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Disabilities are no hurdle to exercise

Opportunity and adaptations get the job done

By KELLY BOTHUM The News Journal Reprinted with permission from The News Journal <u>http://www.delawareonline.com/apps/pbcs.dll/article?AID=20107130305</u>



Marcus Johnson gets a workout with Wii boxing at the Easter Seals adult day program in New Castle. The Wii "keeps people motivated. ... We're trying to make physical activity a part of life," says Jeanne Conners, program coordinator for Easter Seals. (The News Journal/FRED COMEGYS)

Marcus Johnson faces more challenges being active than most people. He is in a wheelchair, the result of cerebral palsy and an intellectual disability that limit his movement and make it harder for him to participate in traditional exercise programs.

But watching him compete in a game of Wii boxing at the Easter Seals adult day program in New Castle, it's easy to see his excitement as he swats the controller while trying to defeat his opponent on the screen. His attention is engaged and his upper body is in motion as he lands the knockout punch, earning him congratulations from the crowd gathered around him.

While video games may not be considered vigorous activity for most people, it is an important way for Johnson and other people in the Easter Seals program, which serves adults with developmental disabilities, to avoid the trap of being inactive.

"It keeps people motivated," said Jeanne Conners, program coordinator for Easter Seals, which served 21,500 individuals in Delaware and Maryland's Eastern Shore last year. "It gives them a new energy. We're not always trying to make it an exercise thing. We're trying to make physical activity a part of life."

That's important, considering people with disabilities are more likely to be sedentary, putting them at higher risk of developing obesity-related conditions.



Powerlifter Jon Stoklosa, who has Down syndrome, trains for an upcoming national Special Olympics competition. (The News Journal/WILLIAM BRETZGER)

To be active, people with disabilities often require more interventions, special adaptive equipment and increased support than those without disabilities, said Eileen Sparling, project coordinator for Healthy Delawareans with Disabilities, part of the Center for Disabilities Studies at the University of Delaware. The problem is that the adaptations and support aren't always readily available.

"Disability is not an illness, and there isn't any reason someone with disability or limb loss shouldn't be able to be physically active," said Sparling, whose project focuses on addressing health disparities for residents with disabilities. "Maybe marathon running or basketball isn't the right thing, but there's swimming, there's chair yoga or doing something else that allows them to lead a healthy life."

In Delaware, about 20 percent of the population has some kind of disability, according to data from the state behavioral risk survey, which details health-related behaviors of adults. This includes people with cognitive and physical disabilities, those who have lost a limb and people with sensory impairments.

According to the survey, 38 percent of Delaware residents with disabilities reported they were obese, compared with 24 percent of people without disabilities. Sixteen percent said they were told by a doctor they have diabetes, compared with 6 percent of those without disabilities. And 42 percent were told they had high blood pressure, compared to 26 percent of those without disabilities.

While 50 percent of Delaware residents without a disability said they met physical activity requirements -- 150 minutes of vigorous exercise each week -- only 34 percent of those with a disability did.

Seeking inclusiveness

It's hard to draw conclusions about why people with disabilities have higher rates of these conditions, Sparling said, but some of the reasons likely include a lack of access to opportunities for physical activity and also barriers to getting needed preventive health care. A 2007 report from the Institute of Medicine found 20 percent of physicians could not serve people with disabilities because they lacked accessible equipment.

Sparling said a person in a wheelchair visiting the doctor might not get weighed regularly because there is no way to get the person out of the seat or on a scale that can handle the additional weight of the chair. Or a physician with a patient who is deaf or blind may have a hard time communicating relevant health-related messages.

James Rimmer, director of the federally funded National Center on Physical Activity and Disability, said there is no evidence suggesting people with disabilities are at greater risk of health problems, but the problem is that they can incur so-called secondary conditions, such as diabetes, higher cholesterol or depression, in addition to their disability. With these secondary conditions, they may become less active, require medication or undergo changes to their metabolism. Over time, these conditions may contribute to poorer health





For Mark Saul, physical activity comes in the form of cone stacking at the Easter Seals adult day program in New Castle.

Linda Willey works out on a stepper at the Easter Seals

center. (The news Journal/FRED COMEGYS)

While there's been plenty of talk about the need for Americans to eat better and be more active, very little has been said about ways that people with physical and intellectual disabilities can be healthier, said Rimmer, a professor in the department of disability and human development at the University of Illinois at Chicago.

"People with disabilities have been exempt from the public health movement in this country," Rimmer said. "When they talk about children and the need for a safe place to walk to school, they don't consider a kid with autism who may need adaptations so they could do this. The access to health and wellness activities, unfortunately, are not at an equitable level."

Being more inclusive about opportunities for physical activity and healthy eating will benefit even people who don't consider themselves disabled. Rimmer pointed to a 14-week online program developed by the National Center on Physical Activity and Disability that offered weekly e-mails and texts to participants, geared toward inclusive health practices. Of the 2,800 people who signed up for the program, only 800 identified themselves as having a disability, suggesting a potential for reaching groups that otherwise might be excluded.

"If we get to the individual who has the most difficulty, it makes it great for everyone else above that," Rimmer said.

Creating opportunities

In 2007, Delaware became one of 16 states to receive a five-year, \$1 million grant from the Centers for Disease Control and Prevention focused on promoting physical activity in the disability community. Among the goals are raising awareness among the general public and health professionals about the need for physical activity among people with disabilities and also developing opportunities for people with disabilities to be physically active.

Some programs already exist, such as, "Yes You Can," developed by athlete Vickie George, who has multiple sclerosis. Offered at the Brandywine YMCA, it is a personalized weight-training program for people with disabilities. There's also "Sit and Be Fit," a group chair exercise program for people with limited mobility that meets weekly at Garfield Park Community Activity Center.

Last year, Sparling's project developed a program at Bellevue State Park offering bikes adapted with a third wheel for more stability for people with balance or cognitive issues who might not otherwise be able to ride.

"The idea is having accessible opportunities for everyone," Sparling said.

At Easter Seals, clients in the day program have access to adaptive exercise equipment, including a seated stair-stepper and an elliptical machine, Conners said. Some clients who are in wheelchairs practice standing or walking using specially designed walkers.

The exercise equipment, frequent walks, the Wii and opportunities through Special Olympics foster the idea that physical activity is a lifestyle choice, one that can help other aspects of their life, such as getting to the bed or playing games with friends, Conners said. For some clients, the physical activity is paying off -- they have lost weight as a result of spending time on the stair-stepper or taking up new hobbies.

Dr. Karyl Rattay, director of the Delaware Division of Public Health, said the state's focus on obesity prevention -- called Healthy Eating Active Living, or HEAL -- is taking the disabled population into account and how they can be included when developing broader intrerventions to address health.

"It's not the disability that's limiting them," Rattay said. "In other words, if they were supported and had the opportunity of being physically active, they could have same health protection than someone without disability."

'We don't baby anybody'

Jon Stoklosa is an example of what is possible for people with disabilities.

Stoklosa, 28, of Newark, is a premier powerlifter who can benchpress 375 pounds, squat 405 pounds and dead lift -- pick up a barbell off the ground to his thighs -- 415 pounds. A gold medalist in the Special Olympics World Games in 1999, Stoklosa is readying for the national Special Olympics competition this weekend in Nebraska.

Stoklosa, who has Down syndrome, works out with a group of 16 other athletes with developmental disabilities as part of a powerlifting team. The team of 16 men and one woman includes participants with autism, some who don't speak and some who require special accommodations in order to lift the heavy weights. Together, the team practices weekly at Fusion Fitness Center in Newark -- though they're off for the summer -- working out next to other lifters without disabilities.

"We do this in a regular gym because we want to show other people how hard these guys work," said Stoklosa's father, Hank, who has coached the team since 2003. "They have to work to get there. We don't baby anybody. The whole reason to do this is to build an inner strength and outer strength and that builds the confidence."

Stoklosa, who lives at home and works at Acme in Pike Creek, packs a lot of strength in his 5-foot-5 body. At age 12, he started lifting weights at home with his brothers.

When he competes, Stoklosa's skills impress other powerlifters, said his coach, Brandon McGovern, who trains mostly high school and collegiate athletes through his company, Peak Performance of Delaware.

"It's a tremendous amount of weight he lifts. Not only does Jon do the weight, his technique is perfect. I think that's the biggest eye-opener," said McGovern. "That seems to wow everybody. To see him execute the way he does really impresses people."

Hank Stoklosa said the response from people outside the disability community has been solidly positive. He's even had a couple people inquire about helping out as coaches after watching them. "Every one of them on the team, they leave everything on the floor," he said. "That's really cool to see."