



Prognosis: Guarded

How Health Disparities Impact the Lives
of People with Intellectual Disabilities

A FINAL REPORT FROM THE ARC OF THE UNITED STATES

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- ▶ The Walmart Foundation
- ▶ The Arc of San Francisco, CA
- ▶ The Arc of Alameda County, CA
- ▶ The Arc of Massachusetts
- ▶ Berkshire County Arc, MA
- ▶ The Arc of Brockton Area Arc, MA
- ▶ The Arc of Bristol County, MA
- ▶ The Charles River Center, MA
- ▶ Northeast Arc, MA
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- ▶ The Arc of Moore County, NC
- ▶ The Arc of Stanley County, NC
- ▶ The Arc of the Triangle, NC
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- ▶ The Arc of North Carolina
- ▶ The Arc of North Carolina - Wilmington office
- ▶ The Arc of Greater Pittsburgh (ACHIEVA)
- ▶ The Arc of Luzerne County, PA
- ▶ The Arc of Philadelphia, PA
- ▶ Association for Community Living, Inc., MA
- ▶ Bay Cove Human Services, MA
- ▶ Bridgewell, MA
- ▶ Community Connections, Inc., MA
- ▶ Nonotuck Resource Associates
- ▶ Road to Responsibility, Inc.
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- ▶ Association of University Centers on Disabilities, MD
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- ▶ Eruption Athletics, PA
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Introduction

The term ‘health disparity’ is used to describe the difference in the health status between different groups of people. In 2002, the Surgeon General issued a report¹ highlighting health disparities between individuals with intellectual disabilities (ID) and their peers without disabilities. More recent studies have reported that these differences continue to persist since the initial report was released over 10 years ago.

The “cascade of disparities” that exists between people with ID and their peers without disabilities is well documented². These include a lack of access to health care, an absence of healthy foods including fresh fruits and vegetables, and deficiencies in exercise and wellness activities. Research shows that 5% of adults with ID report overall poor health, a marked difference as compared to the 1% of adults without disabilities answering the same question³. According to The Centers for Disease Control and Prevention (CDC), adults with any disability experience three times the risk of heart disease, diabetes, stroke, and cancer as compared to the general population⁴.

For decades, the CDC has mounted multiple strategies to close the gaps in health disparities between people with disabilities and their peers without disabilities. Their efforts identified numerous sub-population groups, including people with ID, who were affected by these disparities, such as the number and availability of qualified health care providers available to serve them and the percentage of people with ID that do not have dental insurance. Subsequently, the CDC’s interest in identifying and replicating successful interventions to eliminate these challenges is an important component of their current and future plans. In response, CDC entered into a three-year and eight-month cooperative agreement with The Arc of the United States in August 2012 to create the HealthMeet® program.

The mission of HealthMeet® is to reduce health disparities and increase the longevity and quality of life for people with ID by providing free community-based health assessments, individualized recommendations for follow-up care, and exercise and nutrition programs. In addition to assessments, HealthMeet® provided training and education for individuals with ID, their families, direct service professionals, health care professionals, and nursing and medical students and raised public awareness of health issues that impact people with ID.



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- 1 U.S. Department of Health and Human Services (2002). Closing the gap: A national blueprint to improve the health of persons with mental retardation. Author. Retrieved from: <https://www.nichd.nih.gov/publications/pubs/closingthegap/Pages/index.aspx>
 - 2 Krahn, G.L., Hammond, L. & Turner, A. (2006). A cascade of disparities: health and health care access for people with intellectual disabilities. *Mental Retardation Developmental Disabilities Reviews* 12(1), 70-82.
 - 3 Havercamp, S.M. and Scott, H.M. (2014). National surveillance of adults with disabilities, adults with intellectual and developmental disabilities, and adults with no disabilities. *Disability and Health Journal* 8(2), 165-172.
 - 4 The Centers for Disease Control and Prevention. (2014) CDC Vital Signs. Retrieved from: <http://www.cdc.gov/vitalsigns/pdf/2014-05-vitalsigns.pdf>

To implement this mission, The Arc developed partnerships with 29 chapters of The Arc, four direct service organizations in Massachusetts, and 296 health care professionals in five states: California, Massachusetts, New Jersey, North Carolina and Pennsylvania. This team was joined by 11 national disability organizations, public health agencies, colleges and universities, and other key stakeholders.

The Arc of the United States (The Arc) is pleased to share this final report *Prognosis: Guarded - How Health Disparities Impact the Lives of People with Intellectual Disabilities* which describes the results of the 2,467 health assessments completed between April 2013 and July 2015. In addition to these data, we are pleased to share the additional health promotion interventions implemented by chapters and The Arc to address persisting health disparities.

While *Prognosis: Guarded* is not the only report to identify health disparities between the general population and people with ID, it does offer an important perspective about a group of people that warrant additional attention. According to the CDC, knowledge about the health of post-school age adults with intellectual disabilities is not as well understood as the health of school-age children⁵. *Prognosis Guarded* deserves a thoughtful review as it details the health status of over 2,400 people, of whom the vast majority (90%) is over age 22.

While we are deeply concerned with many of the results, some which paint a grim picture of the reality of the health status of many people with ID, The Arc and its chapters are equally encouraged to have demonstrated a number of strategies and action steps that address these worrisome trends. Let's begin by examining the health assessments that were integral to the HealthMeet® program.

5 Centers for Disease control and Prevention & National Center on Birth Defects and Developmental Disabilities Health Surveillance Work Group. (2009). U.S. Surveillance of Health of People with Intellectual Disabilities. Retrieved from: http://www.cdc.gov/ncbddd/disabilityandhealth/pdf/209537-a_idmeeting-short-version12-14-09.pdf

The HealthMeet® Process and Assessment

The Arc and the CDC created a process for people with ID interested in learning more about their health status. To this end:

- ▶ An assessment instrument was created
- ▶ A health care professional assessor recruitment and training strategy was designed
- ▶ A method for conducting each assessment was established
- ▶ A plan for conducting assessments was formed and
- ▶ A system for collecting data, sharing it with the person and analyzing it was constructed.

Several organizations and resources were used to develop HealthMeet. The University of Illinois – Chicago’s HealthMatters™ program helped to inform the overall process. Some of the assessment questions were adapted from other health assessments (CDC’s Behavioral Risk Factor Surveillance System and Special Olympics, Inc.). Additional questions were developed by The Arc and CDC team.

The design of assessor training materials was led by The Arc of San Francisco and guidance on assessor recruitment was supported by the National Association of County and City Health Officials and chapters of The Arc.

The 50-question health assessment was designed to gather information about lifestyle habits, vital signs, body composition, respiratory health, vision, hearing, oral health, and foot/mobility health.

The assessment included questions such as “Do your teeth or mouth hurt?” as well as measurements including height, weight, and blood pressure. A number of standardized tests such as The Whispered Word Test that screens for hearing loss were also included.

Assessments were carried out in a private area by a health care professional or a medical or nursing student under clinical supervision. Those assessed were accompanied by caregivers if desired by the individual. Each person received a verbal summary and written document that detailed the assessment results and a recommendation for follow-up care, as needed.

TherapServices created a Health Insurance Portability and Accountability Act (HIPAA) compliant cloud-based system to collect, store, and clean the health assessment data. Some assessors used a laptop or tablet to enter the data into the system. Other assessors recorded assessment information on to a paper form, which was then entered into the system by chapter staff.

TherapServices and The Boggs Center for Developmental Disabilities at the Rutgers Robert Wood Johnson Medical School (The Boggs Center) devised a HIPAA compliant protocol to transfer the data from TherapServices to The Boggs Center for analysis. The Boggs Center obtained Institutional Review Board approval and following HIPAA rules, analyzed and reported the data to The Arc. All personal and identifying



information was fully protected and data was only reported in aggregate. States and chapters received separate reports. If data was collected on 10 people or less, these data were excluded from the state report to assure that no one individual could be identified.

The following state and local chapters of The Arc and partner organizations from California, Massachusetts, New Jersey, North Carolina and Pennsylvania conducted HealthMeet® assessments:

- ▶ **CALIFORNIA:** The Arcs of San Francisco and Alameda County
- ▶ **MASSACHUSETTS:**
Chapters: The Arc of Massachusetts, Berkshire County Arc, Brockton Area Arc, The Arc of Bristol County, the Charles River Center, and Northeast Arc
Partners: Association for Community Living, Inc., Bay Cove Human Services, Bridgewell, Community Connections, Inc., Nonotuck Resource Associates, and Road to Responsibility, Inc.
- ▶ **NEW JERSEY:** The Arc of Atlantic County, The Arc of Essex County, The Arc Gloucester, and The Arc of Monmouth
- ▶ **NORTH CAROLINA:** The Arc of Buncombe County, The Arc of Gaston County, The Arc of Moore County, The Arc of Stanley County, The Arc of the Triangle, The Arc of Union/Cabarrus, and The Arc of North Carolina Wilmington office
- ▶ **PENNSYLVANIA:** The Arc of Greater Pittsburgh (ACHIEVA), The Arc of Luzerne County, and The Arc of Philadelphia

HealthMeet® Assessors

Chapters and partners reached out to local healthcare professional associations, state, county and local health departments, hospitals and clinics, as well as medical and nursing schools at local colleges and universities to recruit assessors. The Arc partnered with the American Association on Intellectual and Developmental Disabilities, the Association of University Centers on Disabilities, and the National Association of County and City Health Officials to publicize the need for assessors as well. Many assessors already had connections to chapter and partner staff and board members or heard about the recruitment effort from people with ID and families. **The results were impressive, as 296 of medical clinicians joined the HealthMeet® program.**

A training webinar was created for the HealthMeet® program, archived, and made available to each assessor. Once assessors arrived to implement assessments, they received additional instructions through an in-person training provided by the chapter or partner. In 2015, The Arc created a HealthMeet® procedure manual and updated the webinar. Assessors were invited to provide The Arc with written feedback about their experience and recommendations for program improvements.

HealthMeet® Participant Profile

The following are some basic demographics of the over 2,400 HealthMeet® assessments.

DISABILITY

- ▶ 80% of individuals reported at least one disability diagnosis;
 - ▶ 69% reported having an intellectual disability;
 - ▶ 11% reported having Down Syndrome;
 - ▶ 9% reporting having a diagnosis on the autism spectrum; and
 - ▶ 9% reported having cerebral palsy.

GENDER

- ▶ 52% were male and 48% were female.

AGE

- ▶ 27% of HealthMeet® participants were between the ages of 27-39 years old while 53% were 40 years of age or older;
- ▶ The average age was 42.4 years;
- ▶ In general, those receiving assessments were an older group – over half (53%) were 40 years of age or older;
- ▶ Several chapters reached out to particular segments of the community including older people with intellectual disabilities.

RACE

- ▶ 62% were White, 18% were Black, 7% were Latino (of any race), 6% were Asian/Pacific Islander, and 7% were of other races.

GUARDIANSHIP

- ▶ 67% were their own legal guardian.

HOME

- ▶ The largest proportion (48%) of people lived with their parents or family, 38% lived in a group home, and 13% lived in their own home or apartment.
- ▶ Several chapters reached out to particular segments of the community including people living in rural communities.

HEALTH STATUS

- ▶ Most individuals were positive when asked about their health; 83% rated their health as good (59%) or very good (24%);
- ▶ Participants over the age of 40 were less likely to report ‘very good health’ as compared to their under 40 cohort. This is reflective of the general population.

TOBACCO AND ALCOHOL USE

- ▶ 7% of participants reported using tobacco and 12% used alcohol.
- ▶ Males (15%) were more likely than females (10%) to report alcohol use.

HEALTH INSURANCE

- ▶ Almost all (98%) respondents reported having a source of health insurance.
 - ▶ Medicare (49%) and Medicaid (37%) were the most common forms of health insurance.
 - ▶ Private insurance coverage was held by 13% and varied by disability type and age. Those with autism were more likely (32%) than participants with ID (13%) or other disabilities (10%) to have private health insurance.
 - ▶ 25% of the 14-21 year-old participants had private health insurance coverage; this was over twice the rate (10%) of those over 40.

ACCESS TO DOCTORS

- ▶ Nearly all individuals (97%) reported having a doctor and that the doctor understood their health (96%).

EMPLOYMENT

- ▶ 44% reported engaging in work which resulted in pay.

CONNECTIONS TO CHAPTERS OF THE ARC

- ▶ 74% of participants reported participating in activities affiliated with the Arc at some point in their lifetime; and
- ▶ 72% reported that they currently participate in The Arc's activities.

UNHEALTHY WEIGHT/BMI

Body Mass Index (BMI) is calculated by dividing a person's weight by their height and is commonly used to estimate the percentage of body fat a person has. The higher the BMI score, the higher amount of body fat one has. The overall obesity (BMI ≥ 30) rate in the U.S. adult population is 41% and the extreme obesity rate (BMI ≥ 40) is 6%⁶. As can be seen in Figure 1, less than one in five of those receiving assessments (22.5%) had a BMI representing a healthy weight (BMI 18.5 – 24.9), compared with 29% of the U.S. population⁷. The overall obesity rate (obese and extremely obese) of participants was 46.2%, which is slightly higher than the general population; those who were extremely obese (11.8 %) were twice the general population. Just as important were the number of people who were underweight; 3.4% had a BMI score 18.5 or below, compared to 2% of the general U.S. population. There were no significant differences between participants living in family homes, on their own, or in group homes with respect to BMI. Additionally, results indicated a higher risk of being overweight for male participants (32%) as compared to female participants (24%).

TABLE 1: BMI OF U.S. GENERAL POPULATION COMPARED TO THAT OF HEALTHMEET® PARTICIPANTS.

| BMI RANGE | % OF U.S. GENERAL POPULATION | % OF HEALTHMEET® PARTICIPANTS |
|------------------------------|------------------------------|-------------------------------|
| ≤ 18.5 (underweight) | 2% | 3.4% |
| 18.5 – 24.9 (healthy weight) | 29% | 22.5% |
| 25-29.9 (overweight) | 33.3% | 27.9% |
| ≥ 30 – 39.9 (obese) | 35.3% | 34.4% |
| 40+ (extremely obese) | 6.6% | 11.8% |

POOR ORAL HEALTH

Assessment data revealed a second area for concern; poor oral health. While routine six-month preventive dental visits are the norm for the 60% of Americans with dental insurance⁸, many people with intellectual disabilities do not have dental coverage or see a dental professional on a regular basis⁹.

- 6 Fryar, C.D., Carroll, M., and Ogden, C.L. (2014). Prevalence of overweight, obesity, and extreme obesity among adults: United States, 1960-1962 through 2011-12. Retrieved from: http://www.cdc.gov/nchs/data/hestat/obesity_adult_11_12/obesity_adult_11_12.htm
- 7 Centers for Disease Control and Prevention. (2014b). Healthy weight, overweight, and obesity among adults aged 20 and over, by selected characteristics: United States, selected years 1960-1962 through 2009-2012. *Health, United States*, 2013. Retrieved from: <http://www.cdc.gov/nchs/data/hus/2013/069.pdf>
- 8 National Center for Health Statistics (2015). *Health, United States, 2014: With special feature on adults aged 55-64*. Hyattsville, MD. Retrieved from: <http://www.cdc.gov/nchs/data/hus/14.pdf#084>
- 9 Armour, B. S., M. Swanson, H. B. Waldman, and S. P. Perlman. (2008). A profile of state-level differences in the oral health of people with and without disabilities, in the U.S., in 2004. *Public Health Reports* 123(1):67-75. Retrieved from: <http://www.ncbi.nlm.nih.gov/pubmed/18348482>

Signs or symptoms of oral health issues were observed in more than one-third (35%) of individuals assessed. The rate of missing teeth (25%) was 2.5 times higher than the U.S. general population (10%)¹⁰. Sixteen percent of those assessed received a referral for follow-up and more critically, 4% of those screened had indications of a potential urgent oral health issue.

Poor oral health can lead to a number of harmful outcomes including periodontal diseases, gingivitis, and untreated dental caries¹¹. In addition, missing teeth can impact nutrition by decreasing consumption of fresh fruits and vegetables.

There are a number of potential issues that result in poor oral health. Some people may be afraid to obtain dental care or fully participate in dental examinations; some people do not report tooth pain that can lead to infections; and many do not have dental insurance or are unable to find a local dental professional with experience or willingness to serve people with ID.

FOOT HEALTH CONCERNS

According to the Animated Dissection of Anatomy for Medicine report highlighted in the NY Times,¹² foot pain can often be attributed to medical conditions including arthritis, diabetes, obesity, and medications. Given this research and health care challenges faced by many people with intellectual disabilities, it's not surprising that many receiving HealthMeet® assessments reported foot health concerns.

As part of the assessment, people were asked to remove their shoes and socks for examination. Foot health assessments included a visual inspection to identify injuries, calluses, blisters, cracks, toe nail length, fungus, and foot temperature. Assessors also completed a Basic Gait Analysis using the Get Up and Go Test¹³. Finally, assessors asked a series of questions about foot health and then rated the foot examination as either “pass” or “fail”; 81% of participants received a rating of “pass”.

A number of central themes were uncovered during the foot health assessments including:

- ▶ 55% reported foot pain;
- ▶ 31% had signs or symptoms of infection;
- ▶ 14% showed behaviors to suggest discomfort or abnormalities;
- ▶ 6% were identified as potentially having an urgent foot care issue;
- ▶ 15% received a recommendation for follow-up care;
 - ▶ Of these, the largest problem area was toe nails that were not properly clipped.

10 National Institute of Dental and Craniofacial Research. (2000). Oral Health in America: A Report of the Surgeon General. Retrieved from: <http://www.nidcr.nih.gov/datastatistics/SurgeonGeneral/gr/chap4.htm>

11 National Institute for Dental and Crainiofacial Research. (2016). Practical Oral Care for People with Intellectual Disability Retrieved from: <http://www.nidcr.nih.gov/oralhealth/Topics/DevelopmentalDisabilities/PracticalOralCarePeopleIntellectualDisability.htm#OralHealthProblems>

12 Animated Dissection of Anatomy for Medicine (2008). Foot Pain In-Depth Report. *New York Times*. Retrieved from: <http://www.nytimes.com/health/guides/symptoms/foot-pain/print.html>

13 Barry, E., Galvin, R., Keogh, C., Horgan, F., & Fahey, T. (2014). Is the timed up and go test a useful predictor of risk of falls in community dwelling older adults: a systematic review and meta-analysis. *BMC Geriatrics*, 14:14.

AT RISK OF FALLS

The cost and impact of falls is well documented in the older adult population, but less studied among people with ID. In 2013, the average cost of fall-related injury was between \$14,306 and \$21,270 per incident—for a total cost of \$34 billion annually¹⁴.

Of female HealthMeet® participants, 15% stated that they felt dizzy when walking compared to 8% of male participants. Overall, 17% of all receiving assessments said they often feel unsteady when walking; females (22%) were more likely than males (14%) to report unsteadiness when walking. During the last year, 17% of those receiving assessments reported falling at home. The risk of falling in the previous year was significantly higher for women (22%) compared with men (14%). This is more than three times the fall injury rate (5%) among non-institutionalized older adults in the United States¹⁵.

HARMFUL UNHEALTHY DIETS AND SEDENTARY LIFESTYLES

Of those assessed, 67% said they did not meet the federal recommendations of daily fruit and vegetable intake. However, their rates were better than the general population who report not eating the recommended fruit (76%) or vegetable (87%) daily servings¹⁶. Only 4% of individuals that received assessments reported eating more than five servings of fruits and vegetables per day. Males (17%) were more likely than females (12%) to report eating less than one serving of fruits and vegetables per day.

TABLE 2: DAILY FRUIT AND VEGETABLE INTAKE OF HEALTHMEET® PARTICIPANTS.

| DAILY SERVINGS OF FRUIT AND VEGETABLES | % OF HEALTHMEET PARTICIPANTS | RECOMMENDED: ¹⁷ |
|--|------------------------------|---|
| ≤ 1 | 14.5% | 2 cups of fruit daily 2.5 cups of vegetables daily |
| 1-2 | 51.9% | |
| 3-5 | 27.8% | |
| ≥5 | 4.2% | |

Based on assessment results, 26% of HealthMeet® participants were referred to nutritional counseling. Women (31%) were more likely than men (21%) to receive a referral. Younger people (13%) ages 14 – 21 were less likely to receive a referral than older individuals (32%) age 27-39. Those living with their family or in a group home were more likely to eat greater servings of fruits and vegetables than their peers living in their own homes.

14 National Council on Aging. (2015). Issue brief: Funding for elder falls prevention. Retrieved from: <https://www.ncoa.org/wp-content/uploads/Falls-Funding-Issue-Brief-8-15.pdf>

15 Schiller, J.S., Kramarow, E.A., & Dey, A.N. (2007). Fall injury episodes among noninstitutionalized older adults: United States, 2001-2003. *Advance Data from Vital and Health Statistics*, (392), 1-16.

16 U.S. Centers for Disease Control and Prevention (2015). Adults meeting fruit and vegetable intake recommendations. Available at: <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6426a1.htm>

17 U.S. Department of Health and Human Services and U.S. Department of Agriculture. *2015 – 2020 Dietary Guidelines for Americans*. 8th Edition. December 2015. Available at <http://health.gov/dietaryguidelines/2015/guidelines/>.

INADEQUATE PHYSICAL ACTIVITY

According to the CDC, 80% of American adults do not get the recommended amount of exercise¹⁸. The CDC recommends that adults aged 18 - 64 get a minimum of 150 minutes of moderate physical activity per week which is equivalent to 30 minutes of exercise five times a week¹⁹.

During the assessment, participants were asked about their level of physical activity. One in five (20%) reported no regular exercise and 47% said they exercised for at least 30 minutes, three or more days per week. **Of this group, younger people [age 14-21] reported more exercise (68%) than older people [age 40+] (43%).** Individuals living in group homes reported exercising more than those living with their family.

Assessors asked people about watching television and playing computer/video games—23% reported five or more hours per day, women watched/played less than men, and individuals living in their own home watched more (six hours). The average screen time for the general population is four hours and 51 minutes; however, video games, computer, tablet and smart phone use increases this number to 11 hours of screen time per day²⁰.

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- 18 Jaslow, R. (2013). CDC: 80 percent of American adults don't get recommended exercise. Retrieved from: <http://www.cbsnews.com/news/cdc-80-percent-of-american-adults-dont-get-recommended-exercise/>
- 19 CDC. (2015). How much physical activity do adults need? Retrieved: <http://www.cdc.gov/physicalactivity/basics/adults/index.htm>.
- 20 The Nielsen Company (March 2015). The total audience report. Retrieved from: <http://www.nielsen.com/us/en/insights/reports/2015/the-total-audience-report-q4-2014.html>.

Promising Solutions

Unhealthy weight, poor oral health, poor foot health, risk of falls, unhealthy diets, sedentary lifestyles, and inadequate physical activity. These harsh realities are faced by many of the over 2,400 people receiving health assessments from chapters of The Arc and partners between 2013 and 2015.

Although the outcomes are reflective of the current research literature, it still is unacceptable that these harsh realities exist for many people The Arc serves. Fortunately, The Arc had the foresight to design health and wellness opportunities within the HealthMeet® program's early planning stages. Here is an accounting of those strategies and their results.

Empowered Health

Empowered Health is a term used throughout the world to describe the importance of people taking responsibility for improving or maintaining their own health. The Empowered Health movement is a tool that we can use in our pursuit of self-determination and full community membership. As we know, no matter how knowledgeable and supportive family, friends, and professionals may be, people who have ID must take ownership and play an active role in improving their own health to the degree to which they are able. This section of the report describes what we created and learned during the HealthMeet® program.

HEALTHMEET® EMPOWERING PARTICIPANTS

While the average age of those obtaining assessments was 42.4 years, many HealthMeet® participants neither have information about nutrition nor the responsibility for grocery shopping or meal preparation. The Arc realized that, from the very beginning, a self-advocacy component was necessary. To this end, The Arc partnered with the Research and Training Center on Community Living at the University of Minnesota to design a series of online learning modules about exercise, nutrition, personal care, and healthy relationships as part of their Self-Advocacy Online program²¹. These modules developed by and for people with intellectual disabilities, are part of a larger program that includes personal stories and interactive, educational videos. The videos use plain, captioned language and feature people with ID. The video and audio messages are interactive, accessible, informative, and most of all - fun.

The Arc hired Self-Advocate Santa Perez to author a number of checklists²² for use by self-advocates. The topics, listed below, were selected by Ms. Perez, who personally faced challenges with access and obtaining respectful services in these areas throughout her lifetime:

- ▶ Selecting your doctor;
- ▶ Talking to your doctor;
- ▶ Talking to your doctor regarding women's health;
- ▶ Talking with your doctor regarding men's health; and
- ▶ Selecting a fitness center.



21 Self-Advocacy Online <http://www.selfadvocacyonline.org>

22 HealthMeet® Self Advocacy Resources: <http://www.thearc.org/healthmeet/self-advocacy-resources>

The Arc's HealthMeet® assessor training included a set of standards that established expectations for respect and self-determination within the health assessment environment:

- ▶ Assessors were taught to speak directly to the person, and not his/her caregiver or staff member if they were present in the room;
- ▶ Assessors learned that even if a person answered a question in an unexpected way, to presume competence and record the person's answer on the assessment form;
- ▶ Caregivers or staff interested in accompanying a person during an assessment were permitted to do so only if the person gave his/her consent; and
- ▶ Resource materials developed for self-advocates were reviewed by self-advocates prior to release.

The Arc of New Jersey created several resources for self-advocates on important subjects including cancer, diabetes, and sun safety. The materials, along with links to other resources, were posted on the HealthMeet® website²³ and distributed to chapters of The Arc. Many chapters of The Arc distributed these and other helpful materials to individuals obtaining health assessments.

The Arc of Alameda interviewed self-advocates and family members and presented their thoughts, concerns and recommendations about nutrition, exercise and wellness. These powerful accounts describe the personal journeys that people have navigated throughout their lives. [Building Healthy Habits Through HealthMeet®](#)²⁴ is a formidable expression about the realities that people with ID and their families face every day.

INCLUDING PROPER NUTRITION AND EXERCISE INTO DAILY LIFE

Knowing which foods are healthy, having the finances to purchase fresh fruits and vegetables, having access to transportation for grocery shopping, taking the time and having an interest in preparing healthy meals is a lofty challenge for people with and without disabilities alike. Additionally, the reality is that many people with ID are not in control of the foods that are purchased or the meals they are served.

To this end, a number chapters of The Arc provided information about nutrition and held educational activities before, during, and following HealthMeet® assessments. These included:

- ▶ Creating interactive lectures focusing on food groups and portion sizes;
- ▶ Hosting one-on-one and small group nutrition classes presented by a local supermarket nutritionist as well as during agency staff meetings;
- ▶ Organizing 'Lunch and Learn' meetings to discuss nutrition, exercise, body mechanics, and personal care;
- ▶ Arranging healthy eating presentations delivered by a Registered Dietitian;
- ▶ Joining residents and preparing healthy meals at their home;
- ▶ Visiting a farm to learn more about where our foods are from; and
- ▶ Carefully reviewing a restaurant menu and selecting the most nutritious foods at a group dinner.

The lack of physical activity reported by HealthMeet® participants is concerning. Participating chapters of The Arc accepted this challenge, creating a variety of activities to support people with ID in adopting a more active lifestyle. The Arc Gloucester created

23 HealthMeet® website: <http://www.thearc.org/healthmeet>

24 Building Healthy Habits Through HealthMeet®: http://www.thearc.org/file/documents_programs_healthmeet/The-Arc-of-Alameda-Success-Stories-FINAL-10.25.16.pdf?erid=8762795&trid=aobd2999-f8ab-4614-8e3f-418611ef70f5

[Healthfully Yours](#)²⁵, a curriculum with monthly themed nutrition, exercise, and health promotion group activities aimed at infusing lessons in a fun and accessible way. These include:

- ▶ Implementing the HealthMatters™ curriculum at local chapters;
- ▶ Hosting Zumba, line, and thematic dance classes;
- ▶ Presenting exercise classes;
- ▶ Coordinating weekend Get Moving events in community parks and shopping malls;
- ▶ Working with local fitness trainers that have experience in working with people with intellectual disabilities;
- ▶ Teaching local fitness trainers how to support people with ID;
- ▶ Enjoying the pool and other community activities; and
- ▶ Participating in charity walks, runs and proudly representing their local chapter of The Arc.

HealthMatters^{™ 26} is an evidence-based health promotion program authored by our partners at The University of Illinois at Chicago, Department of Disability and Human Development, College of Applied Health Sciences (UIC). A comprehensive approach to wellness, this program was designed to teach people with ID about exercise and healthy eating. Between November 2012 and March 2016, UIC presented 10 train-the-trainer workshops to 236 professionals) working at 99 chapters of The Arc and other disability service providers. These trainers and their organizations pledged to implement *HealthMatters*[™] in their local communities. During this period, 50 12-week courses were held for 542 people with ID. A total of 686 pounds were lost by program participants. In 2015, The Arc received additional funding from The Walmart Foundation which enabled us to expand the program to additional communities.

Numerous chapters of The Arc obtained food replica kits and a cookbook²⁷ to assist them in teaching people with ID about proper nutrition. The food replica kits were particularly helpful since they illustrated serving sizes. Just about everyone in the class, students and teachers alike, were surprised when they learned that not all apples are created equal, since a small apple contains 14g of carbohydrates but a large apple has 31g of carbohydrates²⁸.

GROWING COMPETENT HEALTH CARE PROFESSIONALS

While 97% of those receiving health assessments reported their physician understood their health, anecdotal stories about health care providers who were ineffective communicators, insensitive or disrespectful to people with ID, and focused solely on people's cognitive limitations (and not physical health) were frequent. These accounts led The Arc to contract with the Association of University Centers on Disability (AUCD) to create two online modules²⁹ on health promotion and communication strategies. The modules were designed for university students in neurodevelopmental and related disabilities disciplines and publicized to all University Center on Disabilities directors, many of which included the modules as part of the Leadership Education in Neurodevelopmental and Related Disabilities

25 Healthyfully Yours curriculum: http://www.thearc.org/file/documents_programs_healthmeet/Healthfully-Yours---The-Arc-of-Gloucester-FINAL-1.30.17.pdf

26 HealthMatters Program: <http://www.healthmattersprogram.org/healthmatters.html>

27 Cooking by Color: Recipes for Independence: <http://www.downsyndromenutrition.com/productlist/79-cooking-by-color.html>

28 New Health Guide. (2016) How Many Calories in an Apple? Retrieved from: <http://www.newhealthguide.org/How-Many-Calories-In-An-Apple.html>

29 Resource Modules on Health of People with Intellectual Disabilities: <http://www.iddhealthtraining.org/>

(LEND) programs. Six thousand students completed the modules. Based on overwhelmingly positive feedback, modules were made available to anyone interested, including individuals working in the field.

While we are very fortunate that the national LEND network graduates competent and caring health care professionals who choose to serve people with ID, there are countless professionals graduating from schools that spend a negligible amount of coursework and fieldwork teaching students how to serve people with ID. The HealthMeet® program seized the opportunity to reach out to a number of colleges and universities that do not have a LEND program at their school.

Chapters in California, North Carolina, and Pennsylvania developed partnerships with colleges and universities to join the HealthMeet® program. They recruited university faculty and their students to, under clinical supervision, conduct and/or observe health assessments or provide other support for the HealthMeet® program as part of their residency, internship, practicum, field placement, or community health rotation. This resulted in hundreds of students, many with little or no prior experience with people with ID, taking the opportunity to meet people with ID. This resulted in increased levels of awareness and comfort and establishing a foundation on which to develop skills they can use when they serve people with ID in the future. Many students reported that their apprehension in working with people with ID decreased and that meeting people with ID for the first time through a HealthMeet® assessment was an important experience for them. The following universities participated in the HealthMeet® program:

- ▶ Drexel University College of Nursing and Health Professionals;
- ▶ Drexel University College of Medicine;
- ▶ Thomas Jefferson University School of Population Health;
- ▶ University of Pennsylvania School of Social Work;
- ▶ Philadelphia College of Osteopathic Medicine;
- ▶ University of Pittsburg Medical Center Medical Education Program;
- ▶ University of San Francisco; and
- ▶ Cape Fear Community College Nursing Program.

The Arc produced additional continuing education opportunities for health care professionals and academic students including more than 50 webinars attended by over 4,100 people. These webinars are available on our [website](#) and were viewed over 6,927 times. We also delivered health promotion presentations to disability service providers, health professionals, self-advocates, and families at statewide and national conferences including the 2014 [National Down Syndrome Congress](#) conference and The Arc's 2014 National Convention.

Lastly, The Arc's [Website](#), blogs, and [Twitter](#) and [Facebook](#) accounts were used to disseminate information on health promotion and disparities to the health care professionals employed throughout our nearly 700 chapter member network. These social media outlets plus our print newsletters reached over 200,000 people directly and the nearly 1.5 million people with intellectual disabilities they serve.

RAISING EXPECTATIONS FOR IMPROVED ORAL HEALTH

Several chapters of The Arc are taking a leadership role in actively engaging the dental community and bringing to their attention the enormity of poor oral health experienced by people with ID. Achieva/The Arc of Greater Pittsburgh has been a trailblazer in addressing oral health disparities and people with intellectual disabilities for decades. Their contributions continued during the HealthMeet® program included authoring articles for dental professional publications and recruiting licensed dentists in Pennsylvania to

complete the *Practical Oral Care for People with Developmental Disabilities*³⁰ training, a free program offered by NIH's National Institute of Dental and Craniofacial Research.

Another Pennsylvania venture directed by The Arc of Luzerne County was to produce an informational recruitment workshop attended by 12 dental professionals. The program included an overview of oral health disparities, general information about serving people with ID, and testimonials from oral health professionals that serve people with ID in their current practice. The Arc of Luzerne County was able to recruit five dental professionals interested in expanding their practice to include more people with intellectual disabilities.

The Arc of Luzerne also worked with a local dentist to host an open house for people with ID and their caregivers. Knowing that many fear dental appointments, the idea was to hold a tour and provide information about what people can expect at a dental appointment. The program gave people with ID and their caregivers the chance to tour the office, view the equipment, and ask questions about examinations.

These resources were assembled as part of The State of Pennsylvania: The Arc's Oral Health Initiatives toolkit available on our website.

This analysis of the over 2,400 health assessments and a review of the resources developed to address health disparities is an important, introductory step. However, it's our reaction and call to action that is most critical.

30 Practical Oral Care for People with Developmental Disabilities Series available at: <http://www.nidcr.nih.gov/oralhealth/Topics/DevelopmentalDisabilities/>

Mobilizing for Improving Health

The Arc and its chapters titled this report *Prognosis: Guarded* because without serious changes to the way we currently support, intervene, and monitor the health of people with intellectual disabilities, the more likely their health will continue to decline and disparities will grow.

This report describes and links to the numerous HealthMeet® resources developed to cultivate more self-advocates, expand proper nutrition and accessible exercise programs, develop competent health care professionals and intensify the focus on quality oral health services. Fortunately, there are some simple and low cost solutions to shifting the current environment and we invite you to invest your time to review these resources to determine which ones will help you in your winnable battles to improve the lives of people with intellectual disabilities.

The Arc's Commitment to Reverse the Status Quo

Data from the assessments confirmed the existence of health disparities for program participants. The Arc remains committed to identifying opportunities for interventions which will work toward erasure of health disparities between people with I/DD and their peers without disabilities. This section of the report will outline what The Arc network will do to make a difference in the healthy lives of people with intellectual disabilities and not allow these findings to sit on the proverbial shelf gathering dust. The Arc promises to:

- ▶ Publicize this report to all key stakeholders; people with ID, family members, friends, professionals, researchers, and decision makers;
- ▶ Enroll new chapters and other organizations supporting people with ID to use these resources in their local communities;
- ▶ Commit to finding affordable local community nutrition, exercise and health promotion programs already used by the general public;
- ▶ Gather and share inspirational success stories through social media, conferences, exhibits, and webinars;
- ▶ Obtain funding to expand our ability to diminish health disparities on a grand scale;
- ▶ Replicate evidence-based programs that address the health concerns faced by people with ID;
- ▶ Continue to work with current partners that share our concerns and passion to eradicate these barriers; and
- ▶ Recruit new, non-traditional partners that share our concerns but come to the discussion for different reasons, new perspectives and innovative ideas.

HealthMeet® participants have provided us with important information about health disparities between individuals with ID and the general population. We learned that their most prominent healthcare issues are weight, oral and foot health, and risk for falls. The Arc's partnership with



the CDC has reinvigorated us to ask how can we leverage this knowledge and resources to create healthy environments in our 660+ chapter network?

The Arc firmly believes that ignoring health disparities experienced by people with ID will not only exacerbate our inability to improve quality of life but also contribute to rising health care costs. We are proud to join The Centers for Disease Control and Prevention in the fight to address the winnable battles for improved nutrition, increased physical activity, and a decrease in obesity among people with ID.

The Arc will be proactive and continue to leverage this evidence by committing to work in partnership to change the course. Whether you are a self-advocate, family member, professional, researcher, funder, policy maker, or community leader, we invite you to use this report to understand the issues and join us to implement solutions - both sweeping and small.

We need leaders from all over the U.S. to contribute their wisdom, energy, and enthusiasm to address this issue. Your partnership is welcome. Some ways you can address this issue include:

- ▶ The HealthMeet® [website](#) is filled with resources on what chapters of The Arc are doing to support healthier lifestyles. We invite you to use these resources beginning today;
- ▶ Learn more about the health disparities that exist among people with ID;
- ▶ Volunteer your time at a local chapter of The Arc to support a health promotion program;
- ▶ If you're a medical student or professional, contact a local chapter of The Arc to learn more about how you can lend your expertise to a program.

We must take responsibility to support people with disabilities and their families so they can take charge of living healthy lives.

The prognosis is good.

Achieve with us.