Addressing Primary Health Care Service Gaps for Transition-Aged youth with Cerebral Palsy (CP)

Project Summary

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WHAT WAS THIS STUDY ABOUT?
Our research focused on gaining an in-depth understanding of the enablers and barriers to primary health care services for transition-aged youth with CP, and to inform strategies to improve access to primary health care services for this population. Youth are expected to transition to the adult system at 18 years of age.

WHAT DID WE DO?
We aimed to interview 15 family physicians to gain an understanding of their perspectives and experiences with providing primary care for transition-aged youth with CP. Due to difficulty with recruitment of family physicians, we expanded our study to include the perspectives of parents, transition-aged youth with CP, and Pediatricians; partners in the circle of care. Interviews are currently in process.

We made connections with the Child and Adolescent Health Committee, the Developmental Disabilities committee and the Physicians of Ontario Neurodevelopmental Advocacy Network to further highlight the need for improved primary health care services for transition-aged youth with CP.

IMPACT FOR CLIENTS, FAMILIES AND CLINICAL PRACTICE
Our goal is to improve access to primary health care services and ultimately outcomes for transition-aged youth with CP by sharing the knowledge gained from this research at provincial and national forums and through publication.

SHARING OUR WORK
- Abstract submission to the BRI Symposium
- Manuscript submission for publication
- E-newsletter
- Slider story on the Holland Bloorview Webpage
- CP parent talk group session

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WHAT DID WE LEARN?

- Building connections is key to accessing family physicians and community resources
- Connections take time to develop
- Linking with associations and committees with similar interests, advances research
- Gaining multiple perspectives from the entire circle of care is essential
- Family leaders provide exceptional perspective and linkages for research
- Others are interested in advocating for and improving transition to primary health care services for transition-aged youth with CP

NEXT STEPS?

- In Phase II, we will continue to recruit participants from the broader circle of care (Family Physicians, Pediatricians, parents and transition-aged youth) to gain more insight into the enablers and barriers to primary health care services for this population
- We will share the knowledge gained from Phase I and Phase 2 interviews to our broader community partners and co-create recommendations for improving the transition process at organizational, provincial and national forums
- Sharing our findings will highlight the need for improved transition planning and partnerships to strategically address barriers that limit access to primary health care services for this population. These activities will enable transition-aged youth with CP to continue to reach their fullest potential as adults

WHO ARE WE?

Erin Brandon: Nurse Practitioner - Paediatrics, Complex Care Neuromotor and Rett Syndrome Pathway Clinics, Child Development Program (CDP)
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