

ICDR TOOLKIT

# Health Disparities and Disabilities in Research

A Toolkit for  
Interagency Collaboration



INTERAGENCY COMMITTEE ON  
DISABILITY RESEARCH

## TABLE OF CONTENTS

Introduction . . . . .	1
About the Interagency Committee on Disability Research (ICDR) . . . . .	1
Purpose of this Toolkit . . . . .	2
Health Disparities among People with Disabilities . . . . .	3
I. Physical Activity among People with Disabilities . . . . .	4
Federal Resources and Federally Funded Research . . . . .	5
Other Resources . . . . .	7
II. Obesity and Weight Management among People with Disabilities . . . . .	8
Federal Resources and Federally Funded Research . . . . .	9
III. Cancer among People with Disabilities . . . . .	11
Federal Resources and Federally Funded Research . . . . .	11
IV. Sexual and Reproductive Health among Women with Disabilities . . . . .	13
Federal Resources and Federally Funded Research . . . . .	13
Other Resources . . . . .	15
V. Aging and Disability . . . . .	16
Federal Resources and Federally Funded Research . . . . .	16
VI. Immunizations in Individuals with Disability . . . . .	20
Federal Resources and Federally Funded Research . . . . .	20
Other Resources . . . . .	21
Best Practices for Inclusion Strategies . . . . .	22
Federal Resources and Federally Funded Research . . . . .	22
Other Resources . . . . .	27
Opportunities for Future Research . . . . .	28
References . . . . .	29

# Introduction

Individuals with disabilities experience significant health disparities compared to those without disabilities. While disparities are often thought to mean racial or ethnic disparities, there are many dimensions of disparities that exist in the U.S., especially among health outcomes. According to Healthy People 2020, a health disparity exists if a health outcome is seen to a greater or lesser extent between populations (Healthy People 2020, 2020). Things like race, ethnicity, age, disability status, and socioeconomic status can contribute to one's health outcomes.

Health disparities affect people who are born with a disability, acquire a disability as a result of an accident or injury, or develop a disability because of chronic conditions like diabetes or harsh environmental conditions such as structural bias and residential segregation. There is much research and evidence of barriers to accessing primary, preventive, and specialized care among people with disabilities. Yet, people with disabilities are infrequently included in health and wellness research, and broader public health programs and initiatives often do not include persons with disabilities as a target population.

## **About the Interagency Committee on Disability Research (ICDR)**

The Interagency Committee on Disability Research (ICDR) was authorized by the amended 1973 Rehabilitation Act to promote coordination and collaboration among federal departments and agencies conducting disability, independent living, and rehabilitation research programs, including programs relating to assistive technology research and research that incorporates principles of universal design.

The ICDR adopted a vision to be widely recognized for facilitating and coordinating federal interagency efforts and for promoting collaborative relationships that

maximize the best use of federal resources for disability, independent living, and rehabilitation research. The ICDR has a long history of promoting collaboration and coordination across the government to meet the needs of the disability community and leverage limited resources. In its 2018–2021 Strategic Plan, the ICDR developed the following three goals:

**Goal #1:** Improve interagency coordination and collaboration in four thematic research areas: transition, economics of disability, accessibility, and disparities.

**Goal #2:** Develop a government-wide inventory of disability, independent living, and rehabilitation research.

**Goal #3:** Promote ongoing stakeholder input on gaps and priorities for disability, independent living, and rehabilitation research.

To address Goal #1 (improve interagency coordination and collaboration), the ICDR initiated a focus on inclusion of people with disabilities among health and wellness research as well as broader public health programs and initiatives that include people with disabilities as a target population.

## **Purpose of this Toolkit**

The purpose of this toolkit is to highlight resources across federal agencies, federal grantees, and non-federal entities conducting health and wellness research and implementing public health programs and initiatives. This toolkit highlights best practices and effective strategies for including people with disabilities as a priority audience or target population. This toolkit presents areas for future research related to health disparities and people with disabilities and is meant to help facilitate further research and collaboration by federal agencies and departments around the health disparities of people with disabilities.

# Health Disparities among People with Disabilities

Adults with disabilities are four times more likely to report poor or fair health than people with no disabilities across a range of health indicators and social determinants of health (Krahn et al., 2015). The health needs of people with disabilities may depend on the type of limitation and other underlying disability. For some people who acquire a disability through injury, their disability can be differentiated from their health status, but for others, health status can more directly lead to their disability status (Krahn et al., 2015).

Health disparities show up in many ways across disability status. Adults with disabilities have higher rates of chronic disease than adults without disabilities, and yet they are less likely to receive preventive care (Krahn et al., 2015). People with disabilities report higher rates of obesity, smoking, cases of diabetes, and lack of physical activity (Krahn et al., 2015). Disability status also contributes to inequalities in the social determinants of health. Disability status in adults is associated with a lower likelihood of employment, less access to internet, and inadequate transportation (Krahn et al., 2015). It has also been found that difficulties accessing health care and services contribute to unhealthier behaviors and poorer mental health (Krahn et al., 2015).

People with disabilities are often not included in public health programs and services. Inclusion in these effective health practices is a useful tool to improve the health of people with disabilities. The ICDR identified a number of topic areas to address related to health disparities among people with disabilities. This toolkit includes information on resources and programs in the following six topic areas:

- I. Physical Activity
- II. Obesity and Weight Management
- III. Cancer
- IV. Sexual and Reproductive Health among Women
- V. Aging
- VI. Immunizations

This toolkit features existing resources and programs, including both federal and non-federal resources as well as federally funded research projects, as they relate to each topic area in order to help address the existing disparities. The toolkit also pulls together identified best practices and effective strategies for disability inclusion for researchers and the public to address these health disparities.

## **I. Physical Activity among People with Disabilities**

---

Adults with disabilities are three times more likely to develop chronic diseases like heart disease, diabetes, or cancer than those without disabilities (National Center on Birth Defects and Developmental Disabilities, 2020). Reducing sedentary behavior, and increasing physical activity, has been shown to reduce the incidence of these diseases (U.S. Department of Health and Human Services, 2018). However, nearly half of all adults with disabilities get no aerobic physical activity (Centers for Disease Control and Prevention, 2014). Some barriers to participation among people with disabilities in physical activity include knowledge, attitudes, beliefs, social support, time, and accessibility issues, among others (Center for Research on Women with Disabilities, n.d.a).

## Federal Resources and Federally Funded Research

The **Move Your Way** campaign is a physical activity campaign from the U.S. Department of Health and Human Services to promote the recommendations from the *Physical Activity Guidelines for Americans*. The campaign includes a guide for adults, including those with a disability, that provides everything from interactive instructions on getting started with physical activity to information on the actual physical activity needs of adults.

The **I Can Do It! (ICDI)** program helps schools offer an integrated program of physical education, physical activity, and training in good nutritional behaviors to students with disabilities in grades K–12. This program prioritizes an inclusive, integrated approach for children with and without disabilities to all participate in physical activity in school.

The **Model Systems Knowledge Translation Center**, a national center to help facilitate the process of knowledge translation for those with spinal cord injury (SCI), traumatic brain injury (TBI), and brain injury, includes a number of resources on **Exercise and Fitness after SCI** that include factsheets, slideshows, and videos. These include information on:

- **Exercise after SCI Factsheet.** People with SCI should be physically active, including stretching, aerobic exercise, and strength training. This factsheet provides an overview of the exercise guidelines as well as options for people with SCI.
- **Adaptive Sports and Recreation Factsheet.** Adaptive sports and recreation may help people with SCI increase physical activity and help them engage with the community. This can include outdoor recreation activities, performing arts, individual sports, teams, or competitive sports.

- **Video Series on Exercise and Fitness After SCI.** The videos feature health care professionals as well as individuals with SCI who share their fitness routines and explain how exercise has improved their quality of life.

The **Sport for All Initiative** and **Project Play** focus on eight strategies to increase physical activity participation among all children and adolescents. The Sport for All Initiative highlights the benefits associated with participation in sports, including meeting the recommendations of physical activity.

The Centers for Disease Control and Prevention (CDC) hosts a resource page that is dedicated to **Increasing Physical Activity Among Adults with Disabilities**. This resource page highlights the *Physical Activity Guidelines for Americans*. These guidelines include a section dedicated to increasing physical activity for adults with chronic health conditions or disabilities. The guidelines also include special considerations for specific health conditions, such as:

- **Physical activity in adults with osteoarthritis.** This is a common condition in older adults. Getting regular physical activity can help lower the risk of developing other chronic diseases.
- **Physical activity in adults with selected physical disabilities.** Physical activity can reduce pain and improve fitness, function, and quality of life for people with disabilities. Physical activity can benefit the following disabilities: Parkinson's disease, multiple sclerosis, SCI, and stroke.

This infographic on **Increasing Physical Activity among Adults with Disabilities** is for doctors and other health professionals to use to recommend aerobic physical activity options that match each person's specific abilities and connect them to resources that can help them be physically active.



The **National Center of Health, Physical Activity, and Disability** (NCHPAD) is a public health practice and resource center focused on improving the health, wellness, and quality of life of people with disabilities. NCHPAD supports local, state, and national organizations in adopting guidelines, recommendations, and adaptations that promote **inclusion of children and adults with mobility limitations in public health practices**. Disability inclusion helps people with disabilities benefit from health promotion and prevention activities. This also means understanding how people function and participate in society to ensure that everyone has the same participation opportunities.

NCHPAD offers a **14 Weeks to a Healthier You** program. This program is a free, personalized, web-based physical activity and nutrition program targeted to people with mobility limitations, chronic health conditions, and physical disabilities to help increase physical activity and improve nutrition. Participants register for the NCHPAD program and are provided with personalized resources and exercises for 14 weeks.

The **Step It Up! The Surgeon General's Call to Action to Promote Walking and Walkable Communities** is a program with the goal of increasing walking by working together to increase access to safe and convenient places to walk and wheelchair roll and to a culture that supports walking for all Americans.

## **Other Resources**

**Walk with Ease** is an evidence-based program designed by the Arthritis Foundation. It is focused on helping people who suffer from arthritis get physical activity. This program was specifically designed to help people who can stay on their feet for 10 minutes without increased pain. It includes a guidebook and walking schedule. The program is available in classroom settings, led by a certified instructor. It can also be accomplished at home.

**Exercise is Medicine™** provides resources and tools for healthcare providers and health and fitness professionals to access and review every patient’s physical activity program at every visit. It is a global health initiative with the goals of making physical activity assessment and promotion a standard in clinical care and connecting health care with evidence-based physical activity resources for people of all abilities.

- The *Healthcare Providers’ Action Guide* provides physicians and other healthcare professionals with a tool for integrating physical activity in their daily practice.
- The *Health and Fitness Professionals’ Action Guide* provides health and fitness professionals with a guide for how to work effectively with physicians and other healthcare providers to use exercise and physical activity as a highly effective patient care prescription.

## **II. Obesity and Weight Management among People with Disabilities**

---

Overweight and obesity status affect people differently. The CDC reports that children and adults with mobility limitations and intellectual or learning disabilities are at the greatest risk for obesity (CDC, 2019c). About 20% of children ages 10 through 17 who have special health care needs are obese, compared with 15% of children of the same age without disabilities or special health care needs (CDC, 2019c). Research suggests that people with disabilities can find it more difficult to eat healthy and control their weight. This can be due to limited access to healthy food, lack of resources or access to resources, and pain or difficulty chewing or swallowing.

## Federal Resources and Federally Funded Research

Obesity is more prevalent among people with disabilities than for people without disabilities and it is an important risk factor for other health conditions. This resources factsheet on **Overweight and Obesity Among People with Disabilities** outlines the specific challenges, how to increase physical activity, and resources specific to people with disabilities. The CDC has a resources page dedicated to **Disability and Obesity** that highlights information and statistics about the obesity epidemic, its impact on people with disabilities, and challenges that people with disabilities face regarding weight management and obesity.

The **Nutrition Obesity Research Centers**, funded by the National Institute of Diabetes and Digestive and Kidney Diseases, focus on resources and programs to foster interdisciplinary basic, clinical, public health research related to nutritional sciences and/or obesity. There are 11 research centers around the country.

The **MOVE! Weight Management Program** is supported by the U.S. Department of Veterans Affairs National Center for Health Promotion and Disease Prevention. It is a weight management and health promotion program designed to improve the lives of veterans. MOVE!'s core ideas include encouraging healthy eating behaviors, increasing physical activity, and promoting even small weight losses. Veterans receive help from a MOVE! care team to help reduce health risks, prevent or reverse certain diseases, and improve quality of life.

The **Healthy Weight and Obesity Factsheets** describe ways that people and organizations can help combat obesity among people with disabilities and assist them in achieving a healthy weight and an improved quality of life. Included is a brief on **Achieving Healthy Weight and Obesity Prevention**, which highlights considerations to address obesity and disability in the community. Other factsheets

include [Health Department Strategies](#), [Healthy Weight and Obesity Prevention in the Workplace](#), and [Healthy Weight and Obesity Prevention in Schools](#).

Lack of access to accessible health care facilities has been cited as a barrier to people with disabilities in receiving care. This factsheet on [What Healthcare Professionals Can Do to be Accessible](#) provides considerations for health care professionals as to what barriers people with disabilities are experiencing.

The University of Alabama at Birmingham Spinal Cord Injury Model System [EatRight® Weight Management Program](#) is designed for individuals with spinal cord impairments, including people with SCI, dysfunction, and disease. EatRight is a 12-week program. It includes a workbook and videos to guide users through the weekly lessons.

The Center for Research on Women with Disabilities (CROWD) has a resources and information page on [Weight Management: Disability and Overweight/Obesity](#) specific to women with disabilities. It includes a number of resources, such as [Barrier to Weight Management](#), [Limits to Clinical Guidelines](#), and [Resources for Managing Your Weight](#).

CROWD also has an intervention program. The [GoWoman Weight Management Program for Women with Mobility Impairments](#) is designed for women with mobility impairments to lose weight and increase physical activity. It is a 16-week program adapted from the Lifestyle Change Program component of the Diabetes Prevention Program, in which facilitators and group members work together to help each participant reach personal goals.

The [Steps to Your Health](#) is a CDC-funded, evidence-based wellness promotion program developed for individuals with disabilities. Its purpose is to promote healthy lifestyles in people with disabilities and prevent debilitating secondary

conditions. It is an 8-week small group instructional program that targets achieving and maintaining a healthier lifestyle, including good nutrition, preventing obesity and its complications, increasing physical activity, dealing with stress, and improving communication.

### **III. Cancer among People with Disabilities**

---

People with disabilities are at increased risk for certain cancers and are less likely to receive the recommended cancer screenings than people without disabilities (CDC, 2019a). These cancer disparities include breast, colorectal, cervical, and prostate cancer. The barriers to cancer screening that people with disabilities face may include inaccessible screening exams, preconceived notions by health care providers, communication barriers, and cost barriers (Arana, 2017). For example, breast cancer is the most common cancer among women in the U.S., and receiving a mammography screening regularly is important. (CDC, 2019a). Women with disabilities are less likely than women without disabilities to have received breast cancer screening during the past 2 years (CDC, 2019a). Due to their low rates of screening, they are more likely to be diagnosed with late-stage breast cancer and to have higher mortality (Arana, 2017). Other increased risks of cancer include bladder cancer. People with SCI are more likely to develop bladder cancer than the general population (Craig Hospital, 2015).

#### **Federal Resources and Federally Funded Research**

The CDC has a resource page for **Women with Disabilities and Breast Cancer Screening** that includes information on mammograms, tips for getting screened, and additional resources. The U.S. Preventive Services Task Force has a **Summary of Recommendations on Breast Cancer Screening**. The CDC also has resources on improving the use of mammography among women with disabilities.

**Every Woman Matters: Portraits of Montana Women Living with Disabilities** is a multimedia exhibit created by the **Montana Disability and Health Program** to highlight the importance of breast cancer screening among women with physical disabilities. Information on where to find and plan for accessible mammography is organized in the **online Montana Mammography Directory**.

The **New York Department of Health (NYSDOH) Disability and Health** program has worked closely with the NYSDOH Breast and Cervical Cancer Early Detection program to increase providers' understanding on how to better serve women with disabilities. The **Oregon Office on Disability and Health** has a directory to better inform Oregon women with disabilities of the accessibility/usability features of their area mammography facilities.

The **Right to Know Campaign** and **Right to Know Tip Sheet** are resources centered around the barriers to breast cancer screening for women with physical disabilities. This breast cancer screening campaign raises awareness about breast cancer among women with physical disabilities and encourages women to get screened. The campaign developed health promotion materials, and it features women with physical disabilities who have survived breast cancer.

This video, **Smoking's Effects on Secondary Complications of Spinal Cord Injury**, focuses on how the many complications people experience after SCI are made worse with smoking, including risk of cancer. Bladder cancer is more common among people with SCI than the general population. This page from Craig Hospital on **Bladder Cancer Risk Factors** provides resources specific to bladder cancer among people with SCI. Resources include the risk factors, symptoms, treatment, and actionable steps to decrease risk.

## **IV. Sexual and Reproductive Health among Women with Disabilities**

---

According to the CDC, 36 million women in U.S. have disabilities. These women may need specific care based on their individual needs in addition to the same general health care as women without disabilities (National Center on Birth Defects and Developmental Disabilities, 2019). Women with disabilities may not receive the same amount of sexuality and reproductive health information from the same sources as non-disabled women, and they obtain less of their education through sexual experience (CROWD, n.d.b).

### **Federal Resources and Federally Funded Research**

**CROWD** promotes, develops, and disseminates information to improve the health and expand the life choices of women with disabilities. The site provides information on sexuality and reproductive health, among other topics.

CROWD's resources include research on **Sexual Functioning**, a publication on **Sexuality and Reproductive Health**, resources on **Sexuality and Reproductive Health for Women with Disabilities**, and information on **Access to Reproductive Health Care** and **Access to Pelvic Health Care**. There are also a number of resources dedicated to reproductive health topics specific for women with disabilities, including **Contraception, Fertility, Menstruation, Pregnancy and Delivery**, and the **Well Woman Exam**.

As part of a Pelvic Health Initiative, this **Pelvic Health Webinar Series** includes four webinars designed to help women with mobility impairments achieve and maintain their highest level of pelvic health. It includes information from scientific literature, clinical practice, and information from women with mobility impairments. Webinar topics include: (1) pelvic health for women with mobility impairments, (2) pelvic health transitions for girls with mobility impairments, (3) bladder and bowel issues

that affect sexuality, and (4) access to quality pelvic health care for women with mobility impairments. The webinar series website includes an archive video of the session, transcription, and downloadable PDFs of the presentations.

The **Spinal Cord Injury Model System** features a video series called **Reproductive Health for Women with Spinal Cord Injury Video Series**. The series helps educate women and health care professionals on specific medical issues and care of women with SCI. Women with SCI have unique health care issues related to their obstetric and gynecological needs. Part I covers the **Gynecological Examination**, and Part II covers **Pregnancy and Delivery**.

This panel discussion on **Women and Spinal Cord Injury** from the University of Washington features five women with spinal cord injuries who share their experiences and offer useful information about staying healthy as a female living with SCI. Accompanying the video is a report on **Women and SCI: Health and Wellness: Opportunities and Challenges**. The paper covers topics of reproductive health as well as preventive health issues, including mammography, pelvic exams, and osteoporosis.

The **Model Systems Knowledge Translation Center** developed a factsheet on **Pregnancy and Women with Spinal Cord Injury** to help women prepare for pregnancy, labor, and delivery after SCI. It also gives tips on working with a health care team to keep the mother and baby healthy. It walks through each trimester with considerations for women with SCI.

The CDC has resources on **Tips for Communicating with Female Patients with Intellectual Disabilities**, specifically regarding sexual and reproductive health information.



## Other Resources

The Paralyzed Veterans of America and the Consortium for Spinal Cord Medicine published a clinical practice guideline called *Sexuality and Reproductive Health in Adults with Spinal Cord Injury*. It highlights 85 recommendations, including topics of male and female fertility, dysfunction and treatment, and relationship issues.

The Patient-Centered Outcomes Research Institute conducted a project on *Workshops to Transform the Health Care of Women with Disabilities*. This multipart project included a survey of women and health care providers regarding obstetrical, gynecological, and breast care for women with disabilities; review and analysis of survey data by broadly representative stakeholders; and a review of the pilot research results and design of prospective patient-centered research at a second workshop. This project resulted in a report called *Transforming Healthcare of Women with Disabilities Workshop I Report* and a published article titled *Reproductive Healthcare Experiences of Women with Cerebral Palsy*.

*The Association of Maternal and Child Health Programs' TOOLBOX* was created for maternal and child health programs that target women with disabilities and special health care needs. It provides links to tools that will increase knowledge about recommended services, identify service gaps, identify accessible health care facilities and transportation, and improve health care interactions between clinicians and women with disabilities. Resources include tools to *Increase Knowledge and Use of Recommended Services, Identify Service Gaps and Monitor Progress, and Empower Clinicians and Women with Disabilities to Interact Effectively*.

## V. Aging and Disability

---

Medical and rehabilitation advancements may be contributing to longer life expectancies for people with disabilities, and the increased proportion of older adults has resulted in increased prevalence of new-onset disabilities. Older adults are projected to become the fastest-growing age demographic. Approximately 12.4% of the population is over 65, and by 2030 it is projected to rise to 20.4% (Goetz et al., n.d.). People aging with disabilities (those living into old age with existing disabilities) are a growing population that have specific health care needs, but the services and existing research for this population are not well organized to meet their needs (Goetz et al., n.d.). This represents a need to address aging and disability as the need will continue to grow.

### Federal Resources and Federally Funded Research

The **No Wrong Door System** initiative is a collaborative effort of the Administration for Community Living, the Centers for Medicare and Medicaid Services, and the Veterans Health Administration to support states working to streamline access to long-term services and support for older adults, people with disabilities, and their families.

The **State Councils on Developmental Disabilities** are federally funded, self-governing organizations charged with identifying the most pressing needs of people with developmental disabilities in their state or territory. Councils are committed to advancing public policy and systems change that help these individuals gain more control over their lives. There are 56 Councils across the U.S. that work to address identified needs by conducting advocacy, systems change, and capacity-building efforts that promote self-determination, integration, and inclusion. Key activities include conducting outreach, providing training and

technical assistance, removing barriers, developing coalitions, encouraging citizen participation, and keeping policymakers informed about disability issues.

**State Units on Aging** are designated state-level agencies that are responsible for developing and administering multiyear state plans that advocate for and assist older residents, their families, and, in many states, adults with physical disabilities. There are 56 State Units on Aging located across the country. State Units on Aging can be found at [Eldercare](#).

The **Aging and Disability Evidence-Based Programs and Practices** initiative helps the public learn more about available evidence-based programs and practices in the areas of aging and disability and determine which of these may best meet their needs. Information about the initiative process is included in the ***Aging and Disability Evidence-Based Programs and Practices (ADEPP) Guide to Reviewing Evidence-Based Programs***. Programs included:

- **EnhanceFitness**, a multicomponent, group physical fitness activity program that aims to help older adults at all levels of fitness become more active, energized, and empowered to sustain independent lives and prevent functional decline. The program includes 1-hour classes that are held two or three times per week in a variety of settings, including community centers, senior housing facilities, YMCA facilities, and retirement communities.
- **Fit and Strong!**, a multicomponent physical activity and behavior change program for older adults with mild to moderate osteoarthritis in their lower extremities.
- **Healthy Steps for Older Adults**, a program for adults ages 50 and older and adults of any age with a disability. It provides screening, assessment, and education to reduce the incidence of falls.

- **HomeMeds**, a medication-use improvement program developed for agencies providing in-home services and health care to older adults.
- **Improving Mood-Promoting Access to Collaborative Treatment**, an intervention for older adult patients who have a diagnosis of major depression or dysthymia, often in conjunction with another major health problem.

CROWD has a page on **Aging** as it specifically relates to women with disabilities. This page highlights some of the characteristics of aging with a disability, the onset of new problems, and worsening of existing problems.

This **Aging and Spinal Cord Injury** factsheet helps explain changes in the body as people with SCI age. This includes learning about the issues people with SCI experience as they age, common health conditions associated with SCI, awareness of environmental factors and barriers and overcoming them, and how to work with doctors and health care providers to track and address problems.

The University of Washington **Rehabilitation Research and Training Center (RRTC) on Healthy Aging and Physical Disability** has a number of resources and research on healthy aging. Topics include **How to Manage Disability-Related Pain as You Age**, **Living Well with Age-Related Vision Loss**, **Tips for Healthy Eating and Healthy Aging**, **Aging with a Disability: Tips for Your Sex Life**, and **How to Stay Physically Active**.

The Healthy Aging RRTC has a webinar series available for viewing on **State of the Science: Advances at the Intersection of Aging and Disability**. Topics of the webinar series are **Long-Term Services and Supports and Caregiving for Adults Aging with Disability**, **Autonomy and Access Issues for Adults Aging with Disability**, and **Healthcare Policy and Implications for Adults Aging with Long-Term Disability**.

This research on **How to Age Well with Secondary Problems** tested a conceptual model of secondary health conditions, age, and function in persons aging with long-term physical disabilities. Secondary conditions include things like chronic pain, fatigue, depression, worsening muscle spasms, or chronic infections. Increasing age was associated with greater rates of physical and health problems and poorer function. The data suggests a five-factor approach for conceptualizing secondary conditions and their impact and emphasizes the importance of age in symptom severity and impact.

This research on **What Successful Aging Means to People with Physical Disabilities** describes what successful aging looks like for middle-aged and older adults with physical disabilities. Four major themes emerged about how to age well:

- **Adaptation and resilience** means adjusting to life changes, enjoying life's pleasures, and keeping your mood up in spite of setbacks.
- **Autonomy** means being able to make choices and take charge of your life, including having a voice in the adaptations or assistance you used.
- **Social connectedness** means having strong connections to family members, spouses, and friends, including other people with the same disability.
- **Physical health** means managing symptoms such as pain and fatigue and having good access to medical care from knowledgeable physicians.

This paper from a state of the science titled ***Aging with and Into Disability: Current Status and Future Directions*** focuses on reviewing research findings and identifying a research agenda in key areas at the intersection of aging and disability. The paper summarizes findings and recommendations resulting from the conference.

## VI. Immunizations in Individuals with Disability

---

People with disabilities are vulnerable to complications from vaccine-preventable diseases, and they should have equitable access to immunizations. (O’Neill et al., 2020). For people with SCI, stroke, or multiple sclerosis; chronic illnesses like diabetes or emphysema; or the elderly, a vaccine-preventable infection like the flu can be a more serious and life-threatening disease than for people without those conditions, leading to severe complications including pneumonia and death.

### Federal Resources and Federally Funded Research

This paper *Vaccination in People with Disability: A Review* summarizes the research on immunizations in people with disabilities in order to ensure a comprehensive understanding of knowledge in this area and direct further research.

Certain groups of people are more at risk for flu complications, including people with certain disabilities. The CDC’s page on **People at High Risk for Flu Complications** highlights some of these risk areas. The flu can also make certain chronic health problems worse, such as for people with asthma or chronic congestive heart failure who may experience worsening of these conditions due to flu.

The flu vaccine is an important preventive tool for people with chronic health conditions. It has been associated with **lower rates of some cardiac events** among people with heart disease, especially among those who had a cardiac event in the past year. The flu vaccine also has been shown to be associated with reduced hospitalizations among people with **diabetes** and **chronic lung disease**.

For people with SCI, this information from St. Luke’s Rehabilitation Institute highlights the **Importance of the Flu Shot for People with Spinal Cord Injury**.

Adolescents with chronic medical conditions are at risk of HPV infection, associated complications, and under-immunization and often identify a pediatric subspecialist as their main provider. This study *HPV Vaccination of Adolescents with Chronic Medical Conditions: A National Survey of Pediatric Subspecialists* assesses the HPV-related understanding, beliefs, and practices of pediatric subspecialists.

### **Other Resources**

This guide on *Immunizations and Multiple Sclerosis* from the Multiple Sclerosis Council for Clinical Practice Guidelines and the Paralyzed Veterans of America provides clinicians with evidence-based strategies and information to evaluate risks and benefits of immunizations in patients with multiple sclerosis.

# Best Practices for Inclusion Strategies

Strategies for inclusion of people with disabilities means including input from people with disabilities in program or structural design, implementation, monitoring, and evaluation. Disability inclusion also means including people with disabilities in everyday activities and encouraging them to have roles similar to their peers who do not have a disability, allowing people with disabilities to take advantage of the benefits of the same health promotion and prevention activities as those who do not have a disability (CDC, 2019b). People with disabilities need public health programs and health care services in the same way the people without disabilities need them.

## Federal Resources and Federally Funded Research

The CDC has information dedicated to **Disability Inclusion** and **Disability and Health Inclusion Strategies** that highlight ways to include people with disabilities into everyday activities. This involves practices and policies designed to identify and remove **barriers** such as physical, communication, and attitudinal barriers.

### Including People with Disabilities in Public Health Programs and Activities

highlights approaches to inclusion in education and counselling programs that promote physical activity, improve nutrition, or reduce the use of tobacco, alcohol, or drugs; blood pressure and cholesterol assessments during annual health exams; and screening for illnesses such as cancer, diabetes, and heart disease.

The **Reaching People with Disabilities through Healthy Communities** is a CDC-funded project with the National Association of Chronic Disease Directors. It uses



an **Inclusive Healthy Communities Model** to promote disability inclusion strategies and make healthy living easier for all people across community sections like school, work, and in health care settings using a **policy, systems, and environmental** approach to change. The **Inclusive Healthy Communities Model** uses a phased approach to create change at the local level through community coalitions to plan and implement sustainable improvements. The six phases of the model include:



Source: CDC, 2020

- **Commitment**
- **Assessment and Training**
- **Prioritization and Planning**
- **Implementation**
- **Evaluation**
- **Communication and Dissemination**

The CDC’s **Disability and Health State Programs** currently fund 19 State Disability and Health Programs to improve health and quality of life among people with disabilities through adaptation and implementation of evidence-based strategies. The funds help develop and strengthen internal capacity and

health-related disability programs in order to improve knowledge and awareness about the usefulness and effectiveness of programmatic, policy, systems, and environmental changes for people with select functional disability types. They also support programs to plan, implement, evaluate, and disseminate non-research activities aimed at promoting inclusion and accessibility and reducing health disparities between people with and without disabilities. These include the following programs:

- **Capacity-Building Programs** have limited capacity or experience in developing, implementing, evaluating, and disseminating programmatic, policy, systems, and environmental changes for people with mobility and/or intellectual disabilities. Examples of existing programs include:
  - **Project CHEER** (Community Health Education and Exercise Resources) is Kentucky's State Disability and Health program. It addresses the health disparities experienced by individuals with cognitive and mobility disabilities through education, empowerment, and accessibility.
  - The **Missouri Disability and Health Collaborative** is setting out to make public health fitness and nutrition strategies fully accessible for people with intellectual disabilities.
  - **Chronic Disease Prevention and Management for Individuals with Disabilities** in Vermont aims to make the Health Promotion and Disease Prevention chronic disease programs accessible to all Vermonters, including individuals with physical and/or intellectual disabilities. The chronic disease programs include cancer control, physical activity and nutrition, tobacco control, oral health, diabetes prevention, asthma, cardiovascular disease, and breast and cervical cancer screenings.

- **Core Implementation Programs** are “implementation ready” and have the existing infrastructure to implement, evaluate, and disseminate programmatic, policy, systems, and environmental changes for people with mobility and/or intellectual disabilities. Examples of existing programs include:
  - The **Alabama Disability and Health Program** was created to improve the health of people with disabilities and promote equity in health, prevent chronic disease, improve emergency preparedness, and increase the quality of life among people with disabilities.
  - Florida’s **Disability and Health Program** is focused on a more inclusive approach to its programs and services.
  - The **Ohio Disability and Health Program** works to substantially improve the health and quality of life of over 2 million Ohioans with disabilities through the adaptation and implementation of evidence-based strategies with four main activities that include physical activity, nutrition intervention, tobacco cessation, and training and education.
  
- **Core Implementation Programs with Enhanced Activities** are a subset of Core Implementation Programs that have the knowledge, skills, and ability to accomplish the following additional activities: mentoring a capacity-building awardee to establish infrastructure and support disability-related activities through peer-to-peer networking; and/or accessing and utilizing Medicaid data to identify patterns of health and health care utilization for people with intellectual and developmental disabilities. Examples of existing programs include:
  - The **Inclusive Health and Wellness Initiative for Iowans with Disabilities** works to promote and maximize health, prevent chronic disease, and increase the quality of life among Iowans with disabilities. Activities to improve the health of Iowans with disabilities through increased physical

activity, better nutrition, and healthy weight include improving the public health system capacity; building healthy, inclusive communities; developing disability service organization capacity; and increasing health care provider knowledge and accessibility.

- **Kansas Disability and Health Program** seeks to improve the health of all Kansans with disabilities, but specifically focuses on people with intellectual and developmental disabilities and people with mobility limitations. The program improves consumers' access to and knowledge in areas of oral health, nutrition, and physical health.
- The **Massachusetts Health and Disability Program** works to ensure that the needs of people with disabilities are included in public health programs, services, data collection, policies, and systems. The program focuses on supporting the Health and Disability Partnership, data collection and reporting, advancing policy initiatives, helping health promotion and disease prevention programs and services, improving access to health care programs and facilities, and ensuring emergency preparedness includes people with disabilities and their care providers.
- The **Michigan Health Promotion for People with Disabilities Initiative** is a statewide partnership committed to reducing the health disparities between people with disabilities and people without disabilities through member collaboration, expertise, and leveraged resources.
- The **New Hampshire Disability and Public Health Project** aims to improve the health and quality of life of people with disabilities by collaborating with state and regional public health efforts to advance accessibility and inclusion of people with intellectual and/or mobility disabilities in public health, health care, and health promotion activities.

Worksite wellness programs have become a key component in the fight against obesity and chronic disease as well as the rising costs of health care in the U.S. Employees with disabilities are often overlooked in the workforce. This *Inclusive Worksite Wellness Guide* addresses the inclusivity of workplace wellness programs. It provides a comprehensive examination of worksite wellness and offers tips, strategies, and resources to ensure that worksite wellness programs are inclusive of people with disabilities.

### **Other Resources**

The National Association of County and City Health Officials has a number of resources, including *Five Steps for Inclusive Communication: Engaging People with Disabilities* and a *Directory of Community-Based Organizations Serving People with Disabilities*.

# Opportunities for Future Research

The ICDR identified strategies for inclusion of people with disabilities in health and wellness programs and research initiatives as an area of focus. With the programs and initiatives outlined above, there is further research needed in the following areas:

1. **Long-term benefits of physical activity.** Studies have not investigated whether the long-term benefits of physical activity like reduced risk of cardiovascular disease, osteoporosis, and obesity that occur in people without disabilities also occur among people with disabilities (CROWD, n.d.a).
2. **Promoting physical activity.** There is limited research focusing on how to promote physical activity among people with disabilities. More research is needed on how to effectively promote physical activity among people with disabilities.
3. **Immunizations in individuals with disability.** In-depth qualitative data and data from a variety of healthcare providers related to immunizations among people with disabilities are notably lacking. This information is needed in order to grow the research base to develop effective immunization interventions in this population (O'Neill et al., 2020).
4. **Aging with a long-term physical disability.** While there is research on the development of disabilities as one ages, there are fewer published studies around aging with a long-term physical disability. This is an area where more information is needed.

# References

- Arana, E. (2017, March 02). *Cancer disparities among people with disabilities: How local health departments can help*. National Association of County and City Health Officials. <https://www.naccho.org/blog/articles/cancer-disparities-among-people-with-disabilities-how-local-health-departments-can-help>
- Centers for Disease Control and Prevention. (2014, May). Adults with disabilities. *CDC Vital Signs*. [www.cdc.gov/vitalsigns/disabilities](http://www.cdc.gov/vitalsigns/disabilities)
- Centers for Disease Control and Prevention. (2019a). *Cancer screening prevalence among adults with disabilities*. <https://www.cdc.gov/cancer/dcpc/research/articles/screening-disabilities.htm>
- Centers for Disease Control and Prevention. (2019b). *Disability inclusion*. <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-inclusion.html>
- Centers for Disease Control and Prevention. (2019c). *Disability and obesity*. <https://www.cdc.gov/ncbddd/disabilityandhealth/obesity.html>
- Centers for Disease Control and Prevention. (2019d). *Women with disabilities and breast cancer screening*. <https://www.cdc.gov/ncbddd/disabilityandhealth/breast-cancer-screening.html>
- Centers for Disease Control and Prevention. (2020). *Reaching people with disabilities through healthy communities*. <https://www.cdc.gov/ncbddd/disabilityandhealth/reaching-people.html>
- Center for Research on Women with Disabilities. (n.d.a). *Physical activity*. Baylor College of Medicine. <https://www.bcm.edu/research/labs-and-centers/research-centers/center-for-research-on-women-with-disabilities/a-to-z-directory/healthy-behaviors/weight-management/physical-activity>
- Center for Research on Women with Disabilities. (n.d.b). *Sexual health*. Baylor College of Medicine. <https://www.bcm.edu/research/labs-and-centers/research-centers/center-for-research-on-women-with-disabilities/topics/sexual-health>
- Craig Hospital. (2015). *Bladder cancer risk factors*. <https://craighospital.org/resources/bladder-cancer>
- Goetz, M. C., Molton, I. R., Jensen, M. P., Amtmann, D., Johnson, K., Kraft, G. H., Bombardier, C., Ehde, D., Harniss, M., Yorkston, K., Borson, S., & Verrall, A. (n.d.). *Aging with and into disability: Current status and future directions*. University of Washington. <http://agerrtc.washington.edu/SOS>
- Healthy People 2020. (2020). *Disparities*. U.S. Department of Health and Human Services. <https://www.healthypeople.gov/2020/about/foundation-health-measures/Disparities>
- Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health, 105 Suppl 2(Suppl 2)*, S198–S206. <https://doi.org/10.2105/AJPH.2014.302182>

National Center on Birth Defects and Developmental Disabilities. (2019, October 28). *Disability and health information for women with disabilities*. Centers for Disease Control and Prevention. <https://www.cdc.gov/ncbddd/disabilityandhealth/women.html>

National Center on Birth Defects and Developmental Disabilities. (2020, April 23). *Increasing physical activity among adults with disabilities*. Centers for Disease Control and Prevention. <https://www.cdc.gov/ncbddd/disabilityandhealth/pa.html>

O'Neill, J., Newall, F., Antolovich, G., Lima, S., & Danchin, M. (2020). Vaccination in people with disability: A review. *Human Vaccines & Immunotherapeutics*, 16(1), 7–15. <https://doi.org/10.1080/21645515.2019.1640556>

U.S. Department of Health and Human Services. (2018). *Physical activity guidelines for Americans, 2nd edition*. [https://health.gov/sites/default/files/2019-09/Physical\\_Activity\\_Guidelines\\_2nd\\_edition.pdf](https://health.gov/sites/default/files/2019-09/Physical_Activity_Guidelines_2nd_edition.pdf)









