

Sex, pregnancy and living with disabilities

May 2 2016, by Christine Phelan Kueter



How regularly do women with disabilities receive pelvic exams and Pap tests? Primary care related to their sexual and reproductive health? And how often do they experience unintended pregnancies in a country where roughly half of all pregnancies are unplanned?

Inspired by a former patient living with cognitive disabilities who suffered long-term consequences of untreated [sexually transmitted infections](#), University of Virginia nursing professor Jeanne Alhusen's study is the first of its kind to assess contraception access and experience of unplanned pregnancy among women living with physical, sensory or cognitive disabilities, with an ultimate aim to inform initiatives that could boost this population's ability to access reproductive health services in the long term.

"Contrary to what many believe, many women living with disabilities have active sexual lives," said Alhusen, who received a \$454,000 grant from the National Institutes of Health to lead the two-year study. "It's high time that we ensure their reproductive health access as well by understanding what issues they face."

An estimated 1 million American women of childbearing age live with a physical, sensory or cognitive disability that impacts their ability to care for themselves, work outside the home, live independently or be mobile. Despite some advances in this group's inclusion into mainstream society, enormous gaps exist related to their ability to access affordable, timely and high-quality reproductive health care.

Health care provider discomfort and inexperience, guardian protectiveness and patients' own information and education gaps all inhibit these women's access and ability to receive quality reproductive health care, Alhusen said. With the closing of many American mental institutions, the advent of group homes, a more inclusive employment environment and the passage of the Americans with Disabilities Act, it's incredibly short-sighted to ignore the sexual health of those living with disabilities at a time when so many are such a part of mainstream society, she said.

"While the association between the lack of access to family planning and

unintended pregnancies is well-established, it's not clear that women with disabilities are as able as other women to benefit from these services," which may suggest the need "for specially designed services or initiatives to improve their access," Alhusen said.

Drawing from the National Survey for Family Growth dataset, which includes a subset of 950 women living with varied disabilities queried about family planning and [unintended pregnancy](#), Alhusen will determine whether women with disabilities who received [family planning](#) information were less likely to experience an unintended pregnancy than those who did not receive such care. With help from a nine-member community advisory board of women living with diverse disabilities who have given birth, Alhusen and her colleagues will receive input on all aspects of the research process before recruiting a wider group of approximately 50 urban and rural women living with diverse disabilities for qualitative interviews focused on unintended pregnancies, exposure to violence and discrimination. These women will also be asked to share their experiences about social and economic hardship, along with physical factors that might inhibit their access to [reproductive health](#) services, like transportation, provider availability or rural isolation.

The project – which includes a multi-disciplinary collaboration between nursing, psychology, sociology and psychiatry researchers – began April 1, with findings due by spring 2018.

"Family planning – which enables women to strategically space, plan or delay pregnancies – has been called one of the greatest public health achievements of the 20th century," Alhusen said. "Our hunch is that women living with disabilities are more often going without access to these services, a factor which critically and often adversely impacts their long-term health outcomes, ability to parent, and their child's long-term social, physical and emotional success."

Provided by University of Virginia

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