

Service, Support and Success

# The Direct Support Workers Newsletter

## Not Skirting the Issue:

Discovering Ways to End Poor Health Care for Women with Disabilities



By: Isabella Adjei-Dankwah and Yona Lunsky

When reading Marie's file I noted that, even though she was 55 years old, she had never had a mammogram. I wondered why. We have a new study showing that the reason why is simple: These important procedures are not always done when a woman has a disability. In this article, we're going to tell you what the research shows regarding health care for women with disabilities, and propose some suggestions on what we can do about it.

### **What can we do to help encourage the women we support to be healthier and more comfortable getting medical care?**

Every woman has a right to proper women's health care to prevent disease. The Health Care Access Research in Developmental Disabilities Program (HCARDD, <https://hcardd.ca>) has found that, in this regard, not all women are treated equally. Women with developmental disabilities are less healthy than women without disabilities and they don't get the same level of medical care. We looked at the health of over 20,000 women with developmental disabilities in Ontario, and compared these women to men with similar disabilities, and to women without disabilities.

Here are a few important findings from the HCARDD work that are very relevant to us as staff:

Women with developmental disabilities are more likely to have health problems like diabetes than men with developmental disabilities, and women in the general population.

Women with developmental disabilities are less likely than other women in Ontario to have a pap smear which is how doctors screen for cervical cancer. They are also less likely to get a mammogram to detect breast cancer. Why does this matter? If we have health problems and they aren't detected early, small problems can become big ones, and can even lead to death. Every woman has a right to get health care early before problems become too serious.

## A Great Place to Start

### **Advocating**

There are so many roles that front-line workers can have in supporting the women for whom we care. Advocating along with the women we support is very important when it comes to the regular screening of women. Doctors' appointments can be stressful and overwhelming for all of us, but they can be even harder when you have a disability. As front-line workers, we can work together with the women we support so they can feel prepared for exams, and feel like the expert about their health. I recommend the women I support make their opinion or voice heard when they go to see their family doctor and express their concerns. Sometimes they don't understand what they are being told and need clarification but they are afraid to speak up. We practice asking questions and write down what the woman wants to talk about prior to the appointment. If the doctor directs the questions to me, I redirect those questions to the person who should be asked. It might take some time, but in the long run, the women become stronger advocates for their own health.

### **Role Modeling**

As we all know, there is a saying that says "charity begins at home." Whatever you model, that is what your child will imitate. This is something we learn as new parents. Well, the same is also true in our work.

As female staff, being a good role model is one of the best ways to encourage the women we support to live a healthier lifestyle.

## What We As Staff Can Do

### **Fitness**

Exercising has been part of my life for the past few years. There are numerous ways to motivate the women we serve to become more involved in exercising. This does not necessarily mean going to the gym, but dancing and using exercise videos. Wii Fit or Kinect Dance Central are great video games that get us moving and dancing at the same time. This can be done in the form of fun so people don't even realize how difficult it is because of the fun it creates. I use my personal stories. For example, I tell the women how exercise has helped me over the past few years; this motivates them and they are excited to get involved in their own way. It helps to make exercise part of everyone's routine. Doing exercise with the women I support means that I get my exercise too. When I get off shift, I don't have to worry about needing to get to the gym!

By the time kids with developmental disabilities grow up, many of them no longer participate in organized group sports, maybe because they don't think they are very good, or they don't know where they can play. Participating in sports is not only healthy, it is part of being in the community, and is a great way to interact with others. We won't get the women we work with to do any of those sports activities if they don't see us doing them ourselves. When we just let the men take part, we are showing the women that sports are not for them... There are so many fun sports out there that could be co-ed or women only – sports such as bowling, golf, soccer, snooker or basketball.

One of the best ways to be fit is to walk. If the women we support are too inactive, walking becomes difficult so we need to keep them moving while they can. This could be done by walking to get groceries if the grocery store is within walking distance or making it a morning or an evening activity. Walking an extra bus stop is another great idea.

Lastly, tracking our weight regularly - either weekly or monthly - using a weight monitoring chart can also help us in getting to know if we're gaining or losing weight and the steps we need to take to get to a healthy weight and stay there.

## **Eating**

Eating a well-balanced meal promotes health. As front-line workers modeling healthy ways to eat can help. For example, we can involve the women we support in cooking and, while cooking, we can explain to them the importance of eating fruits and vegetables and cooking fresh food. Cooking fresh food doesn't have to be expensive. Including frozen fruits or vegetables in a recipe is one way to reduce costs, but can sometimes be just as good. Cooking together doesn't just lead to eating healthier food; it is also a great activity to share.

Portion size is also important – this has to be considered when role modeling for the women that we support. The Canada Food Guide can be used to help with meal options and portion sizes. Sometimes we might forget that the portions we serve to the women we support should not be as big as what we serve the men. Their metabolism is different, along with their size, so their food needs are different too. This might be one reason why women with developmental disabilities have more problems with obesity than men. One trick is to serve portions before they get to the table, and to eat more greens and less starch at each meal. It is easier to do this when the greens are there and they are tasty, and when second helpings of the fattier foods are not available to take.

## **Medications**

Some medications that women take can have the side effect of weight gain or can change a woman's metabolism. Medications prescribed to women (and men) with developmental disabilities to help them with emotional or behavioral issues are the most common type of medication that they take. As staff, we need to be aware and we need to make sure that the women we serve are also aware of medication side effects. Diet and exercise are very important, particularly when taking medications that have a side effect of weight gain.

## **Health Detectives**

Helping the people we support become better detectives about their own bodies is very important as they know their bodies better than we do. For instance if they notice any new lump, ache or pain in their body, they should not hesitate to talk about it or let staff know. Front-line workers can support women with disabilities to choose any day of the month to assess their body from head to toe to notice what feels right and observe whether there are any changes. Getting used to knowing their bodies and how they feel when they are working right will help them recognize when things aren't right. It can also help them to feel more comfortable at the doctor's office when getting something examined. It is important for them to know that we as staff are also our own health detectives.

Lisa was a woman in her 30's who was petrified about seeing the doctor. She was part of a women's health group where she came each week with her staff to learn about how to be a healthy woman. When she was learning about breast health, she had daily homework for a week to do a "breast check" - take a look around to see how they look and feel. At first this felt silly and was uncomfortable to do, but she got used to it. In the group, she also practiced speaking up for herself about her health and went to the doctor's to practice asking the doctor questions, and to get more comfortable with being at the doctor's office. When the group ended, Lisa found a rash under her breast. Her skin was quite sore and irritated. She told her staff and they made an appointment to see the doctor who prescribed a cream for Lisa for a yeast infection. Because of what she learned in the group and with her staff, she was able to become a health detective, and get the help she needed without feeling embarrassed.

## Sexual Health

All women who are sexually active should be screened for cervical cancer every three years until age 70. At first it should be every year and after three negative test results (normal), it can be less frequent than that (every two to three years as per the doctor's recommendation). Getting women we support involved in community groups that discuss sexual health is a good way to start.

Birth Control – This can be discussed with the women we support and information brought to their doctors as per their request.

STIs – Teaching the women we support safe sexual practices and the risks associated with engaging in unsafe sexual habits is important.

## Cancer Screening

All women age 50 and up should have a mammogram every two years.

There are videos and resources out there to help women understand more about their health and about examinations for cancer screening. See *Women Be Healthy* (<http://lurie.brandeis.edu/women/>) for details about these resources.

## Medical Appointments

Doctors can make extra time for exams if you call in advance. It is also OK not to do a full exam at one time, but to gradually work your way up to it. You can also request that appointments be at the start or end of day when it is less crowded.

## In Conclusion...

Women with disabilities are women first, and have the same health care rights as all women do. Our job as staff is to not stay quiet in this regard, but to support the women we serve in exercising these rights. Things will change only when women with disabilities know their health rights, and have the information and the skills that they need to be as healthy as they can be.

### **Health Facts**

Here are some facts worth knowing about health, for ourselves and the people we support:

- All women who are sexually active should be screened for cervical cancer.
- All women age 50 and up should have a mammogram.
- Doctors can make extra time for exams if you call in advance. It is also OK not to do a full exam at one time but to gradually work your way up to it.
- You can request that appointments be at the start or end of day when it is less crowded.
- There are videos and resources out there to help women understand more about their health and about examinations for cancer screening. See Women Be Healthy for details about these resources.
- Diet and exercise are very important, particularly when taking medications that have a side effect of weight gain.
- As we age, our metabolism changes. This makes diet and exercise even more important.

### **More Information:**

To learn more about H-CARDD, go to <http://hcardd.ca>

For more information on women's health groups, see: <http://lurie.brandeis.edu/women/>

For information on Special Olympics, see: <http://www.specialolympics.ca/>

Additional websites that provide information and educational resources for individuals who support women with developmental disabilities:

<http://www.ncpad.org/Aboutus>

- This site includes information for health promotion and education for individuals with disabilities and healthcare providers. It focuses on individuals living with physical and/or developmental disabilities, including intellectual disabilities, ASD, and Downs Syndrome. Topics such as exercise, health promotion, and nutrition are discussed in videos, articles, helpful tips and healthy living plans and guidelines.

Specifically:

<http://www.ncpad.org/104/804/Developmental~Disability~and~Fitness>

- This article discusses developmental disabilities and fitness, including tips on how to motivate individuals with developmental disabilities to engage in a fitness activity and general guidelines for developing fitness programs. In addition to this information, the article suggests strategies to foster fitness among staff and caregivers.

<http://www.ncpad.org/386/2130/Focus~on~Secondary~Condition~Prevention~~Osteoporosis~Risk~and~Low~Bone~Mineral~Density~in~People~with~Developmental~Disabilities>

- This article discusses osteoporosis risk and low bone mineral density in people with developmental disabilities. The article also provides preventative strategies to decrease osteoporosis risk among people with developmental disabilities, such as exercise.

<http://www.ncpad.org/302/1888/Treadmill~Program~for~Individuals~with~Severe~Intellectual~Developmental~Disabilities~~BR~~University~of~Florida~Physical~Therapy~Department>

- A treadmill program for individuals with severe intellectual/developmental disabilities created by the University of Florida Physical Therapy Department.

<http://www.ncpad.org/669/2865/2003-03-01>

- This is a link to the Ease into Fitness exercise video, a beginner work-out video for individuals with developmental disabilities. An accompanying viewers guide is also included that poses screening questions to determine if an individual needs a doctor's permission to exercise and a workout calendar to track fitness progress. It also includes helpful health tips and recommendations to motivate engagement in fitness.

<http://dawn.thot.net/health.html#1>

- This site gives information about health issues experienced by women with developmental disabilities, including health statistics, nutrition and eating, and cancer screening programs

<http://www.amchp.org/programsandtopics/womens-health/WomensHealthDisability/Pages/default.aspx>

- This program was developed in the United States and focuses on women with disabilities and special healthcare needs. The site provides health information and links to tools designed to increase the use of clinical preventive services among women with disabilities. Toolbox promotes primary preventative healthcare services and broader health care services among healthcare practitioners.

<http://www.surreyplace.on.ca/Primary-Care/>

- This site includes primary care guidelines for adults with developmental disabilities written in English and French along with clinical tools to help caregivers and primary healthcare providers to better care for adults with developmental disabilities.

<http://www.aging-and-disability.org/en/home>

- This site provides information and practical tools for aging adults with developmental disabilities, their families, caregivers and health practitioners. Information is included about healthy aging and changing needs of adults with developmental disabilities as they age. Topics discussed include nutrition, cancer, physical activity and assistive devices.

<http://www.mountsinai.on.ca/education/CreatingEnablingEnvironment/mammography-education-resources-for-women-with-disabilities>

- An information and educational resource developed by Mount Sinai Hospital about breast cancer screening and mammography for women with disabilities and healthcare providers. The resource includes a 15 minute film about creating an enabling environment for mammography among women with developmental disabilities. The site also provides helpful tips, guides and documents regarding breast health and cancer screening for women with disabilities and those that work with them.

<http://ici.umn.edu/products/impact/231/22.html>

- This is an excerpt from *Aging with Developmental Disabilities: Women's Health Issues* (1999), published by The Arc of the United States, and the Rehabilitation and Research Training Centre on Aging with Developmental Disabilities, University of Illinois at Chicago. It includes information about the effects of health conditions associated with aging on women with developmental disabilities, such as such as menopause and osteoporosis. Information about cancer risk among women with developmental disabilities is also provided. The book excerpt suggests health-related supports and accommodations that older women with developmental disabilities should receive from staff, family and friends.

## **About the Authors**

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