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Disability Rights in an Ableist Health Care Environment: How do Women with Disabilities Understand and Address Systemic Barriers to Preventative Community Health Services?

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This study sought to explore how women with disabilities (WWDs) understand and address their rights to preventative health care within a context of systemic barriers. In addition, the study sought to explore the impact that these barriers have on the lives of WWDs, in terms of their own lived experience. A preliminary review of literature revealed numerous barriers to health care services for WWDs across jurisdictions, despite provisions for equal access made available through human rights and disability legislation.

The study consisted of interviews of five women with disabilities who had previously participated in a barrier-free cancer screening clinic day. The interview questions were generally divided into two parts:

- 1) Types of barriers experienced in accessing health care and how the WWDs felt about it.
- 2) WWDs' understanding of causes of barriers, their understanding of rights, and decision to seek remedy/lodge a complaint.

The interview data confirmed the existence of multiple barriers to health care for WWDs. Two primary themes arose from the data: health care ableism and rights consciousness. The data suggested that issues of health care access for WWDs centered around their relationship with their rights to access, rather than their experience with the access barriers.

A model of rights consciousness was developed, composed of three stages of identity:

- 1) Imposed Identity: identity is externally imposed by society's pre-judgment of WWDs.
- 2) Formative Identity: individuals are questioning and self-reflective; disability is only one component of identity; they are unsure if societal exclusion is appropriate.
- 3) Integrated Identity: there is cohesive inclusion of disability into one's identity; ability to assess whether one has been inappropriately excluded from the mainstream.

Based on this model, the stages of identity development influence WWDs' recognition of exclusion and rights infringement related to health care, as well as their decision and degree of support required to act upon it.