"I felt like we'd just been cut off": the transition to adult healthcare for people with profound intellectual and multiple disabilities

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Background:

Young adults with Profound Intellectual and Multiple Disabilities (PIMD) have significant, complex health care needs, which are less likely to be met after they transition from paediatric to adult health services. This paper explores healthcare transition to adult services for people with PIMD and their family supporters in Australia.

Methods:

12 pairs of participants (a parent decision-maker and a young person with PIMD) and 6 parents (total of 30 participants) were interviewed in depth about the transition to adulthood, including in healthcare. Experiences of healthcare were analysed using a grounded thematic approach.

Results:

Transition into adult health services was complex and difficult for these young people and families, with significant decreases in access, availability, type, and quality of health services and supports. Parents took on health “care manager” roles for their young adults, finding, coordinating, and advocating for access to health care services and supports. Adult health services were poorly equipped to recognise and accommodate these supportive relationships.

Conclusion:

These findings suggest that significant others, by necessity, fill some of the systemic gaps in accessing, coordinating, and managing adult health care for young people with PIMD. This does not address their significant unmet healthcare needs, and not all young adults with PIMD have supporters with the capacity and capabilities to do this care management role. Young people with PIMD require specialised support, case management, and person-centred coordination within and between adult health services, as well as better mechanisms to recognise the complexities of their supportive relationships and healthcare decision-making.

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