

PLAIN LANGUAGE SUMMARY

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

INTRODUCTION

We know that most children with cerebral palsy (CP) live well into adulthood. We also know that adults with CP are at an increased risk of having chronic conditions (e.g. heart disease, arthritis, diabetes, and stroke) compared to those without CP. This means that they may have ongoing needs for medical, rehabilitation, and support services.

However, most services that specialise in CP are provided to children and not adults. Therefore the aim of this review was to find out how many adults with CP accessed health services, how often they use health services, and what were their experiences of trying to use health services for adults with CP?

FINDINGS

- We found 57 studies about adults with CP from 11 different countries. When we added up all of the adults with CP that took part in these 57 studies we counted 14 300 people.
- Over a 12 month period we found out that the most commonly used health service that adults with CP accessed was general practitioner services.
- This was followed by going to the 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 – all over a 12 month period.

- Adults with CP experienced a lot of difficulties with changing from children's to adult services. These difficulties included 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 known, and challenges in trying to use a health system that is very complicated. People who supported adults with CP played an important role in supporting adults to access services with the minimal support available.
- This study highlighted the many difficulties and differences that adults with CP experience when trying to access a health service that adults with CP needed.

WHAT ARE THE NEXT STEPS?

- Adults with CP need access to coordinated health services provided by a multidisciplinary team.
- Service providers need to complete relevant training to understand and meet the needs of adults with CP, which is important for effective service delivery.
- Collaborative working relationships with paediatric services may enable young adults with CP to move from paediatric services to adult services.
- System-level changes and clear care pathways are needed to make sure that adults with CP can access the health services they need.