

Health Inequities Experienced by People with Developmental Disabilities

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Introduction

Developmental disabilities (DDs) are chronic conditions that begin in childhood and are likely to be life-long impacting the ability to live independently as an adult (CDC, 2017). DDs may include Autism spectrum disorder, Down syndrome, intellectual disabilities, Attention-deficit hyperactivity disorder, and cerebral palsy, among others. Young persons with DDs experience increased difficulties in accessing quality health care as they transition from pediatric to adult healthcare services.

Young persons with DDs have complex health care needs. As they grow older, they are more likely than their peers without disabilities to develop chronic health conditions (Thomas et al., 2011). During emerging adulthood (period from adolescence to young adulthood) these individuals are at increasing risk of developing health problems. During this period, they and their families face increased economic, social, health and mental health related challenges. Studies from various countries, including Canada, found that people with DDs are poorly supported by healthcare systems and services (Fisher, 2004; Krahn et al., 2006; Scheepers et al., 2005; Sullivan et al., 2011). Although nurses are strategically positioned to provide care to individuals with DDs, they are not fully equipped with the skills, awareness, supports, and education for this active care role. The major challenges nurses face in providing good care to this population include time constraints, communication challenges and insufficient education and training (Khanlou et al., 2019).



Our study


The overall purpose of our project is to develop guidelines and recommendations to guide nurses and other service providers as how to deliver effective quality nursing care for persons with DDs.


In this Information Sheet, we report on the findings of a survey conducted with nine young adults with DDs, (with the assistance of their caregivers, as needed) to gather the views and perceptions of these youth about their nursing care experiences. A trained interviewer conducted the surveys via an online video platform (Zoom Pro). The participants were six females and three males, between the ages of 16 and 25 years. The DDs impacting these youth included Autism, ADD, cerebral palsy, cortical visual disabilities, global developmental delay, PDD-NOS along with a gene mutation, Fine-Lubinsky syndrome and Dravet syndrome.

In these survey sessions youth told us about i) their health, ii) quality of partnership and collaboration between nurses and young adults with DDs and, iii) about the quality of nursing care and support that they have received.


What is person-and-family-centred-care?


Service providers, people with DDs, caregivers, advocates, researchers, and policy makers have recognized the need for a person-and-family-centred-care (PFCC) approach (Kirkendall et al., 2012).


 PFCC is a collaborative approach to healthcare provision and emphasizes working with the individual and family from service planning, delivery to evaluation.

 PFCC provides care from a holistic approach, including people's environmental, intellectual, emotional, physical, cultural, and spiritual needs.


Person-and-family-centred-care core concept:

 Respect and dignity: listen and honor the perspectives of the persons with DDs, as well as their family's perspectives and choices. Incorporate their values, beliefs, culture, and knowledge in the services provided.

 Information sharing and communication: healthcare providers communicate and share accurate, useful, and necessary information. Involve persons with DDs and family in the healthcare process with full participation in decision making.

 Collaboration: mutually beneficial partnership and collaboration between person with DDs and their family, and healthcare providers in promoting quality care (Johnson et al., 2008).

The benefits of person-and-family-centred-care:

 Supports self-determination to control over their own lives (Holburn, 2022). Recognition, trust, respect, promoting empowerment, fewer misunderstanding, and greater satisfaction with services and better health outcomes (American Academy of Pediatrics, 2012).

What did we find?

- Young adults with DDs have increased health care needs and require more time and more resources.
- Nine participants rated the quality of nursing care that they had received as Excellent/Very Good. One of them rated it as Good/Fair.
- Nursing care provided for people with DDs in some provinces in Canada is better than in other jurisdictions, but it is not enough.
- New nurses had insufficient knowledge to address/support the disability-related caring needs of people with developmental disabilities and the family caregivers had the additional burden of directing the care for their child with DDs in their homes.

A participant commented with regards to other jurisdictions "I am appreciative of the care and services we get but there is a gap" (P9).

Regarding person-and-family-centred-care, one participant stated "clinic nurses (at a private clinic) tried very hard. Listened, tried to understand what I was going through. After so many bad experiences, it was a breath of fresh air" (P3).

What did we find?

- Most of the young adults with a developmental disability lived with family in their home except for one who lived in a group home. The group home was not a choice but the only option, as the family could not afford the cost of home-based DDs care.
- In the survey, young adults rated their care as "poor" because of the costs of receiving it. Some young adults and their caregivers report paying for their healthcare services out of pocket.
- Some young adults reported poor inpatient program experiences. Their perspectives and feelings had been disregarded, and their opinions not taken seriously.

One participant's mother commented on the costs of DDs care: "instead of surrendering my child to a group home, I would have wanted to be able to afford a caregiver in the home. I could have him home, putting him in respite at 6 years of age was a difficult decision "(P5).

One mother speaking about access and cost of care said that "when I travel it costs me \$250 per night (paid out of pocket), hence I could not work outside of home or be away for more than 4 days because it costs me a lot" (P9).

One 16-year-old young adult with a DD said: "we are not able to communicate our problems to the nurses and healthcare staff.... nurses and doctors believe they know more and do not take us seriously" (P3).

What is known in the literature about the cost of care for DDs

- Children with DDs utilize 1.8 times more hospital care (inpatient and emergency department visits), as compared to children without DDs, which is reflected in higher annual costs (Lindgren et al., 2021).
- Health conditions among young adults with DDs lead to 6 times more hospital admissions and longer hospital stays (Balogh et al., 2005; Young et al., 2005; 2007).
- In Canada more than one in three adults with DDs require high-cost health care (Lunsky et al., 2019).
- For 36% of adults with DDs the health care expenditures are greater than \$2,610 CAD annually (Lunsky et al., 2019).

Regarding direct communication one mother facilitating her young adult with a DD said "not enough happens.... (care providers) assume he does not understand...when he is throwing up, he needs comforting and directly communicating with him would help" (P6).

Recommendations

- Individuals with DDs require person-centred care. Nurses should be trained to provide tailored and personalized care.
- Devote more money to respite care for family caregivers and toward more hours of home care for those with DDs.
- Provide nurses with specific training and information about the needs of young adults with DDs. The more information they have, the better nurses can understand the strengths and challenges of these young adults.
- Improve informal communication and assessment tools to inform person-and-family-centred-care nursing care of YADDs (Khanlou et al., 2022).

One participant commented that “nurses in the hospital are amazing, but they should have more opportunities in their education to learn about YADD as a group” (P6).

Selected References:

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ABOUT THE INFORMATION SHEET

This information sheet is part of a series of information sheets produced at our Office and in relation to Intersectional Approach to Families, Immigration, Gender, and Disability Research Program. It provides some of the key findings from our study titled *Toward a Nursing Practice Competency Framework: Person-and-family-centred-care nursing care for persons with developmental disabilities*.

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