

Summary of key findings



The lived experience of transition from adolescence to adulthood for young people with cerebral palsy

Key findings

- The findings include six hermeneutic stories which are striking in terms of honesty from young people bruised by their experience yet excited about the future. These reveal comfort within the family, that the transition years are neither smooth nor well planned, and there is a way of being experienced through the body which is unlike the majority. The stories show there might be an acceptance of a life that is changing in terms of time and space and positionality as participants emerge into adulthood with excitement and wonder but for which feel unprepared, leading to the following themes.
- ***The storm of uncertainty*** - this reveals an insecure existence which is lived most profoundly as being-in-the-world without adequate preparation for adult life, meaning vulnerability is ever-present, and limiting opportunity which is experienced as deeply unjust.
- ***Capsizing in a world of others*** - shows this uncertainty comes with a deep sense of difference regarding relationships with others. Relationships are desired, unavoidable, important and influential as opportunity, and meaning in life is determined by others who exert power and authority over the young people, yet seem to be so unknowing and uncaring.
- ***Securing anchorage*** - highlights the search for sanctuary which seems to alleviate a tension in terms of being heard and understood. With this came greater meaningful engagement with the world as there was belief, trust and respect. Ultimately, being heard and understood provided dignity and an acceptance of difference.

Project aim

To explore the lived experience of transition from adolescence to adulthood for young people living with cerebral palsy and in so doing inform occupational therapists, and others, as to what might promote positive life opportunities. The research question was *what is the lived experience of transition from adolescence to adulthood for young people with cerebral palsy?*

Background

When we consider the living of life with disability we know much about wheelchairs, posture and manual handling, but we know little about the lived experience for those with a high level of disability during the transition from adolescence to adulthood. Gorter et al (2011) highlights the gap between children's and adult services, and many young people living with cerebral palsy seem to find the transition from adolescence to adulthood a stressful and negative period.

There is research from elsewhere in the world but the context of growing up and becoming an adult in the UK is missing. This study, as suggested by Ridosh et al (2011), understands transition as the developmental period when adolescents become young adults whilst increasing self-management of their condition and independence.

The need to improve transition arrangements for young people with disabilities in the UK and achieve the right to be included in mainstream society was firmly placed within the context of national guidance at the beginning of the century (Department of Health, 2001). When we draw upon research from elsewhere in the world there appears to be greater awareness that an integrated and holistic approach to transition is necessary.

This study encourages an understanding of the transition years as a distinct period of time providing practical recommendations to improve the lived experience for young people.

Methodology

This phenomenological research was carried out with a method according to Van Manen (1997), and hermeneutic stories influenced by Crowther et al (2017). The design was informed by a public involvement group to ensure a high level of inclusivity and for the research to be relevant. Data were co-generated via written accounts and unstructured interviews with six participants aged between 18-25 years, living with cerebral palsy as permanent wheelchair-users.

Recommendations

Integration first, coordinator second – integrated services that straddle adolescence and adulthood appear necessary to cater for all needs across health, social care and education. Investment is recommended to ensure collaborative working between children's and adult services facilitated with provision of a specific coordinator to be linked with each young person.

Working with families, preparing for independence – there is a call from young people to be listened to and more involved in the transitioning process. Service development to work with the whole family whilst supporting independence is therefore recommended.

Strengths-based services based on equality and partnership – the findings encourage a focus on better ways to place young people at the centre of new, collaborative, integrated services across the 16-29 age range. Investment in new youth-centred, rights and strengths-based transition services, provided by well-trained professionals with an understanding of disability as a human rights and equality issue across the adolescent to early adulthood period is also recommended.

Publications

Boyle P, Stew G, Galvin KT and Vuoskoski P (2021) Living with disability in a COVID-19 world. *British Journal of Occupational Therapy*. Epub ahead of print 18 May 2021. <https://doi.org/10.1177/03080226211020993>.

Boyle P, Vuoskoski P, Stew G and Galvin KT (2020) Transitioning from adolescence to adulthood for young people living with cerebral palsy: A meta-ethnography. *Disability & Society*. Epub ahead of print 29 September 2020. <https://doi-org.ezproxy.brighton.ac.uk/10.1080/09687599.2020.1822785>.

This study, conducted in 2018-2021, received funding via a Research Career Development Grant from the UK Occupational Therapy Research Foundation

Grant holder: Paul Boyle

Copyright 2021 © Royal College of Occupational Therapists and Brighton University



Acknowledgements

Many thanks to the public involvement group, the participants, my supervisors, Professor Galvin, Dr Vuoskoski, and Dr Stew, my employer, and the Royal College of Occupational Therapists for a Research Career Development Grant.

References

- Crowther S, Ironside P, Spence D and Smythe L (2017) Crafting stories in hermeneutic phenomenological research: A methodological device. *Qualitative Health Research* 27(6): 826-835.
- Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London: Department of Health.
- Gorter JW, Stewart D and Woodbury-Smith M (2011) Youth in transition: Care, health and development. *Child: Care, Health and Development* 37(6): 757-763.
- Ridosh M, Braun P, Roux G, Bellin M and Sawin K (2011) Transition in young adults with spina bifida: A qualitative study. *Child: Care, Health and Development* 37(6): 866-874.
- Van Manen M (1997) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. 2nd Edition. London, ON: The Athlone Press.