

Motivated into action: Gateways project co-investigators Nancy Barry and Linda Muraca are streamlining cancer screening for women with disabilities.

Banishing barriers

When women with mobility disabilities told Laura Muraca, MN oT7, about their frustrating challenges trying to get cancer screening, she was shocked. That's how project 'Gateways' was launched

By Lucianna Ciccocioppo

Linda Muraca, RN, MN oT7 expected the usual questions and concerns from women during one of her AstraZeneca Breast Health presentations that was held at the Centre for Independent Living in Toronto. What she didn't expect were the frustrating stories of deterrence to screening from these women with disabilities.

"It was very disconcerting," said the nurse clinician from Mount Sinai's Marvella Koffler Breast Centre. "They told me, 'Well, I'd love to go for screening, but no one could get me on the table, or the mammogram machine couldn't go down.'" She was shocked, but thought it was an isolated case of things gone wrong.

In a subsequent presentation at CILT, "the stories were even more detailed," says Muraca. She thought: "We need to do something; someone needs to be informed about this." Disability advocate Nancy Barry, BA oT5, completely agreed. CILT's peer support and volunteer coordinator, who has cerebral palsy, says her first mammogram was painful and humiliating. "The technician had never screened someone with a disability. She had no idea how to 'handle' me." It was Barry who had invited Muraca to speak. The two were quickly motivated into action.

Backed with a grant from the Canadian Cancer Society, support from CILT and Bloomberg Faculty of Nursing qualitative research expert Dr. Jan Angus, RN, BScN 7T8, PhD oT1, Muraca led a needs-assessment project as part of her final MN practicum. She and Barry ensured women with mobility disabilities were part of the research questions, not just part of the research. "It made the research richer and appropriate," says Muraca.

Aptly named "Gateways to Cancer Screening," the project ran five focus groups, four in downtown Toronto and one in Peel region, for a diversity mix. Women with mobility and sensory disabilities, women from various multicultural groups and from low-income households were consulted. The methodology was participatory action research, selected to guarantee knowledge transfer from the Gateways Project to cancer-screening services and health-service providers, and

to foster practice change and make it more inclusive.

"This was extremely important for the women because many of them had participated in other projects where the final report sat on a dusty shelf and nothing changed," says Muraca. With a comprehensive background in oncology nursing, an understanding of patient experiences, and an expertise in community health promotion, she wasn't about to let that happen.

The conclusions showed there was work to be done. The biggest deterrence to screening for women with disabilities was not what you think—architectural barriers. Repeatedly, participants placed their bodily experiences, their vulnerabilities and embarrassments at the top of their list of frustrations.

"I know that at my doctor's they do have a bed that can be lowered. But I transfer myself... I can see that if I couldn't do it myself, they wouldn't be able to do it for me. It would mean having to ask someone else to go with me. And who wants to have someone else in the room when you're having a Pap smear?"

"These women are unbelievable self-advocates for their health; they do a ton of work to avoid coming down to a hospital... because it's complicated," says Muraca. The number of steps and potential constraints are numerous: an accessible bus or taxi booking, an appointment that starts and finishes on time, accessible exam tables, accessible change rooms, accessible washrooms, and most importantly, an attendant to help these women in and out of their wheelchairs. There usually isn't one, which means waiting for another available technician to assist, which means waiting for another bus booking, since the scheduled pick-up will be missed. It's a frustrating chain of events that can escalate and add to screening anxieties. It means women with disabilities are unlikely to return for another screening.

"These are important things to find out because these women have the same risks of developing cancers as the rest of us but getting treatment for them would be more difficult," says Muraca. She talks of a disabled woman whose mother died from colorectal cancer, and she





Banishing barriers abroad

A study mapping access to preventative health care in Canada is making its way around the globe as a successful method to help banish barriers to cancer screening for women.

Bloomberg nursing professor Dr. Jan Angus interviewed 35 Canadians from diverse backgrounds about how they were diagnosed and their activities involved in seeking treatment. She then made maps of what had occurred.

Turns out, it wasn't always as simple as going from point 'A' to point 'B.'

"Many women had very effective access to health care, but some women had quite tortuous pathways," says Angus. "It may have taken them several months to connect with a health-care provider, or the health professional didn't think they had cancer and did not refer the patient. Some women had very busy lives and did not keep pressing the issue. There were many factors at play."

These preliminary findings were published in a Brazilian journal, *Texto Contexto*, and translated into Portuguese and Spanish. The study piqued the interest of a nurse researcher in Spain, says Angus, and Clara Juando is currently replicating the project in Barcelona, a city with a large immigrant population.

"Part of my study found new immigrants to Canada have more difficulty accessing health-care providers, for multiple reasons: they may not know where to go for help or they are still not eligible for provincial health insurance (a three month wait); they may have language issues; or may not have the same level of breast cancer awareness that the same population already residing here may have," says Angus.

But the international connections don't stop in Spain. The same study is going on in Nicaragua, where medical professor Dr. Clara González is investigating barriers to cervical cancer screening, thanks to the collaborative efforts of Bloomberg nursing professor Dr. Denise Gastaldo and Dr. Lawrence Paszat, of the Faculty of Medicine.

Preliminary data should be available early spring, says Gastaldo. "We'll take the results to the ministry of health in Nicaragua and to municipal governments to make women's health a priority, and start discussions with policy-makers and politicians about what the best alternatives are to change these patterns." ♣

too died of it. She wasn't screened regularly, says Muraca. "It could have been for a number of reasons, but I wonder—was it the ease of getting checked all the time? Was it missed? Are these women going to present at later stages because of these issues?"

"I've had a colonoscopy three times. They gave me a bottle (which weighed more than I do!) and I know there are other delivery systems that don't require this endless drinking. My father was given three little containers to drink and it worked on him. My suggestion is, because it's difficult to get off from a wheelchair, that doctors be more informed on the elimination processes available."

Muraca wants to streamline the screening process to see disabled women in as frequently as other women for regular checks. "If we're picking up problems earlier, it will save health-care resources down the road, and save on human suffering too." More importantly, health-care providers and clinical staff need disability training, so they can complement the accessible exam tables, screening technology and on-site attendant care. She wants to make screening accessibility a major issue like it was for restaurants and other public venues.

The Gateways Project landed her a 2008 Masters Student Award of Excellence from the Council of Ontario University Programs in Nursing. Her co-investigator Barry won an Access Award from the City of Toronto. The next stage is to hear from the health-care side on screening women with disabilities, create DVDs depicting the troubling scenarios the women described to help train health-care providers, and then evaluate pre- and post-DVD to see what practice changes occurred.

"Some women talked about positive experiences: polite receptionists who asked if any special accommodations were required... at Mount Sinai if you tell the receptionist you are disabled, an extra half hour is booked for you, and you get an extra technician."

Something as simple as better communication is key, says Muraca. "We need to be asking, and they need to be telling." Just one way to banish another barrier. ♣