences of the variation in strategies and positive experiences that adults with cerebral palsy might share. During the interviews, participants were asked about their participation in major areas of adult life (e.g., education, employment, independent living, friendships and intimate relationships, family, and access to healthcare). Participants provided guidance on which areas of life they were willing and able to discuss. Follow up questions and probes concentrated on establishing: (a) what challenges they faced (e.g., with obtaining employment), (b) how they successfully negotiated these challenges, (c) what contributed to their successful outcomes, (c) what supports were helpful in achieving these outcomes, and (d) what additional supports may have been helpful. During the interviews, we gathered information on each of the major areas of adult life. We anticipated that some participants would have encountered challenges that they had not managed to address (e.g., not being able to gain employment despite trying to do so). In such situations, we gathered information on the strategies that they had used. This information enabled us to compare the stories from those who had achieved particular outcomes with those of participants who had been unable to do so.

Interviews were conducted in participants’ homes, the university, and public spaces; two interviews occurred via videoconference technology. The interviews lasted between 29 and 157 minutes. Some interviews in participants’ homes occurred when others were at home (mostly parents but in other instances a spouse, an infant, and a support worker). Their presence sometimes influenced interactions with the participants. In one case, the participant’s mother became part of the interview, seemingly with the approval of the adult with cerebral palsy. In another, a child required frequent attention and there were other interruptions (e.g., phone calls). For the most part, the presence of others did not seem to detract unduly from the topics that participants were willing to discuss.

Data Processing and Analysis

All interviews were independently transcribed verbatim. In cases where the speech of participants was unclear, transcriptions were checked and amended for accuracy. Data were entered into NVivo 10 (QSR International, 2018) qualitative analysis software for management of coding.

The analysis process was inductive and proceeded through several steps (Thompson Burdine et al., 2021; Thorne, 2000). After the first six interviews had been completed, two researchers undertook the first detailed review of the data by reading transcripts, making notes, and identifying early thoughts and reactions to the information gained (Thorne, 2016). These preliminary reactions to the data were used to (i) discuss and confirm the usefulness of the interview schedule in eliciting stories of negotiating the challenges of adulthood; (ii) highlight additional potential prompts to explore the ‘why’ and ‘how’ of some success stories; and (iii) propose the early *ideas buckets* into which chunks of data (quotes) could be put to begin identifying patterns in the findings (Thorne, 2016).

Familiarisation with the entire dataset was achieved through listening to the audio-recordings and reading and re-reading the transcripts, making notes, highlighting commonalities, and grouping ideas into potential themes. One researcher (CG) generated initial codes and built a thematic framework related to major life areas and the four research questions. Braun and Clark's (2006) guidelines for thematic analysis informed our approach to understanding the data. Two researchers (CI, GD) immersed themselves in the individual interviews to understand each story, and how each participant responded to, and reflected on, the experience of negotiating the challenges of adult life. These two approaches (narrative focused and theme focused) allowed the researchers to move between the detail and nuance presented in individual experiences to see the collective patterns, as well as contrasting experiences (Thorne et al., 2004). Bringing together these approaches involved sharing of written summaries and researcher meetings (involving CG, CI, and GD) during which the meanings derived from categories and themes were discussed and considered in relation to individual stories. Common themes were identified along with individual variations across the participants (Thorne et al., 2004), including differences between stories of success and less favourable outcomes. Interview summaries, written to describe what we heard from each participant in relation to our research questions and early categorisation of findings, were then provided to participants. At this stage, we sought feedback from participants to ensure we had not misrepresented their experiences and to offer an opportunity for them to contribute further thoughts. Feedback received confirmed our interpretation of the interviews.

Through the analysis, both factors leading to success and experiences that contrasted with success stories were considered within themes, rather than analysed and described as separate findings addressing the two aims. The thematic summary was presented to the two advisors with cerebral palsy for discussion and consideration of alternative explanations for the findings, and how the relationships among the themes might be interpreted or further organised. The advisors confirmed that the findings resonated with them. Researchers continued to meet to refine and deepen our understanding of how people with cerebral palsy negotiated the challenges of adulthood. The final thematic description (Thorne, 2016) uses a framework to organise the themes about how participants successfully navigated adulthood. This framework and a summary of the themes were shared with participants and further feedback sought. Suggestions about how to use the findings were made by two participants and have been incorporated into the discussion.

Aspects of quality considered as we undertook this study included epistemological integrity, representative credibility, analytic logic, interpretive authority, moral defensibility, disciplinary relevance, pragmatic obligation, and contextual awareness (Liamputtong, 2019; Thorne, 2016). A brief overview of quality considerations is summarised in Supplementary Table 1.

In reporting the results, we provide a description of participants, the organising framework for the themes, and the themes themselves. For each theme, we provide: (i) a description of the theme as a contributor to successful outcomes, (ii) an illustrative quote (or quotes), and (iii) evidence of the challenges that sometimes led to less favourable outcomes.

Results

Participants

The participants were 13 women and 10 men with cerebral palsy (see Supplementary Table 2). More participants were recruited for the 18- to 30-year-old age range (n = 14) than for the 31- to 45-year-old age range (n = 8); one participant, aged 47, was recruited in error and included. In terms of gross motor functioning, there was a spread across GMFCS levels I to IV; however, we were unable to recruit anyone with level V classification (the most severe level of gross motor impairment). All participants communicated verbally, however, four participants required more time to express themselves, slowing the conversational pace, and three participants' articulation difficulties (dysarthria) meant some phrases were very difficult to understand, requiring repetition and persistence. Participants discussed negotiating many challenges of adulthood (see Table 1). Over half the participants were studying or employed, just under half were living independently of their parents, and two were parents themselves.

[INSERT TABLE 1 NEAR HERE]

Organising Framework for the Themes

The themes from the interviews were organised in a framework wherein participants' experiences as children and adolescents (formative experiences) and the environments in which they found themselves in the adult world (present contexts) shaped how they functioned as adults (present functioning) (see Figure 1). In turn, present contexts and present functioning both contributed to participants finding ways to achieve successful outcomes in a variety of life situations.

[INSERT FIGURE 1 NEAR HERE]

One theme weaved through the organising framework and was common to all life situations.

Doing what others do. There was a strong sense from participants that successful outcomes resulted from doing the same sorts of things that others (without cerebral palsy) do. For instance, some participants used Internet dating to begin relationships and others indicated that doing well academically helped them to find employment. As an example, one participant spoke about the transition from secondary education, "*At my high school everyone went to [university] after they finished year 12, that was just the thing to do.*"

The difference for these participants with cerebral palsy was that they sometimes had to do things that were unique to people with disability (e.g., working out when to disclose their cerebral palsy to others) and encountered challenges that are less common in the broader population. These challenges sometimes resulted in less favourable outcomes (e.g., under-employment or living with parents into adulthood).

Whereas the theme – doing what others do – highlighted what people with and without cerebral palsy had in common, the other themes reflected the somewhat unique experiences of people with cerebral palsy and the additional challenges they faced.

Formative Experiences

When describing the genesis of their achievements as adults, participants frequently referred to experiences earlier in their lives, for example, *"I think my Mum set me up for success, and she did it from a young age. Success doesn't automatically happen in adulthood. It's right from the start."*

Eight main themes relating to formative experiences were apparent: determination, pathways for developing competence, typical parental expectations with commensurate support, sibling social support, acceptance and supported involvement in school life, skills for making friends, strategies for coping with bullying, and positive experiences with the healthcare system.

Determination. Determination meant consciously applying effort towards meeting life's challenges and was often described as a central characteristic of participants' personalities. Emerging during childhood and persisting throughout adolescence and adulthood, determination was commonly mentioned as necessary for achievement as an adult with cerebral palsy. Social factors seemed to drive determination, such as wanting to be included in society, to be accepted as a person and to be worthy of attention, and to prove that people with low expectations of them were wrong. For some, this determination seemed to stem from a perceived sense of inferiority that appeared to originate in childhood.

> *It's linked to the insecurity, I think. You're trying to compensate for challenges you've had in your growing up. You're like, "… I've set a task, I know what I need to*

> *achieve; I'll go and do it." If that means I've got to make sacrifices or push myself… Some people with CP would go and be Paralympians, because that's sort of the place they can channel that determination; whereas I feel like for me, it was always getting employment.*

In contrast, limited or no engagement with some of the challenges could be understood as an absence of determination in some areas of life. Some participants reported long delays in approaching challenges (e.g., independence and further education) or choosing not to engage in certain areas of adult life. Being tired of having to find their own ways of approaching challenges was provided as one reason for the lack of engagement. "*I get a bit sick of having to make allowances and having to figure out how to do it ... That's [with] everything – with a job, with relationships, with travel."*

Pathways for Developing Competence. There were many pathways for developing competence. For some, a valued outcome was achieved through using strategies that were different to those of others (e.g., using a wheelchair rather than walking to achieve the goal of keeping up with peers). For others, the physical challenges of cerebral palsy (e.g., difficulties with using writing implements) afforded opportunities to develop genuine strengths (e.g., the ability to memorise information). Doing well academically was a way in which several participants were able to display competence. A key to developing competence was having opportunities to take incremental steps towards significant milestones. For example, work experience and after-school work were useful precursors to part- or full-time employment. *"For my job, actually, my school helped me because when I was at school I had work experience where I work now, and now I work four days a week part-time."*

The challenge to recognising one's own areas of competence was the everyday reminders (e.g., through observing others at school) that participants could not do some things in the same way as others. Being acutely aware of such differences seemed to reduce feelings of belonging. Actual or perceived limitations sometimes resulted in not having opportunities to take incremental steps, which seemed to place them at a disadvantage later in life. For example, not engaging in casual or part-time work as a student raised doubts in some participants' minds (and, perhaps, those of potential employers) about their capacity to work following the completion of their education.

Typical Parental Expectations with Commensurate Support. Many participants talked about being raised in similar ways to their siblings, including being enrolled in mainstream schools and receiving out-of-school educational opportunities. Parental expectations of them were described as like those of their siblings. These expectations were backed up with practical support for skill development (including finding practical workarounds for difficult tasks associated with independent living), emotional support, and successful advocacy (e.g., to obtain resources and necessary accommodations at school).

> *Well, they gave me a lot of support in everything. They didn't really believe that me having cerebral palsy would stop me from doing much. So, they organised all the physio and went to all the school meetings and showed that I had all the adjustments and treated me like you would treat any other kid really. But they were always there when I said that I didn't want to do this anymore or I couldn't do this and they were like, "Yeah, you can. Don't quit."*

In contrast, some participants encountered challenges, such as over-protective parents, families with limited understanding of the social consequences of cerebral palsy, parents with negative attitudes towards cerebral palsy, impaired relationships with family members due to the displacement of frustrations onto them, and family breakdown. When participants were less independent in adulthood, it seemed as if their parents had fostered dependence (e.g. over-protectiveness and resistance to their children moving out of home) and skill development for independent living appeared delayed.

Sibling Social Support. Siblings provided social support in a variety of ways, including (a) valuing them as participants in play and sport; (b) finding humour in disability (and, in doing so, exploring the distinction between humour and bullying), (c) tackling schoolyard bullying (helping other children to understand disability), and (d) acting as role models.

> *My brother was always really good, looking out for me and helping me with things, if we went out together, and he'd often explain to other kids … that, okay, she's got a problem, but she's alright, she's okay up here, you know? He was very protective, and he always knew that I was a bit slower … with walking, I'd often trip and stumble.*

Relationships became strained, however, when siblings perceived they were receiving inadequate attention from their parents compared with their brother or sister with cerebral palsy. In one instance, a sibling left home due to receiving inadequate attention.

Acceptance and Supported Involvement in School Life. Mainstream schooling within environments that nurtured their participation was a precursor to the successes many participants achieved as adults (e.g., employment); they were encouraged to achieve as much as their peers. Principals seemed to set the tone for accommodative schools through their acceptance of students with cerebral palsy and their willingness to allocate resources to support their participation and achievement. A philosophy of inclusion seemed to be standard practice in some schools, and extended to extracurricular activities, including sport.

> *I went to four schools, two primary schools and two high schools. I really found that the school that had the best attitude and was more willing to accommodate and be more flexible with my needs … I was the most successful at and happiest at.*

Sometimes, practical support was received from school administrators (e.g., allocating lockers close to classes), teachers (e.g., advocating for students), teacher aides (e.g., providing assistance to participate), friends (e.g., helping to challenge others' assumptions about cerebral palsy), and allied health practitioners (e.g., promoting the use of special desks and pens). Mobility devices (e.g., motorised scooters), features of the built environment (e.g., ramps), and friends providing physical support helped to make environments physically accessible. Teachers and teacher aides supported the efforts of students to achieve greater independence (through self-advocacy and selecting elective subjects in which higher levels of independence was possible) and to fit in to the school environment. Attending a mainstream school was not the only pathway to meeting adult challenges, however, because some participants had attended special schools.

In contrast, some participants indicated that there were periods during their schooling in which they were discouraged (or excluded) from participation (e.g., principals were reluctant to enrol them and held pessimistic attitudes about their potential) and received limited support (e.g., there was insufficient teacher aide time, teachers were ineffective at advocating for them, lessons and assessment procedures were not accommodative of their needs, and school liaison with allied health practitioners was irregular). Some participants faced environments that were physically inaccessible and were subjected to low expectations (e.g., pervasive attitudes that children with cerebral palsy were fragile, had low ability, and were not worth educating). Such perceptions sometimes resulted in participants being streamed with students of lower academic ability or transferred to special schools. Some received overly pessimistic advice about their employment prospects in general and in specific career paths. One participant spoke of how the careers counsellor at his school denied him the opportunity of undertaking work experience. *"This bastard, he just basically said 'Oh, you've got CP, you can't do anything, I won't put you forward for anything'."*

Skills for Making Friends. Making friends at school involved creating positive opportunities for social connection (with strategies changing with age), displaying confidence, having a positive attitude towards school, communicating capabilities clearly, using humour, and finding people who accepted them. Some participants made friends through taking on leadership positions and participating in extracurricular activities, and some were fortunate to retain friendships throughout their schooling. Inclusion in activities with others contributed to a sense of belonging.

> *Oh, high school was fantastic. High school was one of the best six years of my life, I loved high school. I think the reason I liked high school was because I was with a lot of my friends, so my friends from primary school that had gone off to do secondary school, we were all in the same school together. There was something about it that – I don't know what it is, but the girls seemed so much more supportive, and once you explain that this is what I've got, I've got cerebral palsy, they were cool with it.*

In contrast, some participants lost friends at socially important times or had difficulties making friends (e.g., due to their insecurities or because they could not physically keep up with others). Some were also excluded from playground games or not invited to social activities outside of school. Friends sometimes assumed they would not be able to participate in the planned activities.

Strategies for Coping with Bullying. Many participants described instances of being bullied and adopted various strategies to cope with his behaviour. These strategies centred on being removed from the environments in which bullying took place, obtaining assistance from others to address the bullying, confronting or (alternatively) not engaging the bully, finding an outlet for the emotions resulting from bullying, and mentally processing the bullying behaviours. Being removed from environments meant going to a different school (from primary to secondary school or switching between schools at the same academic level). Obtaining assistance from others involved seeking help from teachers, parents (who spoke with teachers), principals, friends, and siblings. Confronting bullies involved speaking calmly with them one-to-one, asking them to stop, and warning of consequences if they did not alter their behaviour. Not engaging bullies meant ignoring bullying and removing oneself from situations where bullying occurred in the hope that the bullying would stop. Finding an outlet for emotions stemming from bulling meant channelling anger and frustration into certain activities, such as playing sport for people with disability. Mentally processing bullying behaviour involved understanding bullying, recognising that bullies do not understand the situations in which people find themselves, separating bullying about disability from themselves, and keeping being themselves and interacting with others. *"You've just got to try and not make it turn bitter because I would have one person that would bully me but the next second my friend would come up to me and it would be fine."*

Adding to the challenge of coping with bullying was that the perpetrators were not always peers, but were also adults (teachers, teacher aides, and principals). Bullying also took the form of being ignored. Reactions to bullying included anger, frustration, anxiety, depressed mood, stress, shyness, and low confidence, some of which endured into adulthood.

Positive Experiences with the Healthcare System. Some participants spoke about their positive experiences within the public health system, including surgery that improved their physical functioning. The overall experience of surgical care was enhanced when schools ensured that participants' educational needs were met during the recovery phase.

> *I lost count of how many times, as a young baby or a little girl, I'd go into the hospital and they'd set my legs in plaster casts, in the hope that it would help me walk properly. So yeah, I had the tendon lengthening in the 90s, that helped … probably reduced the severity of it maybe by about 40 or 50 percent.*

Unfortunately, many participants recalled negative encounters with the health system, including healthcare professionals expressing pessimism about what people with cerebral palsy might be able to achieve (e.g., pessimism about dating prospects), involvement in painful stretching during physiotherapy, and unfavourable outcomes following surgery (e.g., functional decline, need for further surgery, pain, trauma, and long absences from school affecting education and socialisation). For some participants, efforts to improve their physical functioning (whether successful or not) seemed to have a cost of inhibiting their development in other areas of life.

Present Functioning

Four themes emerged relating to how participants were currently functioning as adults: positive self-concept, well-honed social skills, physical fitness, and ability to find a way.

Positive Self-Concept. Central to the development and maintenance of a positive self-concept seemed to be the acceptance of one's own cerebral palsy coupled with the internalised expectation of taking part in society to the same extent as others. The acceptance of oneself as a person with cerebral palsy seemed to be a journey, rather than a destination, with new challenges in life producing further introspection. Things that seemed to help the acceptance of oneself included self-help books, psychotherapy (in which new ways of dealing with cerebral palsy-related issues were explored), and exposure to the social model of disability. Regarding internalised expectations, assumptions of being employable seemed to foster work preparation and job seeking behaviours. In a similar way, engaging in romantic and sexual relationships required focusing on qualities that may be attractive to a potential date, while turning down the volume of voices with messages that people with cerebral palsy are not worthy of romantic and sexual relationships. A positive self-concept seemed to be one that incorporated favourable perceptions of cerebral palsy, rather than conceiving cerebral palsy to be separate from oneself. The following extract illustrates this participant's early identification with children without disability and rejection of identifying with people with disability. Greater identification with people with cerebral palsy and a sense of belonging within the disability community occurred following a positive relationship with a person with cerebral palsy later in life.

> *When I was younger, I didn't want anything to do with disability. I had able-bodied friends; I went to an able-bodied school. I didn't identify with anyone with a disability. I hadn't met anyone like me. And in my third year of college there was a foreign exchange student from the UK who had cerebral palsy and came over for the entire year to study abroad. She changed my world. And I really think it just takes one person who you identify with and can see yourself in. So maybe I am part of this disability community and I should be more open to it.*

Some participants, however, were clearly still coming to terms with their disability and their limitations, and wondering, "*What's wrong with me?*" For some, there was limited self-acceptance and infrequent exposure to other people with disability. For others, uncertainty over their capacity to function in a work environment seemed to delay or suspend work-preparation and work-seeking behaviours. In addition, the expectation of employer discrimination prevented the submission of job applications. Regarding romantic and sexual relationships, some participants seemed to have internalised messages that they were unattractive and unworthy of love, contributing to negative thoughts and feelings (e.g., fear of rejection and vulnerability, and insecurity) and avoidance behaviours (e.g., reluctance to try online dating).

Well-Honed Social Skills. Participants who had frequent interactions with friends generally held positive expectations about forming relationships and well-honed social skills to help them to get along with others. Effective social skills seemed particularly important for self-advocacy and managing disclosure of disability. Being able to self-advocate seemed to necessitate having confidence in one's own ability, recognising that they understood their abilities the best, refraining from being demanding, and being pleasant to people. Some participants were aware that cerebral palsy can be confronting to others and endeavoured to understand others' perspectives. These participants assumed others were curious about disability and encouraged questions about cerebral palsy. Responding positively to questions provided opportunities to shape others' perceptions of cerebral palsy. Some situations (e.g., job applications and online dating) afforded participants some control over when and how they disclosed their cerebral palsy. When dating, for example, options included disclosing cerebral palsy in online profiles (e.g.., in their usernames, descriptions, and photos showing wheelchairs). Emphasis was placed on simple descriptions (e.g., physical disability) that would be understandable to others.

> *Ever since I was a kid, if someone wants to ask a question or if someone is intrigued by why I walk funny or why I use a walker or sticks or something, people are naturally curious, "So if you want to ask a question, just go and ask me."*

By contrast, there were some participants with few or no friends, who held negative expectations about forming relationships (e.g., expected others to be no more than acquaintances or that others would fear their cerebral palsy). These participants did not appear to have strong role models for social functioning in their lives (e.g., siblings refusing to help them navigate the social world, and parents with few or no friends of their own). Participants' social skills seemed evident during the interviews; participants with seemingly strong friendships were positive, happy, and engaging, whereas there seemed to be higher levels of negativity, anger, and hopelessness during interviews with those who found it difficult to make friends. Negativity was pervasive during some interviews, despite the interviewers' best efforts to reflect on participants' achievements.

Physical Fitness. Participants maintained their physical function through engaging in physical activity and consulting healthcare professionals (e.g., physiotherapists and exercise physiologists) when necessary. Some indicated that they recognised the importance of physical activity for health, independence, and weight management, as well as for making transfers to and from wheelchairs easier. *“I’ve always maintained my physical health to the best of my ability, because I prioritise physical exercise over anything.”*

Some participants, however, experienced functional decline, reduced balance and agility, and injuries from stretching and falls. Some became less physically active upon transitioning from walking to using wheelchairs, and others indicated that they had limited time and energy for physical activity.

Ability to Find a Way. Participants who had more successful experiences were able to find ways to navigate the physical environment and the systems of support that were available to them. In the context of further education, for example, they sought out the disability support services on their campuses and were able to obtain the accommodations they required.

> *It was really good because, you know, it was always hard to compete with all the other students for the tutorial times. So, I would just go to the disability service office and they'd say, "Which tutes do you want?". I would just pick all the good ones; didn't have to get up too early, didn't have to be there too late.*

In contrast, participants experienced difficulties when they were unaware that disability support services were available and were unable to negotiate supports and accommodations that met their needs. Sometimes their difficulties were due to having trouble deciding which supports and accommodations might work best.

Present Contexts

Core features of the contexts in which participants lived their lives were captured in the following themes: availability of natural and professional supports, expectations of involvement in adult activities, and accessible and accommodating environments.

Availability of Natural and Professional Supports. The availability of the right mixes of natural supports (family and friends) and paid supports (e.g., support workers) enabled participants to function effectively in their environments. Sometimes parents continued to provide practical support into adulthood (e.g., trimming fingernails and toenails). Some participants lived close to their parents, so that family members could easily support them if needed; one participant mentioned having a personal alarm for safety. Support workers were the main form of professional support, but participants also gained assistance from medical specialists, occupational therapists, physiotherapists, exercise physiologists and personal trainers, mobile podiatrists, and house cleaners.

> *When I went and saw Mum, she'd do my grooming for me, like my nails. … But now I've actually found a podiatrist who actually comes to my home. … He just does my feet, Mum still does my fingernails. … She still takes me to my appointments when she can. Sometimes she meets with specialists that come here. And also, [Mum's] there when my [disability funding] meetings happen.*

For some participants, the extent to which they could access natural and professional supports was limited. Challenges included parents and siblings who were unwilling or unable to provide support, few or no close friends that they could count on for assistance, limited or no funding for professional support services, and difficulties finding supports when cerebral palsy organisations are focused on children and not adults. An added concern for some participants was when there is nobody to help (e.g., in the event of a fall). In rural areas, there were sometimes few support options.

> *In terms of support, I'm in a really sort of grey area because obviously I don't want to be going to day centre. That's not something that's really relevant for me. But I think being in the country makes it quite difficult.*

Expectations of Involvement in Adult Activities. The expectations of others (e.g., family members) seem to motivate participants' behaviours toward preparing for life as an adult (e.g., independent living and working). Some participants recalled, for example, how their siblings expected them to gain employment. In some instances, the communication of expectations involved direct confrontations during which family members expressed resentment that participants were not making sufficient efforts to achieve greater independence.

> *I remember my brother said to me "What are you going to do with your life? You stay home doing nothing. Mum does everything for you. What are you going to do for your life? You're a waste of energy and a waste of oxygen." … That hurt a lot, but he was right. I had to do something with myself.*

Parental expectations of involvement in adult activities were typically backed up with practical support for skill development, including helping to find solutions for difficult tasks associated with independent living.

For participants who were not as independent as they perhaps could have been, their relationships with their parents seemed to have been a contributing factor. In various instances, there was evidence of high levels of co-dependency between parents and their adult children, and parents who were relatively unsupportive (e.g., limited practical or emotional support) or over-protective (e.g., discouraging age-appropriate risk-taking behaviour). In work settings, some participants encountered employers with unrealistic expectations (e.g., expecting them to use voice recognition software in an open-plan office).

Accessible and Accommodating Environments. Accessible and accommodating environments took many forms, including physical access, practical supports, reasonable accommodations/adjustments, and positive attitudes towards disability. In employment, for example, participants benefited from workplaces that were physically accessible, where reasonable adjustments were made to the physical environments, and where colleagues and clients were accepting and supportive.

> *So, she needed a new height adjustable desk for herself and I'd just started, and she said to me, "Do you think you might want one of these as well?" I said, "Oh that would be helpful because I'd be working in my wheelchair more than I probably would be in a chair and I can adjust the table depending on where I'm sitting and what I'm using." So, I got a height adjustable table. And there was already a disabled toilet … that I could use. They changed that around so that I could more easily get into that, so it was more accessible.*

Encountering some environments that were not as accessible as they could have been seemed a common experience. In tertiary education settings, for example, some participants experienced problems with physical access, dealt with disability service staff who questioned their ability, and found support services to be unreliable (e.g., note takers who were unfamiliar with the subject matter).

Finding a Way

Finding a way involved drawing on individual capacity and the resources available in the environment to achieve successful outcomes. As such, the themes of present functioning and present contexts echo in the themes of finding a way. Four themes encapsulate how participants found ways to achieve successful outcomes for themselves: drawing on knowledge and skills, gravitating towards those who are comfortable with difference, maintaining function, and using natural and paid supports.

Drawing on Knowledge and Skills. Through drawing on their knowledge and skills, participants were able to navigate paths for themselves toward desired outcomes. Understanding and exploiting their strengths was helpful in this respect. When seeking employment, for example, some participants found jobs without extensive physical requirements and, in some cases, chose to work part-time to manage fatigue. Across life domains, participants seemed to be quite adept at developing alternative approaches that enabled them to undertake tasks independently or with minimal assistance from others. During the early years of their children’s lives, for example, participants who were parents grappled with, and learned to do, the tasks of parenting.

> *So, we were making a massive adjustment and that was really, really, really a difficult time for me. … I'm probably more conscious of it now. You see people with disabilities that have kids out and about … and I'm always a little bit fascinated to watch how they do it as compared to how I do it. But there was no disabled parent manual. There was no disabled parent support group. There was no - whatever. I was just working it out myself largely, with [my wife] of course. That was challenging.*

Despite trying to capitalise on their strengths, some participants found that limitations due to cerebral palsy remained an issue. Alternative strategies were not always developed, with many obstacles to finding solutions, including limited motivation for independence, parents not fostering independence, pessimistic health practitioners, cerebral palsy organisations being child-centric, and the limited availability of practical information (e.g., on parenting with cerebral palsy).

Gravitating towards those who are Comfortable with Difference. Gravitating towards people who are comfortable with difference and more willing to accommodate individual needs was a theme that emerged particularly from stories about romantic and sexual relationships, and friendships. Some participants found that they tended to form closer relationships with others who understood difference (e.g., siblings of people with disability). With respect to romantic relationships, some participants connected with people who were proud to be with them, regardless of their cerebral palsy, and to introduce them to the important people in their lives. In terms of sexual relationships, some participants were able to find partners with whom sex was mutually enjoyable.

> *So, for example, when I met my husband, or my now husband, he had no idea [that she had cerebral palsy]. He met me at a Halloween party, and he wasn't interested in the fact that I had – as we say, a sore foot, you know? He was more interested in me, which is great, because you know, a lot of guys always look at the woman, or the girl, and go you know, not a good body, you know, no, won't date her, you know?*

In contrast, some participants experienced situations where potential dates would leave them upon discovering their cerebral palsy. Other participants, in relationships, stated that their partners did not understand cerebral palsy and were not ready to introduce them to family and friends.

> *He hasn't found the courage to tell his parents and his friends that I'm disabled, because he doesn't know how they will react, and he's scared of losing me. He is coming to terms with it, and he will eventually tell them, of course.*

Some female participants described sexual partners who were aggressive and who engaged in sex in ways that were painful.

Maintaining Function. Participants spoke about attending to their physical and mental health. Maintaining physical health involved actions within the healthcare system (finding clinicians who specialise in cerebral palsy) and the community (finding ways to remain physically active). Some participants negotiated the transition to adult medical care through reconnecting with paediatric specialists, who either referred them on to other specialists or continued to see them as adult patients. Engaging in physical activity commonly involved attending fitness centres, either independently or with support from exercise professionals or family. Maintaining good mental health involved being with friends and other people with disability, undergoing psychotherapy, attending fitness centres (benefitting from both exercise and socialisation), and engaging in retail therapy.

> *So, I go to the gym quite a bit. I've always sort of said to myself, if that starts to go downhill, if I stop going to the gym, stop exercising, then I probably need to seriously consider how I am going to get out of this little box. But I use that as sort of a barometer. If I'm exercising and going to the gym, even if I'm not feeling great in the other aspects of my life, as long as the gym's there, because that's a community in itself. … As long as I'm exercising and doing my best to keep fit, then I should be fine.*

Participants who experienced difficulties in maintaining their physical function spoke about the limited availability of services for adults with cerebral palsy, the challenges of finding those services, and the limited knowledge of, and interest in cerebral palsy, among mainstream health practitioners. Poor mental health was invariably associated with adverse social experiences. Participants who had difficulties with their mental health also described unsuccessful attempts to seek help (finding it challenging to relate to psychologists and people in support groups) and to find their community (i.e., others with cerebral palsy who would understand them).

Using Natural and Paid Supports. Finding a way involved participants not only having natural and professional supports available to them (a theme of *Present Contexts*), but also being able to draw on these supports to help them to meet life’s challenges. For example, some participants spoke about selecting and retaining support workers who fostered confidence, independence, and connectedness to others through providing practical assistance with the tasks of daily living.

> *Yeah. We clicked. She’s been with me through the whole process of getting an assistance dog. So, I’ve been approved and I’m on the waiting list. So, I’ve achieved that goal with her help. Non-judgemental. I’m here to help you. What do you want*

> *me to do? You're in charge. Freedom. That's what it is. Freedom. You don't have to be physically independent to be independent.*

Sometimes, participants were unable to benefit fully from the supports that were available to them. At times, they did not ask for assistance, describing themselves as stubborn and independent. In other circumstances, participants were unable to attract and retain support workers who fostered their independence and involvement in the activities that they wanted to undertake. Sometimes, support workers were over-protective, did not have the necessary experience to provide effective support, or seemed to be doing the job just for the money.

Discussion

This study provides a comprehensive description of how people with cerebral palsy negotiate the challenges of adulthood. Our evidence suggests that successful outcomes in adulthood are founded on positive experiences throughout early life and are dependent on aspects of people with cerebral palsy and features of the contexts in which they live. With the participants able to describe both successful and less favourable outcomes, a major strength of this work was that we were able to identify themes that highlighted both the factors that contributed to success and the challenges that inhibited success. The duality of the themes (i.e., success and challenges) adds to their robustness as salient aspects in the development of people with cerebral palsy. In addition, the findings emphasise the importance for people with cerebral palsy of being able to meet challenges in the same ways as their peers (without cerebral palsy) do.

From our conversations with adults who have cerebral palsy, it was evident that successful adult outcomes had their origins in childhood and adolescence. The participants commonly spoke about having parents and teachers with similar expectations of them as they did of other children, receiving necessary practical and emotional supports to enable them to participate and achieve, gaining the acceptance of others, having opportunities to progress incrementally, and getting along with their peers. These findings build on the broader literature. For example, among a large population-based sample of special education students exiting high school (including those with cognitive, emotional, sensory, and physical impairments), successful competitive employment outcomes were most strongly associated with employment experiences during high school and positive parental expectations for post-school employment (Wehman et al., 2015). Consistent with prior research (Carroll et al., 2021; Heller et al., 2002; Magill-Evans et al., 2001), our findings reinforce the importance of adults central to the lives of young people with cerebral palsy having positive expectations about their future and providing necessary supports to enable them to make the most of the opportunities they are afforded.

With the benefit of these formative experiences, our research shows that various aspects of present functioning combine with features of present contexts to enable people with cerebral palsy to find a way to achieve successful outcomes across many life domains. This finding fits well with the ICF, in which functioning and disability are conceptualised as complex interactions between people (including their health conditions) and their environments (World Health Organization, 2001). Our findings may also be compared with previous research focused on the success attributes of people with learning disabilities (Goldberg et al., 2003; Raskind et al., 1999). Similarities include the importance of effective social supports and dogged determination. There were key differences, however. Whereas the research on people with learning disabilities identified *self-awareness* of learning difficulties as a success attribute, our work gives greater emphasis to the acceptance of cerebral palsy and the presence of internalised expectations of taking one’s place alongside others in society. Whereas this previous research had a strong focus on individual motivation (motivation underpinned three of the six attributes – proactivity, perseverance, and goal setting), our findings accentuate aspects of people’s environments that enabled them to be successful. Whereas the need for effective support systems seemed to lessen over time for adults with learning difficulties, ongoing use of natural and paid supports was a reality for many of the adults we interviewed. Our work also has a focus on the maintenance of physical function, which may not be of great a concern for people with learning difficulties. Although some of the differences may reflect researcher choices in how participants’ experiences are synthesized to create meaning, a somewhat more powerful explanation is that cerebral palsy has different effects on people’s lives than other types of impairment.

For the most part, the stories of achievement seemed unremarkable in that the narratives were like those that would be expected of most adults. Consistent with experiences of other people with disability (Bergmark et al., 2011; Olsson Moller et al., 2014), however, cerebral palsy often means having to do things differently to most adults. Finding ways of achieving desired social outcomes involves applying knowledge and skills that have been developed over time and drawing upon resources available in the environment. That is, finding a way is dependent on both individual capacity and the extent to which the environment is supportive of the person’s efforts.

Many of the adults in our research experienced difficulties across many areas of life, which afforded us the opportunity to contrast success with less fruitful attempts to meet (or avoid) some of life’s challenges. Some obstacles to success seemed to reside within the individual: low motivation to engage in some aspects of life; low perceived competence; limited self-acceptance; negative expectations; poor social skills; declining physical function; and limited ability to locate and obtain support. Other obstacles related to their environments: over-protective parents; influential people with negative attitudes toward, and low expectations of, people with cerebral palsy; discouragement or exclusion from participation in activities; insufficient practical support; inaccessible environments; social isolation; and bullying. These findings further illustrate the connections between unaccommodating environments, poor mental health, and unfavourable social outcomes, which have been highlighted in previous work about adults with cerebral palsy (Dune, 2013; Gaskin et al., 2009, 2010, 2011, 2012).

Consistent with some previous work (Reddihough et al., 2013; van Gorp et al., 2019), our research focused on major aspects of adult life, such as living independently from parents, employment, and romantic and sexual relationships, implicitly labelling *success* as participation in these activities. This approach could be criticised for privileging able-bodied norms for adulthood in the society in which this work was conducted and paying insufficient attention to alternative ways of meaningfully leading one’s life. For example, the expectation of moving out of the family home in late adolescence or early adulthood may not be present in cultures where extended family members living in the same household is common. Our approach also contrasts with evidence from older adolescents with cerebral palsy that happiness is the primary marker of success (King et al., 2000). Although people may be free to live their lives, and to define success, in different ways, it is also the case that some people with cerebral palsy experience significant distress (including depression and suicidal ideation) when they are unable to do the things that other adults do (Gaskin et al., 2011, 2012).

The findings from our research also caution us not to treat success as a binary outcome or attach the label of *success* to participation in significant adult activities. Participation requires involvement in any given aspect of life, not just attendance (Imms et al., 2017). Romantic relationships, in which some participants designated themselves as successful, are a case in point. Some adults with cerebral palsy described partners who did not understand nor accept their cerebral palsy, who were unwilling to introduce them to their parents and friends, and who engaged in painful sex. Being able to *tick* the relationship box says nothing about the quality of engagement in the relationship.

Limitations

The main limitation of our research was the size and diversity of the sample we were able to recruit. We recruited 23 people with cerebral palsy, which fell short of our aim of attracting 30 to 40 participants. In particular, we recruited fewer participants than planned in the 31 to 45-year age range and no participants with a GMFCS level V classification. The low recruitment rate of 31 to 45-year-olds seemed to reduce our ability to explore some life situations, especially parenthood. Although not our intention when conceptualising the research, more participants across age ranges, genders, and GMFCS levels would have enabled us to make tentative steps towards comparing the experiences of people with cerebral palsy with different demographic and cerebral palsy-related characteristics. Adopting an intersectional approach (Crenshaw, 1989) to understanding how people with cerebral palsy achieve successful outcomes when faced with compounding experiences of discrimination would seem a worthwhile avenue for future research.

The lack of people with GMFCS level V classifications in our sample limits the transferability of our findings to this population. In addition, although there were several participants for whom communication was difficult, we also did not recruit anyone using alternative or augmented communication devices and who may have been able to provide rich information about how they successfully navigate the life situations of adulthood. Given that greater severity of cerebral palsy is associated with poorer social outcomes (Alriksson-Schmidt et al., 2014; Michelsen et al., 2006; Reddihough et al., 2013), an exploration of success in adulthood and severe cerebral palsy is needed.

Implications for practice

The themes emerging from this research have direct relevance to those seeking to support people with cerebral palsy to improve social outcomes, including people with cerebral palsy themselves, peer supports, disabled persons organisations, disability service and support providers, health professionals, and education institutions. The themes can be thought of as providing multiple entry-points for intervening in the development of people with cerebral palsy. The findings of this study suggest that the contexts in which people with cerebral palsy live should be the primary targets of initiatives to improve social outcomes. Family dynamics and school environments seemed fundamental to how the people we interviewed were functioning as adults. Key elements across environments were the need for acceptance of people with cerebral palsy, healthy expectations of future achievement, and practical and emotional support. There is enormous potential to work with families and schools to enhance these elements in the contexts in which people with cerebral palsy live. Areas of focus include the development of positive attitudes towards people with cerebral palsy, how to foster and support participation, and advocacy. Recognising that many people with cerebral palsy will grow up in less favourable circumstances, there may often be a need to work with people with cerebral palsy to develop their self-concepts and their social and problem-solving skills. Engaging peer support facilitators and appropriate professionals (e.g. psychologists, physical, occupational and/or speech therapists) may be helpful in supporting the work of families, schools, and people with cerebral palsy (Gaskin, 2015). In addition, there is a need to encourage and support involvement in physical activity for fitness and wellbeing (Lawrence et al., 2016).

For those working with adults with cerebral palsy, these findings provide rich contextual understanding of the developmental pathways of people with cerebral palsy. The findings can serve to sensitise those working with cerebral palsy to the issues that this population commonly encounter, and which may affect their current functioning. In some cases, understanding people's pasts may be a fruitful way of supporting their current functioning.

Future research

Future research to address the social inequities experienced by those with cerebral palsy, and other disabilities, will have more impact (at personal, practice, and policy levels) if undertaken with adults with cerebral palsy as co-researchers to guide priorities (which questions are asked), approaches (how they are best answered), and dissemination and translation strategies (Stallings et al., 2019; van Schelven et al., 2020). Given the centrality of adults with cerebral palsy to the research process and the multiple avenues for the provision of support as suggested from the themes of this research, now would be an appropriate time to seek their involvement and input into how the research develops from here.

Conclusion

People with cerebral palsy can, and do, successfully negotiate the many challenges that come with being an adult. From the experiences of people with cerebral palsy who had achieved successful outcomes in many aspects of adult life, we have constructed a comprehensive description of experiences associated with success. Our findings suggest that the origins of success of the adults we interviewed lay in their formative experiences. As adults, their present functioning combined with their present contexts to enable them to find ways of meeting life challenges. The findings from this study could be leveraged to inform the development of strategies to support people with cerebral palsy to achievement positive social outcomes.

Acknowledgements

We acknowledge and thank the participants of this study who contributed their experiences and insights; Elise Davis, who was part of the investigator team for a short period; our consumer advisors, Sue Harris and Janelle McCarthy; our research assistants, Joan Gains and Anna Atkinson; and Cerebral Palsy Support Network and Victorian Cerebral Palsy Register for assistance with recruitment. The study was funded by a Cerebral Palsy Alliance Research Foundation grant (PG6816) and the work undertaken within the auspices of the Australian National Health and Medical Research Council funded Centres for Research Excellence, Cerebral Palsy (APP1057997) and CP-Achieve (APP1171758).

Declaration of Interests

The authors declare no conflicts of interest. The study was funded by a grant from the Cerebral Palsy Alliance Research Foundation (PG6816). The funding agency had no role in the study conduct or interpretation of findings.

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List of Figures

Figure 1. Experiences associated with success: An organising framework.

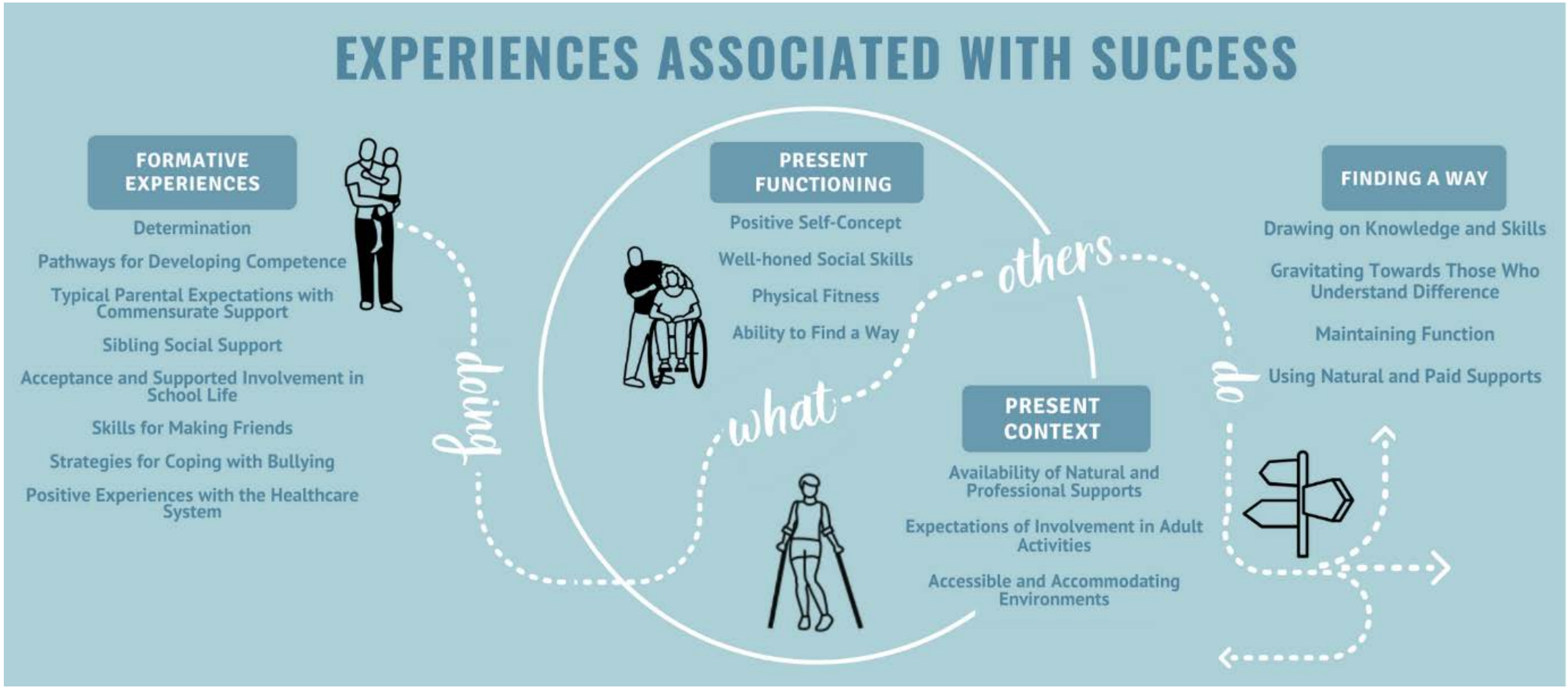

Table 1. Summary of participant stories of success according to age and level of functional mobility.

Age range	**GMFCS level**	**Successes discussed** [a]
18-30	I	University degree; employed part time; volunteer; health maintenance; recreation; travel; friendships
18-30	I	Post-school certificate education; recreation
18-30	I	University degree; employed; independent living; friendships
18-30	I	Studying (post-school certificate); employed; past independent living; driving a car; hobbies
31-47	I	University degree; employed; married; parent; friendships
18-30	II	Studying (university); independent living; friendship;
18-30	II	University degree; employed part time; independent living; friendships
18-30	II	Studying (university); volunteer; recreation
18-30	II	Post-school certificate; employed part time; independent living; intimate relationships
31-47	II	University degree; past employment; driving a car; past intimate relationships
31-47	II	Independently living; married
31-47	II	Past employment; married; caregiving; sport; friendships
18-30	III	Part time employment; health maintenance; recreation; international travel; friendships

18-30	III	Professional qualification; independent living; intimate relationships
18-30	III	University degree; learning to drive; health maintenance; friendships
31-47	III	University degree; employed; promotions at work; independent living; health maintenance; intimate relationships; married
31-47	III	University degree; employed; married; parent
31-47	III	Post school education; employed; recreation; friendships
31-47	III	University degree; employed; friendships;
18-30	IV	Professional qualification; independent living; intimate relationship; friendships
18-30	IV	University degree; employed; independent living; driving a car; health maintenance; international travel; intimate relationships
18-30	IV	University degree; employed; health maintenance; international travel; friendships; intimate relationship
31-47	IV	University degrees; work experience; family relationships

Note: [a] This list includes the main topics discussed in interviews in relation to the research questions. They may not reflect all the central aspects of peoples' lives. GMFCS = Gross Motor Function Classification System – people in levels I and II walk in most situations, those in levels III and IV use wheelchairs for some or all mobility.

Supplementary Table 1. Quality considerations.

Criteria against which to consider quality	**Study decisions, actions and rationale**
Epistemological integrity: A line of reasoning exists to support the assumptions made about the nature of knowledge and decisions taken about how to conduct the research.	The research question focused on the team's desire to learn directly from those with cerebral palsy; in-depth interviews used for data sources, and inductive analysis conducted.
Representative credibility: Claims to knowledge are consistent with the approach to sampling that was taken, and varied perspectives sought.	Sampling strategy aimed to reach diverse experiences. Engagement of multiple researchers brought varied perspectives to the analysis and interpretation of findings, requiring discussion and repeated reviewing of raw data in relation to thematic descriptions and the organising framework. Limitations in the sample acknowledged, especially in relation to our inability to recruit adults with the most complex forms of cerebral palsy.
Analytic logic: Reasoning for decisions taken by the researcher are made explicit and sufficient detail provided to understand how the findings are linked to the processes used.	Rational for participant sampling, interview schedule detailed in report. Steps in, and rationale for, data analysis described, detailed description of participants provided, and verbatim quotes provided with findings.

Interpretive authority: Steps to address trustworthiness are included.	Involvement of multiple researchers to explore alternative viewpoints or interpretations of the data. Participants provided with opportunity to provide additional information and feedback on the researchers' interpretation of their specific interview, and the collective interpretation of the findings. Involvement of adults with cerebral palsy as advisors at key decision points (research questions and interview schedule; interpretation of findings) in the research guided the approach.
Moral defensibility: Rationale provided for why this knowledge is needed and how it will be used.	Researchers argue that current evidence is dominated by an epidemiological approach to learning about participation in life situations of adults with cerebral palsy that fails to respect and account for the deep knowledge of what it takes to participate that adults with cerebral palsy hold. Use of findings through sharing with other adults with cerebral palsy and to inform policy and practice respects the contribution of participants.
Disciplinary relevance: Relevance of this question to this research team – how will findings inform future actions?	The topic in focus – participation in broad life situations – has pertinence for people with cerebral palsy directly, and for varied disciplines.
Pragmatic obligation: Awareness that findings may be used in practice.	Examples of how the findings can be used supports use by readers, and articulation of

	limitations of the study supports readers to make decisions about transferability of the findings.
Contextual awareness: That findings are situated in time and place and are influenced by the perspectives of those involved.	Information provided about the research team and the participants that support reader understanding of the context of the study.

Note: Quality considerations are primarily considered in relation to Thorne (2016) criteria for interpretive description studies, but also common approaches to ensuring qualitative rigour (Liamputtong, 2019).

Supplementary Table 2. Participant characteristics.

	Age 18-30 (n=14)		Age 31-47 (n=9)		Total
	Male (n=5)	Female (n=9)	Male (n=5)	Female (n=4)	(n=23)
GMFCS level					
Level I	3	1	0	1	5
Level II	1	3	2	1	7
Level III	0	3	3	1	7
Level IV	1	2	0	2	4
CFCS level					
Level 1	3	5	4	4	16
Level 2	1	2	1	0	4
Level 3	1	2	0	0	3
Currently studying	2	3	0	0	5
Currently employed	3	3	3	1	10 [a]
Living independently [b]	2	4	3	2	11
Current romantic relationship	0	1	3	2	6 [c]
Parents	0	0	1	1	2

Note: GMFCS = Gross Motor Function Classification System; CFCS = Communication Function Classification System. [a] Two participants identified as underemployed. [b] Living independently from parents. [c] Eight participants had never sought romantic relationships.