Addressing Primary Health Care Service Gaps for Transition-Aged Youth with Cerebral Palsy

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Intro: Youth with childhood-onset disabilities experience challenges with accessing age-appropriate primary health care services as adults. Especially those with cerebral palsy (CP) GMFCS IV & V due to the complexity of their medical needs.

Methods: Qualitative descriptive design. Semi-structured interviews with 16 participants (4 adults with CP, 4 parents, 4 Pediatricians & 4 Primary Healthcare Physicians [PHCP]) from the Greater Toronto Area. Thematic analysis guided data collection & data analysis processes.

Outcomes:

Data analysis revealed agreement across all stakeholders with respect to: accessibility, overlap in care, lack of expertise, and funding barriers when receiving or providing primary care services to young adults with CP.

Discussion:

This is the first study to explore multi perspectives to identify the enablers and barriers to primary care transition for youth with CP. This work highlights the need for accessible clinics, overlap in care, expertise/training in complex medical care and funding allocation to improve service connection for this fragile population.

Accessibility, overlap in care, lack of expertise and funding barriers impact the transition of primary care services for transition-aged youth with cerebral palsy



Quotes

Accessibility

"Her Pediatricians' office was not wheelchair friendly. It was tight, It was definitely tight to get her wheelchair in. When she was young it was ok but as she grew so did her wheelchair. Her Pediatrician would often examine her in the waiting room" (parent 2).

"a good thing with the 'family health team' is that it's like accessible. So I can go there like on my own and not with my parents" (Adult 2)

Overlap in Care

"...at least connect with the family doctor, start having visits there, start transferring information and you can even have some period where simultaneously you're seeing still your pediatrician...then fully transition to the family doctor" (PHC physician 3)

Lack of expertise:

"Where I find it uncomfortable is when they need to access the adult services for the medical issues... it's just that I'm just not as familiar with the adult services". (P 4)

"They (PHCP) needs to have the experience and knowledge about just CP" (Adult 4)

Funding Barriers

"I think if you have a population which is chronically of high-need then you really have to go with a model which doesn't depend on having averageneed patients to maintain its viability...So if you're talking about a group that is well outside the average you have to have a model which can adapt to that".

(PHC physician 1)