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**Author(s):** Boyle, Paul; Vuoskoski, Pirjo; Stew, Graham; Galvin, Kathleen T.

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# **Transitioning from adolescence to adulthood for young people living with cerebral palsy: a meta-ethnography**

Paul Boyle<sup>1</sup>, Pirjo Vuoskoski<sup>2</sup>, Graham Stew<sup>3</sup>, Kathleen T. Galvin<sup>1</sup>

<sup>1</sup> School of Health Sciences, University of Brighton, Eastbourne, UK

<sup>2</sup> Faculty of Sports and Health Sciences, University of Jyväskylä, Jyväskylä, Finland

<sup>3</sup> School of Health, Wellbeing and Social Care, The Open University, Milton Keynes

Corresponding author: Paul Boyle, [p.boyle@brighton.ac.uk](mailto:p.boyle@brighton.ac.uk)

## **Abstract**

Transitioning from adolescence to adulthood appears to be a challenging period for young people living with cerebral palsy. The aim of this review was to highlight the challenges that might be experienced during this period. A systematic search of the literature and meta-ethnographic review examined seven qualitative research papers providing a detailed synthesis in the form of three domains summarised as ‘meaningful preparation for transition’, ‘becoming empowered’, and, ‘overcoming vulnerability’. These inform a discussion which shows that adolescents living with cerebral palsy are not prepared adequately for adult life. Examination of the literature stimulates curiosity as to the nature of living with cerebral palsy whilst transitioning from adolescence to adulthood. No studies have been carried out exploring this experience in the UK and lifeworld research to inform policy and practice in this area is recommended.

**Key words:** cerebral palsy, transition, adolescence, young people, meta-ethnography

## **Introduction**

In the UK the need to improve transition arrangements from children's to adult services for young people living with disabilities was firmly placed within the context of national guidance at the beginning of the century (DH 2001). More recently Berghs et al. (2019) argues for a social model of human rights to enable people with disabilities to have more control over their lives. This is relevant for young people going through the transition process, which might be understood as more than legislation but overlaps with ethical concerns about how we support fellow citizens. The authors are curious about the understanding of human rights by rehabilitation practitioners such as occupational therapists and physiotherapists. As Shakespeare (2014) highlights – rehabilitation - in terms of lived experience, is under-researched and neglected. Interestingly, the Convention on the Rights of Persons with Disabilities (UN 2006) conceptualises rehabilitation as a broader process of social transformation. It seems to us there is much for rehabilitation professionals to learn from disability scholars such as Shakespeare (2014 2019), and we hope this review provides a contribution to the literature that links to some degree rehabilitation research and disability studies.

Cerebral palsy is one of the most common conditions affecting people living with disability who appear to be at risk of limited participation in physical activity (Usuba et al. 2015). This condition is usually caused by an injury to the brain before, during or after childbirth and is a term that covers a range of non-progressive conditions affecting ability (Levitt 2010).

Children with cerebral palsy grow up with this condition with 90% reaching adulthood yet access to therapies appears to be limited (Cassidy et al. 2016). As a consequence there is higher demand placed upon health, education and social care services during the transition from formal children's to adult services, and it appears rehabilitation practitioners need to be better informed about the emotional and physical dimensions of living with cerebral palsy

(Bagatell et al. 2017). The term ‘transition’ from adolescence to adulthood relates to the gradual changing of existing roles and adoption of new ones, with young people becoming more independent and accepting new responsibilities as they mature (Bagatell et al. 2017). In terms of transition from children’s to adult services, typically this might take place between the ages of 16 to 21 years (Bagatell et al. 2017) or sometimes 18-25 years (McLaughlin Carroll 2015).

According to Roebroek et al. (2009) the transition process from adolescence to adulthood is critical for young people requiring a managed transfer of care. They identify a need for a ‘lifespan’ perspective and call for adequate follow-up into adulthood, and for professionals to increase their awareness of both the medical and social issues that might affect children with disabilities. Other studies highlight the gap between children’s and adult services and the traumatic experience as a result for young people and their families (Berg Kelly 2011; Gorter et al. 2011; Hamdani et al. 2011; Kingsnorth et al. 2011; Van Staa et al. 2011; Watson et al. 2011).

The voice and position of people living with disability is important for the authors, who all have an interest in disability, wellbeing and quality of life. We recognise, however, that there have been substantial developments in healthcare leading to greater patient-led services with an increasing curiosity as to wellbeing and the seeking of an alternative philosophically informed way to understand care (Dahlberg et al. 2009), this is a direction of travel we are keen to contribute to. This review, therefore, aims to explore qualitative literature that relates to the transition experience from adolescence to adulthood for people living with cerebral palsy which might highlight the challenges that are experienced. The purpose of the review is to provide findings that might provoke consideration as to the social and human nature of this phenomenon in order to better inform those who work in this area and guide the design of further research.

## Method

There are many differing views as to qualitative literature review methods (Beail and Williams 2014; Grant and Booth 2009; Major and Savin-Baden 2010). One issue is whether the findings of qualitative studies can be synthesised without losing the integrity of the original research (Jensen and Allen 1996; Walsh and Downe 2006). Aveyard (2007) claims that non-systematic methods of literature review are vulnerable as authors can simply select material that is most immediately available and which they mainly agree with. A more systematic approach was therefore required, and we were inspired by the work of Britten et al. (2002), Major and Savid-Baden (2010) and especially Noblit and Hare (1988). We were drawn to the interpretive orientation of Noblit and Hare's (1988) seven stage meta-ethnographic method, including: identifying the area of interest, deciding what is relevant, reading the studies selected, determining how the studies are related, translating the studies to one another, synthesis and expression of the synthesis.

According to Hannes et al. (2011) a qualitative synthesis of research can provide robust evidence to inform practice, and meta-ethnography was considered appropriate as this allows for reinterpretation of conceptual data transcending the findings of previous studies leading to new insights relating to the phenomenon of interest (France et al. 2016). The review was carried out in order to select a diverse range of literature that had direct relevance and to avoid the possibility of selecting studies that we were simply interested in. An open guiding question, as suggested by Hawker et al. (2002), was decided upon to ensure the synthesis was driven by the included studies' findings, this was: *What do we know about transition from adolescence to adulthood for young people living with cerebral palsy and disability?*

### *Search strategy*

There is substantial literature relating to young disabled adults and those living with cerebral palsy. There are fewer that specifically focus on the phenomenon of maturing from adolescence to adulthood as a young person with cerebral palsy, and no such studies that have been carried out in the UK. The challenge was to develop a rigorous search strategy to identify relevant material which might include both the narrower and wider range of literature relating to what we know about the lives of young people living with cerebral palsy.

The World Health Organization's International Classification of Functioning, Disability and Health (ICF) (WHO 2002) was drawn upon to provide a theoretical framework in which to search and interpret the evidence. The ICF undoubtedly dominates the rehabilitation field with many research studies drawing upon this model (Shakespeare et al. 2018). We wondered, however, if there has been too much of an emphasis on the 'impairments' and 'activity limitation' dimensions of the ICF, and for us 'participation' and 'environmental factors' were key when considering what life is like living with disability. In this regard we were curious about lived experience, and participation in the world, and the understanding of health, and disability, as a social and human rights issue as put forward by Shakespeare (2012) and Shakespeare and Kleine (2013).

A systematic approach was used to select and appraise studies which were then analysed. Drawing on and adding to the keywords used by McLaughlin Carroll (2015) in her study on healthcare transition experiences of young adults with cerebral palsy, several terms for young people living with cerebral palsy were used. We searched on title and/or abstract and limited returns to focus on articles relating to disability, cerebral palsy, transition, and young people. Search terms were used on the following online databases: PubMed, Health Research

Premium Collection (HRPC), Allied and Complementary Medicine Database (AMED) and, Cumulative Index to Nursing and Allied Health Literature (CINAHL).

Published material was selected only as we were confident there was substantial literature in the public domain at an early stage of the study design. We recognise there is merit in reviewing grey literature but much of this is likely to be weak in terms of the living of life through the body and our understanding of this, whereas the published literature in relation to the review research question was substantial. As a result, 75 records were identified dating from 1/01/07 to 30/06/19. Duplicates were removed and titles and abstracts were screened to eliminate studies which did not meet the inclusion criteria, which were; peer reviewed qualitative research, published in English, studies involving adults and children with cerebral palsy or one other condition within the sample. Studies were excluded if there was a focus on profound intellectual disability, studies with children under 12 years of age, studies focussing only on parental or professionals' views. In addition, reference lists were screened, and two further articles were sourced, this inspired a hand search of two specific journals, *Child: Care, Health and Development* and *Journal of Pediatric Nursing*, which identified two more articles, bringing a total of seven studies that were included in the review.

The articles reviewed were: Freeman et al. (2018) who interviewed nine adults in Canada to find out about information received during the transition to adulthood; Bagatell et al. (2017), focus group study with nine adults in the USA exploring the transition experience; McLaughlin Carroll (2005) who interviewed nine adults in the USA about the meaning of transition to adult care; Björquist et al. (2014), focus group and interview study in Sweden with 12 young people about transition to adulthood and health, wellbeing and support needs; Larivière-Bastien et al. (2013) who interviewed 14 adults in Canada about their feelings during the transition process; Racine et al. (2012) who used an interview and questionnaire method in Canada with 14 adults about perspectives towards autonomy in relation to

healthcare and; Darrah et al. (2010) who used interviews with 76 adults in Canada about education, employment, transportation, and income schemes in relation to transition to adulthood.

The included studies are from three countries only: four from Canada, two from the USA, and one from Sweden. Participant numbers for six of the studies varied from nine to 14, with the seventh study consisting of 76 participants, ages varied considerably from 17 to 34 years. Six of the studies used interviews, two of these also used supplementary methods such as focus groups or questionnaires. One study used focus groups only. Despite the varied methods the included studies were all assessed as relating to the review question. According to Atkins et al. (2008) differing perspectives relating to the same phenomenon can be a strength in terms interpretive approach and overall synthesis if there is a link to the question under investigation.

### ***Interpretation and synthesis of the literature***

The selected papers were individually screened using the Critical Appraisal Skills Programme (CASP 2006) tool for qualitative research, and the qualitative part of the Mixed Methods Appraisal Tool (MMAT) (Pluye et al. 2011). We took an inductive approach noting anything conceptually interesting and relevant to our understanding of the general background to identify five key concepts which were then compared across studies and modified through repeated reading. The key concepts were: a want to improve quality of life, being let down, reliance on others, the young person as expert and, placed in a position of vulnerability.



The interpretation of the studies' findings and synthesis was guided by Noblit and Hare's (1988) meta-ethnographic approach and Britten et al's (2002) method. The process of synthesis was interpretive comprising of the weaving together of various aspects of the included studies. The first author made lists of words, phrases and themes through extensive journaling and expression of interpretations on whiteboards which led to the identification of commonalities and contradictions within and across the studies, these were then discussed with the other authors. This translating process helped to show how the studies related to each other and bring about the key concepts which were then linked to the findings of the original researchers, in meta-ethnography these are understood as second-order interpretations. Further synthesis through the identification of links and connections between the second-order interpretations and the concepts led to a series of analytical maps which ultimately led to our interpretations (third-order interpretations) which guided the structure of the review (Britten et al. 2002; Cahill et al. 2018).

## **Findings**

The following section critically engages the selected studies providing a detailed synthesis of the literature in relation to the third-order interpretations, which can be summarised as: 'meaningful preparation for transition', 'becoming empowered', and 'overcoming vulnerability'. The findings show that adolescents living with cerebral palsy are likely to be ill-prepared for transition to adult life, there is a want to be informed and empowered, and there appears to be much to learn in relation to the subjective experience of living through the body. There is some evidence, it seems, as to the consideration of the experience of living with cerebral palsy and the transition from adolescence to adulthood, but these are all from studies outside of the UK and with participants with varying levels of disability.

*Meaningful preparation for transition: the young people themselves arguably know best as to what might be beneficial for them. Preparation for transition then, in order to be meaningful, requires flexibility and consultation.*

Four studies produce findings that encourage consideration as to being meaningfully prepared for transition and in particular with regard to time and space and relations with others. Darrah et al. (2010) highlight the paradoxical issue within community services for young adults with motor disabilities in Canada. Their qualitative study carried out one-hour, semi-structured interviews with 76 adults, aged 20-30 years, with either cerebral palsy or spina bifida. They were interested in educational, employment, transportation and income service programmes for young adults with motor disabilities in relation to the transition to adulthood. The research question focussed on the experience of the participants in relation to independence but there is little consideration as to theory that might have informed the study design. The findings highlight the paradox that these services may aim to foster independence but in actuality have an opposing effect and call for services to be flexible and individualised for each person.

The themes are clear with relevant supporting quotes but the theory behind the data analysis is absent, as such the method lacks credibility. There is limited information as to who carried out the interviews, who did the data analysis and how this was done, raising questions as to the rigour of the study. The authors state they used standardised questionnaires but do not justify these or provide examples, nor do they explain how these were used in relation to the interviews. Following the interviews six people were invited to participate in a focus group but reasoning for this additional layer of data collection is not provided, nor is there explanation as to who was invited and how the focus group was facilitated, again raising questions as to the study's rigour. Darrah et al's (2010) findings do encourage consideration

as to how flexible transport options may support young people to live better lives, and highlights the discomfort that may be experienced when others are making important decisions about their lives, raising questions as to who knows best.

In another Canadian study, Racine et al. (2012) recruited 14 young adults, aged 18-25 years, with cerebral palsy who completed questionnaires and were interviewed to find out about their perspectives towards autonomy in relation to healthcare. The study focused on 'autonomy' but this term is not defined. Racine et al. (2012) found that views towards autonomy can vary depending on the context of healthcare and the relationship between the young person and those around them, including parents and professionals. However, no detail as to where the interviews took place and who was present is provided. The level of disability for participants appears to vary substantially and there is insufficient detail relating to communication abilities or difficulties nor to measures adopted to facilitate participation, raising questions as to the role of both the participants and the researchers in the study.

Although the methods are clearly explained there is insufficient detail regarding the study design and use of the questionnaire or consideration as to theory drawn upon. The data is presented well and relates clearly to the findings, data analysis appears to have been carried out credibly with evidence of investigator triangulation and how themes were formed. The discussion relates well to the findings and current practice leading to recommendations that are logical. The role of the research team is not examined however, especially in relation to their position and influence in the study. Similarly, the authors provide little consideration as to the study's limitations, indicating a lack of reflection on the part of the research team.

Racine et al's (2012) findings do provoke some consideration as to ways in which quality of life can be improved, possibly via enhancing autonomy but this does not necessarily mean no involvement from others. Indeed, measured input from others is welcome but the young

people want to be consulted more and there appears to be an issue with professionals liaising with parents more so than with the young people themselves.

In Björquist et al's (2014) study there appears to be some understanding of the family as being beneficial for wellbeing, but this can be somewhat suffocating too. They carried out a qualitative study in Sweden to gain a deeper understanding of how adolescents with cerebral palsy experience their own health, wellbeing and need of support during the transition to adulthood. They recruited 12 participants aged between 17-18 years with a range of motor and cognitive abilities. The participants looked forward to being adults but did not feel ready and needed further support. Family life was seen as important as there was always someone available, they ate well and went to bed on time. But this meant being controlled, having rules to follow and overprotective parents. Participants talked about the importance of socialising with peers and to have someone close to them in their life, although difficulty was experienced with finding a loving partner. The participants talked about not knowing what to do to develop relationships and that having personal assistants around all day was problematic.

The ability to manage a variety of activities of daily living was also evident. Participants usually participated in organised activities and using transport during the day was possible but problematic in the evening, as was travelling somewhere new. Partaking in spontaneous activities such as going to the cinema could be impossible and required planning. Managing personal finances could be difficult too in relation to buying expensive items. Life skills, such as cooking and ordering fast-food, were also issues as well other practical activities of daily living. The participants discussed being less physically active than they used to be, and that physiotherapy could feel meaningless. They had no experience of group activities organised for adolescents as these were provided during the day when they were at school and their

awareness about adult services was lacking as they only had a vague idea of what support was available.

Despite the above the participants looked forward to being independent and treated with respect as adults. They expressed wanting to have a family, children and someone to share their life with as well as friends. They expressed feeling not ready or willing to leave the family home and were worried about what kind of support they would need as adults. On this point they wanted more information, provided verbally and placed value also on having a coordinator who is well-known to them. Support from others who were not their parents was also wanted.

Björquist et al's (2014) study is situated well within the literature. There is a clear explanation of the methods but insufficient detail regarding methodological theory. There are hints of descriptive phenomenology but there is no evidence of reflection or consideration of the role of the researchers. More detail of the participants level of disability could be provided. Proxies were allowed to assist the participants, but their role is not outlined. There is good detail of the interview and focus group techniques, including pilot interview and example questions. There appears to be good use too of inclusive techniques to encourage participation but how this worked within the focus groups with varying levels of ability and communication is not clear. Data collection via interviews and focus groups enhanced participation but there is no detail as to how the data sets compare and to what extent this was taken into account during analysis. The findings support well the study's implications relating to the suggestion for a navigator and for a flexible and steppingstone approach to transition.

McLaughlin Carroll (2015) emphasises the expertise of the young people but that their experience as they transition to adult healthcare in the USA is one of unfamiliarity and fragmentation. The aim of this study was to uncover the meaning of transition to adult-

centred care. McLaughlin Carroll (2015) interviewed nine young people between the ages of 19 to 25 years. Participants were living with cerebral palsy and widely varying levels of physical disability, raising curiosity as to whether all had experience of the same phenomenon. The study provides a strong ethical consideration and detailed explanation of the phenomenological methodology inspiring confidence in the finding that the young people are “expert novices with evidence and experience-based expectations, negotiating new systems interdependently and accepting less than was expected” (McLaughlin Carroll 2015, 157).

McLaughlin Carroll (2015) found that young adults accepted less than was expected. This raises questions as to aspiration and ambition, particularly in countries with advanced healthcare systems where there may be increasing societal expectations as to how people with disabilities can live meaningful lives. McLaughlin Carroll (2015) describes the transition process as an important life event calling for a more considered and supported approach. She claims to have carried out a phenomenological study but the generalised consideration of her findings are arguably not in-keeping with this methodology which is more about providing a deeper understanding rather than findings that can be generalised across a population (Finlay 2006). Her implications for practice too are rather ambitious highlighting the need for nursing professionals to address transition issues, including planning and working with families. The study is helpful however as the recognition of the transition years as being an important life event encourages consideration of the many facets of a young person’s life including leisure, body image and relationships for example, and raises questions as to who knows best.

***Becoming empowered:*** *becoming an adult requires some form of empowerment; that is to be well informed is key. Even better is for those around the young person, in positions of*

*influence, to invest in naturally occurring ways in which to support youth to learn and understand about the adult world through peers and professionals.*

All seven studies produce findings about being in the world and relationships with peers, family, friends and professionals. There appears to be an existence here that is subject to the authority of others, lacking equality, and raising questions as to how the young people might become better empowered. Darrah et al. (2010), highlight the paradoxical issue within community services, their findings highlight that these services may aim to foster independence but in actuality have an opposing effect, and call for services to be more flexible and individualised for each person. The findings seem to show how the young people experience being let down in terms of educational opportunity and there seems to be a reliance on others to find employment.

Racine et al. (2012) found that views towards autonomy can vary depending on the context of healthcare and the relationship between the young person and those around them, including parents and professionals. These relationships can be beneficial when the young person's views are heard but there appears to be a power imbalance with health professionals, as a result services appear to be experienced by the young people as insufficient leaving a sense of being let down.

Larivière-Bastien et al. (2013) aimed to explore how individuals in Canada feel respected during the transition process, how values/preference are considered, and how young people are prepared with decision making. They identified several tension points relating to the transition from paediatric to adult healthcare, including fear and apprehension before the transition, lack of cooperation by providers during the transition, and feelings of abandonment after the transition. They carried out semi-structured interviews with 14 young adults between the ages of 18 to 25 years with cerebral palsy but provide little detail as to

how the interviews were carried out or the potentially powerful role of the researcher in the process. Again, there is little detail as to methodological theory nor is there consideration as to the varying levels of disability experienced by the participants raising questions as to the commonality of the phenomenon under investigation. The findings are thought-provoking however in terms of the young people feeling let down and ill-prepared for adult services.

Björquist et al. (2014) aimed to gain a deeper understanding as to how adolescents with cerebral palsy experience their own health, wellbeing and support needs during the transition to adulthood. The findings support well the study's implications relating to the suggestion for a navigator, and for a flexible and steppingstone approach to transition. This is recognised as possibly going some way to reduce feelings of being let down as there would be one nominated person responsible for ensuring the young person is informed, and further that all issues important to him/her are addressed such as relationships. However, the study's limitations impede confidence in the findings and inform little in relation to finding out more about the personal lived experience of the young people themselves.

McLaughlin Carroll (2015) provides thoughtful findings emphasising the expertise of the young people but that their experience as they transition to adult healthcare is continually unfamiliar and fragmented. McLaughlin Carroll's (2015) findings encourage consideration as to the relationships experienced by the young people, and especially with professionals and parents, which appear to be a key factor in relation to wellbeing and quality of life.

Bagatell et al. (2017) carried out a focus group study in the USA with nine young adults living with cerebral palsy aged 19 to 34 years. They set out to explore the transition experiences, perceptions, and needs of young adults with cerebral palsy. The findings inform that young people with cerebral palsy found the transition to adulthood problematic. They reported the transition process was not smooth and gradual but rather they were "thrust into



adulthood” with little preparation and that services reduced drastically when they entered adult services (Bagatell, 2017, 80). The participants highlighted the difficulty they experienced with simply being able to understand how adult services work. Frustration was experienced when not knowing who to contact in relation to services as diverse as vocational rehabilitation, obtaining a driver’s license, and liaising with disability services. They reported difficulty with navigating the fragmented and complex array of various agencies and not knowing what questions to ask, and that guidance would be helpful.

Other findings related to the participants understanding of their changing body and not knowing what is normal. They talked about balance, pain and fatigue and expressed frustration with the difficulty in locating knowledgeable practitioners. There was a desire for professionals who could help with managing the changes going on in their body. A final theme related to stereotypes and prejudice; the participants wanted to be treated as equals in society and not as inferior but this was difficult as they experienced negative reactions from others. Related to this were other troubling experiences when viewed by others as being intellectually disabled, or for their adult needs such as a desire to date and intimacy, marry and have children were not addressed.

Bagatell et al. (2017) recommend a holistic approach to encourage collaboration, with possibly a case manager or care coordinator to act as a facilitator, this might better assist young people to navigate complex care systems. They call also for practitioners to be more informed as to the needs of young people. In particular, they highlight the need to better understand the perspective of the individual and argue that the transition to adult services should not be so abrupt. There seems to be an understanding of the transition years as a period of change when uncertainty about one’s own body and the future is deeply felt. There might be a reliance on others experienced by the young people which requires careful

handling as sometimes the expectations placed on the young people is too high and access to knowledgeable practitioners is necessary but not guaranteed.

Bagatell et al's (2017) findings are not presented within the context of a clear qualitative methodology to substantiate the data analysis, nor is the role of the researchers given sufficient attention. Justification for the use of focus groups is good however in that this method allows for discussion to test assumptions but arguably is not the best to explore the personal subjective experience of individuals. Focus group locations are not provided nor is there detail as to how the focus group guide was developed raising questions as to how the environment may have affected these as well as the style and tempo of questioning.

The study recruited participants with varying levels of disability with some having significant communication difficulties but how this was facilitated is not clear. The focus group moderator appears to have appropriate experience, but facilitation was rather structured with a direct opening question and a card activity to generate discussion. Such techniques to explore personal experience could be considered as limited in that participants are not free to express unhindered views and considerations, this might be particularly so for those with communication difficulties. The process of data analysis is clearly explained, this appears to follow a classic thematic analysis but there is insufficient consideration of methodological theory informing or justifying this. Only the first author and an unnamed research assistant were involved in data analysis with little detail about their backgrounds raising questions as to the validity of the findings.

Freeman et al's (2017) Canadian study aimed to explore the information needs of young people with cerebral palsy when looking back at the transition period. Interviews with nine adults between the ages of 20 to 40 years highlighted the importance of making available timely information which is an ongoing need during the transition period. They emphasise the

importance of providing information and supporting the seeking of information in a way that is sensitive to the adult-world needs and wants of the young people, such as sexuality. There is a strong argument that the information giving process is provided in such a way that links closely to the everyday lives of the young people.

Freeman et al's (2017) study provides some detail as to methodological theory but this is limited and the role and influence of the researchers is neglected. The findings could be expanded upon to enhance confidence, particularly in relation to the participants' level of disability which appears to vary considerably. The study provides a sense too of what life might be like for young people who want to be adequately informed yet appear to rely on practitioners who may or may not be sufficiently knowledgeable about what is important for the young people themselves.

*Overcoming vulnerability: there is a want for well-designed services that need to be sensitive to the experiences of the young people. Services need to recognise their failings and the consequences of this in terms of wellbeing for the young people. There is a need for flexible services that transcends the adolescence period.*

Four studies provoke consideration as to the raw emotional journey that appears to be experienced and part of the transition from adolescence to adulthood. The want and expectation for flexibility through time and space for the young people comes across in the literature and encourages thought regarding transition and the 'becomingness' of an adult when there is a background of potential vulnerability. Darrah et al's (2010) findings show how services often, paradoxically, restrict independence and strengthen the argument for services to be more individualised and flexible. The potential for being positioned in a place of vulnerability is evident as the findings show that living with low income makes the reality

of independence impossible, and the search for employment, very often, might be experienced as hollow due to a reliance on well-intentioned government assured income initiatives. These findings raise questions as to the design of services which might better recognise the unintended consequence of placing young people in positions of vulnerability and encourage innovation to overcome this so as to enhance wellbeing and quality of life.

There is convincing evidence suggesting that maturing from adolescence to adulthood is a troubling period for young people living with cerebral palsy. Larivière-Bastien et al. (2013), for example, were interested in the transition from children to adult healthcare services, particularly in relation to ethical principles such as respect and autonomy. Their study found there was a tension regarding respect for individual's values and recognition of their decision-making capacity. This resulted in young people experiencing fear, sadness and abandonment during this period. The study does not address, or explore, other issues that may be experienced too such as intimacy and relationships. There appears to be conceptual evidence in the findings that links with other studies around the potential for the young people to be placed in a position of vulnerability. The participants seem to have confidence in paediatric services knowing and involving them which is not experienced in adult services which can lead to a fear about losing a connection with those who know them well. A factor that is compounded when paediatric and adult services do not collaborate leading, ultimately, to a sense of abrupt transition, abandonment and sadness.

The description of being "Thrust into adulthood" captures well the possible failings of the process of transition from formal children to adult services (Bagatell et al. 2017, 80). A sense of panic comes across in the findings as the transition is not smooth and there is, what appears to be a shock experienced when entering adult services, and possibly 'adulthood' too. This becoming of an adult then is accompanied with a deep and ever-present sense of vulnerability as the young people are exposed and subject to the views of others, raising

questions about equality and the possible neglect of what might be important to the young people themselves. Freeman et al. (2018) too, recognise the importance of understanding what is relevant for young people, such as relationships, and highlight the need and urgency to ensure they are informed adequately. Without effective ways to inform young people there is a danger that they will remain ill-prepared for adult life. Arguably, this places the young people in a position of vulnerability as their wants and needs are neglected.

## **Discussion**

In-keeping with meta-ethnography a line of argument now follows that links the third-order interpretations to the wider body of literature. Three Canadian studies inform on the role of professionals, the availability of services and the concepts of autonomy and independence (Darrah et al. 2010; Larivière-Bastienne et al. 2013; Racine et al. 2012). In the light of related research there appears to be concerns about the availability of therapies and what these may offer in terms of autonomy for young people (Cassidy et al. 2016; Racine et al. 2012). Yet therapy professionals are likely to be knowledgeable as to how cerebral palsy can limit mobility and self-initiated movement (Wright-Ott 2010). According to Pountney et al. (2004) assistive technologies, including specialist seating, can help improve quality of life for children and young people, and occupational therapists in particular are commonly regarded as vital in assessing for and recommending such systems (Kenny and Gowran 2004).

Specialist interventions, which may include postural management, are supported by research and recommended by NICE (2016) (Ryan 2016; Ryan et al. 2014; Ryan et al. 2009; Stier et al. 2016). Despite this, the evidence from Canada is that some professionals may provide limited interventions even though there is a positive understanding as to the importance of

supporting people in the community (Cassidy et al. 2016; Darrah et al. 2010). Whether this support contributes towards autonomy is not clear, as professionals and parents may have differing views (Racine 2012). Disturbingly it appears that some young adults in the USA may simply become accustomed to accepting less (McLaughlin Carroll 2015), whilst in the UK although sophisticated technologies are available, provision is patchy and not universal (Whizz-Kidz 2011).

It may be helpful to consider the wants and aspirations of this group in relation to the notion of 'independence', a term which appears to resonate with young people living with disability (Darrah et al. 2010). Being completely autonomous may not altogether be desired, possibly in recognition of societal barriers; but a want for greater freedom, common for most young people growing up, comes across in the literature (Darrah et al. 2010). There is an appreciation as to the benefit of therapy, but the how and why such interventions can support autonomy and independence is not clear (Cassidy et al. 2016; Darrah et al. 2010; Racine et al. 2012). The limited information regarding communication difficulties experienced by participants in these studies and the absence of this important aspect of life for the young people as a consideration indicates research teams that possibly lacked a client-centred and reflective approach. A factor that is reinforced by the limited consideration of patient and public involvement in the research designs as well as adherence to methodological theory. In the UK the principle of consultation with those living with disability in order to gather views is recommended by the NIHR (2020) to ensure research is relevant, reliable and useful.

The Canadian findings provide some detail as to the nature of difficulties that young people with cerebral palsy might encounter. Problems in relation to self-care, productivity and leisure are common, increasingly so for those with higher levels of disability (Nieuwenhuijsen et al. 2009). This may not altogether be unexpected but the findings, and third-order interpretations highlighted above, provoke curiosity as to the aspiration of young

people with cerebral palsy to partake in adult life. Self-care and mobility remain important during the transition to adulthood but the suggestion that age-appropriate interventions are necessary is indicative of a desire to be treated like adults and enjoy what adult life may have to offer (Nieuwenhuijsen et al. 2009).

In terms of models of disability, it can be seen that an aspiration for independence might require consideration of a variety of factors, as suggested by Morrow (2004), including the biological and psychological consequences of a particular condition as well as social factors including family support and provision of appropriate services. While it appears clear that those with higher levels of disability and lower levels of education struggle in multiple domains (Donkervoort et al. 2007), consideration of wellbeing and personal experience is lacking in the literature suggesting a gap in our understanding as to the lived experience of ‘becoming’ an adult for young people living with cerebral palsy.

The above Canadian studies help us to acquire some understanding, albeit limited, of perception and experience in relation to accessing and partaking in rehabilitation. Services are inconsistent however, and there appears to be a desire for more from young people, which is to be expected in countries with advanced healthcare systems. In the USA for example, Bagatell et al’s (2017) study provides rich detail as to the transition experience for young adults with cerebral palsy. Like other studies, this research highlights a problematic journey to adulthood which is described powerfully as “thrust into adulthood”, reflecting an understanding of disability as a complex phenomenon (Bagatell et al. 2017, 80; WHO 2002). This description captures well the feelings of the participants, especially so in relation to not understanding how adult services work and frustration as a result. The findings appear to be a call for practitioners to make greater effort to understand the young people’s situation and in turn help them to be better informed about the changes going on in their body. Bagatell et al’s

(2017) study is particularly interesting, as it is one of the few that provides some exploration of young people's desire to date and have intimate relationships.

To address these issues, Bagatell et al. (2017) call for a case manager or care coordinator to assist young people to find their way through complex healthcare systems. Björquist et al. (2014) suggests the same, recommending further that this person is well-known to the young person. Roebroek et al. (2009) too called for careful management of the transfer of care during the transition years for young people with cerebral palsy and spina bifida. Provision of such may also be helpful for parents worried as to who will help their child manage complex healthcare systems after their death (Burkhard 2013).

Björquist et al's (2014) study explores similar issues to Bagatell et al. (2017) but focusses on the experience of younger individuals who, at the age of 17-19 years, are in the middle of the transition period. Their study identifies issues of importance to the young people in relation to being more independent and wanting to be treated as an adult but also their interest in forging loving relationships. Their study describes what comes across as an 'emptiness' in their lives as they want to be an adult and develop loving relationships but feel unprepared for this (Björquist et al. 2014). This is an important issue as Reddihough et al. (2013) found that this group are more likely to be single. Björquist et al's (2014) study reminds practitioners of the importance of personal relationships supporting the argument for sensitive research focussing on the experience of becoming an adult. According to Wiegerink et al. (2010), it is not clear how physical limitations might restrict sexual activity suggesting that sensitive discussion of an exploratory nature might be helpful to throw light on this important area.

Bagatell et al. (2017) and Björquist et al. (2014), to some degree illuminate the experience of *becoming* an adult with cerebral palsy. Like the other studies the research takes place outside of the UK, raising questions as to the experience of growing up with cerebral palsy in Britain.



Although the detail regarding methodological theory is lacking in both, the method is clear with both using focus groups and one, Björquist et al. (2014), combining this with interviews. Both set out to explore perception and experience and provide informative findings which can be built upon with further research that allows for a focus on those in the UK living with a higher level of disability. Crucially, there is little evidence of researcher reflexivity in these studies strengthening the argument for further research of a sensitised, interpretive and reflexive nature.

The third-order interpretations are helpful especially when considering future research as we know that young people living with cerebral palsy miss out on the same life opportunities that others enjoy (Dodd et al. 2010). There is evidence to suggest that older adults with cerebral palsy can be concerned about self-image (Sandström 2007), but this may be especially so for younger adults who could be particularly self-conscious during a period when their bodies are changing rapidly and also may require some level of physical assistance to allow greater intimacy with another.

This review of the literature might stimulate curiosity for readers about living through the body and recognising the importance of intimacy and relationships for young people who live with a high level of disability. Discussion in this sensitive area may require specialist training, as suggested by Wiegerink et al. (2010), to help practitioners develop the required skills and confidence to support young people. This is especially important as we know that this group are often socially marginalised (Dodd et al. 2010). In this regard the challenge for practitioners wanting to support those with higher levels of disability arguably relates to accessing and making use of deep, rich, personal, lived experience research material to draw upon.

The above studies are helpful in order to acquire some understanding of the limitations regarding therapy and rehabilitation in relation to maturing from adolescence to adulthood for young people living with cerebral palsy. However, plenty remains undiscovered as we consider the embodied nature of living through the body with cerebral palsy in the UK, and further, ask the question what is life like for young people living with a high level of disability as they mature from adolescence to adulthood. Ridosh et al. (2011) encourages us to listen to young people's stories, raising questions as to what we can truly understand and how. According to Gjermestad et al. (2017) research relating to disabled people's everyday lives has often focussed on living conditions and living situation, and that attention as to equality rights must be central.

In the above studies, there is little consideration of disability as a human rights and equality issue, as understood by Shakespeare et al. (2018). Nor is there any significant patient and public involvement in the research design and/or analysis. This may reflect the research emphasis and culture within the health sciences which have been criticised for not sufficiently including the voices of disabled people themselves (Shakespeare et al. 2018). The view that rehabilitation practitioners might not listen is disturbing for those who value client-centred practice, but worse is to be seen as oppressive. As Shakespeare et al. (2018, 62) put it "rehabilitation is understood as a practice that is 'done to' rather than 'done with' the collaboration of the patient", which can be experienced by disabled people as the professional's voice superseding that of the patient (Finkelstein 1980). The argument therefore for qualitative research privileging the experience of the young people themselves based upon an inclusive design with a strong patient and public involvement element is compelling.

We did not want to simply review the literature in a purely narrative form as the findings could have been considered to be unreliable (Aveyard 2007). Instead, the systematic search

and meta-ethnographic approach undertaken helped us to identify the key writers and researchers in the subject area and logically synthesise the findings. We used a rigorous and transparent method that could be repeated enhancing the review's credibility. However, we have not reviewed grey literature which might have further contributed to the third-order interpretations and line of argument. By focussing on peer-reviewed, published literature the studies identified were of sufficient quality to apply a systematic approach. We are aware that this review is made up of our representation of researchers' representations of the data collected, this interpretation on our part could be considered as some way removed from the original participants' experiences (Sandelowski 2006).

## **Conclusion**

This review focussed on seven research studies, in-keeping with meta-ethnography a line of argument synthesis shows that adolescents living with cerebral palsy are ill-prepared for transition to adult life, that they want to be informed and empowered, and that there is much to learn in relation to living through the body and how we might understand vulnerability and what this might mean for young people. There is some evidence as to the consideration of the experience of living with cerebral palsy and the transition from adolescence to adulthood, but these are all from research studies carried out in countries other than the UK and with participants with substantially varying levels of disability. The systematic approach used in this review found that there are no studies that explore this phenomenon in the UK, and few that focus on the personal lived experience of those with higher levels of disability. The third-order interpretations outlined above, coupled with the dearth of literature relating to young people in the UK stimulated our curiosity as to the textual and embodied nature of living with cerebral palsy and transitioning from adolescence to adulthood within British society. Despite

the current emphasis in health and social care in the UK on independent living there is limited evidence to guide supportive services for this group. We recommend, therefore, lived experience research to provide a deep, contextual exploration as to how young adults with cerebral palsy who have lived through, or are living through, the transition period in the UK experience their lives.

**Declaration of interest statement:**

The authors declare that there is no conflict of interest.

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