THE NISONGER CENTER

Health Characteristics and Access to Healthcare Services of Adults with Down Syndrome

BRIEF REPORT

Marc J. Tassé, PhD, Susan M. Havercamp, PhD, Betsey A. Benson, PhD,
Kandamurugu Manickam, MD, Dawn C. Allain, MS, CGC, Suzanne Davis, BA, & Patricia Navas, PhD

Picture: *Classroom Friends*; Author: Manuel López Francés
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Health Characteristics and Access to Healthcare Services of Adults with Down Syndrome

Marc J. Tassé, PhD[2], Susan M. Havercamp, PhD[2], Betsey A. Benson, PhD[2],
Kandamurugu Manickam, MD[3], Dawn C. Allain, MS, CGC[3], Suzanne Davis, BA[2], & Patricia Navas, PhD[2]

Brief Report

Persons with intellectual and developmental disabilities experience worse health than typically developing peers. This health differential is often described in terms of health disparities – which refers to differences caused or facilitated by social or access issues (Havercamp, Scandlin, & Roth, 2004). Following growing concerns regarding the health status of people with intellectual disability (ID), the US Surgeon General commissioned a national conference and report that examined the health disparities of persons with intellectual disability. The US Surgeon General's report concluded the following: "Like other Americans, persons with mental retardation [now referred to as intellectual disability] grow up, grow old, and need good health and health care services in their communities. But people with [ID], their families, and their advocates report exceptional challenges in staying healthy and getting appropriate health services when they are sick. They feel excluded from public campaigns to promote wellness. They describe shortages of health care professionals who are willing to accept them as patients and who know how to meet their specialized needs." (U.S. Department of Health and Social Services, 2002; p. xi). It has been reported that individuals with intellectual disability must contact on average 50 physicians before they can find one who has been trained to treat persons with disabilities (Corbin, Holder, & Engstrom, 2005).

Down syndrome occurs in 1 in every 700 births, resulting in the most frequent genetic condition associated with intellectual disability (Parker et al., 2010). Because of associated congenital health issues, life expectancy of individuals with Down syndrome is generally lower than the general population. However, according to the Center for Disease Control and Prevention (CDC), people with Down syndrome in the United States live much longer now than 30 years ago. Current average life expectancy of individuals with Down syndrome is approximately 55 years of age, with many living well into their 60s and 70s. However, adults with Down syndrome are more likely to be overweight/obese and have more secondary health problems than adults from the general population (Rubin, Rimmer, Chocoine, Braddock, & McGuire, 1998). Being overweight is a major risk factor for many chronic diseases, including heart disease, Type II diabetes, and arthritis (Leon, Koupilova, Lithell, & McKeigue, 1996). Being overweight also exacerbates other health problems, such as high blood pressure, high blood cholesterol, sleep apnea, etc.

We developed an online health survey to examine the health of adults with Down syndrome. Health information was collected between July 2011 and May 2013 on adults with Down syndrome living in Ohio. The survey included questions addressing: 1) Current physical and mental health problems, 2) Frequency of routine health screenings, 3) Healthy behaviors, and 4) Access to healthcare services. This report summarizes some of the findings obtained from the online health survey.

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[2] Nisonger Center - UCEDD, The Ohio State University.

[3] Department of Internal Medicine, Division of Human Genetics, The Ohio State University Wexner Medical Center.

Health Indicators

Information about health indicators was recruited for 291 adults with Down syndrome living in Ohio. The survey was completed, in most cases (70%), by a parent of the adult with Down syndrome and the adult with Down syndrome completed the survey by himself/herself in 6.5% (n=19) of the cases. Siblings completed the survey in 10% of the cases, while direct support professionals filled in the survey in 14% of the cases. The age of the adults with Down syndrome ranged from 18 to 79 years old (average age = 34 years old). More than a half of participants (n=154 or 53%) were men *(see Figure 1)* and most cases of Down syndrome (74%) were reported as resulting from trisomy 21 *(see Figure 2)*. Fifty eight people (19.9%) did not know the type of Down syndrome, and 3.8% (n=11) reported it as resulting from translocation or mosaic (2.1%).

As other studies have reported (Havercamp, Scandlin, & Roth, 2004; Prasher, 2008; Rimmer & Yamaki, 2006; Rubin et al., 1998), a higher than expected prevalence of obesity (49% vs. 35%) is present in these adults than the general population. The standard weight status categories associated with Body Mass Index (BMI) for adults in the general population are shown in Table 1. The average height (61 inches) and average weight (157 lbs) of the adults with Down syndrome in our sample yield an average BMI of 30.1, which falls in the obese range.

Figure 1. Gender

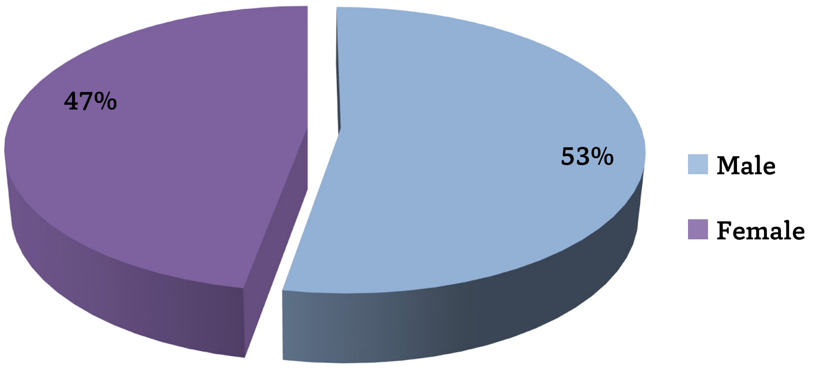


Figure 2. Types of Down syndrome

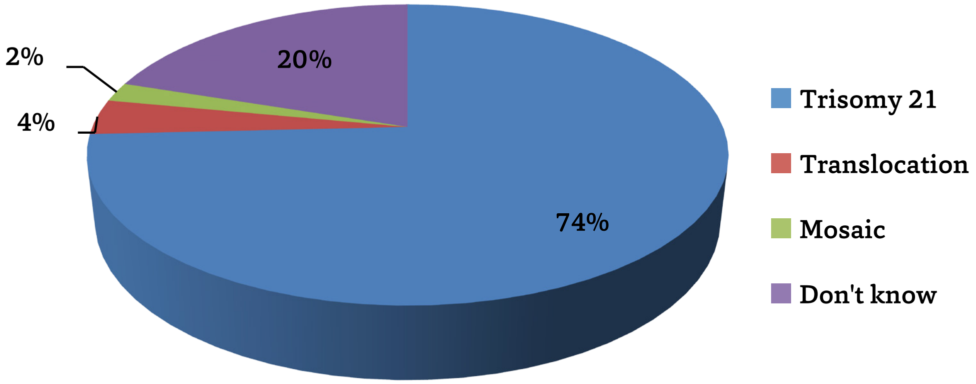


Table 1. BMI ranges

BMI	Weight Status
Below 18.5	Underweight
18.5 – 24.9	Normal
25.0 – 29.9	Overweight
30.0 and Above	Obese

* Source: Centers for Disease Control and Prevention

Figure 3. BMI

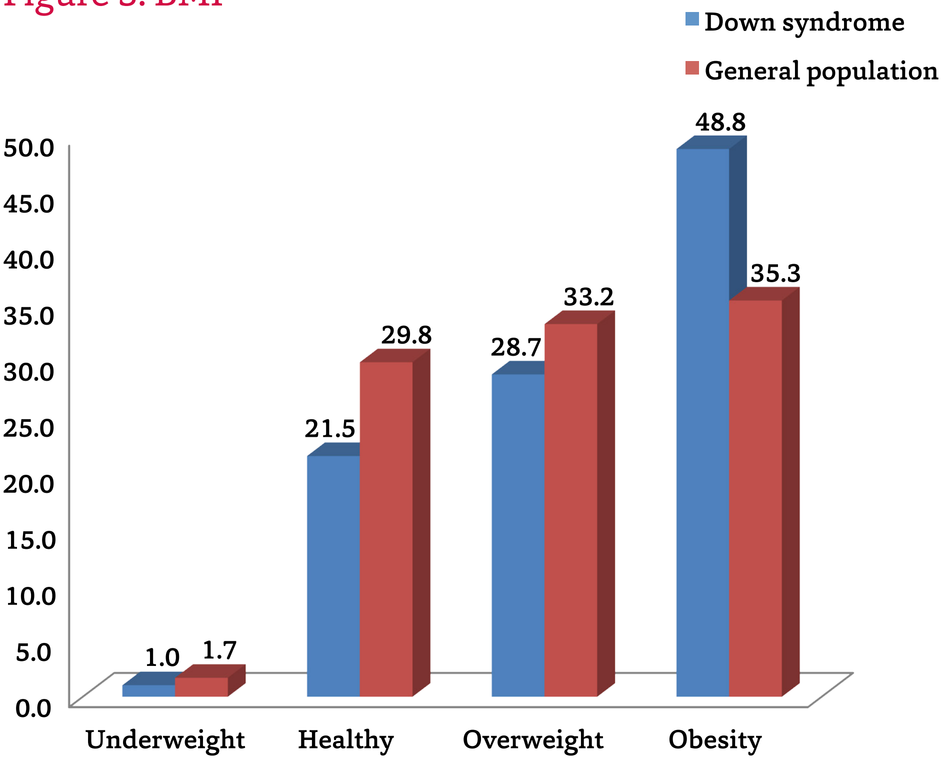
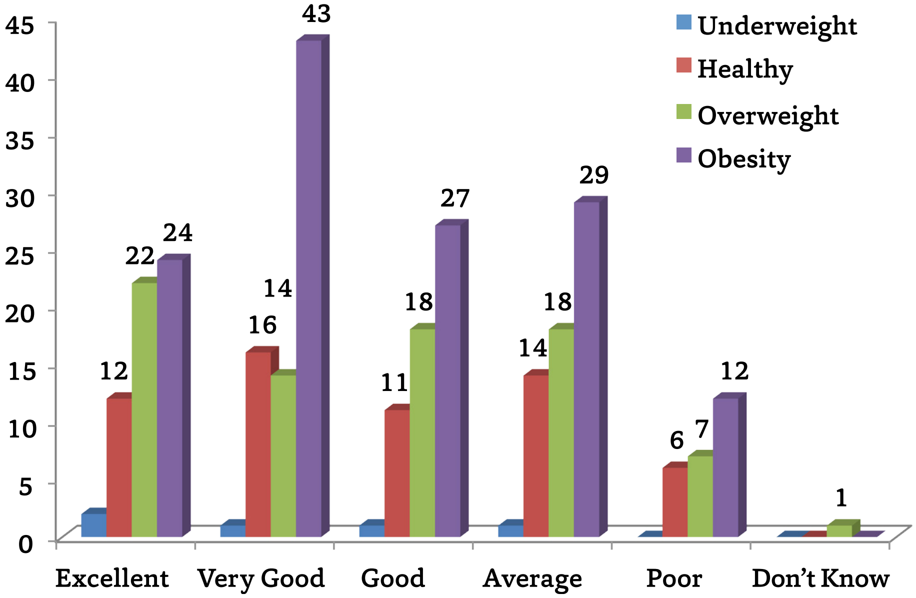


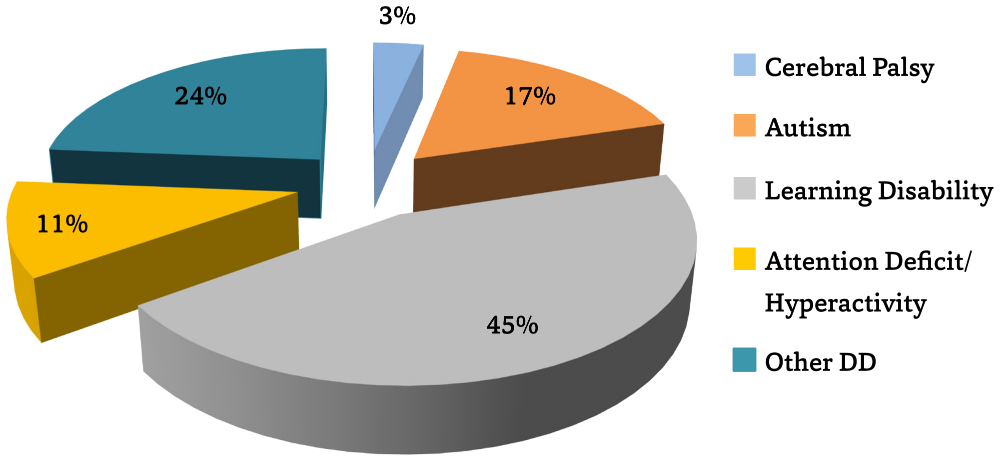
Figure 4. Eating habits by weight status



As shown in Figure 3, higher rates of obesity were found for adults with Down syndrome compared to the rates of obesity in the general population (CDC: Years 2007-2010). Despite having a BMI in the obese range, 70% of these adults report considering their eating habits as Good, Very Good, or Excellent *(see Figure 4)*.

With regard to where they live, a large majority (71%) of the adults with Down syndrome reported living in their parent's or relative's home.

Figure 5. Co-occuring disabilities



Sixty-five percent (65% or n=189) of adults with Down syndrome in our survey reported having moderate intellectual disability and 17% also reported having a co-occurring diagnosis of autism spectrum disorder *(see Figure 5)*.

When specifically asked about co-occurring health problems, only 32 individuals (11%) of our total sample reported having no other secondary health condition. Eighty-eight percent (88% or n=256) of the total group of adults with Down syndrome who completed our health survey reported at least one secondary health condition. The most common health conditions reported, included:
34% = Hypothyroidism,
33% = Skin Conditions,
24% = Allergies, 21% = Sleep Apnea,
and 20% = Digestive Problems
(see Figure 6).

Figure 6. Physical health conditions

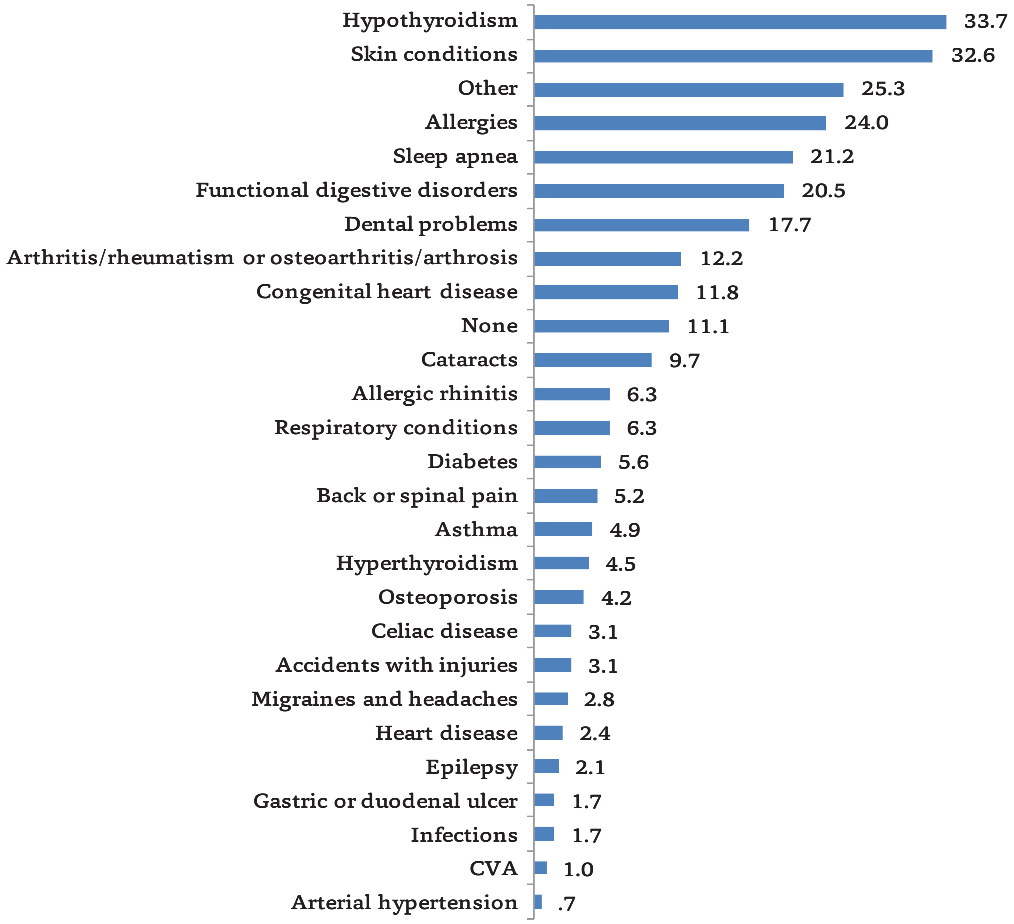


Figure 7. Last complete examination

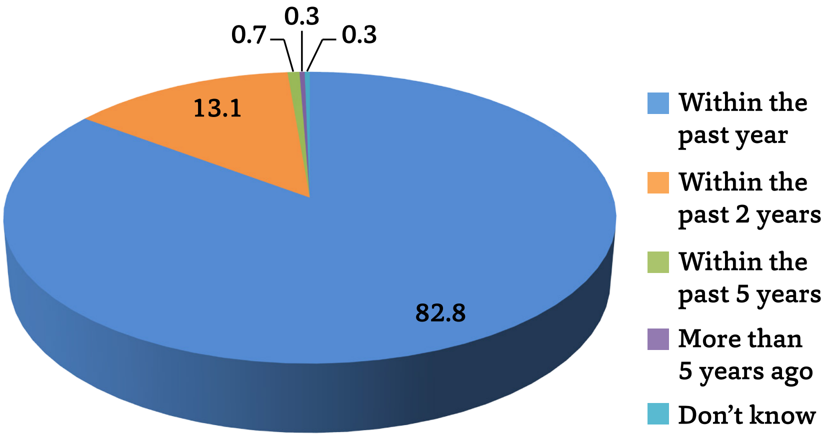
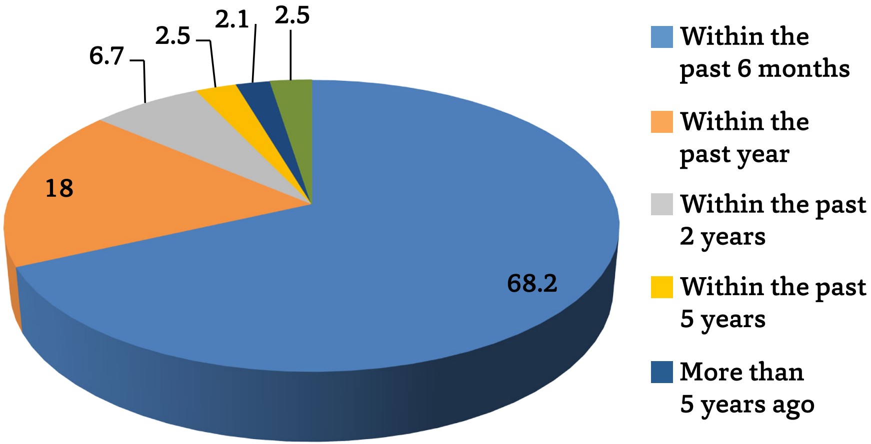


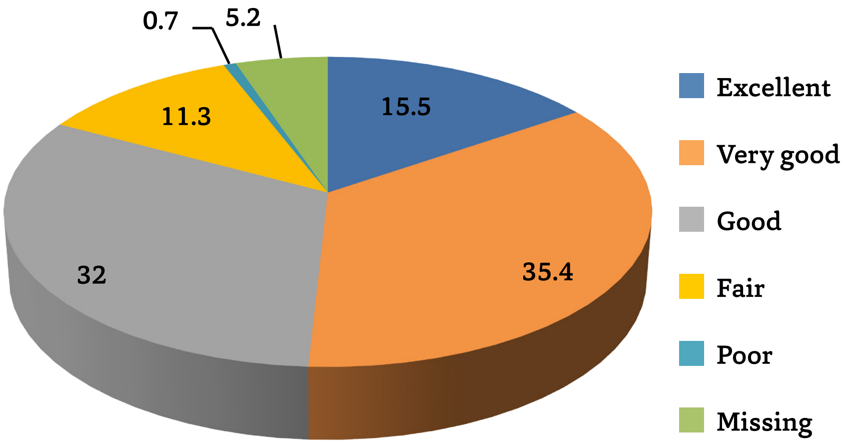
Figure 8. Last dental visit



The good news regarding health care and access to health care is that 95% percent of all adults with Down syndrome reported having a primary care provider and 83% reported having had a complete physical examination in the past year *(see Figure 7)*. Moreover, 86% reported having been to the dentist's office in the last year *(see Figure 8)*.

Other studies have reported different cancer rates in persons with Down syndrome. Fourteen adults with Down syndrome in our sample (or 5%) reported having been diagnosed with cancer, a similar rate compared with the general population rate of cancer survivors (Siegel et al., 2012). Seven of these fourteen cases were reported as leukemia, a type of cancer that has been documented as being associated with Down syndrome over the last years (Wechsler et al., 2002). Considering men and women who have a history of other cancer types, lower rates of breast and prostate cancer have been found in our sample compared to the general population (one and two cases, respectively). We also asked about routine cancer screening. As the American Cancer Society recommends, women age 40 and older should have mammograms every 1 to 2 years. Thirty-five women in our sample of adults with Down syndrome were over the age of 40 years. Of these women, three did not know if they have had a mammogram.

Figure 9. General health

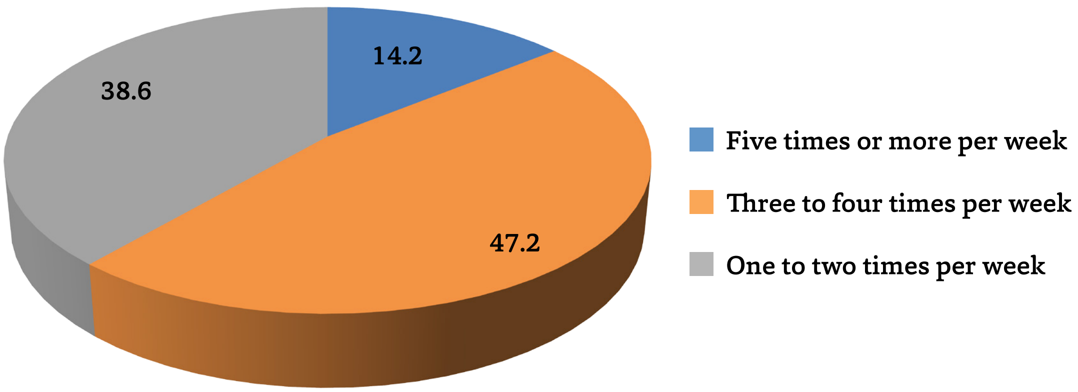


Among the remaining 32 women with Down syndrome over the age of 40 years, 78% reported having had a mammogram in the last 2 years and six (19%) reported never having had a mammogram. These rates are very similar to those in the general population as reported by the 2010 National Health Interview Survey (NHIS): 72.4% of women overall followed this recommendation. With regard to Pap test, both the American College of Obstetrics and Gynecologists and American Cancer Society recommend women to have a Pap test every 3 years beginning at the age of 21 years. Overall, according to the data provided by the 2010 NHIS survey, 83% of women aged from 21 to 65 years old reported having a Pap test within the past 3 years. This rate is much higher than the rate reported by our sample. Of the women with Down syndrome in our sample (n=137), 114 were 21 and older. Of these 114 women, 7 reported not knowing if they had had a Pap test done. Among the remaining 107 women 21 years old and older, 45 (39.5%) reported having had a Pap test done within the last 3 years, and 45.6% (n=52) reported never having had a Pap test done.

With regard to PSA test, American Cancer Society recommends that men have a chance to make an informed decision with their health care provider about whether to be screened for prostate cancer. Recommendations vary as a function of whether or not there is a risk of prostate cancer (e.g., 50 years old for men who are at average risk; 45 years old if that risk is high; and 40 years old when the risk is even higher). Although information about prostate cancer risk was not available, we looked at the frequency of PSA exam reported among the men over 50 in our sample. A total of 19 men in our sample were over the age of 50 years. Of these 19 men, three did not know if they had had a PSA test done. Only 31% of the remaining 16 men (n=5) reported having had a PSA test done during the last year and an equal number (n=5 or 31%) of men over the age of 50 reported never completed a PSA test.

General health is perceived as being “very good” or “excellent” in 51% of the adults with Down syndrome in our survey and < 1% considered their health as “poor” *(see Figure 9)*.

Figure 10. Times per week



Regarding their physical activity, 65% of adults with Down syndrome reported being engaged in "moderate" level of physical activity. For the majority of the individuals in our sample (70%), this level of activity lasts for 30 minutes or more per day. In addition, for more than half (61%), the frequency of their moderate activity is reported to occur at least three or more times per week *(see Figure 10)*.

Conclusions

- The adults in our survey benefitted from unusually good access to primary health care. Most have a primary care physician and most report having had a complete physical exam in the last year.
- One hypothesis is that this better than average access to health care (compared to other adults with developmental disabilities) is likely attributable to a high proportion of the adults living with parents or family members.
- Adults with Down syndrome in our survey reported being very physically active and the vast majority were in good to excellent health.
- Breast and prostate cancer rates appear to be reported lower than the rates seen in the general population.
- As expected, rates of certain health conditions were reported to be significantly higher in these adults with Down syndrome, including: hypothyroidism, skin conditions, sleep apnea, to name a few.
- Based on the calculated Body Mass Index, the rate of obesity in our sample was almost 50%, significantly higher than the rate reported in adults in the general population. Interestingly, the rate of diabetes was lower than would be expected in a comparably overweight/obese population.

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Research Team Members

Marc J. Tassé, **PhD**, Director, Nisonger Center - UCEDD, Professor, Departments of Psychology and Psychiatry, The Ohio State University. Email: Marc.Tasse@osumc.edu, Tel.: 614-685-3193.

Susan M. Havercamp, **PhD**, Director of Health Promotion and Healthcare Parity, Nisonger Center - UCEDD, Associate Professor, Departments of Psychiatry and Psychology, The Ohio State University. Email: Susan.Havercamp@osumc.edu.

Betsey A. Benson, **PhD**, Director of Adult Behavior Support Services, Nisonger Center - UCEDD, Associate Professor, Departments of Clinical Psychiatry and Psychology, The Ohio State University.

Kandamurugu Manickam, **MD**, Assistant Professor, Department of Internal Medicine, Division of Human Genetics, The Ohio State University Wexner Medical Center.

Dawn C. Allain, **MS**, **CGC**, Assistant Professor, Department of Internal Medicine, Division of Human Genetics, The Ohio State University Wexner Medical Center.

Suzanne Davis, **BA**, Clinical Research Assistant, Nisonger Center - UCEDD, The Ohio State University. Email: Suzanne.Davis3@osumc.edu, Tel: 614-685-3195.

Patricia Navas, **PhD**, Postdoctoral Fellow, Nisonger Center - UCEDD, The Ohio State University. Doctoral degree in Psychology, University of Salamanca - Spain.
Email: Patricia.Navasmacho@osumc.edu.

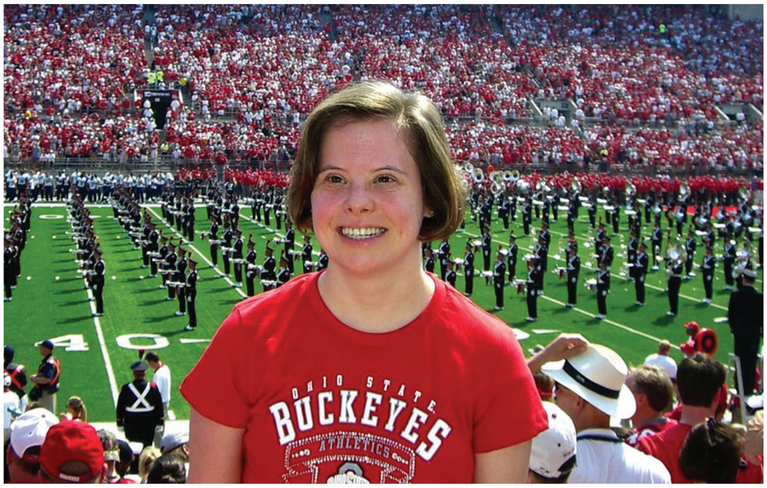

Photo courtesy of Lindsay Gantzer

Nisonger Center

A University Center for Excellence in Developmental Disabilities

Our Mission

The mission of The Ohio State University Nisonger Center is to work with communities to value and support the meaningful participation of people with disabilities of all ages through education, service and research. The Center provides assistance to people with disabilities, families, service providers and organizations to promote inclusion in education, health, employment and community settings.

Our Vision

Through interdisciplinary collaboration we will lead in research, education and service to improve the lives of persons with disabilities, their families and service providers worldwide.

Our Values

The Nisonger Center incorporates the values of community inclusion, cultural diversity and self-determination across the lifespan.

The Ohio State University Nisonger Center
McCampbell Hall
1581 Dodd Drive
Columbus, Ohio · 43210-1257
Tel: (614) 685-3192
Fax: (614) 366-6373
http://nisonger.osu.edu

The Ohio State University