Breast and cervical cancer screening among women with disabilities: Using a Community-Engaged Student Assistant (CESA) to strengthen research in the community

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Background
Health disparities in cancer morbidity and mortality are important public health problems. The National Cancer Institute reports that lower rates of cancer screening are among the factors contributing to more advanced disease at diagnosis and higher cancer death rates. As many as one in five women in the United States are living with disabilities, and women with disabilities often lack access to health services. Access to primary care and cancer screening services may be very limited, especially among low-income women. In Alaska, the influence of climate, geography, and public transportation may intensify problems with access to screening.

Methods

Study Design
- Mixed methods approach
- Structural barriers framework (e.g., economic, social, policy, organizational)
- Criterion-based purposive sampling
- Data collection via in-person interviews with an investigator-initiated survey instrument and a standardized Quality of Life assessment tool

Study Population
- Women who have a disability and are living independently in the community
- Ages 18 – 65 years
- Annual Income < $20,000
- Able to respond to questions in English
- Reside in the Anchorage area

Recruitment
Recruitment involves our community partners, along with the following targeted recruitment plan:
- Piloting an educational intervention targeting direct service professionals working with women with disabilities;
- Enlisting Health Women Alaska to encourage their clients to participate in the study. Healthy Women Alaska was designed to meet the needs of women with disabilities in Alaska by adapting an existing curriculum to promote cancer screening awareness, knowledge, and action among direct service professionals; and
- Encouraging direct service professionals to collaborate to increase awareness and participation in health promotion/prevention activities among the women they serve.

To increase study recruitment and enrollment, a Community Engaged Student Assistant (CESA) from the UAA Center for Community Engaged Learning collaborated with the project team. The role of the CESA entailed the following:
- Meeting with staff in community agencies who coordinate case management services;
- Engaging case managers’ interest and collaboration in increasing awareness and participation in health promotion/prevention activities among the women they serve; and
- Participating in Healthy Women Alaska training with case management staff.

Lessons Learned
The challenges of studies targeting hard-to-reach groups have been noted by multiple investigators. Low-income women who experience disabilities living in the community may be hidden from traditional recruitment activities. Creative, flexible strategies are needed to recruit participants from this important group of women. Collaborating with a CESA champion as a member of the research team extended our community-based recruitment efforts.