

RESEARCH BRIEF

Health service use and experiences among adults with cerebral palsy: a mixed method systematic review

Manjula Manikandan¹, Claire Kerr², Grace Lavelle³,
Michael Walsh⁴, Aisling Walsh^{1*}, Jennifer Ryan^{1,5*}

¹Department of Public Health and Epidemiology, Royal College of Surgeons in Ireland
University of Medicine and Health sciences, Ireland.

²School of Nursing and Midwifery, Queen's University Belfast, UK.

³Institute of Psychiatry, Psychology & Neuroscience, King's college London, UK.

⁴National Clinical Programme for People with Disability, Clinical Design and Innovation
Office, Health Service Executive, Dublin, Ireland.

⁵College of Health and Life Sciences, Brunel University London, UK.

*Joint Senior author

Acknowledgements

The authors acknowledge the support from the Royal College of surgeons in Ireland (Ms Grainne McCabe) for supporting the development of search terms.

We would like to thank our Public and Patient Involvement (PPI) members Ailish McGahey, Éabha Wall, Dr. Frances Hannon, Fiona Weldon, Jean Oswell, Jennifer Crumlish, Jessica Gough, Kevin Foley, and Sarah Harrington for interpretation of findings.

We would also like to thank Dr Jennifer Fortune (Research Fellow, RCSI) for supporting our PPI meetings.

Funders

This work was conducted as part of the SPHeRE Programme under Grant No. SPHeRE/2018/1.

This study is funded by the Royal College of Surgeons in Ireland (RCSI) University of Medicine and Health Sciences through the StAR programme.



Health service use and experiences among adults with cerebral palsy: a mixed method systematic review

Executive summary

- This review summarises the international literature about health service use by adults with cerebral palsy (CP), and their experiences of health services.
- Considerable variation existed in the proportion of adults using medical and rehabilitation services, with relatively low proportion of adults using dietician and urologist services.
- The services accessed by the largest proportion of adults with CP, and accessed the most frequently, was general practitioner services.
- Adults with CP experienced both individual and health system challenges when attempting to access health services.
- Appropriate service models and education of service providers is required to meet the health service needs of adults with CP.

Introduction

Most children with cerebral palsy (CP) survive well into adulthood.¹ Adults with CP present with ageing-related complications such as functional decline, balance problems, fatigue, pain and falls, in addition to their CP.²⁻⁴ Adults with CP experience increased risk of non-communicable disease compared to those without CP⁵ and may have ongoing needs for medical, rehabilitation and support services.⁶ However, most services that specialise in CP are provided to children and not adults.⁷ Therefore this review aimed to determine the proportion and frequency of adults using health services, and explore the experience and perceptions of health services for adults with CP.

Methods

This mixed-method systematic review was conducted following the Joanna Briggs Institute (JBI) guidelines for mixed methods review.^{8,9} The findings were then integrated using the Anderson and Newman model of health care utilisation.¹⁰ The review methodology is explained in figure 1.

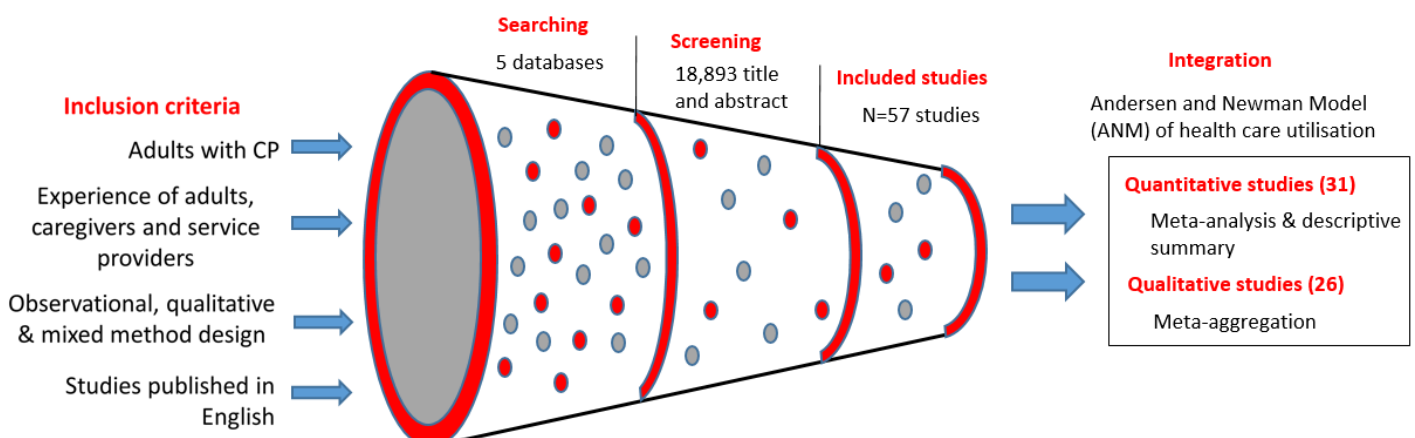


Figure 1. Review methodology

Results

- 31 quantitative studies of health service use by adults with CP and 26 qualitative studies of related experience and perceptions of health service were included in the review.
- Over a 12 month period, the majority of adults used general practitioners (GP; 84% and 404 visits per 100 person-years), followed by dentist (65%), physiotherapy (44%), hospital (33%), emergency department (28%), occupational therapy (27%), rehabilitation specialist (22%), orthopaedic surgeon (16%), speech therapist/pathologist (16%), psychologist/psychiatrist (11%), neurologist (11%), urologist (7%) and dietician (7%) services.
- Adults experienced challenges with the transition from children's to adults' services, environmental or physical barriers to accessing services, lack of knowledge and experience among service providers about CP, increased needs associated with ageing that were not well recognised, and challenges in navigating a fragmented health system.
- Caregivers played an important role in supporting adults to access services with the minimal support available.
- The integrated findings highlighted that adults' personal factors, resources and needs were both positively and negatively associated with health service use. Contextual factors, such as the health care system and environment, were a barrier to health service use highlighting the lack of equity in service provision for adults with CP.

Conclusion

- The review showed that the largest proportion and highest rate of health service visits were for GP services.
- Adults faced challenges as they transitioned from well-established paediatric multi-disciplinary services to fragmented adult services.
- Variation and lack of equity in health services for adults with CP was evident.

Recommendations

Research implications

- There is a need for consistency in reporting of health service use among adults with CP, particularly regarding the time period over which the health service use is studied.
- Studies should examine the wide range of factors associated with health services among adults with CP.
- Qualitative studies exploring service provider perspectives, experiences of mental health services by adults with CP and recommendations for ideal service delivery models are warranted.

Clinical implications

- Adults with CP need coordinated health services provided by a multi-disciplinary team.
- Adequate training for service providers to understand and meet the needs of adults with CP is important for effective service delivery.
- Collaborative working relationships with paediatric services may facilitate successful transition to adult services.
- System-level changes and clear care pathways are needed to ensure that adults with CP can access the health services they need.

References

1. McConnell K, Livingstone E, Perra O, Kerr C. Population-based study on the prevalence and clinical profile of adults with cerebral palsy in Northern Ireland. *BMJ Open*. 2021 Jan 1;11(1):e044614.
2. Ryan JM, Cameron MH, Liverani S, Smith KJ, O'Connell N, Peterson MD, et al. Incidence of falls among adults with cerebral palsy: a cohort study using primary care data. *Developmental Medicine & Child Neurology*. 2020 Apr 1;62(4):477–82.
3. Bottos M, Feliciangeli A, Sciuto L, Gericke C, Vianello A. Functional status of adults with cerebral palsy and implications for treatment of children. *Developmental Medicine & Child Neurology*. 2001 Aug 1;43(8):516–28.
4. van der Slot WMA, Nieuwenhuijsen C, Van Den Berg-Emons RJG, Bergen MP, Hilberink SR, Stam HJ, et al. Chronic pain, fatigue, and depressive symptoms in adults with spastic bilateral cerebral palsy. *Developmental Medicine & Child Neurology*. 2012 Sep 1;54(9):836–42.
5. Ryan JM, Peterson MD, Matthews A, Ryan N, Smith KJ, O'Connell NE, et al. Noncommunicable disease among adults with cerebral palsy. *Neurology*. 2019 Oct 1;93(14):e1385.
6. Pons C, Brochard S, Gallien P, Nicolas B, Duruflé A, Roquet M, et al. Medication, rehabilitation and health care consumption in adults with cerebral palsy: a population based study. *Clinical Rehabilitation*. 2017 Jul 1;31(7):957–65.
7. McDowell BC, Duffy C, Parkes J. Service use and family-centred care in young people with severe cerebral palsy: a population-based, cross-sectional clinical survey. *Disability and Rehabilitation*. 2015 Dec 4;37(25):2324–9.
8. Lizarondo L, Stern C, Carrier J, Godfrey C, Rieger K, Salmond S, et al. Chapter 8: Mixed Methods Systematic Reviews. In: Aromataris E, Munn Z, editors. *JBIManual for Evidence Synthesis [Internet]*. JBI; 2020 [cited 2020 Nov 2]. Available from: <https://wiki.jbi.global/display/MANUAL/Chapter+8%3A+Mixed+methods+systematic+reviews>
9. Stern C, Lizarondo L, Carrier J, Godfrey C, Rieger K, Salmond S, et al. Methodological guidance for the conduct of mixed methods systematic reviews. *JBIM Evidence Synthesis*. 2020;18(10).
10. Andersen RM. Revisiting the Behavioral Model and Access to Medical Care: Does it Matter? *Journal of Health and Social Behavior*. 1995;36(1):1–10.

Contact

 @Manjula_M_K_N

manjulamanikandan@rcsi.com

