Healthy People 2020 Progress Review

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Healthy People 2020 Progress Review: Improving Health Outcomes through Inclusion and Participation

August 11, 2016

Karen B. DeSalvo, MD, MPH, MSc

Acting Assistant Secretary for Health
U.S. Department of Health and Human Services

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Progress Review Agenda and Presenters

Chair

- Karen B. DeSalvo, MD, MPH, MSc, Acting Assistant Secretary for Health, U.S. Department of Health and Human Services

Presentations

- Charles Rothwell, MBA, MS, Director, National Center for Health Statistics
- Alison Cernich, PhD, Director, National Center for Medical Rehabilitation Research, NICHD, NIH
- John Tschida, MPP, Director, National Institute on Disability, Independent Living, and Rehabilitation Research, ACL
- Georgina Peacock, MD, MPH, FAAP, Director, Division of Human Development and Disabilities, National Center on Birth Defects and Developmental Disabilities, CDC
- Jennifer Madans, PhD, Associate Director for Science, National Center for Health Statistics

Community Highlight

- Meg Traci, PhD, Project Director, Assistant Research Professor, The Montana Disability and Health Program

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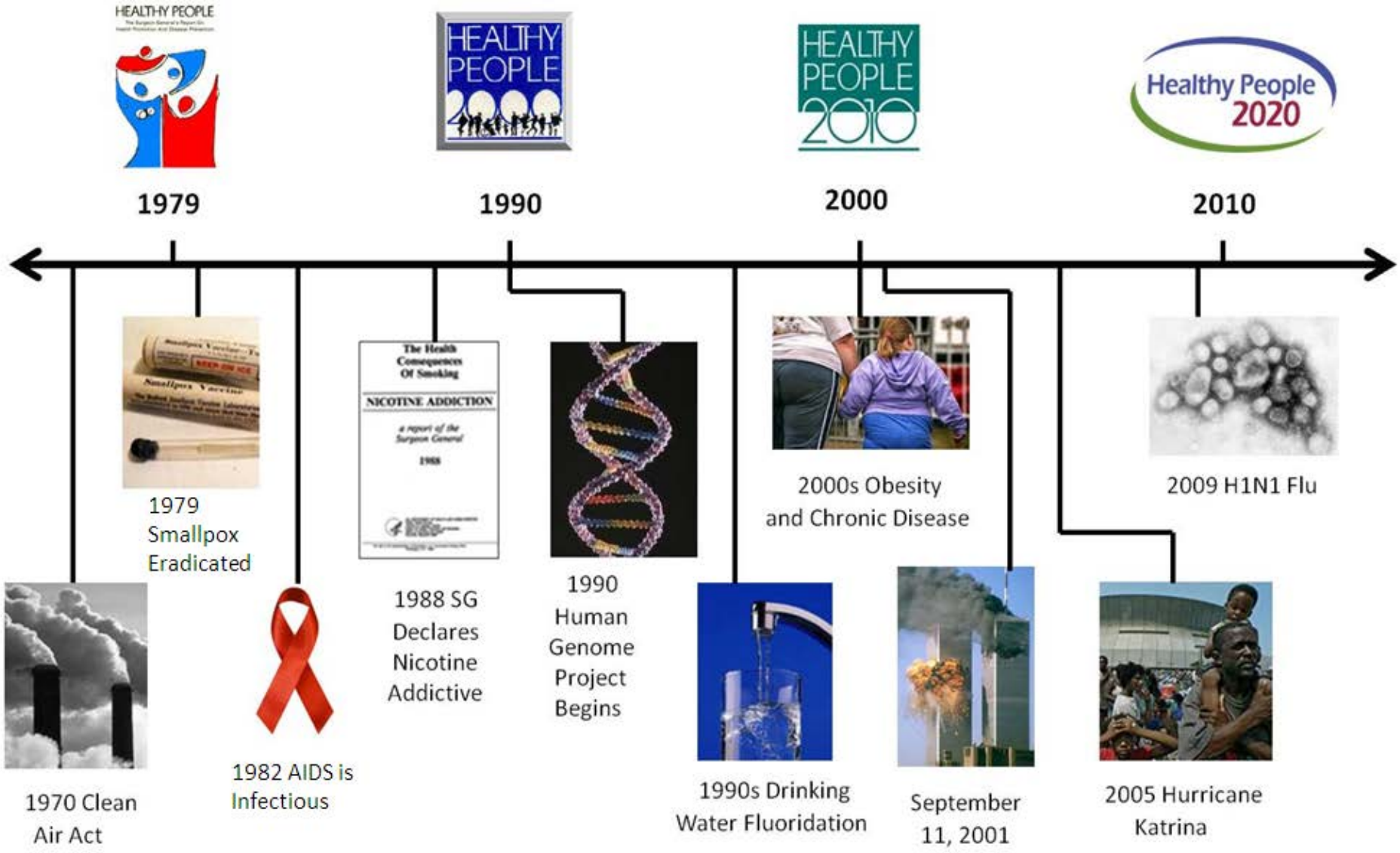
Healthy People at the Forefront of Public Health

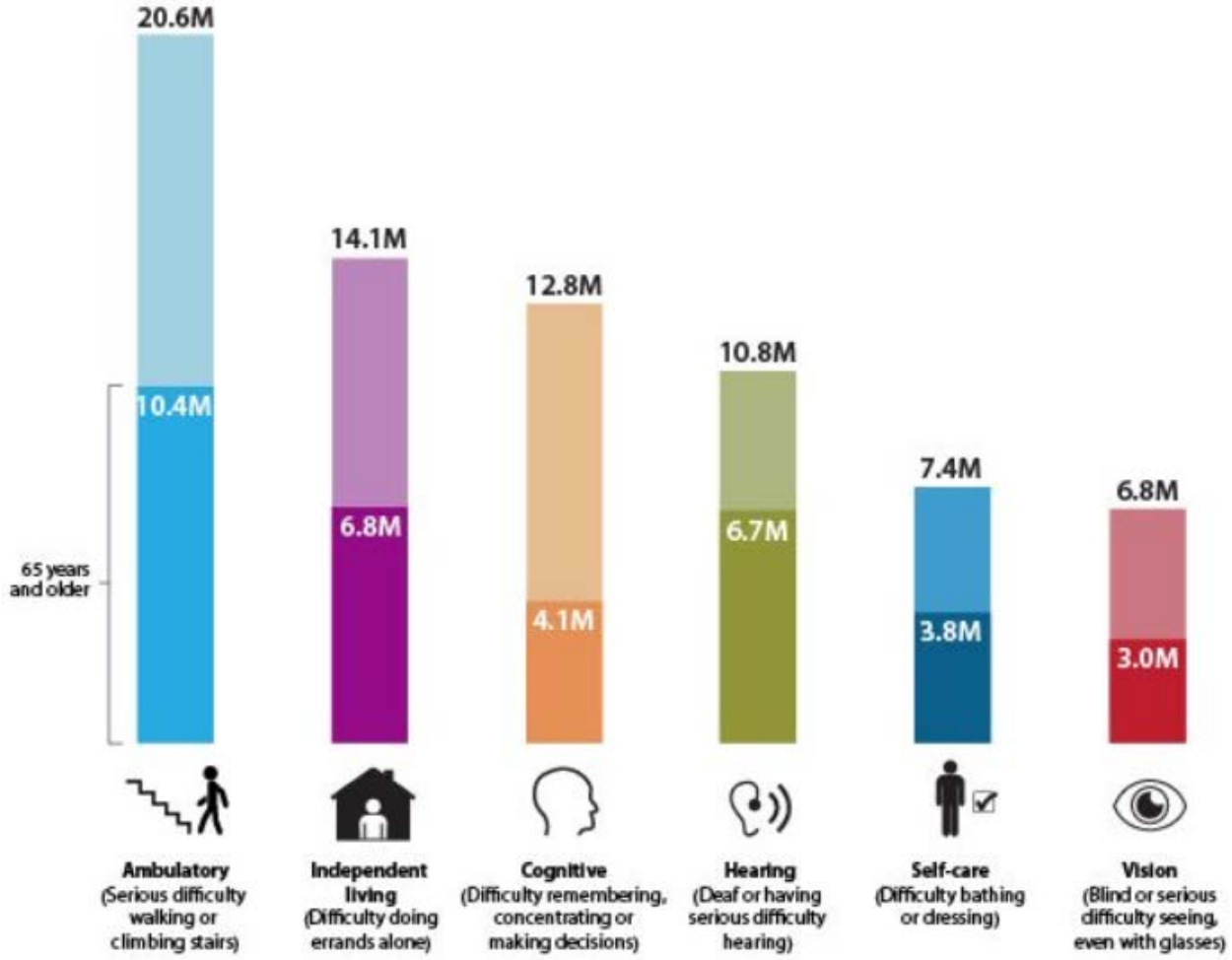


Evolution of Healthy People

Target Year	1990	2000	2010	2020
Overarching Goals	• Decrease mortality: infants–adults • Increase independence among older adults	• Increase span of healthy life • Reduce health disparities • Achieve access to preventive services for all	• Increase quality and years of healthy life • Eliminate health disparities	• Attain high-quality, longer lives free of preventable disease • Achieve health equity; eliminate disparities • Create social and physical environments that promote good health • Promote quality of life, healthy development, healthy behaviors across life stages
# Topic Areas	15	22	28	42
# Objectives/ Measures	226	312	1,000	~1,200

Prevalence of Disabilities for Ages 18+

Individuals in Millions



United States Census Bureau

U.S. Department of Commerce
Economics and Statistics Administration
U.S. CENSUS BUREAU
census.gov

Source: 2014 American Community Survey
www.census.gov/acs

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Impact: Poor health among people with disabilities

- Less likely to receive recommended preventive health care services, such as routine teeth cleanings and cancer screenings
- At a high risk for poor health outcomes such as obesity, hypertension, falls-related injuries, and mood disorders such as depression
- More likely to engage in unhealthy behaviors that put their health at risk, such as cigarette smoking and inadequate physical activity

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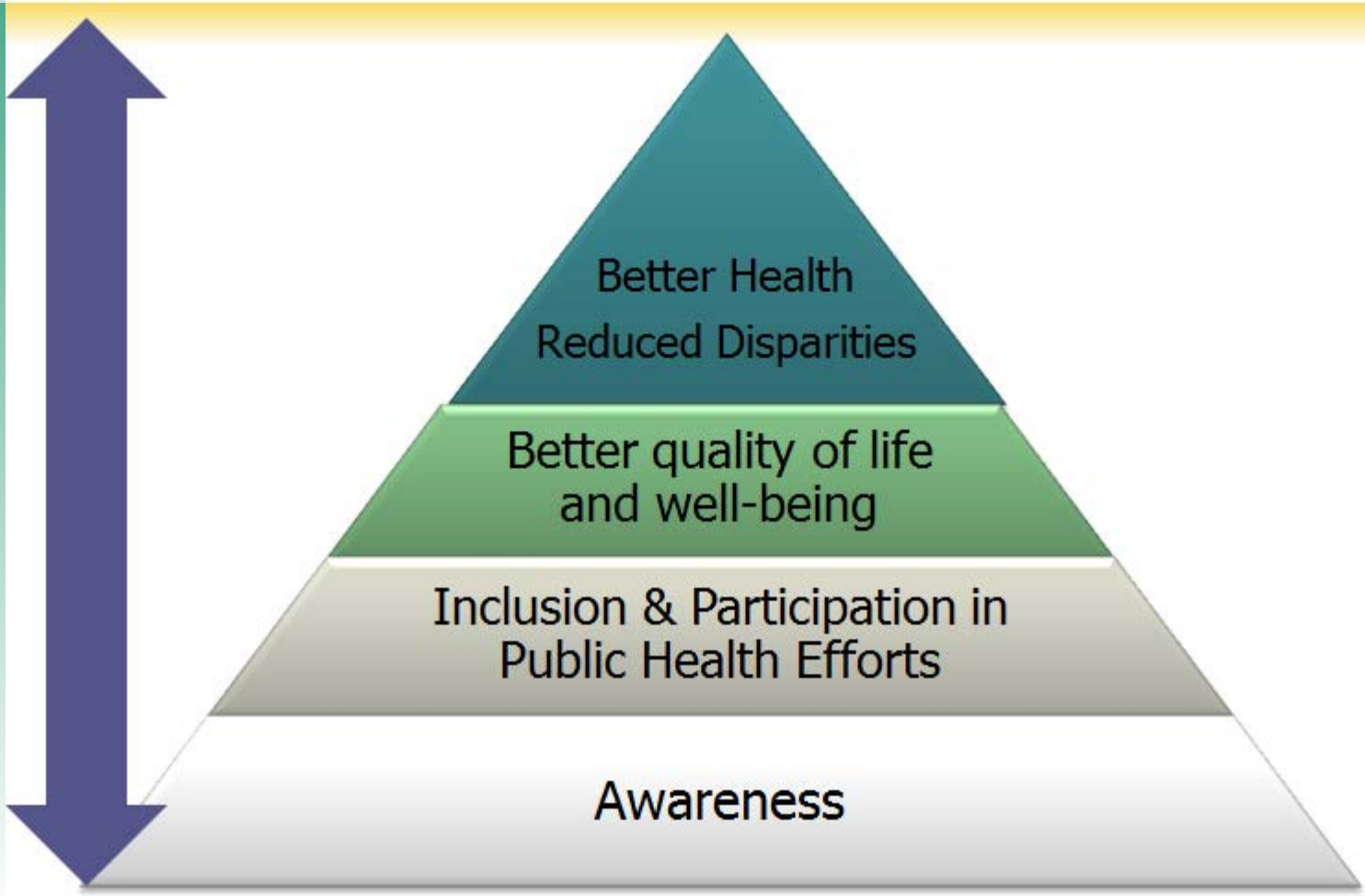
Actions Impacting Disability and Health



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Heath-Related Quality of Life and Well-Being

- Multi-dimensional and includes domains that relate to physical, mental, emotional, and social functioning.
- Beyond direct measures of population health such as life expectancy and causes of death, and focuses on impact of health status on quality of life.
- Well-being – positive aspects of a person's life
  - Positive emotions
  - Life satisfaction

SOURCES: https://www.healthypeople.gov/2020/topics-objectives/topic/health-related-quality-of-life-well-being

Charles Rothwell, MBA, MS
Director, National Center for Health Statistics
Centers for Disease Control and Prevention

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Presentation Overview

- Tracking the Nation's Progress
- Disability and Health
- Health-Related Quality of Life and Well-Being

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Tracking the Nation's Progress

- 21 HP2020 Measurable Disability and Health Objectives:
  - 5 Target met
  - 2 Improving
  - 7 Little or no detectable change
  - 3 Getting worse
  - 4 Baseline data only

- 2 HP2020 Measurable Health-Related Quality of Life and Well-Being Objectives:
  - 2 Baseline data only

NOTES: Measurable objectives are defined as having at least one data point currently available and anticipated additional data points throughout the decade to track the progress.

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Presentation Overview

- Tracking the Nation's Progress
- Disability and Health
  - Data Systems and Health Promotion Programs
  - Barriers to Primary Care
  - Education Systems
  - Unemployment
  - Serious Psychological Distress
- Health-Related Quality of Life and Well-Being

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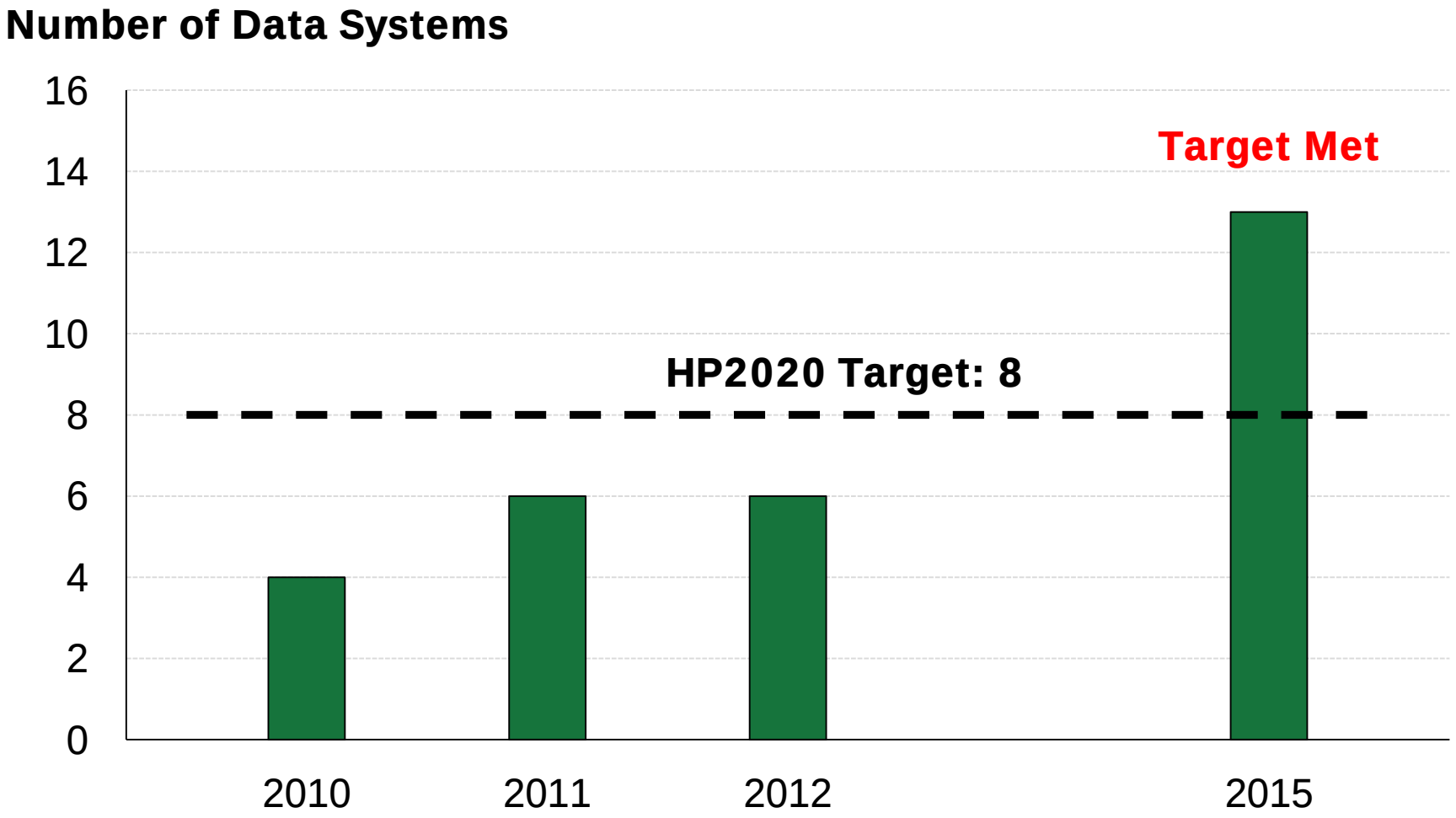
Operational Definition – Adults with Disabilities

American Community Survey Disability Questions:

- Is this person deaf or does he/she have serious difficulty hearing?
- Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?
- Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?
- Does this person have serious difficulty walking or climbing stairs?
- Does this person have difficulty dressing or bathing?
- Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?

NOTES: The American Community Survey (ACS), Census Bureau uses this set of six questions to identify adults with disabilities. A response of "yes" to any of the questions indicates that the person has a disability.

Population-based Data Systems with American Community Survey Disability Questions



NOTES: Data are for the number of Healthy People 2020 population-based data systems that include in their core the American Community Survey set of six questions that identify adults with disabilities.
SOURCE: Periodic assessment of Healthy People data sources by staff of the National Center on Birth Defects and Developmental Disabilities, CDC.

Obj. DH-1
Increase desired

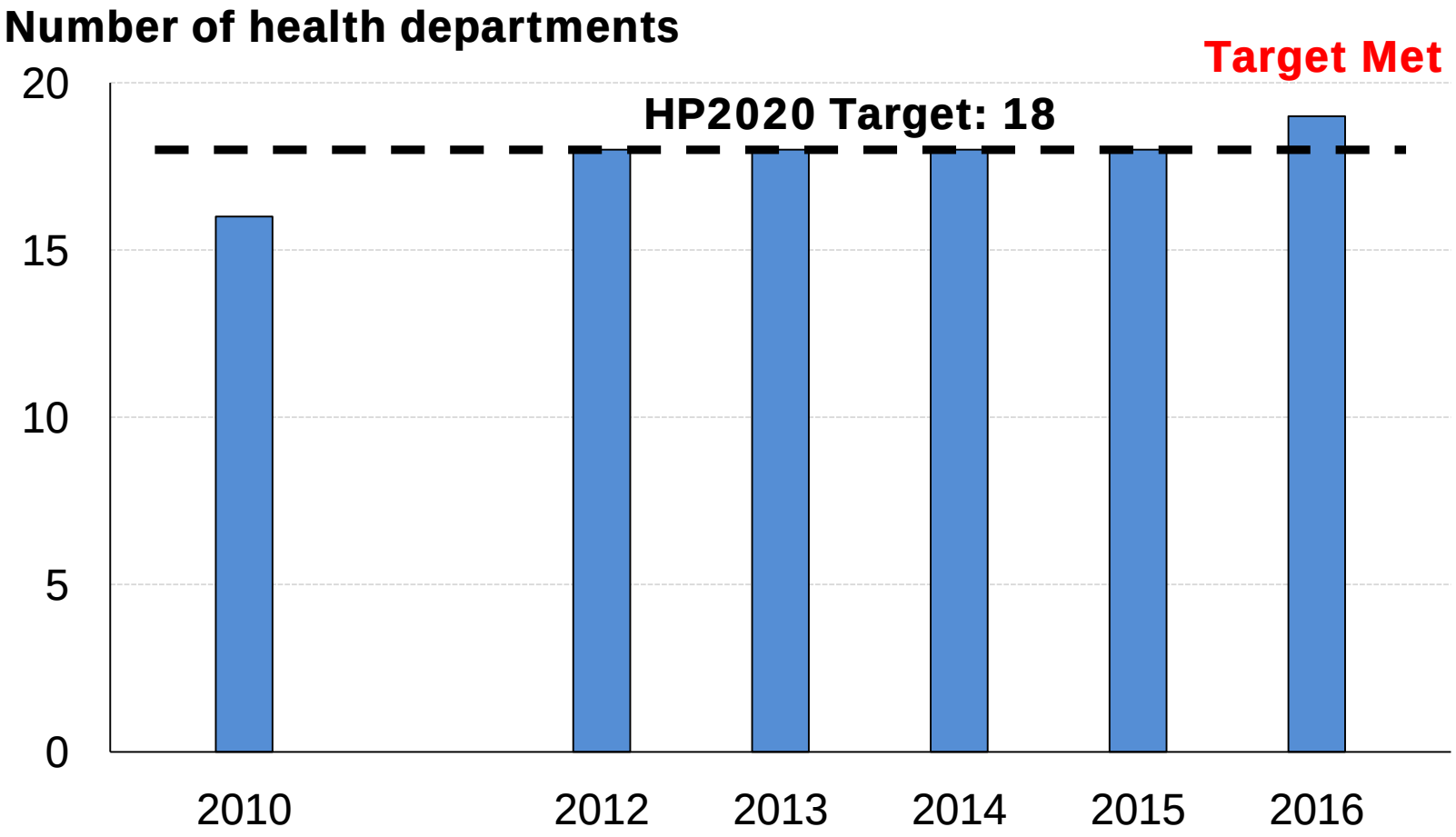
Health Disparities by Disability Status

Health Care Access	Disability % (SE)	No disability % (SE)
Breast cancer screening (women 50-74 years, NHIS 2015)	65.8% (2.483)	72.2% (1.287)
Use of oral health care system in past year (2 years+, MEPS 2013)	37.1% (1.959)	44.4% (0.570)
Health Behaviors		
Meeting physical activity guidelines (18 years+, NHIS 2015)	9.6% (1.010)	23.6% (0.534)
Healthy weight (20 years+, NHANES 2013-14)	23.2% (1.886)	29.5% (0.955)
Current cigarette smokers (18 years+, NHIS 2015)	28.0% (1.547)	13.7% (0.409)

SOURCES: National Health Interview Survey (NHIS), CDC/NCHS;
Medical Expenditure Panel Survey (MEPS), AHRQ;
National Health and Nutrition Examination Survey (NHANES), CDC/NCHS.

Objs. C-17, OH-7, PA-2.4, NWS-8 , TU-1.1

State Health Promotion Programs for Persons with Disabilities

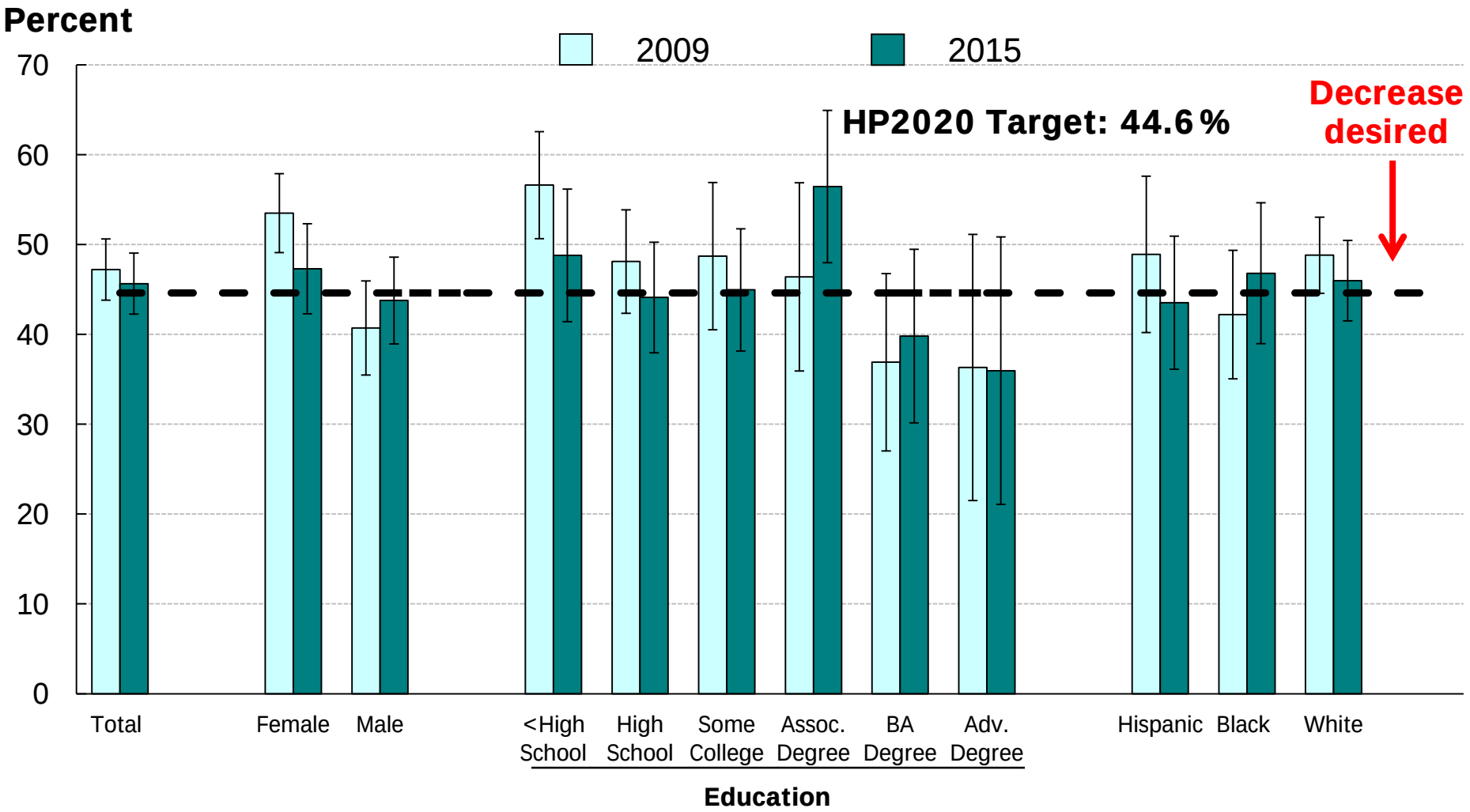


NOTES: Data are for the number of state and the District of Columbia health departments that have at least one health promotion program aimed at improving the health and well-being of persons with disabilities.

SOURCE: Periodic assessment by staff of the National Center on Birth Defects and Developmental Disabilities, CDC.

Obj. DH-2.1
Increase desired

Barriers to Primary Care, Adults with Disabilities

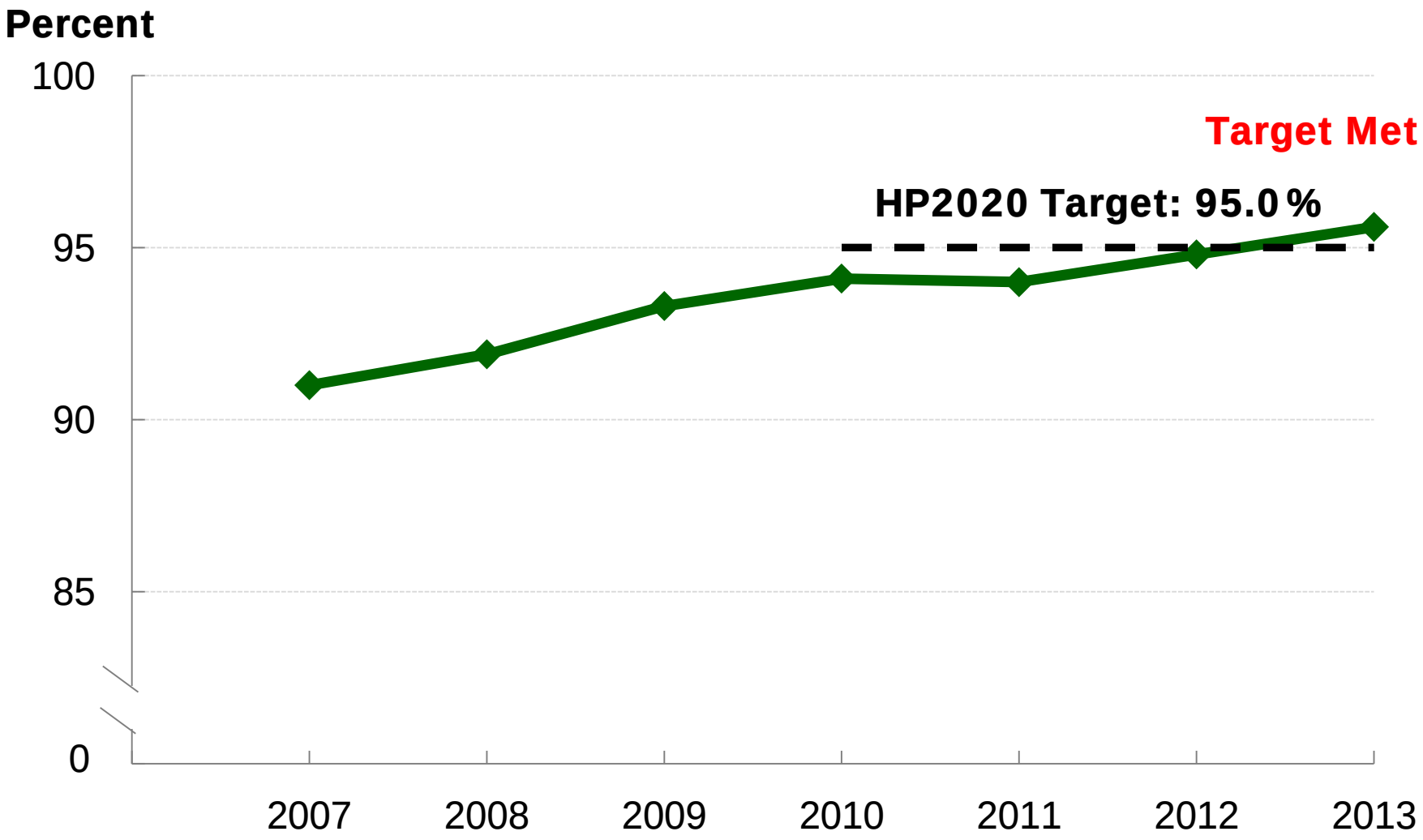


NOTES: I = 95% confidence interval. Data are for adults aged 18 years and older with disabilities who experienced delays in receiving primary and periodic preventive care due to specific barriers. Educational attainment data are for adults 25 years and over. Respondents were asked to select one or more races. The categories black and white include persons who reported only one racial group and exclude persons of Hispanic origin. Persons of Hispanic origin may be of any race. Data are age-adjusted to the 2000 standard population.

SOURCE: National Health Interview Survey (NHIS), CDC/NCHS.

Obj. DH-4

Early Intervention Services, Children with Disabilities

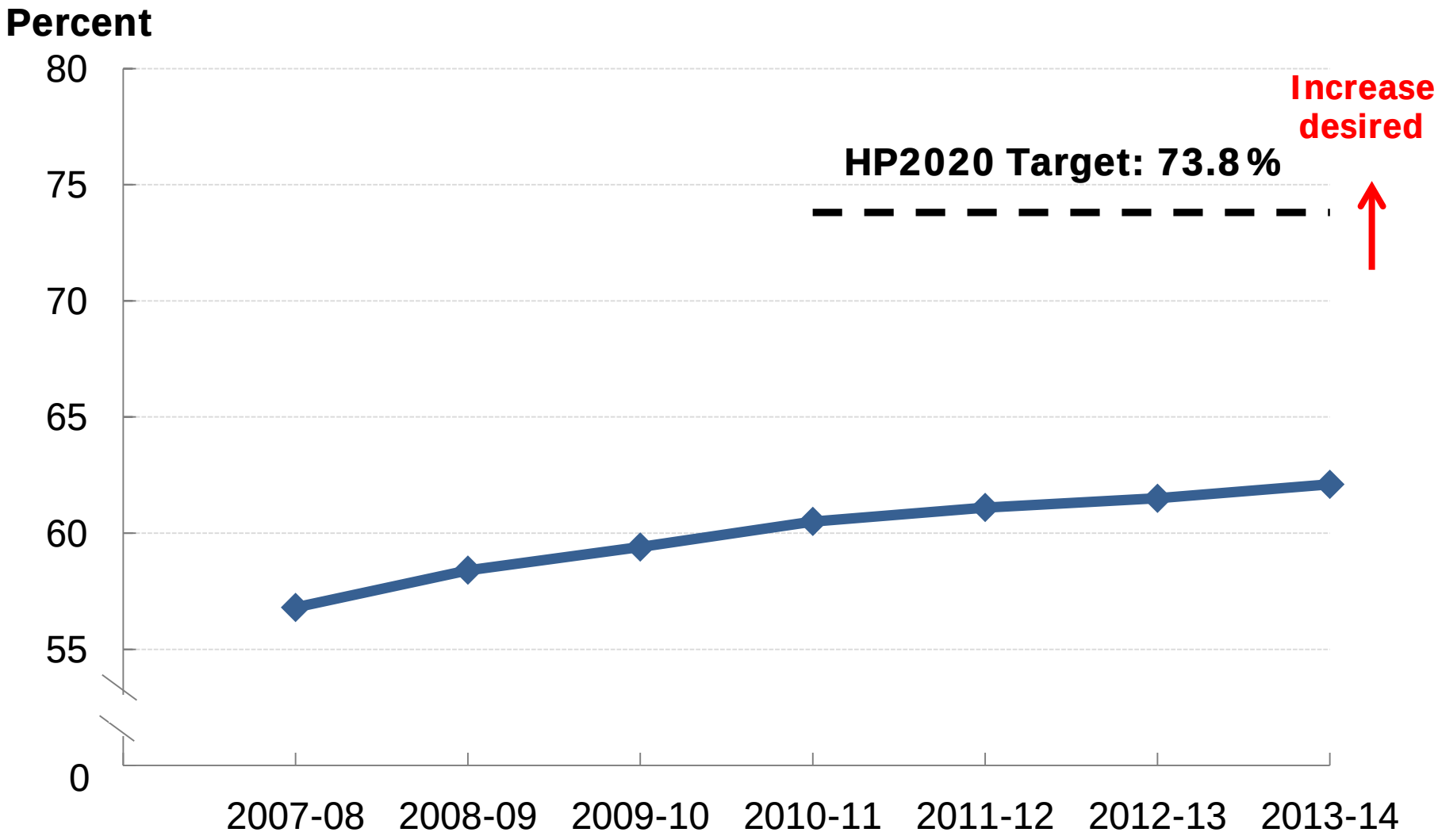


NOTES: Data are for children aged 2 years and under with disabilities, who received early intervention services in home or community-based settings.

SOURCE: Individuals with Disabilities Education Act data (IDEA data), ED/OSERS.

Obj. DH-20
Increase desired

Regular Education Programs, Children and Youth with Disabilities

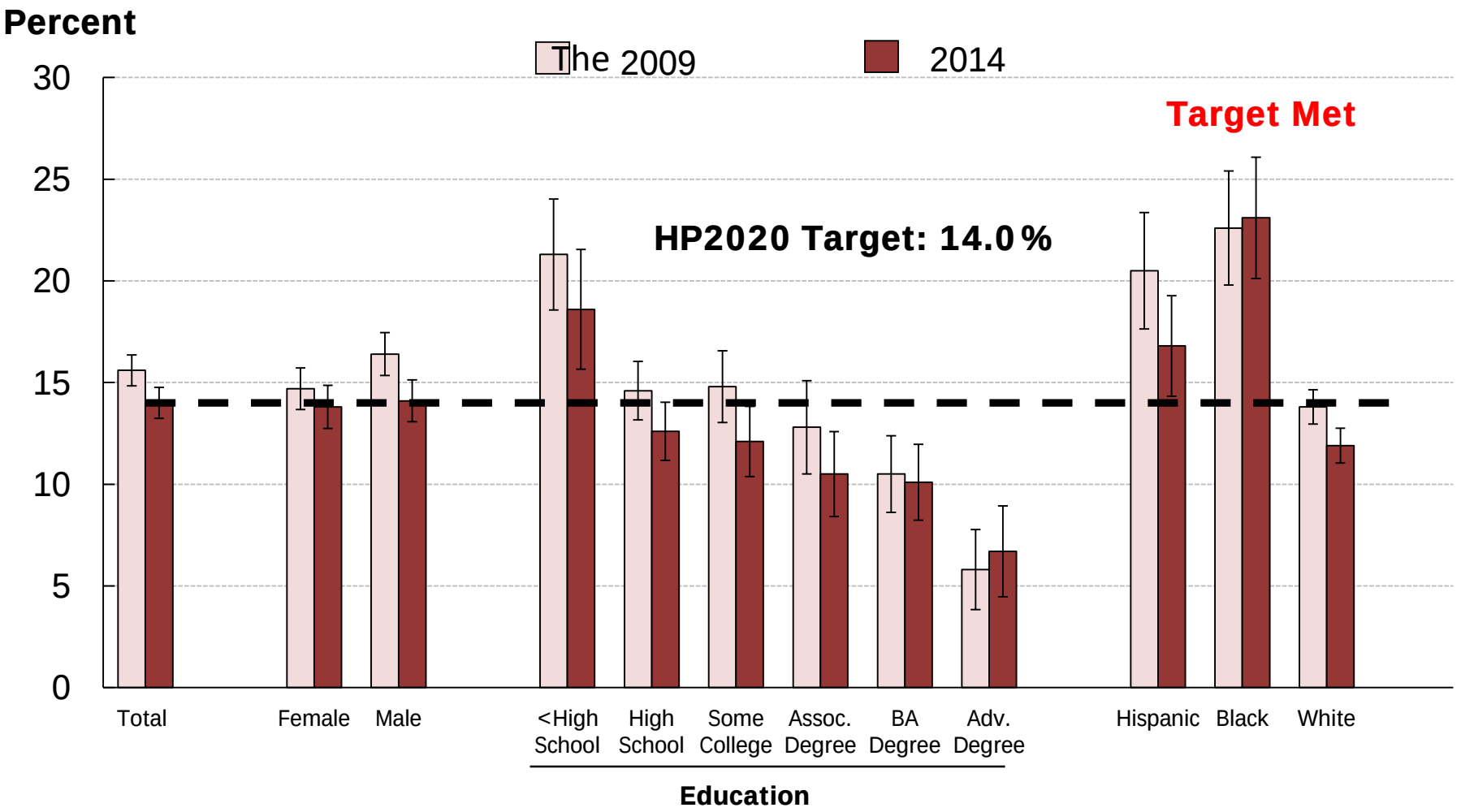


NOTES: Data are for students aged 6 to 21 years with disabilities who spent at least 80% of the day in regular classrooms. Data are for school years.

SOURCE: Individuals with Disabilities Education Act data (IDEA data), ED/OSERS.

Obj. DH-14

Unemployment, Adults with Disabilities

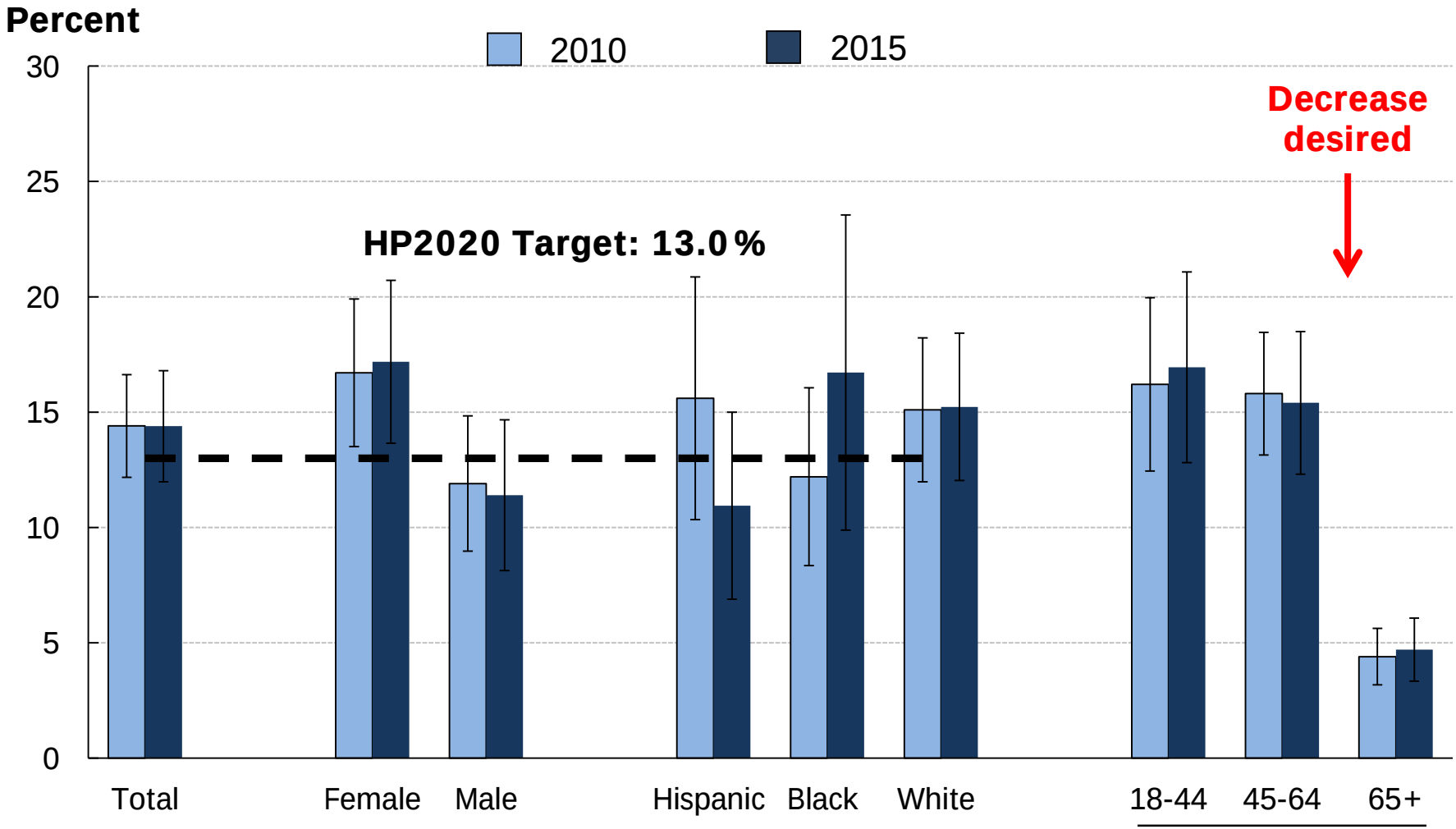


NOTES: I = 95% confidence interval. Data are for persons aged 16 to 64 years with disabilities who want a job, are available to work, and are actively looking for work. Educational attainment data are for adults 25 to 64 years. Respondents were asked to select one or more races. The categories black and white include persons who reported only one racial group and exclude persons of Hispanic origin. Persons of Hispanic origin may be of any race. Data are age-adjusted to the 2000 standard population.

SOURCE: Current Population Survey (CPS), Census and DOL/BLS.

Obj. DH-15
Decrease desired

Serious Psychological Distress, Adults with Disabilities



NOTES: I = 95% confidence interval. Data are for adults aged 18 and older with disabilities who experienced serious psychological distress in the past 30 days. Respondents were asked to select one or more races. The categories black and white include persons who reported only one racial group and exclude persons of Hispanic origin. Persons of Hispanic origin may be of any race. Except for age specific estimates, data are age-adjusted to the 2000 standard population.

SOURCE: National Health Interview Survey (NHIS), CDC/NCHS.

Obj. DH-18

Presentation Overview

- Tracking the Nation's Progress
- Disability and Health
- Health-Related Quality of Life and Well-Being
  - Patient Reported Outcomes Measurement Information System (PROMIS)
  - Physical Health
  - Mental Health

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PROMIS Measures of Physical Health

1. In general, how would you rate your physical health?

Excellent
Very good
Good
Fair
Poor

2. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

Completely
Mostly
Moderately
A little
Not at all

3. In the past 7 days, how would you rate your fatigue on average?

None
Mild
Moderate
Severe
Very severe

4. In the past 7 days, how would you rate your pain on average?

Use a scale of 0-10 with 0 being no pain and 10 being the worst imaginable pain.

NOTES: PROMIS physical health measures use 4 NHIS questions on physical health, responses are combined and the data are divided in 2 categories: good or better physical health vs. fair or poor physical health.

SOURCE: Hays RD, Bjorner J, Revicki RA, Spritzer KL, Cella D. Development of physical and mental health summary scores from the Patient Reported Outcomes Measurement Information System (PROMIS) global items. Quality of Life Research 2009;18(7):873–80. http://www.ncbi.nlm.nih.gov/pubmed/19543809.

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PROMIS Measures of Mental Health

1. In general, would you say your quality of life is: Excellent Very good Good Fair Poor	**2. In general, how would you rate your mental health, including your mood and your ability to think?** Excellent Very Good Good Fair Poor
3. In general, how would you rate your satisfaction with your social activities and relationships? Excellent Very Good Good Fair Poor	**4. In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed, or irritable?** Never Rarely Sometimes Often Always

NOTES: PROMIS mental health measures use 4 NHIS questions on mental health, responses are combined and the data are divided in 2 categories: good or better mental health vs. fair or poor mental health.

SOURCE: Hays RD, Bjorner J, Revicki RA, Spritzer KL, Cella D. Development of physical and mental health summary scores from the Patient Reported Outcomes Measurement Information System (PROMIS) global items. Quality of Life Research 2009;18(7):873–80. http://www.ncbi.nlm.nih.gov/pubmed/19543809.

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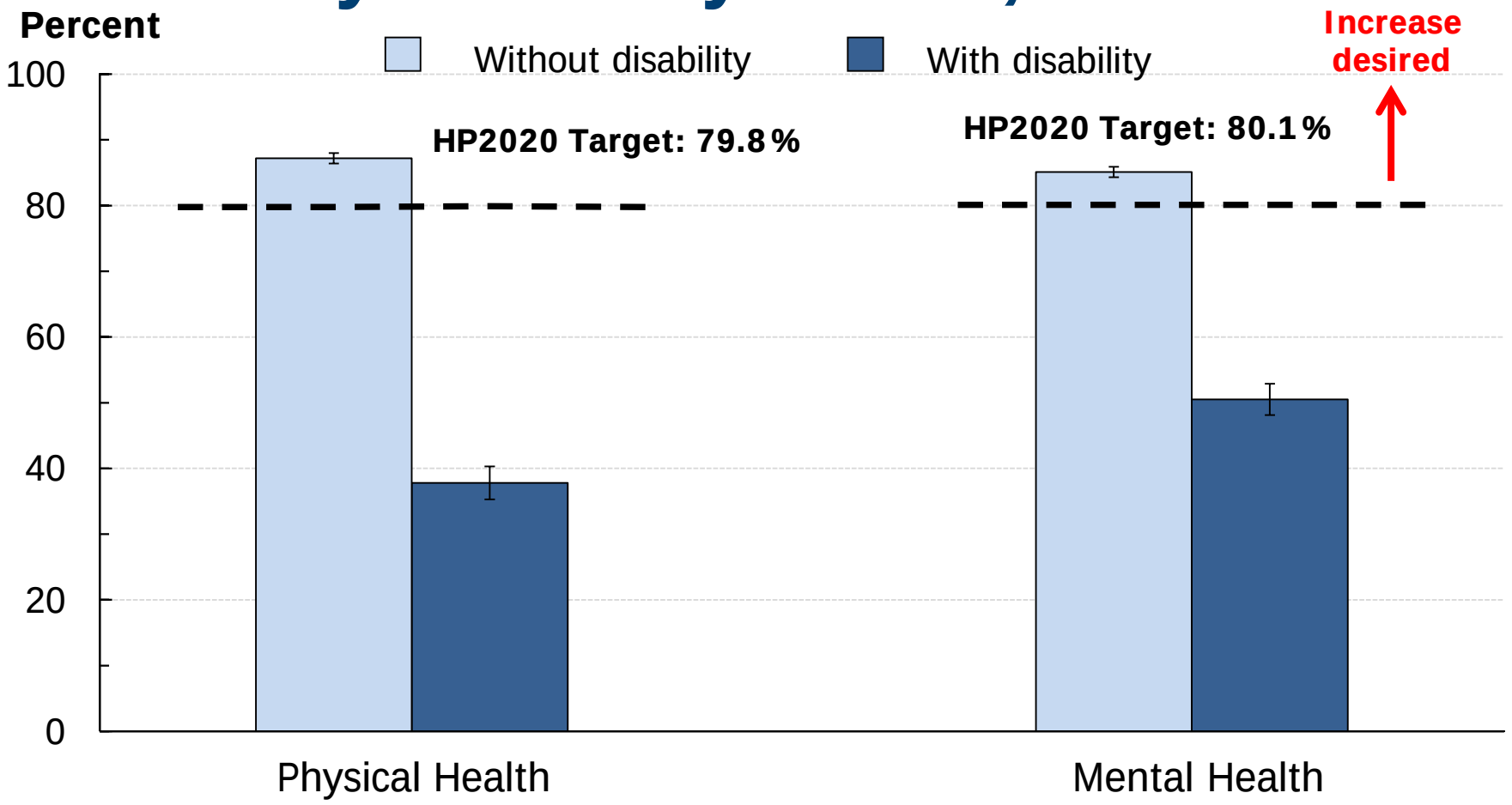
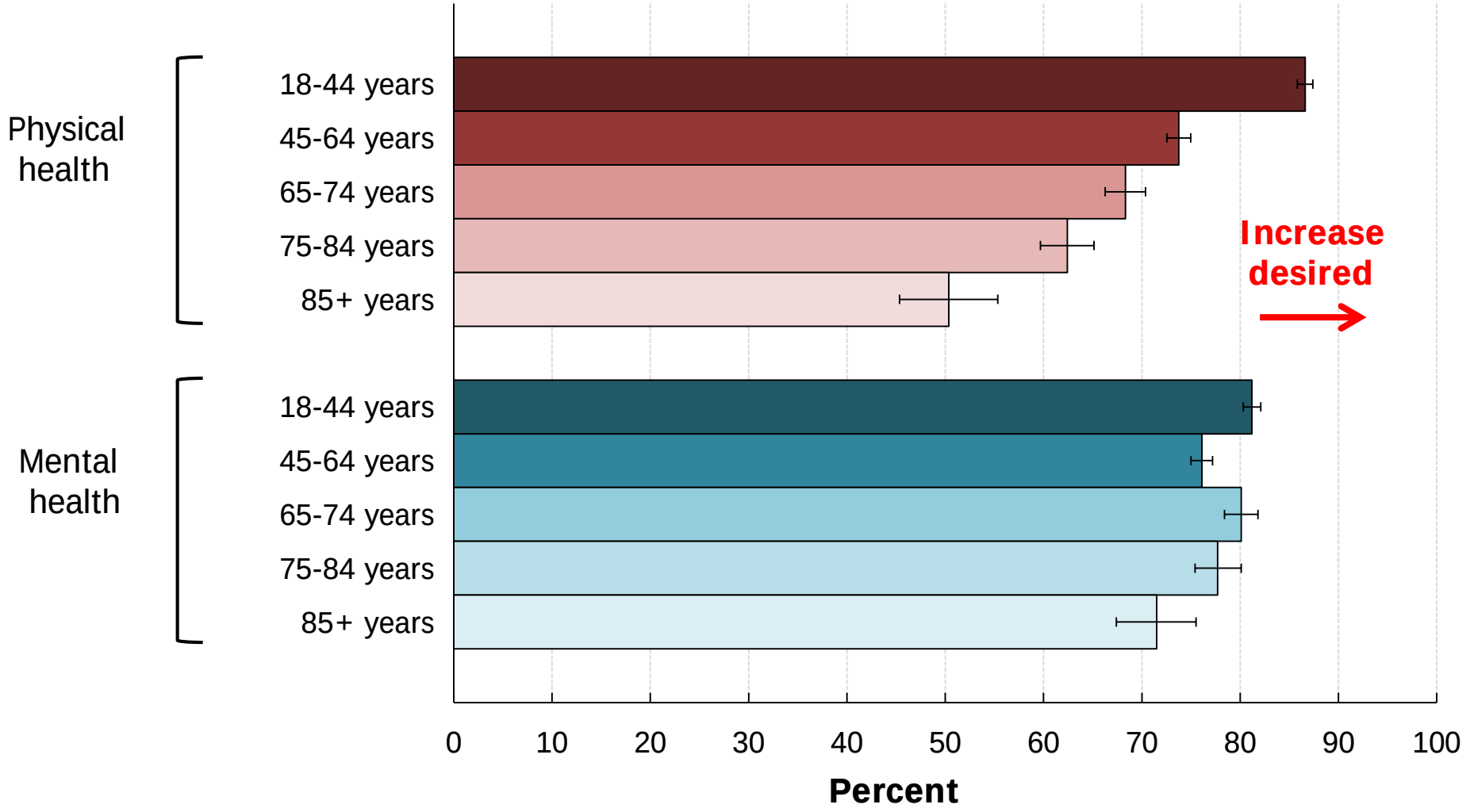
Self-Reported Good or Better Health by Disability Status, 2010



NOTES: I = 95% confidence interval. Data are for adults aged 18 and over who self-reported good or better physical or mental health in the past month (based on 8 PROMIS questions). Data are age adjusted to the 2000 standard population.
SOURCE: National Health Interview Survey (NHIS), CDC/NCHS.

Objs. HRQOL/WB-1.1 & 1.2

Self-Reported Good or Better Physical and Mental Health, 2010

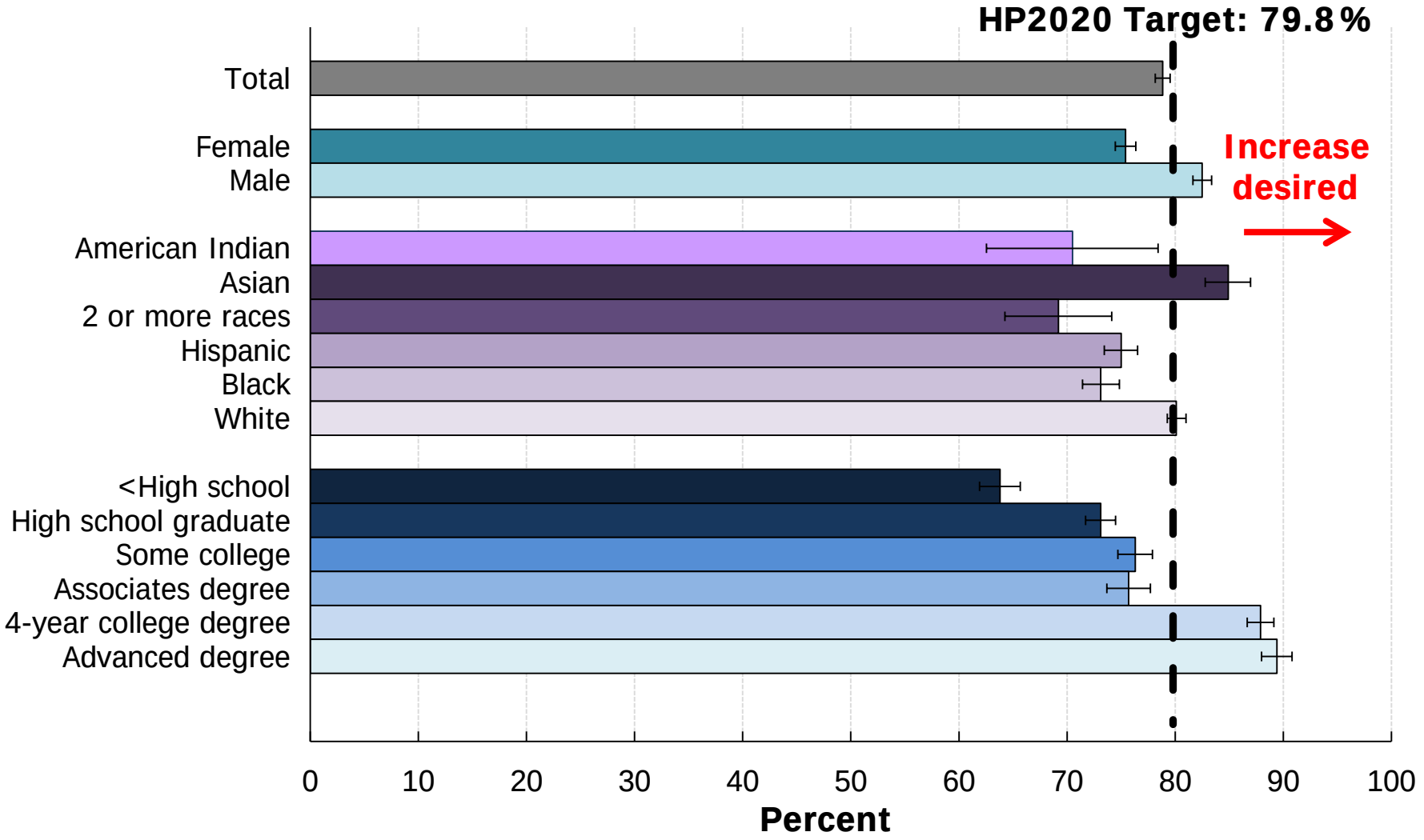


NOTES: ⊢ = 95% confidence interval. Data are for adults aged 18 and over who self-reported good or better physical or mental health in the past month (based on 8 PROMIS questions).

SOURCE: National Health Interview Survey (NHIS), CDC/NCHS.

Objs. HRQOL/WB-1.1 & 1.2

Self-Reported Good or Better Physical Health, 2010

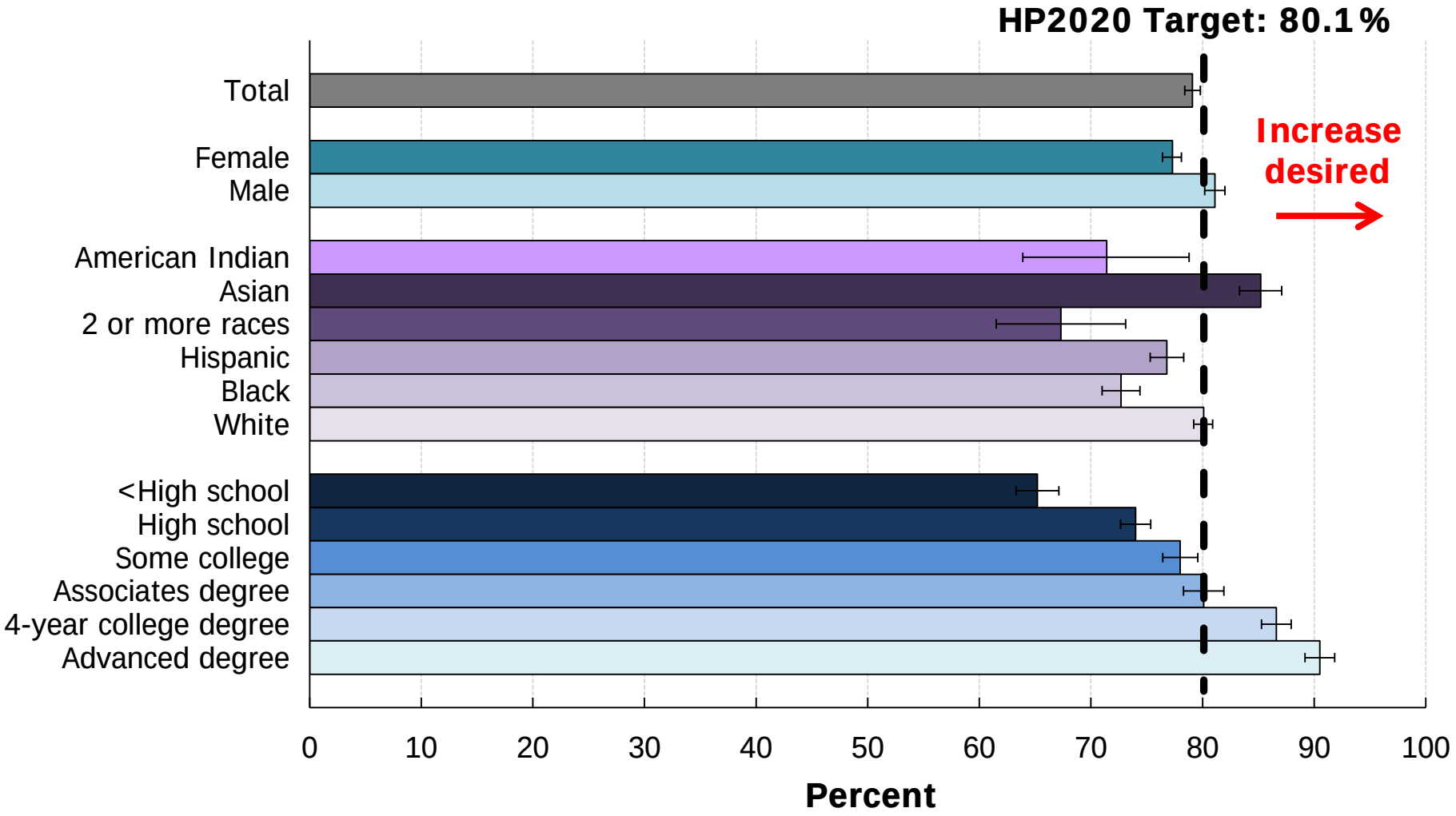


NOTES: ⊢ = 95% confidence interval. Except for education, data are for adults aged 18 and over who self-reported good or better physical health in the past month. Respondents were asked to select one or more races. American Indian includes Alaska Native. The categories black and white exclude persons of Hispanic origin. Persons of Hispanic origin may be of any race. Data are age-adjusted to the 2000 standard population. Educational attainment data are for adults 25 years and over.

SOURCE: National Health Interview Survey (NHIS), CDC/NCHS.

Obj. HRQOL/WB-1.1

Self-Reported Good or Better Mental Health, 2010



NOTES: — = 95% confidence interval. Except for education, data are for adults aged 18 and over who self-reported good or better mental health in the past month. Respondents were asked to select one or more races. American Indian includes Alaska Native. The categories black and white exclude persons of Hispanic origin. Persons of Hispanic origin may be of any race. Data are age-adjusted to the 2000 standard population. Educational attainment data are for adults 25 years and over.

SOURCE: National Health Interview Survey (NHIS), CDC/NCHS.

Obj. HRQOL/WB-1.2

Key Takeaways: Disability and Health

Improvements in Inclusion and Participation:

- The number of Healthy People 2020 population-based data systems that include ACS disability questions (n=13) has increased.
- The number of states (n=19) with support for disability and health promotion programs has increased.
- Use of early intervention services in community settings by children aged 2 years and under with disabilities has increased.
- There has been an increase in the proportion of students aged 6 to 21 years with disabilities who spent at least 80% of their day in regular education classrooms.

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Key Takeaways: Disability and Health

Opportunities for Improvement:

- Disparities persist in unemployment of adults with disabilities by race/ethnicity and educational attainment.
- Barriers to primary care and serious psychological distress have shown little or no change.
- So far in the decade, 7 out of 21 Healthy People 2020 Disability and Health objectives have reached the targets or are improving.

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Key Takeaways: Health-Related Quality of Life and Well-Being

- Overall, more than 75% of adults reported good or better physical and mental health.
- The largest disparity in health-related quality of life was by disability status.
- Fewer than 40% of adults with disabilities reported good or better physical health and 50% reported good or better mental health.
- Disparities in health-related quality of life exist by age, sex, race/ethnicity, and education.

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Disability and Health Program Highlights Related to HP2020 Objectives

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Office of Disease Prevention and Health Promotion

Disability and Health Programs

NIH Eunice Kennedy Shriver National Institute of Child Health and Human Development

- Translational Science
- Universities & Small Business

NATIONAL INSTITUTE ON DISABILITY INDEPENDENT LIVING, AND REHABILITATION RESEARCH
NIDILRR

- Translational Science
- University Research and Training Centers & Community Independent Living Centers

National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

- Translational Science
- State Health Departments, Universities & National Organizations

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Alison Cernich, Ph.D., ABPP-Cn
Director, National Center for Medical Rehabilitation Research, NICHD, NIH

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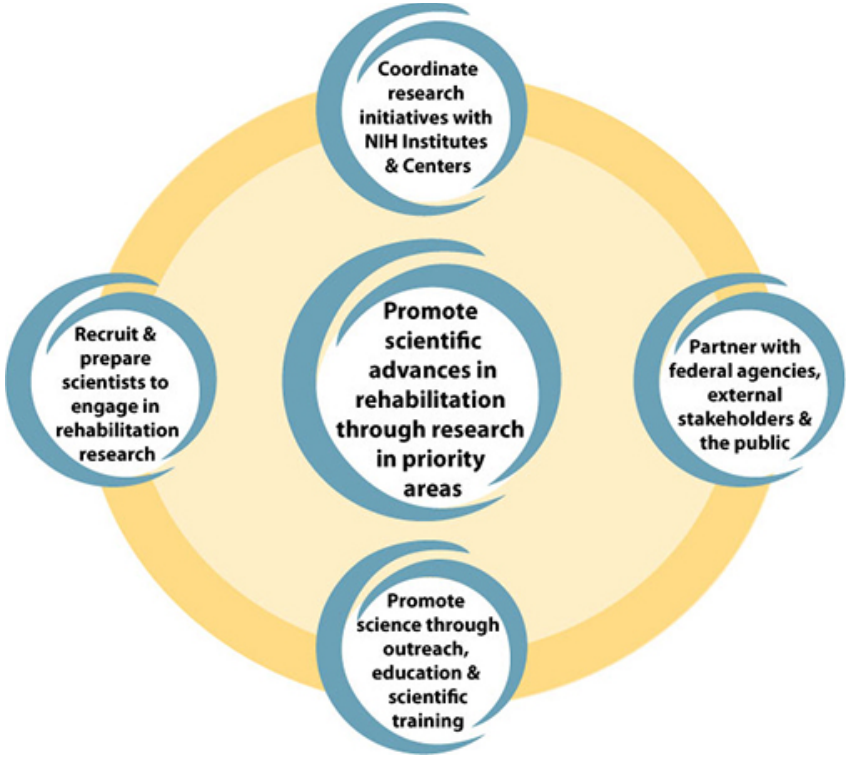
OFFICE OF DISEASE PREVENTION AND HEALTH PROMOTION

National Center for Medical Rehabilitation Research

Mission

Enhance the health, productivity, independence, and quality-of-life of people with physical disabilities through basic, translational, and clinical research.



National Center for Medical Rehabilitation Research

Building Research Capacity

TREAT
CENTER FOR TRANSLATION OF REHABILITATION ENGINEERING ADVANCES AND TECHNOLOGY

REACT
Rehabilitation Research Resource to Enhance Clinical Trials

Alliance for Regenerative Rehabilitation Research and Training
www.AR3T.pitt.edu

MR3 Medical Rehabilitation Research Resource
NETWORK

NATIONAL CENTER OF NMAR NEUROMODULATION FOR REHABILITATION

NCSRR
NATIONAL CENTER FOR SIMULATION IN REHABILITATION RESEARCH

CLDR
Center for Large Data Research & Data Sharing in Rehabilitation

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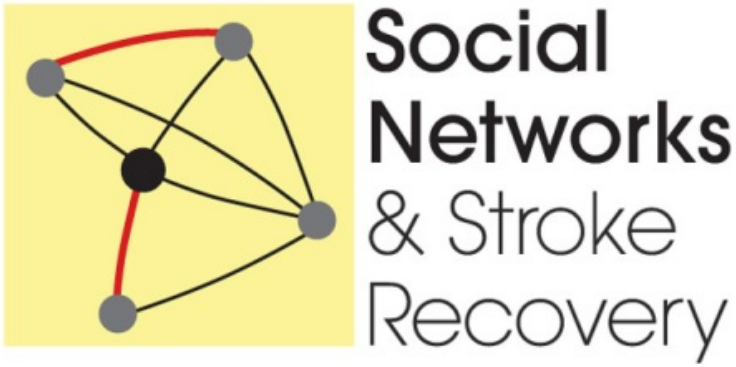
NCMRR-Supported Networks:
NCMRR-Supported Networks

Translational Research on Social Emotional Support

- **Impact of Social Network Structure on Stroke (K23HD074621)**

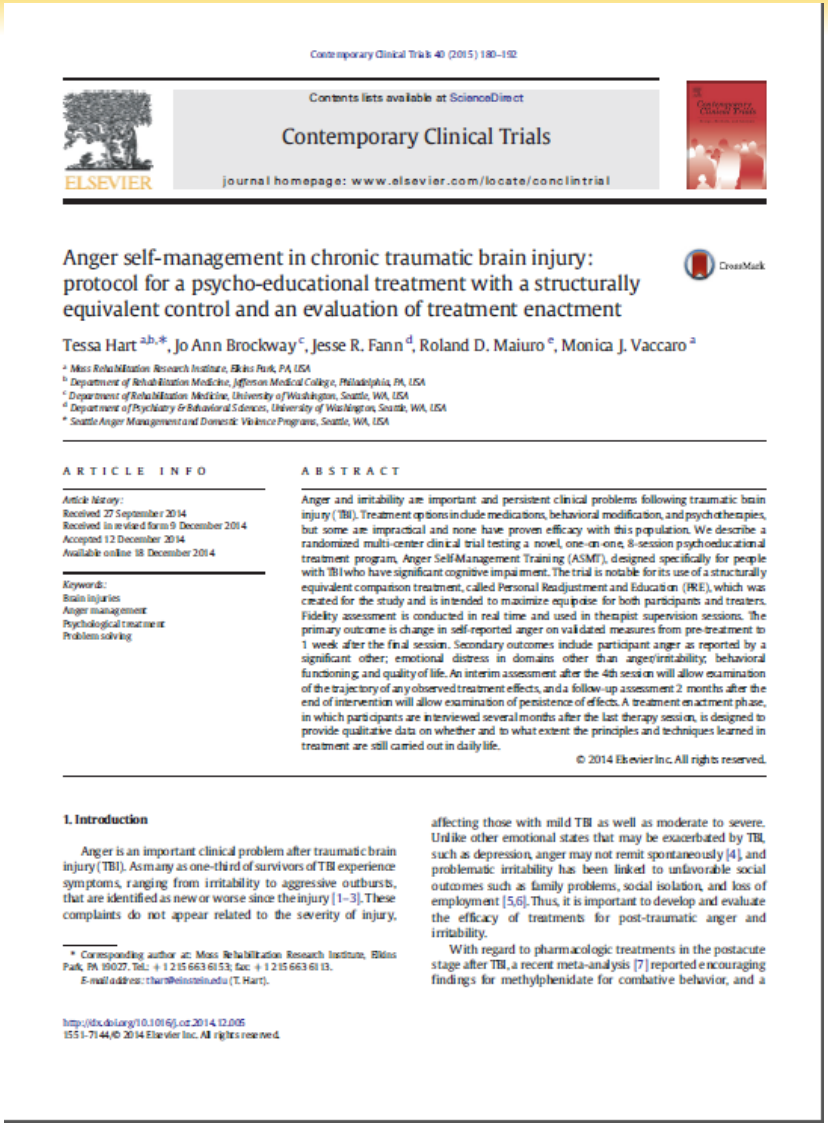


  - Examine stroke recovery in relationship to the social structures in which patients are embedded, and the influence of those social elements on functional outcomes
  - Implement a novel social network intervention and will assess its ability to improve stroke recovery

Network video: Stroke Recovery Network Video

Translational Research on Psychological Distress

- **Anger Self-Management in Post-Acute Traumatic Brain (R01HD061400)**
- **Improving Anxiety-Management and Rehabilitation Outcomes in Critical Care (K23HD074621)**



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Anger self-management in chronic traumatic brain injury: protocol for a psycho-educational treatment with a structurally equivalent control and an evaluation of treatment enactment

Tessa Hart [a,b,*], Jo Ann Brockway [c], Jesse R. Fann [d], Roland D. Maiuro [e], Monica J. Vaccaro [a]

[a] Moss Rehabilitation Research Institute, Elkins Park, PA, USA
[b] Department of Rehabilitation Medicine, Jefferson Medical College, Philadelphia, PA, USA
[c] Department of Rehabilitation Medicine, University of Washington, Seattle, WA, USA
[d] Department of Psychiatry & Behavioral Sciences, University of Washington, Seattle, WA, USA
[e] Seattle Anger Management and Domestic Violence Programs, Seattle, WA, USA

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Problem solving

ABSTRACT

Anger and irritability are important and persistent clinical problems following traumatic brain injury (TBI). Treatment options include medications, behavioral modification, and psychotherapies, but some are impractical and none have proven efficacy with this population. We describe a randomized multi-center clinical trial testing a novel, one-on-one, 8-session psychoeducational treatment program, Anger Self-Management Training (ASMT), designed specifically for people with TBI who have significant cognitive impairment. The trial is notable for its use of a structurally equivalent comparison treatment, called Personal Readjustment and Education (PRE), which was created for the study and is intended to maximize equipoise for both participants and treaters. Fidelity assessment is conducted in real time and used in therapist supervision sessions. The primary outcome is change in self-reported anger on validated measures from pre-treatment to 1 week after the final session. Secondary outcomes include participant anger as reported by a significant other; emotional distress in domains other than anger/irritability; behavioral functioning; and quality of life. An interim assessment after the 4th session will allow examination of the trajectory of any observed treatment effects, and a follow-up assessment 2 months after the end of intervention will allow examination of persistence of effects. A treatment enactment phase, in which participants are interviewed several months after the last therapy session, is designed to provide qualitative data on whether and to what extent the principles and techniques learned in treatment are still carried out in daily life.

1. Introduction

Anger is an important clinical problem after traumatic brain injury (TBI). As many as one-third of survivors of TBI experience symptoms, ranging from irritability to aggressive outbursts, that are identified as new or worse since the injury [1–3]. These complaints do not appear related to the severity of injury, affecting those with mild TBI as well as moderate to severe. Unlike other emotional states that may be exacerbated by TBI, such as depression, anger may not remit spontaneously [4], and problematic irritability has been linked to unfavorable social outcomes such as family problems, social isolation, and loss of employment [5,6]. Thus, it is important to develop and evaluate the efficacy of treatments for post-traumatic anger and irritability.

With regard to pharmacologic treatments in the postacute stage after TBI, a recent meta-analysis [7] reported encouraging findings for methylphenidate for combative behavior, and a

* Corresponding author at: Moss Rehabilitation Research Institute, Elkins Park, PA 19027. Tel.: +1 215 663 6153; fax: +1 215 663 6113.
E-mail address: thart@einstein.edu (T. Hart).

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1551-7144/

DH-18 Psychological distress

Translational Research on Quality of Life

NeuroQoL

- **Quality of Life for SCI Clinical Trials: Development of the SCI-QOL (R01HD054569)**

The Spinal Cord Injury – Quality of Life (SCI-QOL) measurement system: Development, psychometrics, and item bank calibration

David S. Tulsky[1,2], Pamela A. Kisala[1]

[1]Department of Physical Therapy, University of Delaware, College of Health Sciences, Newark, DE, USA, [2]Kessler Foundation Research Center, West Orange, NJ, USA

Though spinal cord injury (SCI) was historically regarded as an ailment not to be treated,[1] medical, pharmaceutical, and technological advances in the 20th and 21st centuries have improved acute and long-term SCI rehabilitation outcomes. Consequently, SCI has become an increasingly common cause of long-term disability, with over 250 000 Americans[2,3] and over 85 000 Canadians[4] living with SCI. Traumatic SCI is a catastrophic injury that changes the lives of individuals in a split second. SCI is characterized by a broad and unique set of functional limitations and secondary complications that affect physical (e.g. altered urinary and bowel function,[5–7] pressure ulcers,[8,9] chronic and neuropathic pain) cognitive,[10,11] emotional (e.g. depression,[12,13] anxiety disorders),[14] and social (e.g. unemployment)[15] areas of health and functioning. Individuals who sustain SCI must adjust immediately to a new way of life that is often characterized by significant physical limitations, alterations to basic physiological functions, intense emotions, disruption of social relationships, and barriers to participating in their usual activities – essentially, every possible area of health-related quality of life (HRQOL). Individuals with SCI have described the secondary complications of SCI to be equally or even more troublesome than the primary functional limitations of SCI, such as the inability to walk.[16] Furthermore, SCI is heterogeneous because the associated functional impairments and secondary medical issues are directly related to the location and neurological completeness of injury. An individual who sustains an American Spinal Injury Association (ASIA) Impairment Scale (AIS) grade D injury may be able to walk unassisted, while an individual with high-level and complete (AIS grade A) tetraplegia will be unable to move below the neck and will require constant mechanical ventilation. Due to the suddenness and severity of SCI, the wide range of potential secondary complications, and the diversity of functioning and complications within the population of individuals with SCI, healthcare professionals must assess a wide variety of areas of functioning, examine changes over time, and identify and mitigate potential risk factors. To do so, the healthcare provider must be able to measure and monitor a wide variety of issues that a person with SCI might experience. Until now, there have not been the proper tools to do so.

The lack of available SCI-relevant measurement instruments to conduct standardized, effective assessment of a wide variety of HRQOL domains has been rather disheartening. In 2001, Tulsky[17] chaired a state-of-the-science conference for rehabilitation professionals that focused on the current state of quality of life measurement for individuals with disabilities. Several keynote addresses,[18,19] as well as Tulsky and Rosenthal's synthesis[17] of the conference, pointed out that, by and large, when HRQOL variables were utilized in clinical trials, rehabilitation researchers, including specialists in SCI medicine, were forced to use existing general scales that were developed and intended for the general population. These measurement tools did not capture areas of functioning that were important to individuals with physical disabilities, and often contained items that were irrelevant, inappropriate, or even offensive.[20–22] Unfortunately, despite the flaws in these measurement tools for use with persons with disabilities, there was simply no alternative at that time. Outcomes measurement, in general, had not received

Correspondence to: David S. Tulsky, Department of Physical Therapy, University of Delaware, College of Health Sciences, 540 S. College Ave., Newark, DE 19713. Email: dtulsky@udel.edu

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Mr. John Tschida

Director, National Institute on Disability, Independent Living, and Rehabilitation Research, Administration for Community Living

Healthy People 2020

Office of Disease Prevention and Health Promotion

National Institute on Disability, Independent Living, and Rehabilitation Research

Mission

- Generate new knowledge and promote its effective use to improve the abilities of people with disabilities to perform activities of their choice in the community, and
- Expand society's capacity to provide full opportunities and accommodations for its citizens with disabilities.

Healthy People 2020

Community Living

Independent Living

Applied Science – Centers for Independent Living Centers (CILs)

Core Services:

1) Information and referral.
2) Peer counseling.
3) Independent living skills training.
4) Individual and systems advocacy.
5) Assist those transitioning from institutional settings to community living; those at risk of entering institutions; and youth transitioning into adulthood.

Healthy People 2020

DH-13 Participation in community activities

Applied Science – Rehabilitation Research and Training Centers (RRTCs)

Conduct coordinated and integrated research to:

- Improve rehabilitation approaches and service delivery systems,
- Alleviate or stabilize disabling conditions, or
- Promote maximum social and economic independence for persons with disabilities.

http://www.acl.gov/Programs/NIDILRR/Grant-Funding/Programs/rrtc/resources.aspx

Applied Science – HealthMatters™

RRTCDD
Rehabilitation Research and Training Center on Developmental Disabilities and Health

HealthMatters™

A community-based program to improve health of people with intellectual and developmental disabilities.

Healthy People 2020

Applied Science – Scale Up & Replication of HealthMatters™

HealthMatters™

SCALE-UP & Replication

in four states:

- Alaska
- Kentucky
- Missouri
- Illinois

Georgina Peacock, MD, MPH, FAAP

Director, Division of Human Development and Disabilities
National Center on Birth Defects and Developmental Disabilities
Centers for Disease Control and Prevention

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Department of Health & Human Services · USA

Office of Disease Prevention and Health Promotion

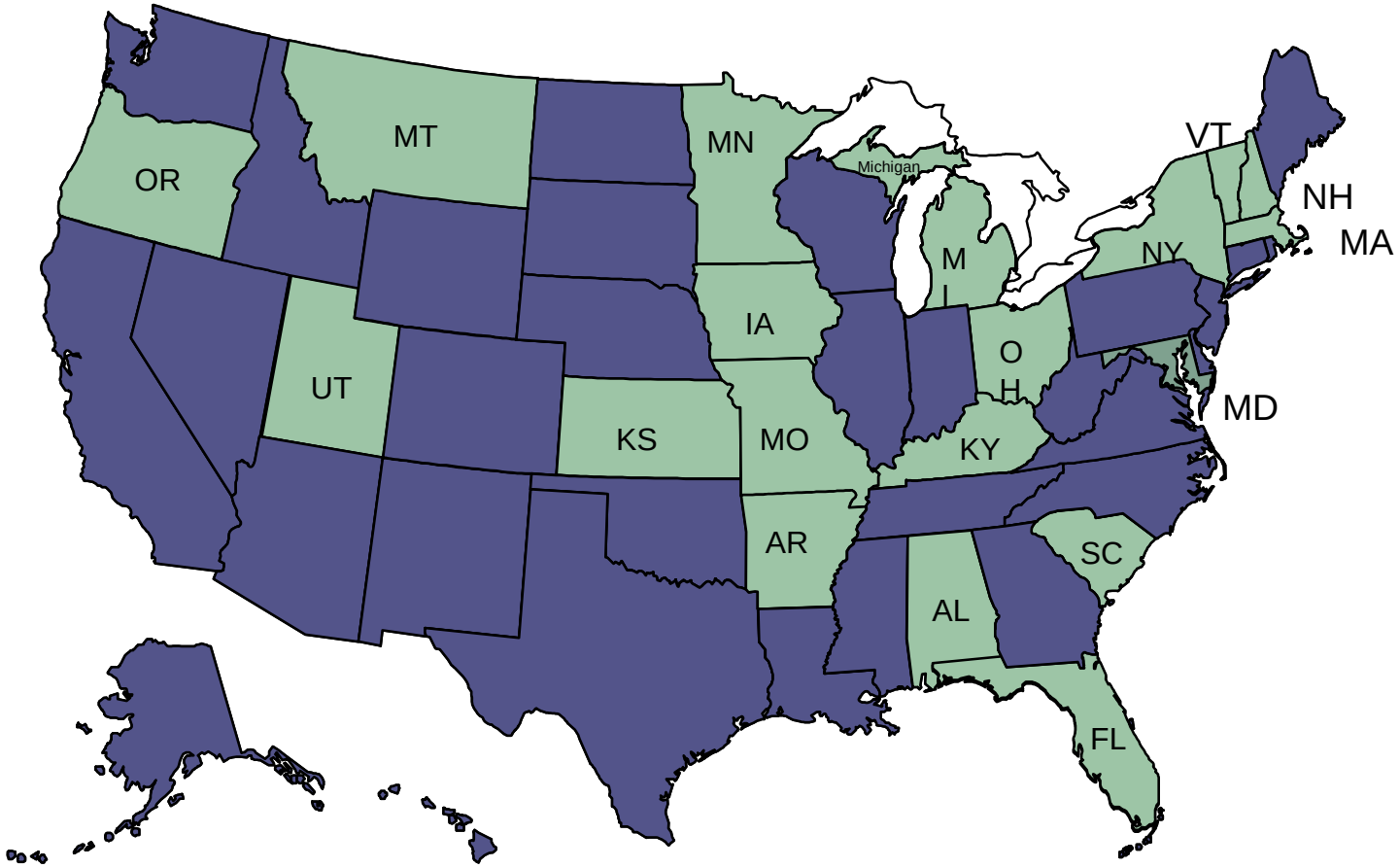
National Center on Birth Defects and Developmental Disabilities

Mission

Promote the health of babies, children and adults and enhance the potential for full, productive living.

Population Science
Health Promotion in States

19 state disability and health programs, 2016



DH-2.1 State Disability and Health Promotion Programs

Population Science
Health Promotion in Primary Care

Removing Barriers to Primary Care

- South Carolina assessed 150 primary care sites that had a patient load of >750,000.
- Modifications were made at 1/3 of the sites: internal medicine, OB/GYN, pediatric, and dental care sites.

BEFORE: No accessible parking

AFTER: Accessible parking with signage and easy slope to the ramp

DH-4 Barriers to primary care

Population Science Health Promotion in Counties (Continued)

Outcomes:

NACCHO
National Association of County & City Health Officials
The National Connection for Local Public Health

Kent County Health Department:
A Story of Successful Inclusion of People with Disabilities

June 2015

Emergency Preparedness at KCHD

Michigan's Kent County Health Department (KCHD) has been including people with disabilities in its programs, policies, and procedures for several years. KCHD realizes how important it is to include people with disabilities in emergency preparedness planning efforts. In 2007, KCHD's emergency preparedness program was mandated to develop partnerships in its jurisdiction to report on and determine how to include people with disabilities in emergency response planning. As a result, KCHD developed a committee of organizations that serve people with disabilities and other human services agencies that provide cultural services to the elderly and children. Today, KCHD has developed a network of 70 organizations that serve vulnerable populations. In the past year, KCHD's emergency preparedness program started to develop a citizen stakeholder group to improve on the department's efforts to include people with disabilities. As a result of this group, which included many people with disabilities, people with disabilities are now included in all emergency management and evacuation planning efforts.

KCHD's goal is to educate individuals in Kent County and ensure they understand emergency information. Within the health department, KCHD expands the reach of its emergency preparedness plans and procedures through word of mouth. Among the community, KCHD is creating five training modules: Introduction to Emergency Preparedness, Fire Safety, CPR, First Aid, and CERT (Emergency Response Team Training). Those who complete the courses will receive a certificate and have an opportunity to become a peer trainer for the Introduction to Emergency Preparedness training module.

Words of Wisdom

"You might think you are doing well, but policies and laws change, so you have to consistently adapt."
—Mary, Immunization Supervisor, Community Clinical Services

"Include people with disabilities from the beginning to the end so in the end you can say, 'We heard this from you. This is what we did to accommodate [you].' Then evaluate to find out if [you] hit the mark or continue to make modifications."—Chelsey, Quality and Performance Manager, Accreditation Coordinator

In addition, The Arc of the United States, the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities and their families, is incorporating KCHD's emergency preparedness procedures into its strategic plan to help promote preparedness messages. KCHD anticipates that involving as many different venues as possible will help to increase the reach and education of emergency preparedness messages. For example, KCHD researched how to create effective emergency messages for the population of Kent County, focusing on people with sensory disabilities. KCHD determined practical ways to reach people with sensory disabilities during disaster situations, such as modifying TV messages with subtitles and sound notifications and using Facebook and Twitter).

Going Above and Beyond

Children's Special Health Care Services (CSHCS) provides programs and services to children with medically diagnosed special needs between the ages of 0 to 21; the agency also emphasizes parental involvement, which is reflected in the CSHCS mission. KCHD participates in CSHCS and serves approximately 2,700 children annually. The KCHD division of CSHCS develops strong support for parents of children that require special healthcare services. Through grant funds, the program has supplemented its on-site parent support group with a virtual meeting space on Facebook and a Facebook page administrator (a parent), which allows group members to communicate effectively.

Historically, parents voluntarily ran the support groups at KCHD. However, participation was inconsistent due to barriers that prevented volunteers from donating time. KCHD applied for a mini-grant from CSHCS to increase parental participation in the parent support group. KCHD used the grant to provide food and offer child care during the support groups. The parents and program supervisor expressed the desire to have a social media platform to use for communication. Communication began with a list service (now with 1,500 participants) and evolved into the Facebook page (with 300 participants) mentioned above.

Participants use Facebook to exchange information, share community events and resources, and support one another. A parent, program supervisor, and public relations manager work together to facilitate the Facebook page. The parents do almost all of the work, including posting events and maintaining resources.

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DH-13 Participation in community activities & PREP-11, 12, 13 Emergency Preparedness

Population Science
Health Promotion in Counties

10 communities have partnered with **5** Disability and Health State Programs

Sioux City Iowa

Helena Area Chamber of Commerce

The City and County of Butte-Silver Bow Montana

Carroll County Iowa 2016 www.carrolliowa.com

Cattaraugus County Incorporated Mar 11, 1808

Benton County

Adams County, Ohio July 10, 1797

Syracuse

Marion Public Health

Umatilla County

DH-8 Barriers to local health and wellness programs
DH-13 Participation in community activities

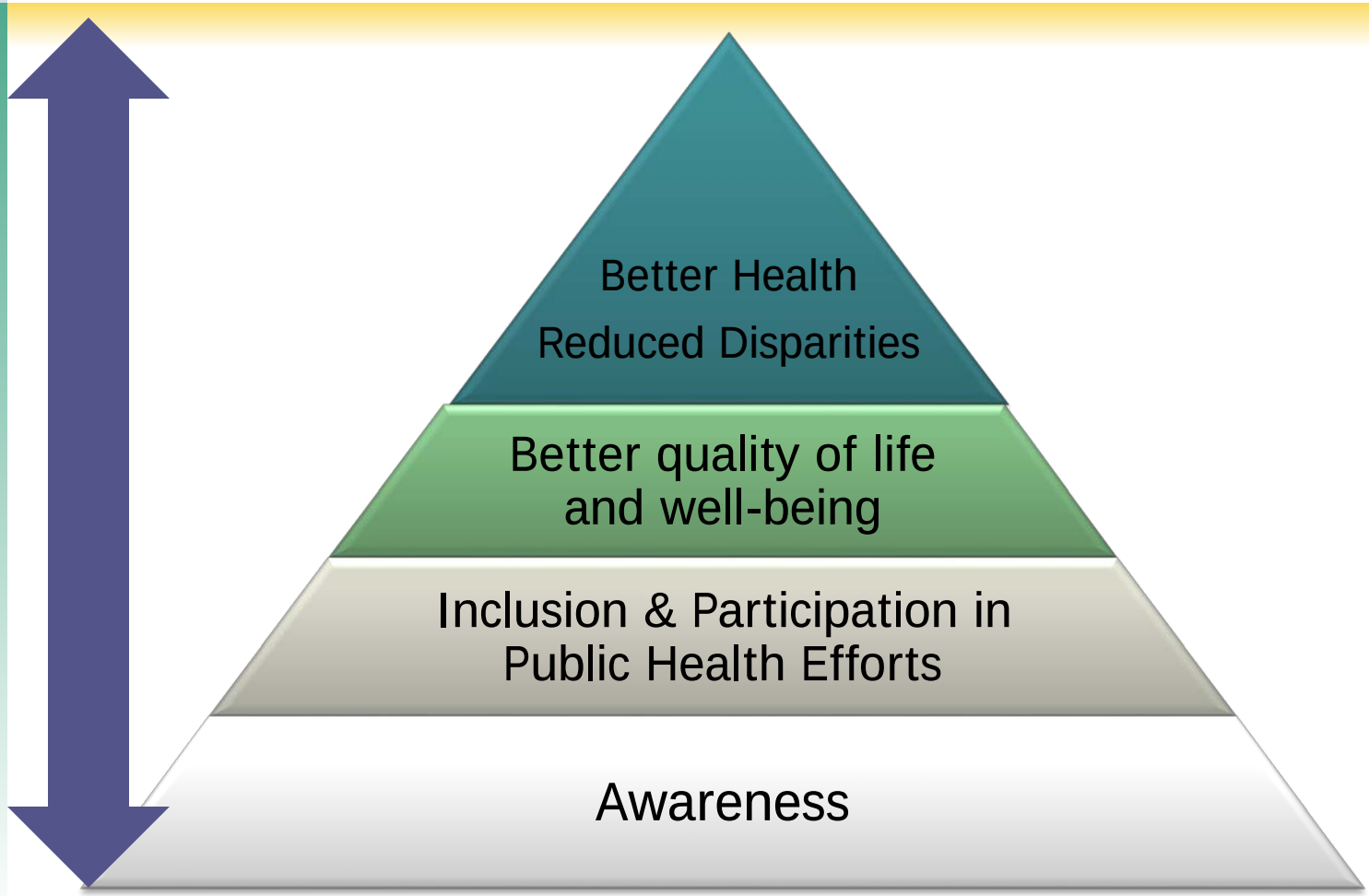
Healthy People 2020

Population Science
Health Promotion in Communities

Living Well with a Disability

DH-4 Barriers to Primary Care;
HRQOL/WB -1.1 Physical Health; HRQOL/WB-1.2 Mental Health

Actions Impacting Disability and Health



Disability and Health Topic Area Contact

For more information please contact:

Lisa Sinclair MPH and Michael H. Fox, Sc.D.
Division of Human Development and Disability
National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

Emails: lsinclair@cdc.gov or mhfox@cdc.gov

Healthy People 2020

Healthy People 2020 Progress Review: Measurement Issues in Health, Disability and Related Concepts

August 11, 2016

Jennifer H. Madans, PhD
Associate Director of Science,
National Center for Health Statistics
Centers for Disease Control and Prevention

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DEPARTMENT OF HEALTH & HUMAN SERVICES · USA

ODPHP

The National Center for Health Statistics

- Functions
  - Monitors the nation's health by collecting, analyzing and disseminating health data;
  - Compares across time, populations, providers and geographic areas;
  - Identifies health problems, risk factors, and disease patterns;
  - Informs actions and policies to improve the health of the American people;
  - Ensures comparability and reliability of health statistics, including consistency of statistical activities; and
  - Undertakes and supports activities to improve methods in the collection of health statistics.

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National Center for Health Statistics
Bureau of Transportation Statistics
National Center for Education Statistics
Bureau of Labor Statistics
Economic Research Service
Federal Statistical System
National Agricultural Statistics Service
Bureau of Justice Statistics
Energy Information Administration
Bureau of the Census
Bureau of Economic Analysis
NSF Science Research Statistics
IRS Statistics of Income
SSA Research Evaluation and Statistics

NCHS Data Systems

1. **National Vital Statistics System (NVSS)**
2. **National Health Interview Survey (NHIS)**
   - National Immunization Survey
   - State and Local Area Integrated Telephone Survey
3. **National Health and Nutrition Examination Survey (NHANES)**
4. **National Survey of Family Growth (NSFG)**
5. **National Health Care Surveys**
   - Hospital Discharge Survey
   - Ambulatory Care Survey
   - Hospital Ambulatory Care Survey
   - Nursing Home Survey
   - Home and Hospice Survey
   - Residential Care Survey

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Monitoring 'Health': A Key Component of Healthy People

- Healthy People
  - Provides a framework for monitoring achievement of health goals;
  - Incorporates a monitoring function;
  - Informs policy and programs;
  - Relies on a large number of specific objectives, with targets; and
  - Traditionally includes key overarching goals.
- Challenge: How to construct overarching measures that encompass the full range of "health"

Healthy People 2020

What is Health?

Multiple definitions of health

- Traditionally medically-based objective definitions
  - Focus on “pathologies” in body structure and/or function
- Health as a social concept
  - Impact of body structure and/or function on a person’s ability to participate in society

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Commonly Used "Objective" Measures

- Medically defined health
  - Laboratory tests
  - Radiological tests
  - Physical exams
  - Performance measures
  - Medical records

Healthy People 2020

Commonly Used "Subjective" Measures

- Summary measures of health
  - Self-reported health status (also used as proxy for objective measures)
  - Composite measures
- Functioning/disability measures
  - Functioning 'within the skin'
  - Interaction with the environment
  - Impact of accommodation

Healthy People 2020

What is Disability?

Multiple definitions of disability

- Medically-based definitions
  - Similar to medically-based definition of health
  - Focus on “pathologies” in body structure and/or function
- Definitions based on limitations in core functional domains
  - Without accommodation (e.g., walking)
- Definitions based on restrictions in participation
  - Similar to social concept of health
  - Incorporates accommodations, including environmental barriers and facilitators

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The Challenges

Multiple definitions of the same terms

- Measurement challenges
- Interpretation challenges
- Policy development challenges

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Healthy People Monitoring Efforts

- Surgeon General's Report 1979 & Healthy People 1990
  - Five indicator-specific targets, with goals mapped one-to-one to these specific indicators
  - Reflected the importance of enhancing life in each of the five major life stages
  - Monitored by mortality by age (under 1 year, 1-14 years, 15-24 years, and 25-64 years)
  - Fifth target, for the population 65 years of age and over, was a morbidity-based measure aimed at preserving independence and defined as difficulty in two or more activities of daily living.

Healthy People 2020

Healthy People Monitoring Efforts

- Healthy People 2000
- Three guiding goals for the decade:
  1. Increase the span of healthy life,
  2. Reduce health disparities, and
  3. Achieve access to preventive services.
- Goal 1 measures
  - Life Expectancy at birth
  - Fair or poor self reported health status
  - Healthy Life Expectancy – years of healthy life (combination of self rated health and activity limitation)

Healthy People 2020

Healthy People Monitoring Efforts

- Healthy People 2010
- Two guiding goals for the decade:
  1. increase the quality and years of healthy life
  2. eliminate health disparities
- Three healthy life expectancy measures
  1. Expected years in good or better health,
  2. Expected years free from activity limitations, and
  3. Expected years free of selected chronic diseases.

Healthy People 2020

Healthy People Monitoring Efforts

- Original plans for HP2020
  - Continue monitoring the 3 healthy life expectancy measures from HP2010
    - Expected years free of activity limitation
    - Expected years in good or better health
    - Expected years free of chronic conditions
- Develop additional measures
    - Mental health
    - Health behaviors/determinants

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Healthy People 2020

- Focus on functioning as the key definition of health for policy development and evaluation
- Functioning is a critical aspect of health for the individual and the society
- Functioning can be seen as the outcome of:
  - Determinants and risk factors
  - Disease states
  - Use of health care
  - Environmental barriers and facilitators
- History of use in Healthy People

Healthy People 2020

Functioning as a Key Definition of Health for Policy Development and Evaluation

- Society can intervene to improve “health/functioning” in multiple places
  - Prevention of pathology
  - Curing the pathology
  - Reduce the impact of pathology
    - Rehabilitation at the person-level (e.g., assistive devices)
    - Modify the environment

Healthy People 2020

Functioning as a Key Definition of Health for Policy Development and Evaluation

- Policy objective – Minimize participation restrictions
- Monitoring function:
  - Measure level of participation and monitor change in participation
  - Measure level of functioning and change in functional abilities 'within the skin' and with accommodation
  - Relate to program and policy interventions

Healthy People 2020

Plan for Foundation Measures

- Focus on a small set of key measures
- Hierarchical framework
- Tier 1 – at birth and at age 65
  - Expected years free of activity limitation (participation)
  - Expected years of free of severe disability*
  - Expected years free of milder disability*
  - Expected years in good or better health

* Functioning in core domains without accommodation

Healthy People 2020

Plan for Foundation Measures

- Tier 2 – all ages and 65 and over
  - Life expectancy
  - Percent without activity limitation (participation)
  - Percent without more severe disability
  - Percent without milder disability
  - Percent in good or better health

Healthy People 2020

Beyond 2020

- Improve measures of functioning, disability and participation
- International Efforts in the Measurement of Functioning and Disability
  - The Washington Group on Disability Statistics
  - The Budapest Initiative on the Measurement of Health Status
  - Joint EU, US and Japan collaboration
- Links to Sustainable Development Goals and UNCRPD which focus on full participation and inclusion

Healthy People 2020

The Living Well with a Disability Program:
A Health Promotion and Wellness Program for Adults with Disabilities

Meg Traci, PhD[1]; Craig Ravesloot, PhD[1]; Tom Seekins, PhD[1],
Glen White, PhD[2], & Tracy Boehm, MPH[1], Naomi Kimbell, MA, MFA[1]

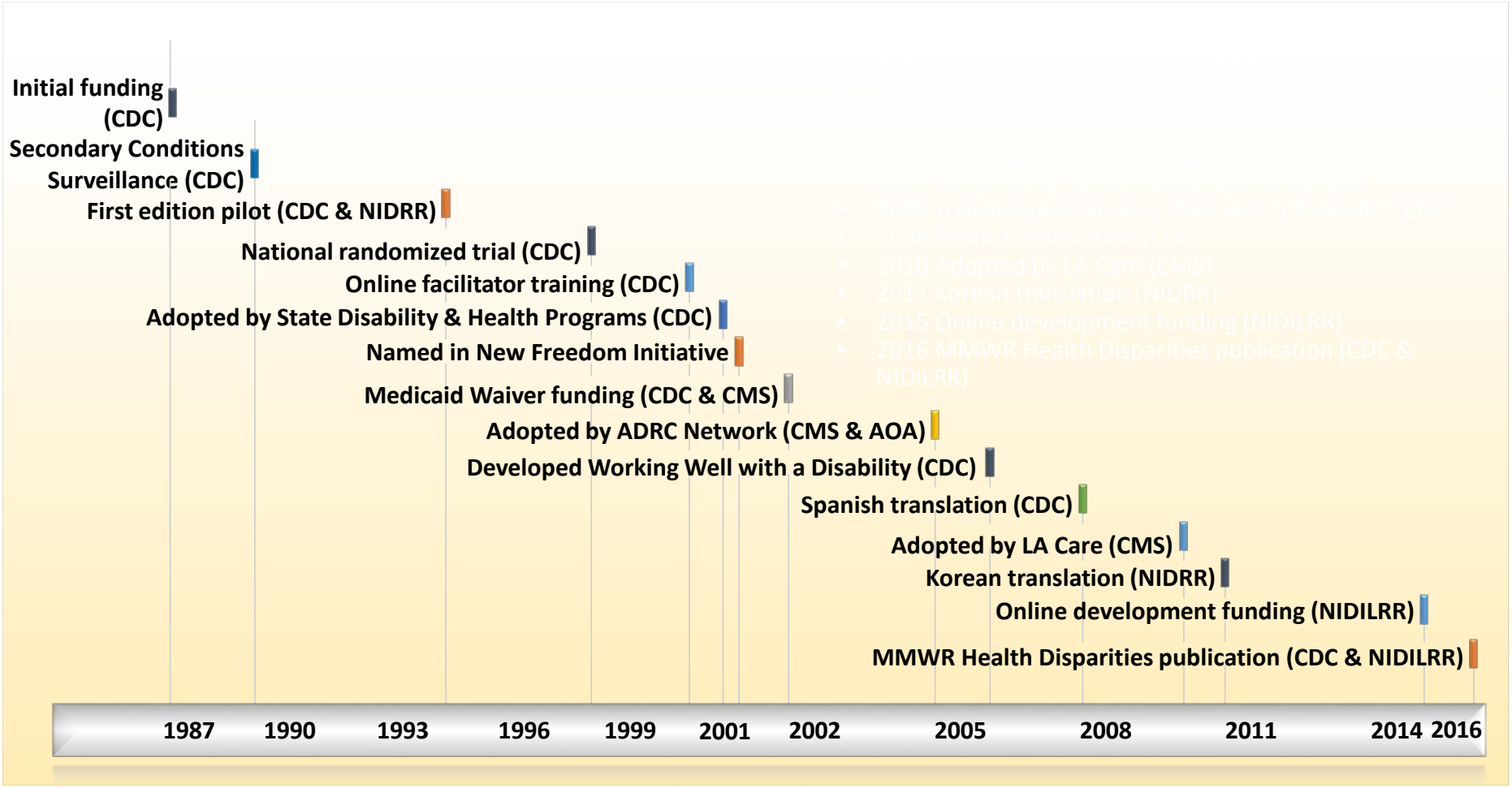
University of Montana, Rural Institute for Inclusive Communities[1], University of Kansas[2]

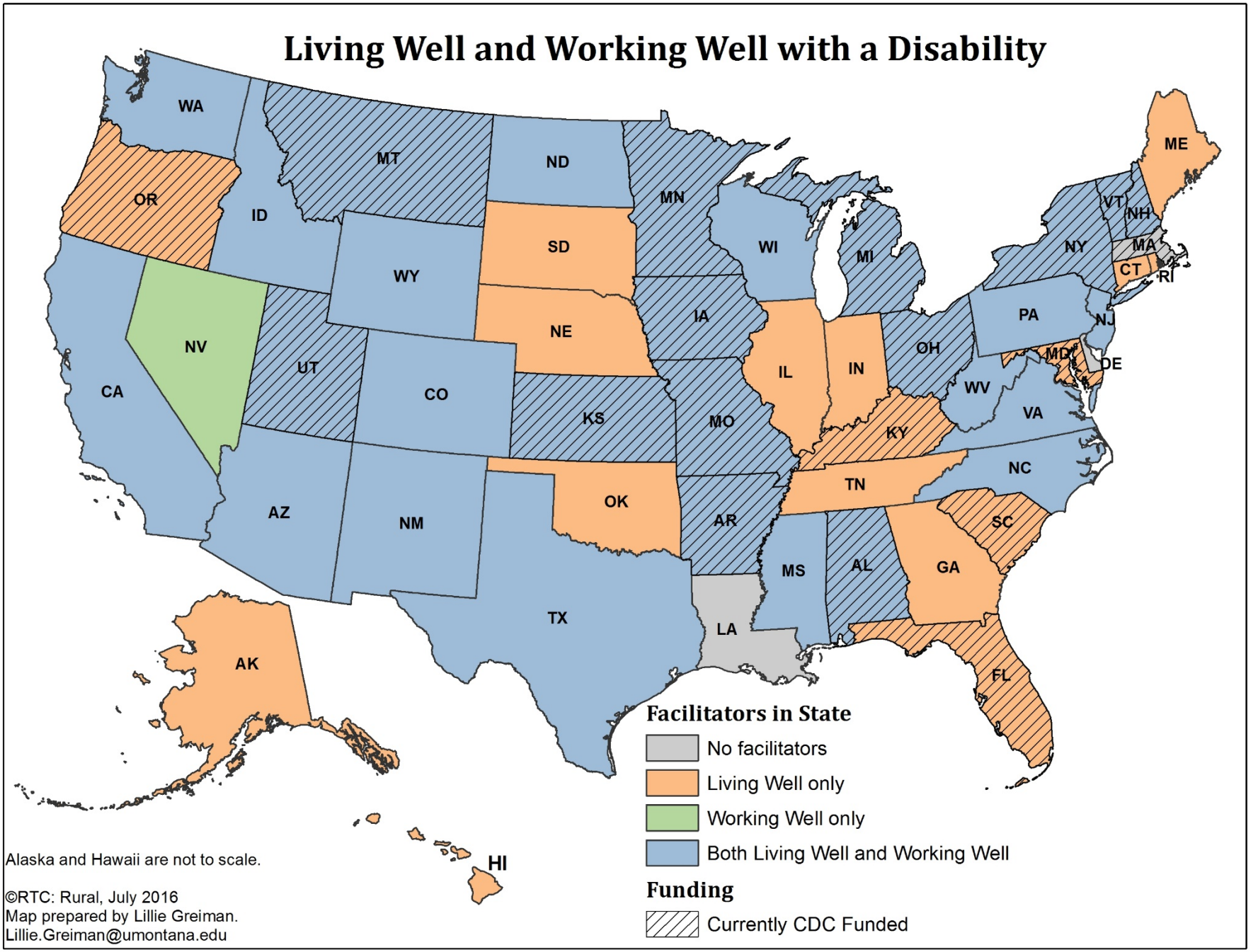
Webinar: Improving Health Outcomes through Inclusion and Participation

Thursday, August 11, 2016 · 12:30 PM ET

Living Well with a Disability

1987 – 2016 Living Well with a Disability Activity Timeline (Funding Source)




Living Well and Working Well with a Disability
WA
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PA
NY
MD
DE
NJ
CT
RI
MA
VT
NH
ME
AK
HI
Facilitators in State
No facilitators
Living Well only
Working Well only
Both Living Well and Working Well
Funding
Currently CDC Funded
Alaska and Hawaii are not to scale.
©RTC: Rural, July 2016
Map prepared by Lillie Greiman.
Lillie.Greiman@umontana.edu

Summary of Map

- From February 1995 to May, 2016, RTC: Rural staff trained 1,181 Living Well with a Disability (LWD) facilitators in 46 states, who served more than 9,448 adults with disabilities.
    - Since 2002, 753 LWD facilitators in current and previous CDC Disability and Health funded states reached over 6,024 workshop participants, whose symptom-free days are estimated at having increased by 71,685 days.

- Since 2010, RTC: Rural staff trained 238 Working Well with a Disability (WWD) facilitators in 30 states, who served more than 1,904 adults with disabilities.

Living Well with a Disability

What do we mean when we say disability?

- The International Classification of Functioning, Disability and Health is a framework for describing the continuum of function and disability. (WHO 2001)
- In this model, disability is not considered an illness
- Unlike previous models of disability, this framework considers not only bodily function but also the disabling characteristics of social, cultural and environmental contexts.
- Disability is seen as a dynamic interaction between a person and these contexts.
- In environments that are inclusive, such as those that include accessible built environments or social structures that support participation for all people, a person with a functional limitation may not experience that limitation as a disability.

Living Well with a Disability

Secondary Conditions: Health risks associated with disability

- Poorer overall health.
- Less access to adequate health care.
- Pain and fatigue.
- Mental health issues, such as depression.
- Engaging in risky health behaviors including smoking.

"Those physical, medical, cognitive, emotional, or psychosocial consequences to which persons with disabilities are more susceptible by virtue of an underlying condition, including adverse outcomes in health, wellness, participation, and quality of life" (Hough, 1999, p. 186).

Living Well with a Disability

What are Living Well and Working Well?

- Living and Working Well are goal-oriented health promotion programs for people with disabilities.
- Living Well focuses on developing a healthy and balanced lifestyle to meet quality of life goals.
- Working Well focuses on developing healthy habits that support employment goals.
- Each program was developed in collaboration with consumers to ensure their relevance to actual health needs.
- The Independent Living philosophy is central to the curriculum.

Living Well with a Disability

How Does Living Well Work?

- Living Well With A Disability is a 10-week workshop for groups of 8-10 people.
- Sessions are two hours long, meet once a week and are led by peer facilitators.
- Peer facilitators have been through the program and can offer support and mentorship to participants.
- Facilitators guide participants using a self-help workbook.

Living Well
with a Disability

Living Well Workshop Goals and Content

- The Living Well workshop begins by developing basic goal setting skills.
- Each chapter in the workbook builds on the next.
- As participants progress through the workshop, they get to test their skills within a supportive peer community.
- The building blocks of healthy communication and healthy reactions to stressful situations are learned early to support additional skills.

Living Well with a Disability

Living Well Workshop Goals and Content, Cont'd.

- The Living Well workshop provides accurate information about healthy lifestyle habits including exercise and nutrition.
- The program helps participants build the skills to find information for themselves and advocate for their needs.
- The workshops are interactive and participants have the chance to ask questions and share ideas for maintaining lifestyle changes.

Living Well with a Disability

Personal Benefits of Living Well

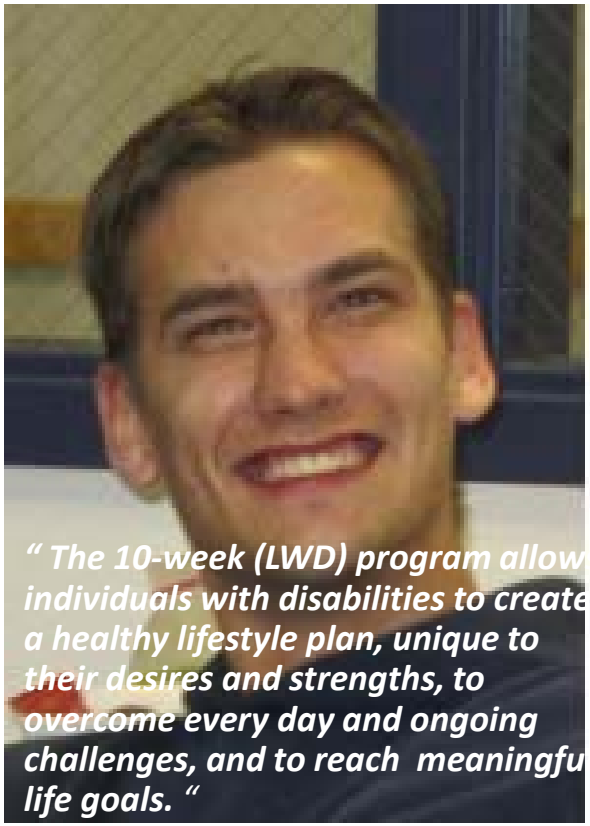
- Compared to pre-workshop measures, following the workshop participants reported:
- Fewer symptom days across physical and mental health symptoms (Health Related Quality of Life – 14)
- Reductions in activity limitation due to secondary conditions (Secondary Conditions Surveillance Instrument)
- Improvements in health behavior (Health Promoting Lifestyle Profile II)
- Improved Life Satisfaction (Behavior Risk Factor Surveillance System item)

Ravesloot, Seekins & White (2005) Living Well with a Disability Health Promotion Intervention: Improved Health Status for Consumers and Lower Costs of Healthcare Policymakers. *Rehabilitation Psychology, 50(3),* 239-245.

Living Well with a Disability

Third-Party Payer Benefits of Living Well

- Compared 2-month retrospective recall of healthcare utilization (outpatient visits, emergency room visits, outpatient surgeries and inpatient hospital days) before and after the workshop. Converted visits to healthcare costs using 1998 Medicare reimbursement rates.
- Program outcome = $3,227 savings per person
- Study-wide cost savings (n=188) = $494,628 over six months
- By May 2015, LWD as implemented by 279 community-based agencies in 46 states to approximately 8,900 persons with disabilities. On the basis of the 6-month cost savings observed in the field trial, these community applications are estimated to have saved as much as $28.8 million, which would have been incurred since February 1995 by health care payers without program implementation.



Ravesloot, Seekins, Traci, Boehm, White, Witten, Mayer & Monson (2016). Living Well with a Disability, a self-management program. *MMWR, 65 (01), 61-67*.

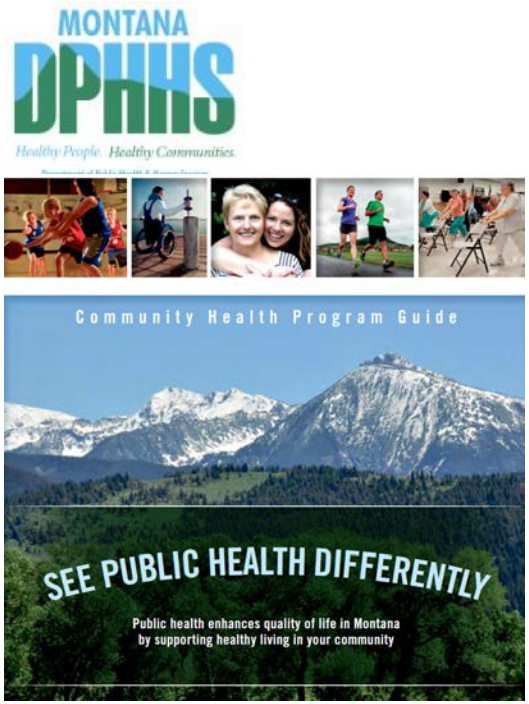
Living Well with a Disability

Implementing the Program

- **Facilitator training**
  - Peer facilitators are trained in in-person or online classroom settings.
- **Program delivery**
  - Workshops are held at local service providers such as Centers for Independent Living.
- **Capacity building**
  - Community stakeholders support program implementation through consumer referrals, funding support and help in providing facilities or coordination services.

Living Well with a Disability

Information and Facts



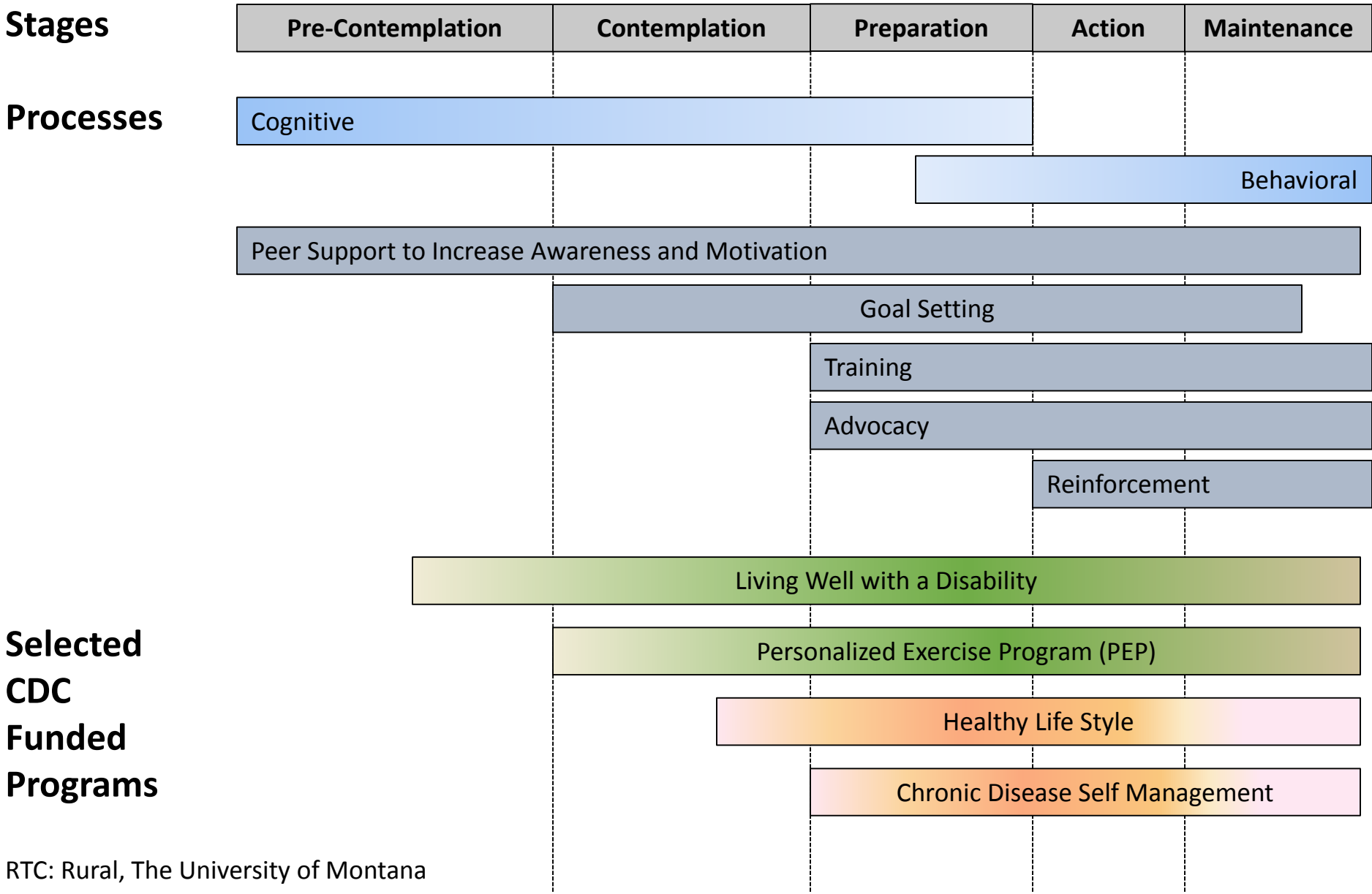
- *See Public Health Differently*[1] is a communication plan of the Montana Department of Public Health and Human Services; the plan leverages partners statewide to promote health and wellness programs to Montanans.
- LWD and WWD are included with other programs, such as Diabetes Prevention and Self Management Education Programs, Arthritis Programs, and the Quit Line.
- Traditional partners share the HP2020 DH-8 objective with CILs and other disability organizations.
  - ➢ Coordination of cross-cutting strategies increases the inclusion of people with disabilities in available local health and wellness programs overall.
  - ➢ Participation rates of Montanans with disabilities
    - 11.5% Montana Breast and Cervical Cancer Screening Program
    - 29.0% CVD/Diabetes Prevention Program
    - 41.2% Montana Tobacco Quit Line
    - 100% Living and Working Well with a Disability

- [1]Guide Available at: ChronicDiseasePrevention.mt.gov
- **Community Health Program Guide –**
- Downloadable PDF
- Accessible/large print version available
- **Interactive Map**
- Accessible list – searchable by county/program name

[2]HP2020 DH-8. Reduce the proportion of adults with disabilities aged 18 and older who experience physical or program barriers that limit or prevent them from using available local health and wellness programs

Living Well with a Disability

Living Well with a Disability and Health Behavior Change



RTC: Rural, The University of Montana

Living Well with a Disability

Healthy Community Living Project[1]

- Development project to expand the Living Well with a Disability program
- Developing and evaluating two online programs that blend face-to-face and online learning using traditional (video) and social (Facebook) media.
- The *Community Living Skills* program is using Self-Determination Theory (Deci & Ryan, 2000) to help people prepare for health self-management.
- The *Living Well in the Community* program is adapting the Living Well with a Disability course content to an online blended learning format.
- Twelve staff from eight CILs around the US are participating in an iterative participatory curriculum development process for program development.

[1] ACL NIDILRR funded Disability and Rehabilitation Research Project (DRRP) 2015-2020 (HHS 90DP0073)

Living Well with a Disability

Resources

Living and Working Well Website:

http://www.livingandworkingwell.org/

Research reports and publications:

http://rtc.ruralinstitute.umt.edu/_rtcBlog/?page_id=5350

Living Well with a Disability

Acknowledgements

- Independent Living Centers and their consumers
- Disability and Health Branch– NCBDDD
- RTC: Rural
- Montana Department of Public Health and Human Services

Living Well with a Disability

Roundtable Discussion

Don Wright, MD, MPH
Director, Office of Disease Prevention and Health Promotion

Healthy People 2020

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Healthy People 2020 Stories from the Field

A library of stories highlighting ways organizations across the country are implementing Healthy People 2020

Healthy People in Action

http://www.healthypeople.gov/2020/healthy-people-in-action/Stories-from-the-Field

Who's Leading the Leading Health Indicators? Webinar

Please join us on
Thursday, September 22nd from 12:00 to 1:00 pm ET
for a Healthy People 2020 *Who's Leading the Leading Health Indicators?* webinar on Reproductive and Sexual Health.

Registration on HealthyPeople.gov available soon

Who's Leading the Leading Health Indicators?

Healthy People 2020

Progress Review Planning Group

- Julie Weeks (CDC/NCHS)
- Althea Grant(CDC/ONDIEH)
- Bill Riley (NIH/OD)
- Mitch Loeb (CDC/NCHS)
- Jennifer Meunier (CDC/NCBDDD)
- Amanda Dudley (CDC/NCBDDD)
- Michael Fox (CDC/NCBDDDD)
- Lisa Sinclair (CDC/NCBDDD)
- Louis Quatrano (NIH/NICHD)
- Hugh Berry (ACL/NIDILRR)
- Barbara Disckind (HHS/OWH)
- Stan Lehman (CDC/OD)
- Jennifer Villani (NIH/OD)
- Irma Arispe (CDC/NCHS)
- David Huang (CDC/NCHS)
- Leda Gurley (CDC/NCHS)
- Beth Pathak (CDC/NCHS)
- Asel Ryskulova (CDC/NCHS)
- Robin Pendley (CDC/NCHS)
- Jim Dahlhamer (CDC/NCHS)
- Carter Blakey (HHS/ODPHP)
- Angie McGowan (HHS/ODPHP)
- Tiffani Kigenyi ((HHS/ODPHP)
- Theresa Devine (HHS/ODPHP)
- Caitie Blood (HHS/ODPHP)
- Yen Lin (HHS/ODPHP)

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