Intersections in Health Care Accessibility and Person-Centered Care

HCBS Conference 2018

Administration for Community Living

PACIFIC ADA CENTER

A member of the ADA National Network

Access to Healthcare Services and Programs Under the ADA:

Lewis Kraus, Pacific ADA Center

HCBS Conference, August 2018

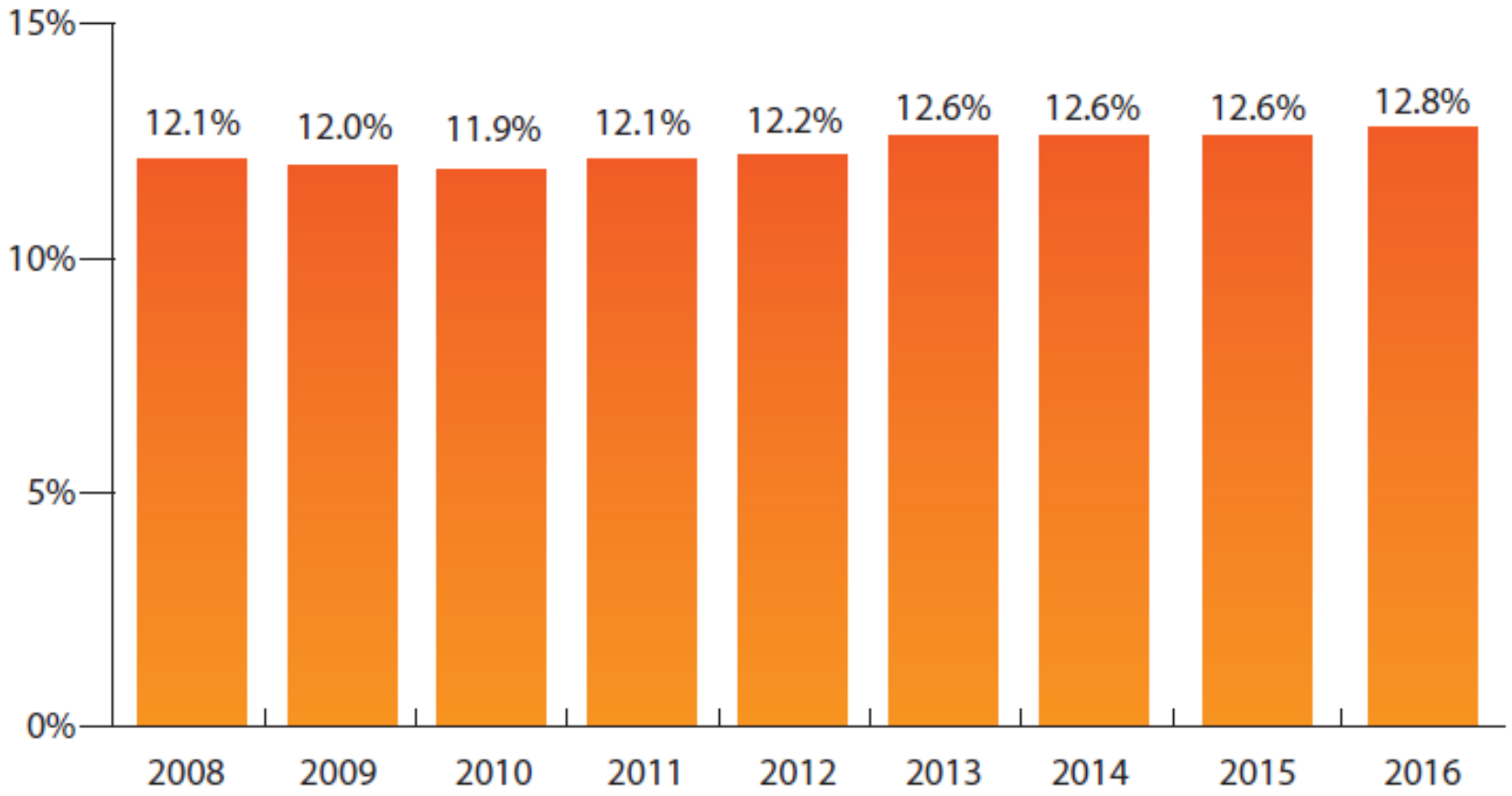
ADA National Network

Information, Guidance, and Training on the Americans with Disabilities Act

Overview

- Health disparities
- The ADA and access to care
- Federal initiatives spurring accessibility
- Research on access to primary care physician offices and services in California

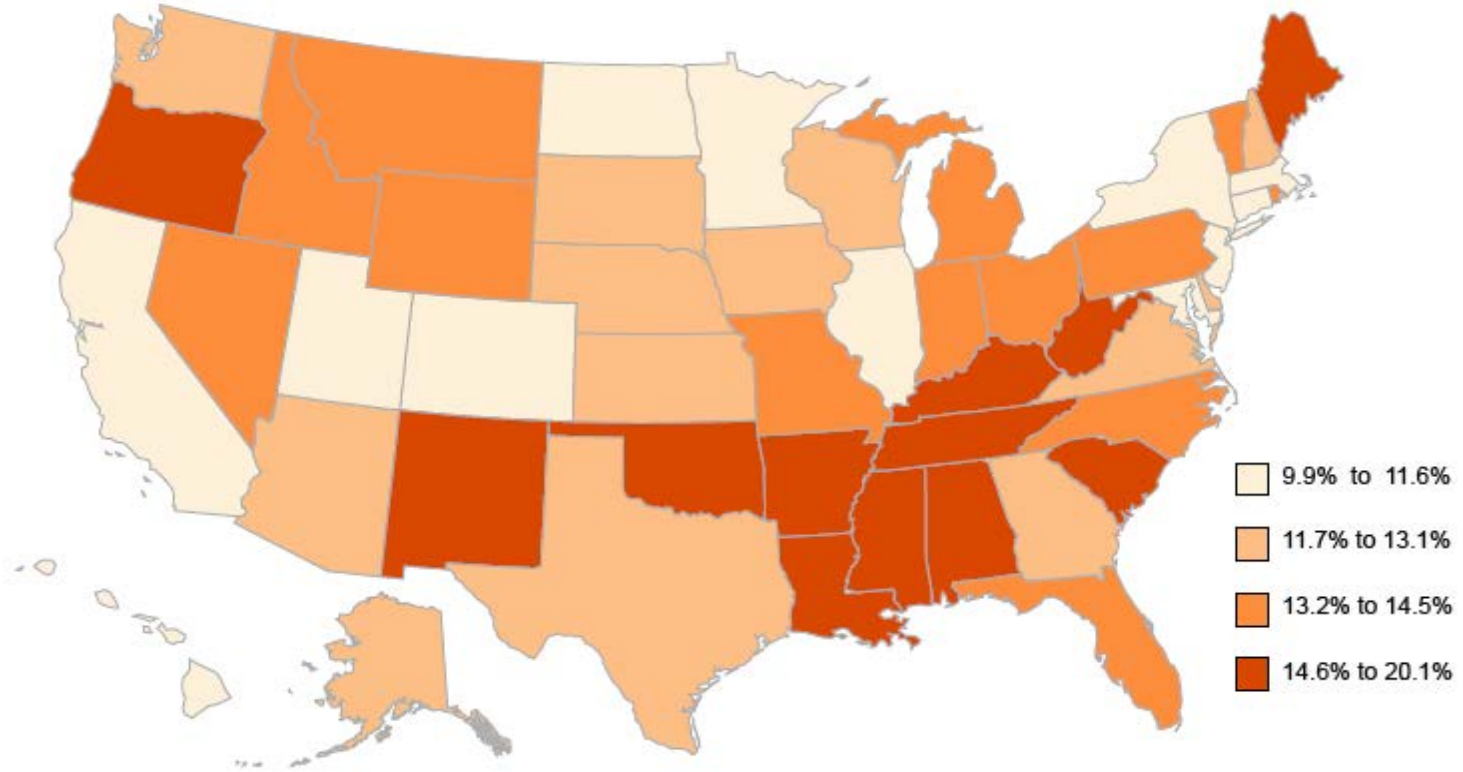
Percentage of People in the US with Disabilities, 2008-2016



Data Source: 2008-2016 American Community Survey, American FactFinder, Table B1810

Kraus, L., Lauer, E., Coleman, R., and Houtenville, A. (2018). 2017 Disability Statistics Annual Report. Durham, NH: University of New Hampshire. http://disabilitycompendium.org/sites/default/files/user-uploads/2017AnnualReportSlideDeck

People with Disabilities Living in the Community as a Percentage of the US Population, by State, 2016



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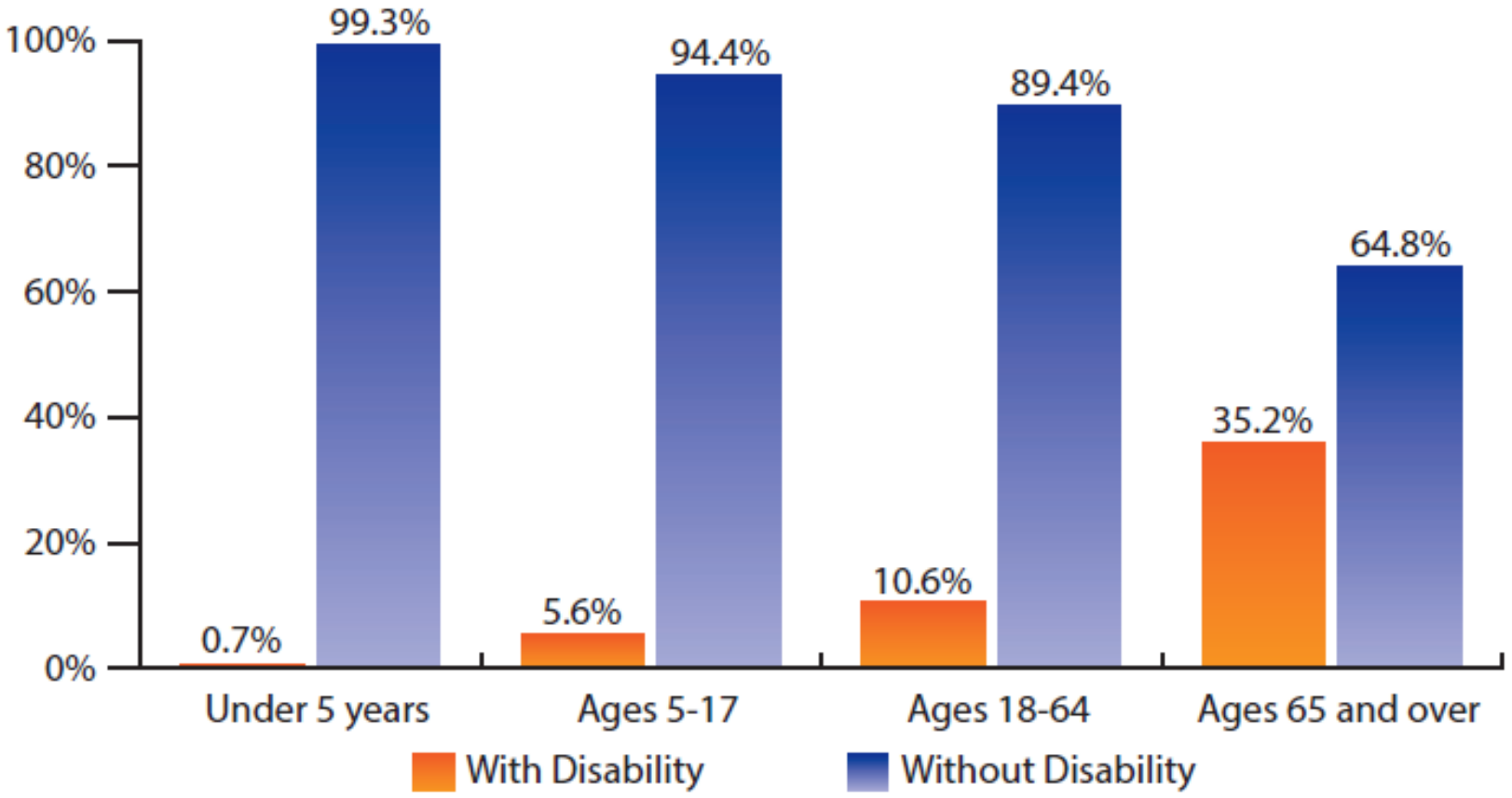
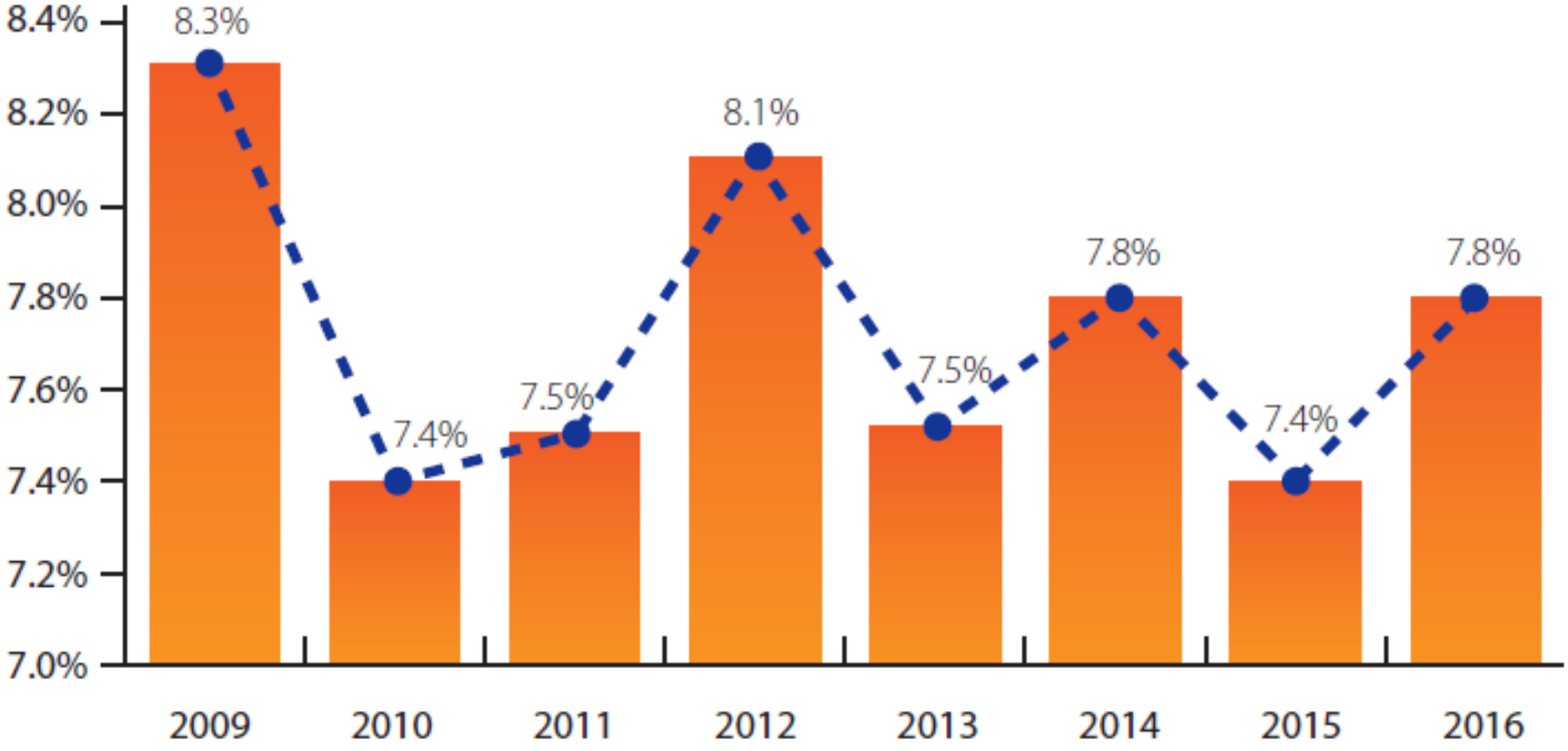
Age Distribution of Disability in the US Population, 2016



Data Source: 2016 American Community Survey, FactFinder Table B1810

Kraus, L., Lauer, E., Coleman, R., and Houtenville, A. (2018). 2017 Disability Statistics Annual Report. Durham, NH: University of New Hampshire. http://disabilitycompendium.org/sites/default/files/user-uploads/2017AnnualReportSlideDeck

Poverty Percentage Gap Among People with and without Disabilities, 2009-2016



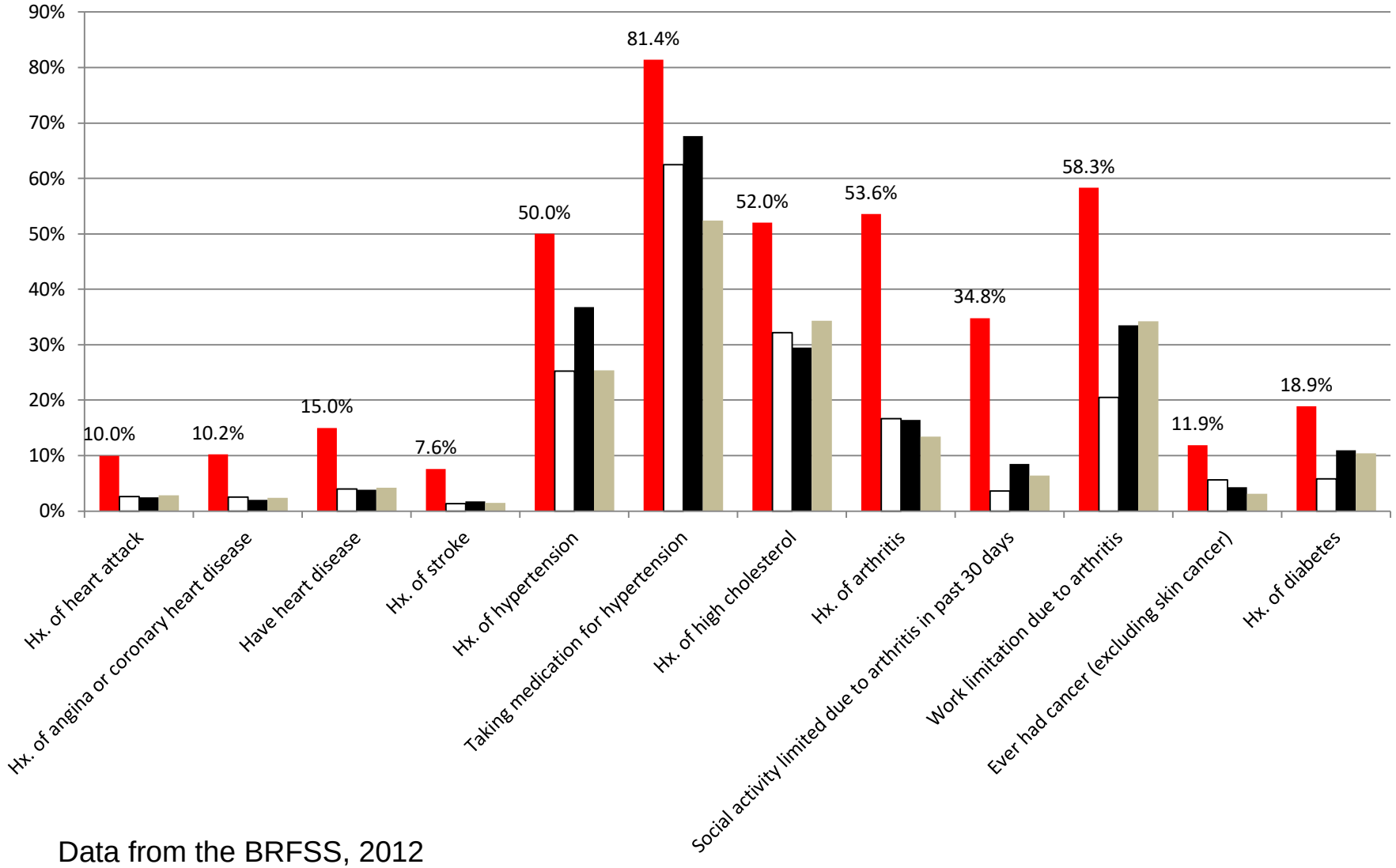
Data Source: 2009- 2016 American Community Survey, American FactFinder, Table B18130

Kraus, L., Lauer, E., Coleman, R., and Houtenville, A. (2018).2017 Disability Statistics Annual Report. Durham, NH: University of New Hampshire. http://disabilitycompendium.org/sites/default/files/user-uploads/2017AnnualReportSlideDeck

Disability Demographics in the Future

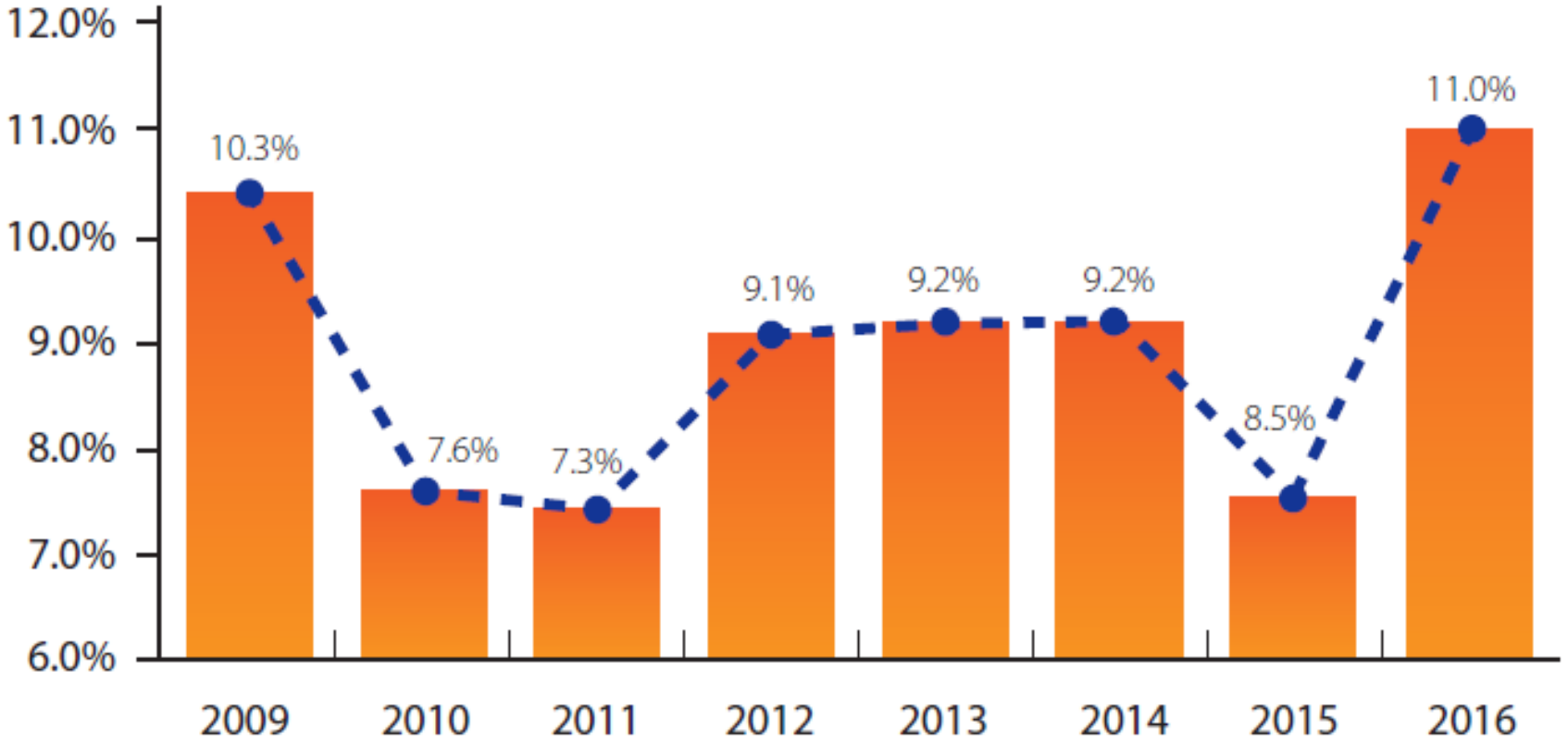
- Growing in numbers as the population ages and with technological advances in care
- 88.5 million or 20% of the total population will be people 65 and older by 2050
- 25.4 percent of people age 65 - 74 report disability (2015)*
- 49.8 percent of people over age 75 report disability (2015)*

Who has this disparity?



Data from the BRFSS, 2012

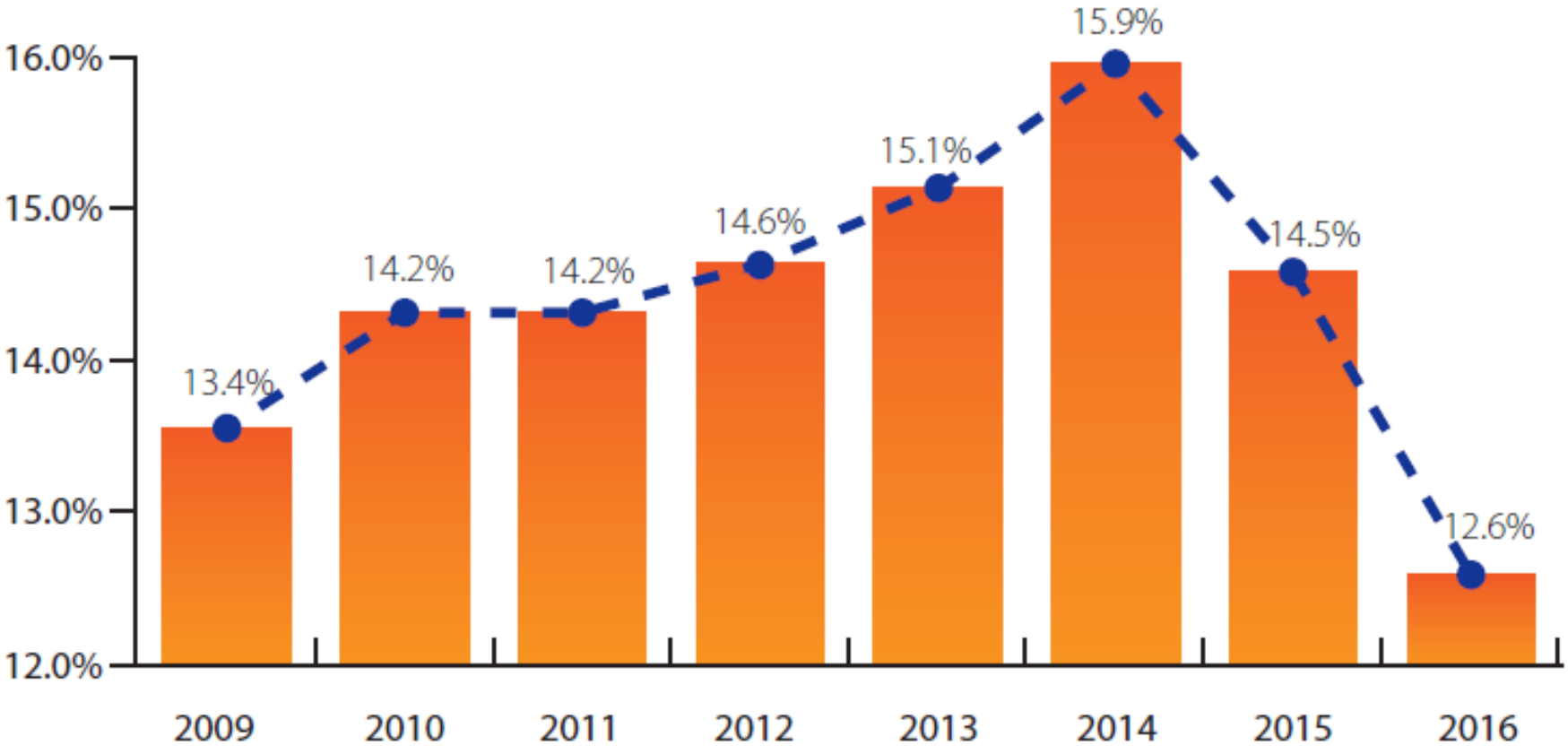
Smoking Percentages Gap Among People with and without Disabilities, 2009-2016



Data Source: Authors' calculations using data from the 2009-2016 Behavioral Risk Factor Surveillance Survey BRFSS

Kraus, L., Lauer, E., Coleman, R., and Houtenville, A. (2018).2017 Disability Statistics Annual Report. Durham, NH: University of New Hampshire. http://disabilitycompendium.org/sites/default/files/user-uploads/2017AnnualReportSlideDeck

Obesity Percentages Gap Among People with and without Disabilities, 2009-2016



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Kraus, L., Lauer, E., Coleman, R., and Houtenville, A. (2018).2017 Disability Statistics Annual Report. Durham, NH: University of New Hampshire. http://disabilitycompendium.org/sites/default/files/user-uploads/2017AnnualReportSlideDeck

Disability, Health and Health Care Disparities Healthy People 2020

- People with disabilities are more likely to:
  - Experience difficulties or delays in getting the health care they need
  - Not have had an annual dental visit
  - Not have had a mammogram in the past 2 years
  - Not have had a Pap test within the past 3 years
  - Not engage in fitness activities
  - Have high blood pressure

Why? Complex, Intersecting Barriers Contribute to Disparities

- Poverty
- Prejudice and stereotypes
- Lack of provider training and cultural literacy
- Physical and programmatic inaccessibility
- Inadequate research
- ADA monitoring, implementation and enforcement

Access to Healthcare: What Does the ADA Require?

Delivery of services in a way that ensures that all people have an equal opportunity to achieve the full benefit of a program or service (Title II or III)

Access to Healthcare: What Does the ADA Require?

- Equitable access to care and services
  - Physical accessibility of buildings and facilities
  - Accessible equipment
  - Effective communication (for sensory disabilities)
  - Modification in policies, practices, and procedures

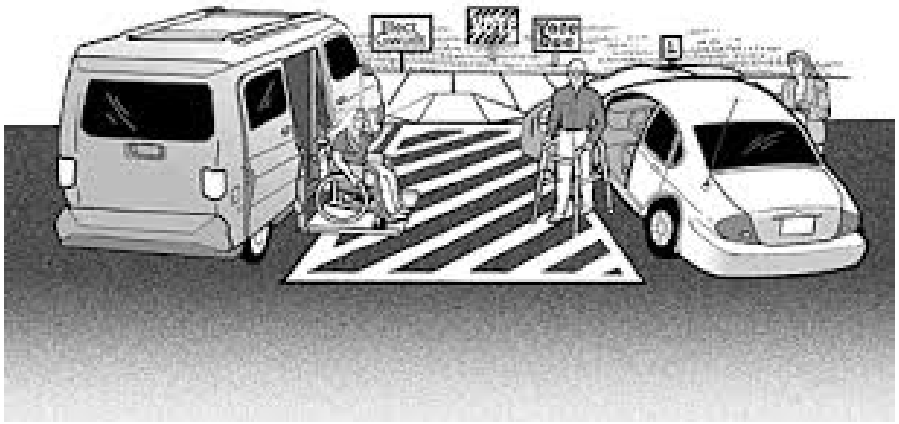
Who Does this Cover?

- People with physical, mental, cognitive, or intellectual limitations such as difficulty:
  - Walking, balancing, climbing
  - Seeing or hearing
  - Reading
  - Understanding or remembering

Physical Accessibility of Facilities

- If parking is available

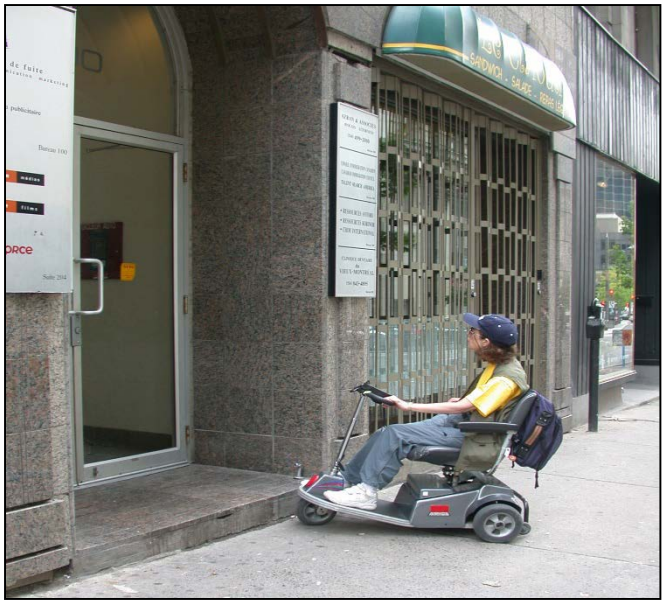
PROBLEM ***SOLUTION***



Physical Accessibility of the Office

- Inaccessible medical buildings, offices, restrooms

Problems



Physical Accessibility of the Office

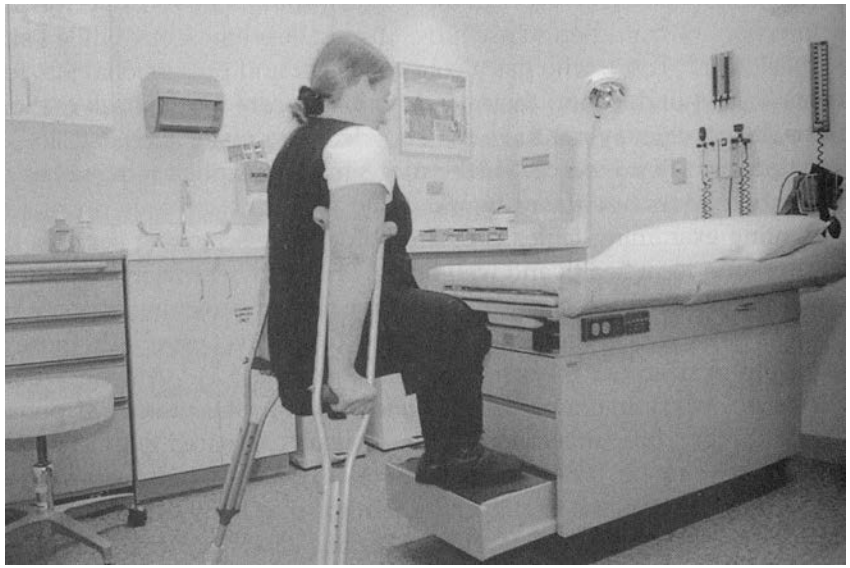
- Inaccessible medical buildings, offices, restrooms

Solutions

Accessible Equipment

- Lack of accessible exam equipment such as exam tables

Problem



Solution

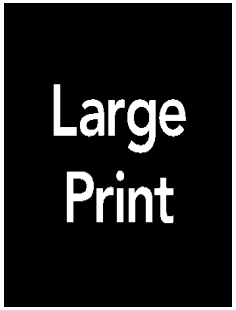
Accessible Equipment

- Inaccessible equipment such as weight scales

Problem ***Solutions***

Effective Communication

- Communicating effectively using the right tools for people with problems seeing, hearing, thinking, remembering , learning and understanding
  - Braille
  - Large print
  - Digital text
  - Audio



Effective Communication

- Communicating effectively using the right tools for people with problems seeing, hearing, thinking, and understanding

Sign Language interpreters

Like any other language interpreters, translate English and American Sign Language (ASL)
So people who are deaf and use (ASL) and people who can hear and speak English can communicate

ASL -- a visual-gestural language
used by millions of Americans of all ages.
ASL is a rich and complete language that has a different grammatical structure than the English language

Modification in policies, practices, and procedures

- Development of a modification process
  - How does someone ask and receive a modification
- Develop staff training
  - Disability awareness
  - Customer service
  - Effective communication (esp. front desk staff)
  - Modification request process

Access Data Research

- ADA architectural requirements are by and large increasing accessibility for outpatient primary care healthcare facilities
- Programmatic accessibility (scales, tables, mammography equipment, policy modifications such as extended exam time, aux. aids and services) lags far behind

Resources

National Network of ADA Centers

1-800-949-4232 (free TA on ADA)

www.adata.org

US Department of Justice

ADA technical assistance

www.ada.gov/

Contact

Lewis Kraus

Co-Director, Pacific ADA Center

510-285-5600

lewisk@adapacific.org

The Centene Provider Accessibility Initiative:

Increasing access to, and quality of, healthcare for people with disabilities

Sarah Triano, Centene Director of Complex Care Policy & Innovation
NASUAD Fall Conference 2018. August 29, 2018. Baltimore, MD

Centene Overview

CENTENE® Corporation

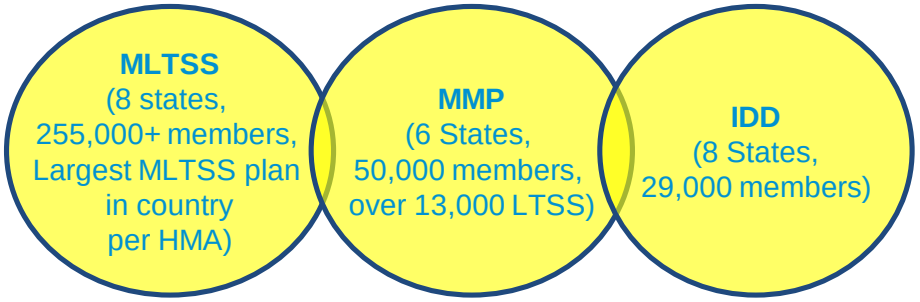
WHO WE ARE

St. Louis
based company founded in Milwaukee in 1984

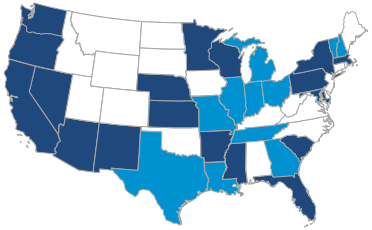
46,000 employees

#19 on Fortune's **Change the World List**

#43 on Forbes' **Global 2000: Growth Champions List**



WHAT WE DO



30 states
with government sponsored healthcare programs

Medicaid (25 states)
Marketplace (16 States)
Medicare (20 States)
Correctional (12 States)

state count reflects pending Fidelis Care (NY) transaction

2 international markets

12.8 million members
includes 2.9 million TRICARE eligibles

~300 Product / Market Solutions

What is the Goal of the Centene Provider Accessibility Initiative (PAI)?

Goal:

- Provide **equal access** to quality health care and services that are **physically and programmatically accessible**
- for our **members with disabilities** and their **companions** with disabilities
- by **increasing the percentage** of providers that **meet minimum** federal and state **disability access standards**.

Why Is Centene Focusing on Provider Disability Access?

- It's the **right thing to do**
- Medicaid and Medicare members with disabilities **receive less preventative care** than those with no disability*
- It's a **federal requirement**
- Beneficiaries with disabilities say we should**

*https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Issue-Brief-Physical-AccessibilityBrief.pdf
**Disability Rights Education & Defense Fund (Producer). (2013). Part One: Tables and Scales.

Stakeholder Input and Feedback

- **Centene National Disability Advisory Council**

- **Health Plan Member Advisory Councils**:
  - California
  - Florida
  - Kansas
  - Michigan
  - Ohio
  - Pennsylvania
  - Texas

How is Centene Accomplishing Our Goal?

PROVIDER ACCESSIBILITY INITIATIVE:

1. **Improving** the accuracy, completeness, and transparency of **provider disability access data in directories** by:
   a. Asking all providers nationwide to **self-report** *standardized* disability access data;
   b. Verifying the *accuracy* of that self-reported data through **on-site Accessibility Site Reviews** (ASRs) conducted by Centers for Independent Living (CILs); and
   c. Uploading self-reported and then verified data into online and print directories using *universal design* principles.

2. Offering Centene providers competitive access to a **national Barrier Removal Fund** (BRF) that includes:
   a. Funding to remediate disability barriers; and
   b. Technical assistance from the **National Council on Independent Living (NCIL), local CIL, and local health plan**.

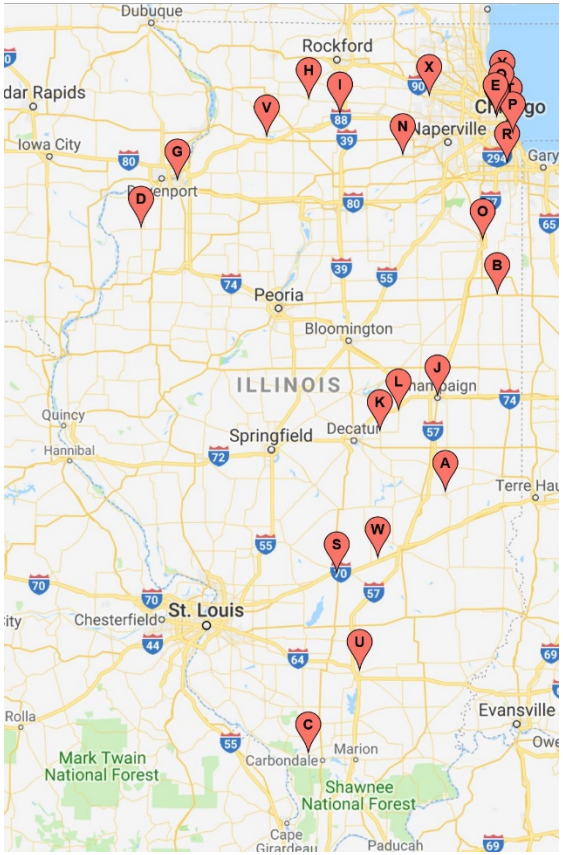
Centene National Barrier Removal Fund

- Partnership with the National Council on Independent Living (NCIL)
- $1 million available in 2018 in 3 states: IL, TX, OH
- Additional funds available in 2019
- Barrier Removal Fund (BRF) Process

1. Funding available for barrier removal in 3 main areas:
   - Building modifications, diagnostic equipment, and/or programmatic access.
2. RFP issued, participating Centene providers apply through NCIL website
3. All applicants complete Centene Disability Access Self-Report Form
4. NCIL pre-screens all applicants for eligibility
5. Local BRF Committees review/score applications, make award decisions
6. BRF Awardees receive:
   - Pre-on-site disability accessibility survey completed by a local CIL;
   - Funding to address priority disability access barriers;
   - Technical assistance from NCIL and the local CIL and local health plan; and
   - A post-accessibility survey to confirm/document improvements.

Barrier Removal Fund Outputs to Date

- **Requests for Proposals issued**: IL (3/13/18), TX (5/29/18)
- **Applications received**: IL (97 apps totaling over $2 million in requests), TX (18 apps totaling close to $300,000 in requests)
- **Funded projects**: 28 in IL approved with 24 different providers
- **TX BRF meeting in October**



Illinois BRF-Specific Outcomes to Date

"Since the installation of our automatic doors, I have been pleased to notice more adult wheelchair patients in our facility receiving much needed services. I see this being a positive addition and great way to meet ALL members of our community. We would not have been able to make these upgrades to our facility at this time without the funds from this grant. Thank you again!"

- Dr. Sarah Patrick, Administrator, Jackson County Health Department

Illinois BRF-Specific Outcomes to Date, Cont.

"I'm really excited to put the new adjustable height tables into place! It is very frustrating for our mobility challenged patients and for our staff when a disabled patient comes in for an annual exam (pelvic exam or pap smear) and we are unable to provide them with comfortable and effective positioning to ensure the best health outcomes. We greatly appreciate the funding provided to make this happen!"

– Breann Swan-Figueroa, Nurse Practitioner, Champaign-Urbana Public Health District

Combined accessible exam table and scale, the UpScale M430, from Medical Accessibility, LLC

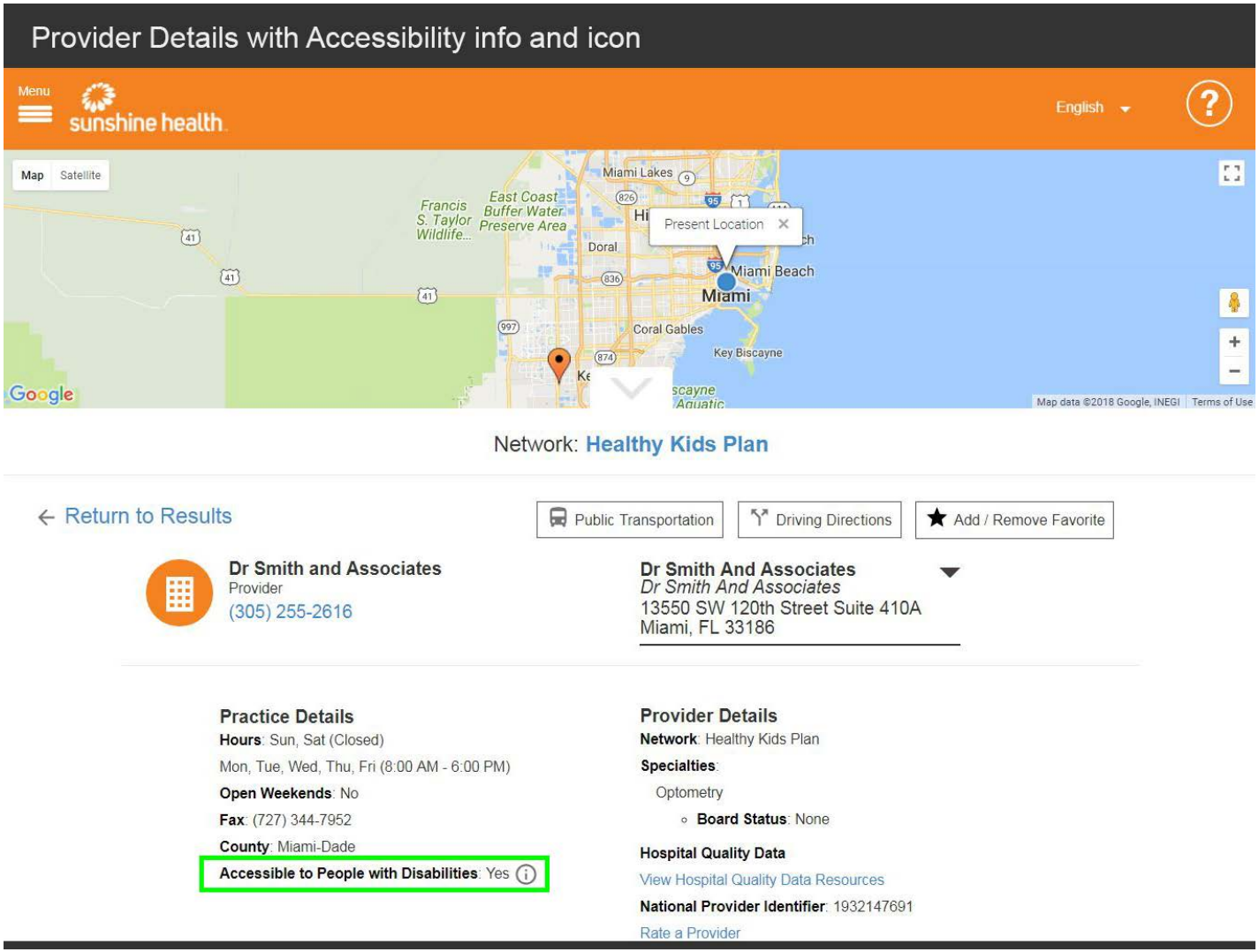
Illinois BRF-Specific Outcomes to Date, Cont.

Rock Island County Council on Addictions

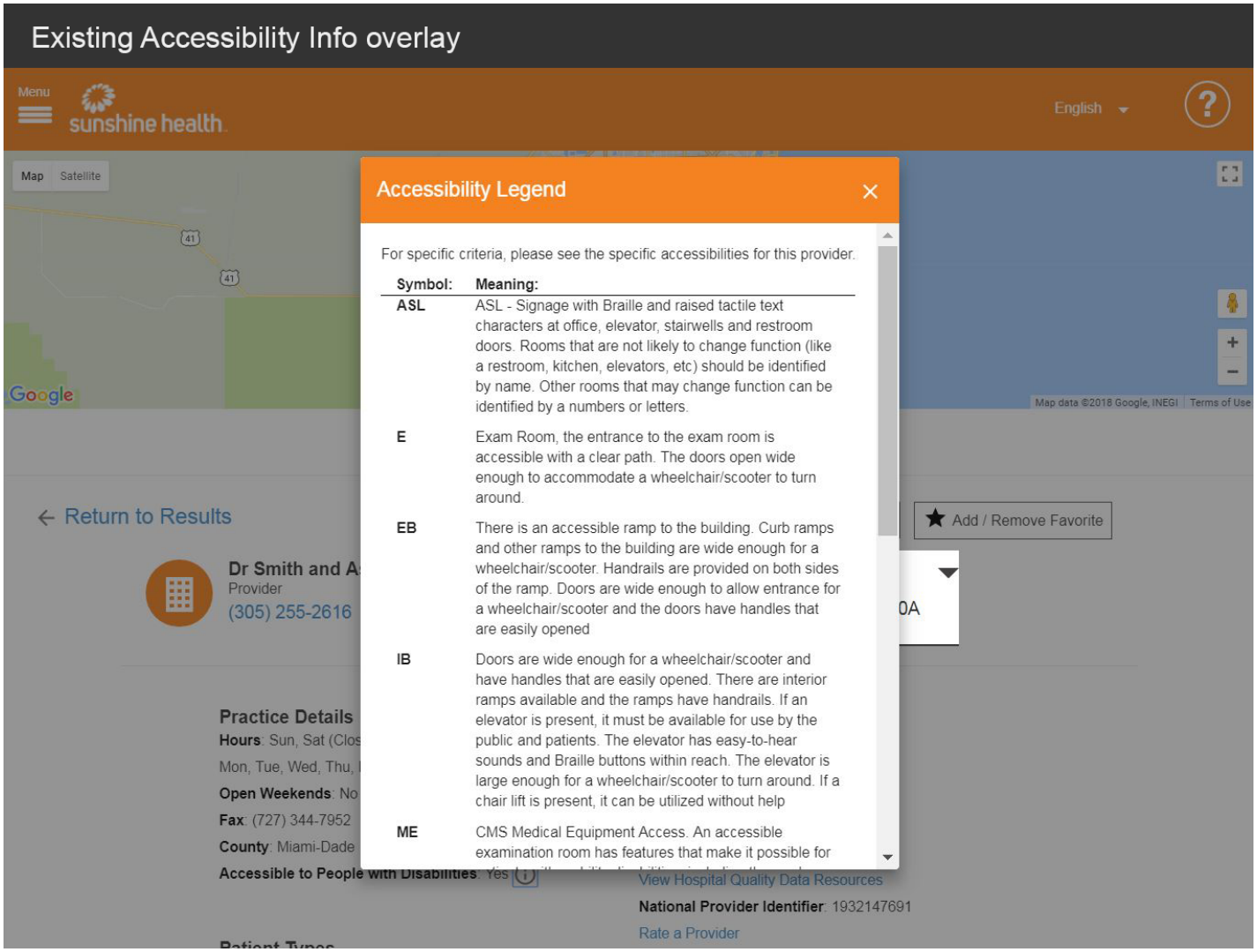
Improving Disability Access Data in Directory

- 3 plans asked no questions on disability access; 20 plans asked only 1 question on “handicapped access.”
- Currently, all Centene providers asked to **self-report** on **4 *standardized* disability** access questions (with 49 critical elements) to establish baseline.
- Self-report ongoing during credentialing and re-cred.
- Verifying the *accuracy* of provider self-reported data through on-site Accessibility Site Reviews (ASRs) by Centers for Independent Living (CILs).
  - Onsite ASRs implemented in CA (2,500 since 2011), and IL. In TX and OH in 2018. Expanded to other Centene states in 2019.
- Provider Directory revisions

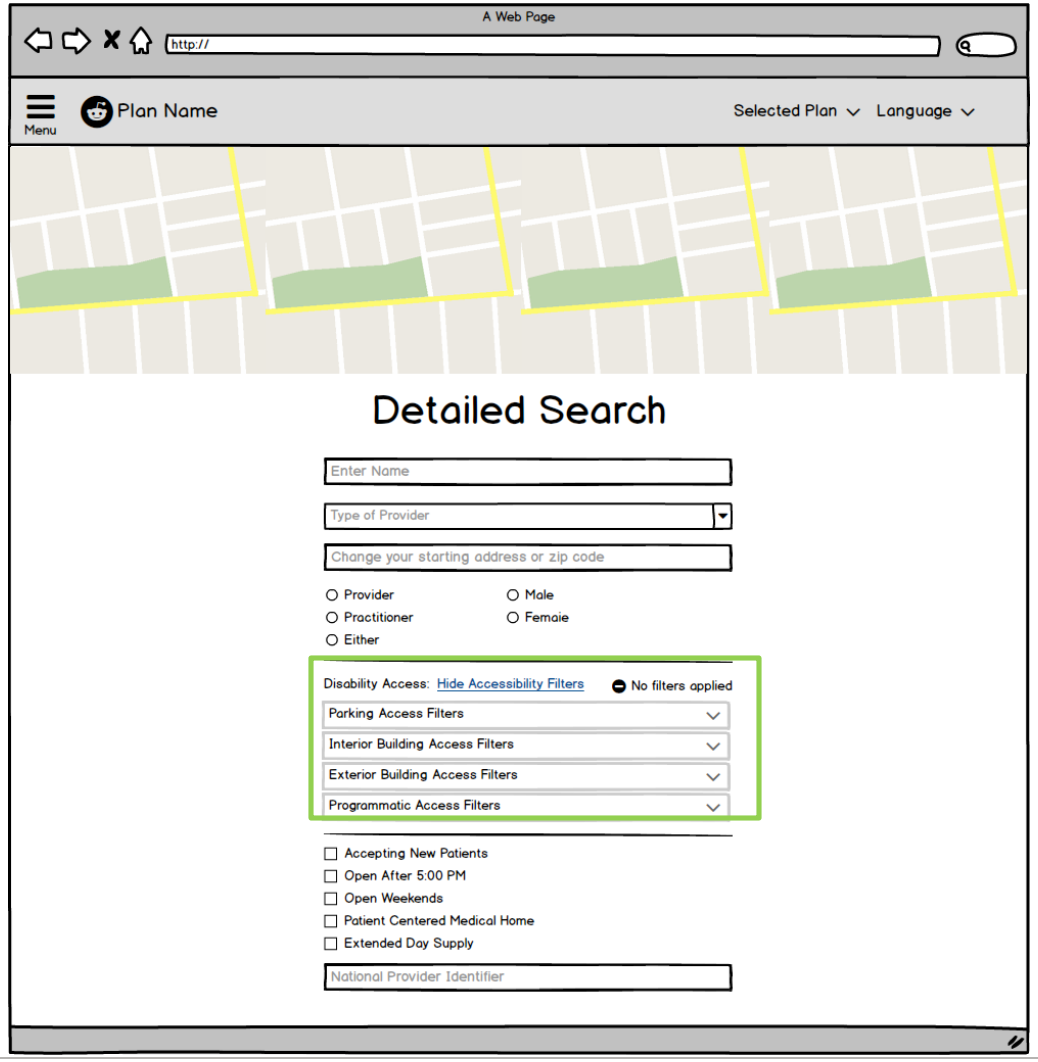
Previous Provider Directory Disability Access Data



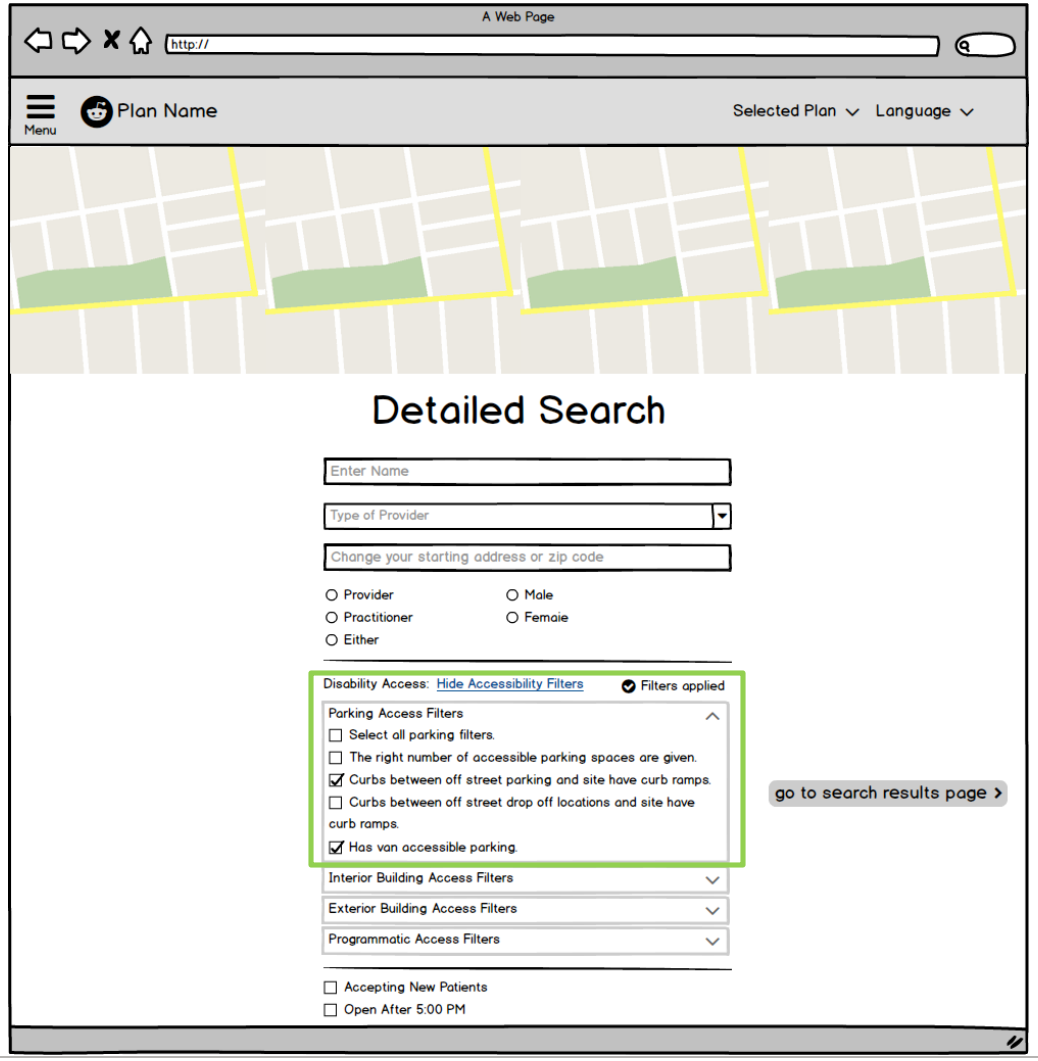
Previous Provider Directory Disability Access Data



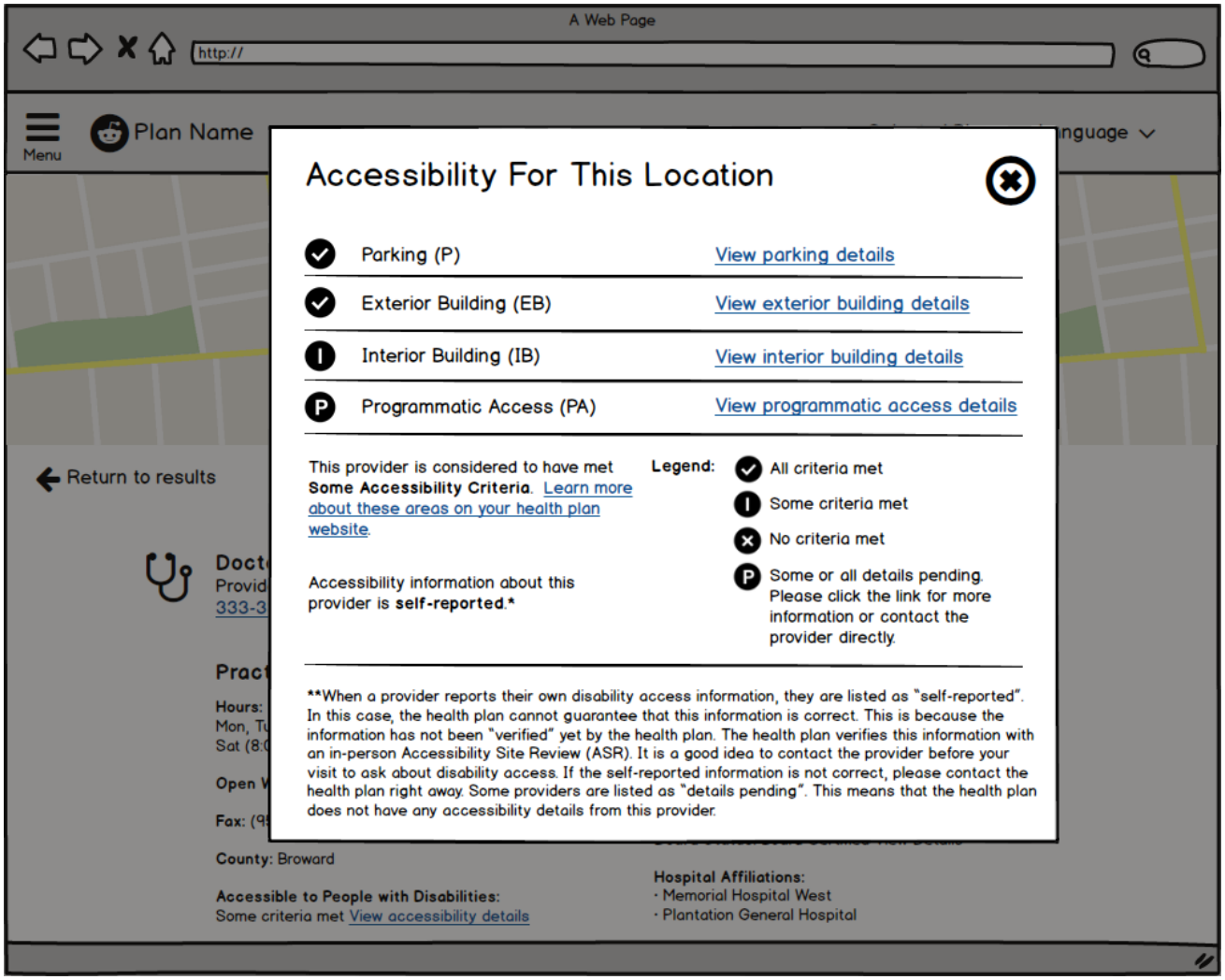
Revised Search on 49 Critical Disability Access Elements within 4 Domains



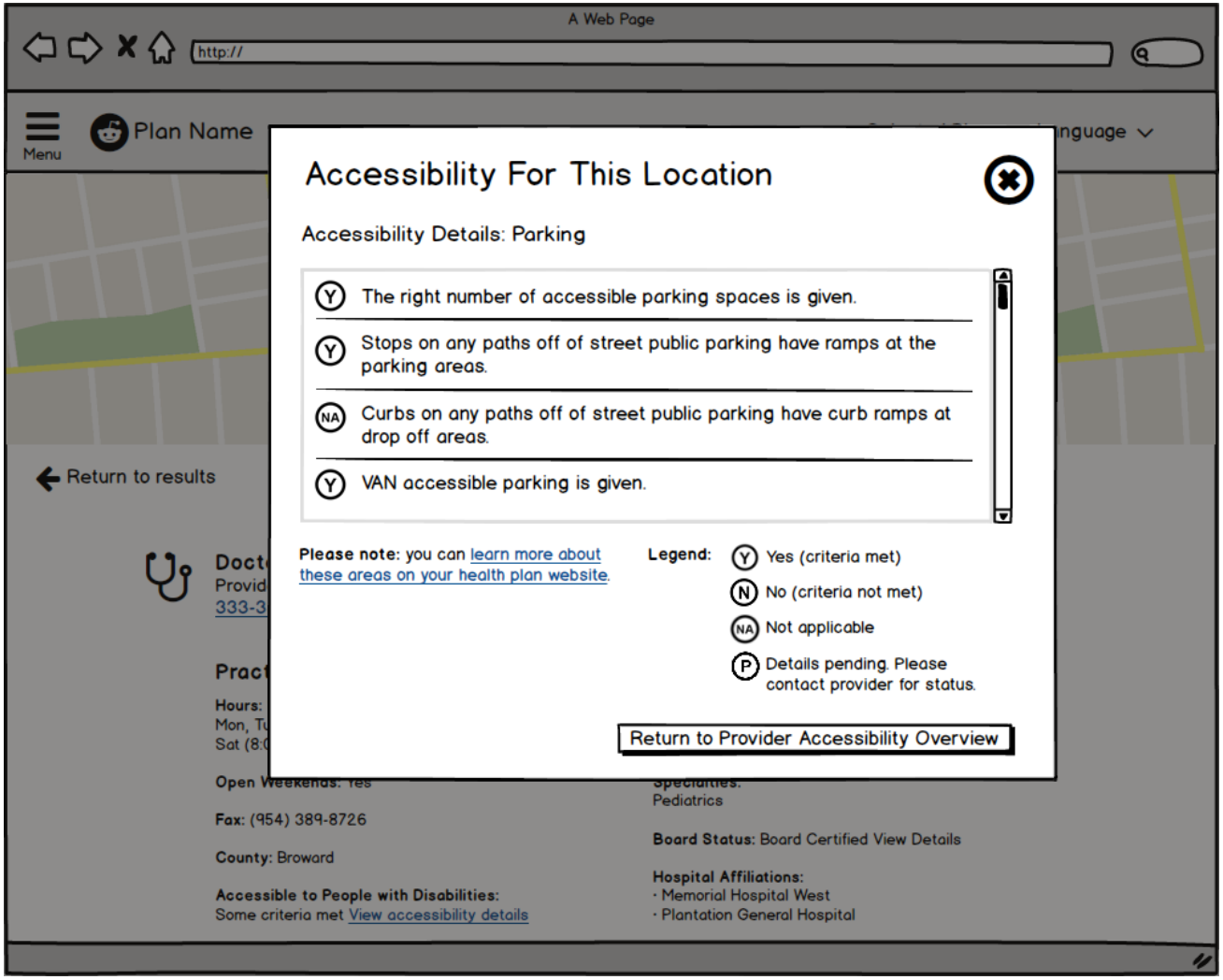
Drill Down into Each Domain



Example Provider Accessibility Screen



Example Provider Accessibility Detail Screen for Parking



Increasing Access to Healthcare for People with Disabilities - Let's Get It Started!

- Please send any additional feedback or questions to:
  - Sarah Triano, Director of Policy & Innovation, Complex Care & Interim PAI Director
    striano@centene.com, 916.246.3722
  - Kait Campbell, Business Analyst, Complex Care & PAI Project Manager
    Kaitlin.M.Campbell@centene.com, 314.320.2562

Children and Youths in Transition: Healthcare Accessibility, Disabilities and Race

Intersections in Health Care Accessibility and Person-Centered Care

Suzanne Rybczynski, MD

Medical Director - Inpatient Pediatric Neuro-Rehabilitation
Kennedy Krieger Institute

We are all born with great potential.
Shouldn't we all have the chance to achieve it?

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Overview: From Theory into Practice

- Pediatric Neuro-rehabilitation/case examples.
- Conceptualization frameworks regarding access to medical care.
- Current research on access to medical care for adults, children and youth with disabilities with focus on race/ethnicity.
- Case: outcomes through the theoretical framework.

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Scope of Practice:

Inpatient Pediatric NEURO-Rehabilitation

- Acute rehabilitation following injuries, illnesses and surgery that affect the central nervous system.
- Traumatic brain and spinal cord injuries
- Post-operative care for children with disabilities primarily CP.
- New vs Old Injuries.
- Ages served: 0 to 21 and 364 days.

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Case 1

- TH: 20 year old African American man with Spinal Cord Injury admitted to our rehabilitation unit following an acute illness.
- Tetraplegic and wheelchair dependent. Needed help to eat.
- BIPAP at night to prevent respiratory compromise.
- Needs assistance with bowel and bladder functioning.
- Discharging to Delaware.

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Case 2

- JM: 12 year old Hispanic girl who attempted suicide by hanging and has severe anoxic brain injury.
- Gastrostomy and tracheostomy.
- Severe spasticity.
- Dependent for all cares on family.
- Discharging to Rural Virginia.

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Case 3

- IG: 6 month old African American girl
- 24 week premature infant.
- Severe seizure disorder, neonatal strokes and chronic respiratory failure rendering her ventilator dependent.
- Discharging to Baltimore City.

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Models of Healthcare Accessibility: Historical Perspective

Meade, et al reviewed prior frameworks and proposed a framework that addresses disabilities and healthcare disparities:

- Aday and Anderson
- 5 A's
- IOM model
- Model of Healthcare Disparities and Disability (MHDD)

Meade MA, Mahmoudi E, Lee SY (2015) The intersection of disability and healthcare disparities: a conceptual framework, Disability and Rehabilitation, 37:7, 632-641

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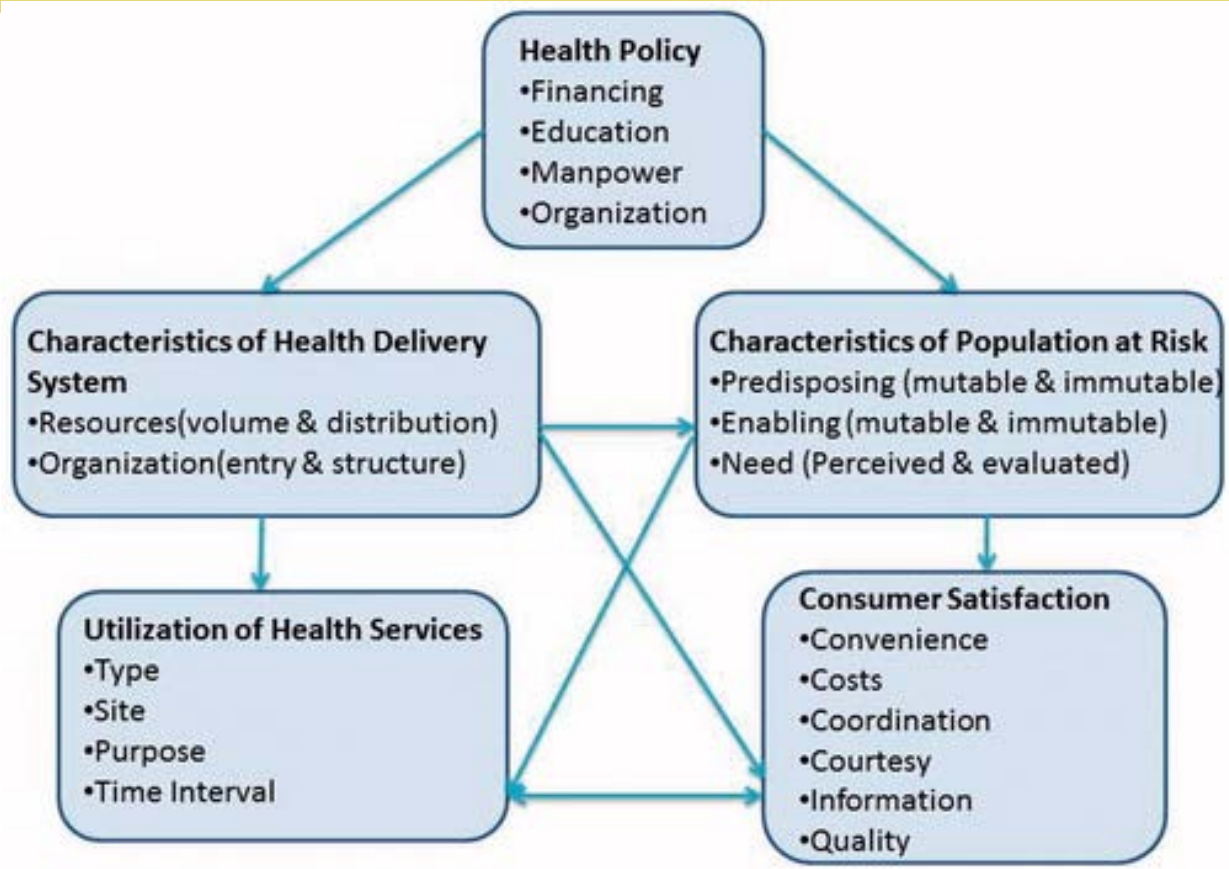
Aday and Anderson Model (1970s)



Health Serv Res. 1974 Fall; 9(3): 208–220

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Aday and Anderson Model

- Describes utilization of healthcare based on availability of services and needs of the consumer of healthcare.
- Does not address need factors such as cultural and contextual features.
- Does not address vulnerable subpopulations such as older adults, minorities or people with disabilities.

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The 5 A's of Accessibility to Healthcare- 1980s

Penchansky & Thomas:

- Affordability: how charges related to patient's ability to pay
- Availability: does the healthcare providers have the resources (personnel and technology) to meet the patient's needs
- Accessibility: Geographic proximity and how the patient can physically reach the healthcare provider.
- Accommodation: how services meet the needs, constraints and preferences of the patient.
- Acceptability: the relationship between patient and healthcare provider in terms of comfort level of providing care (age, sex, race, diagnosis, type of insurance).

Penchansky R, Thomas JW. The concept of access – definition and relationship to consumer satisfaction. Med Care 1981;19:127–40

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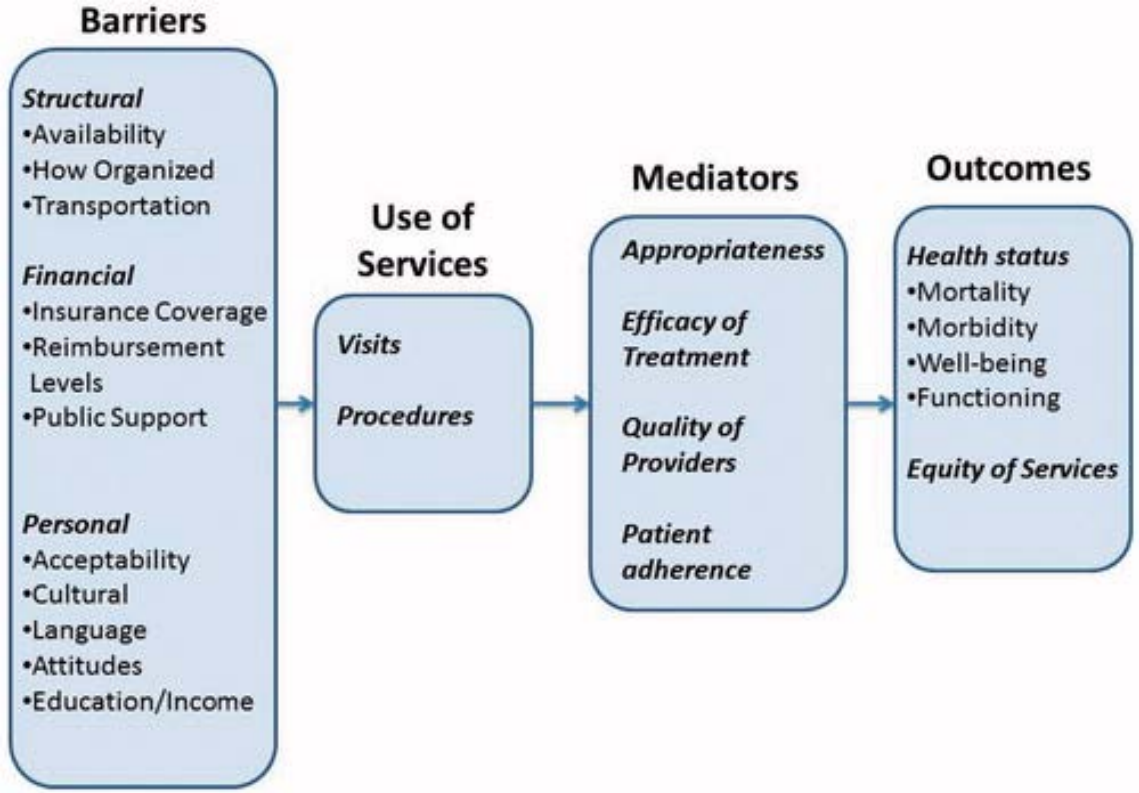
Institute of Medicine (IOM)
Model of Access to Healthcare Services (2000s)



Cooper LA, Hill MN, Powe NR. Designing and evaluating interventions to eliminate racial and ethnic disparities in health care. J Gen Intern Med 2002;17:477–86

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IOM Model

- Addresses the how the interaction of the individual and systems factors can support or hinder healthcare utilization.
- Describes how health and access to healthcare are influenced by healthcare systems AND individual's own life styles, culture and health behavior.
- Does not address access-related factors, clinical needs, preferences and appropriateness of interventions which is critical for individuals with disabilities.

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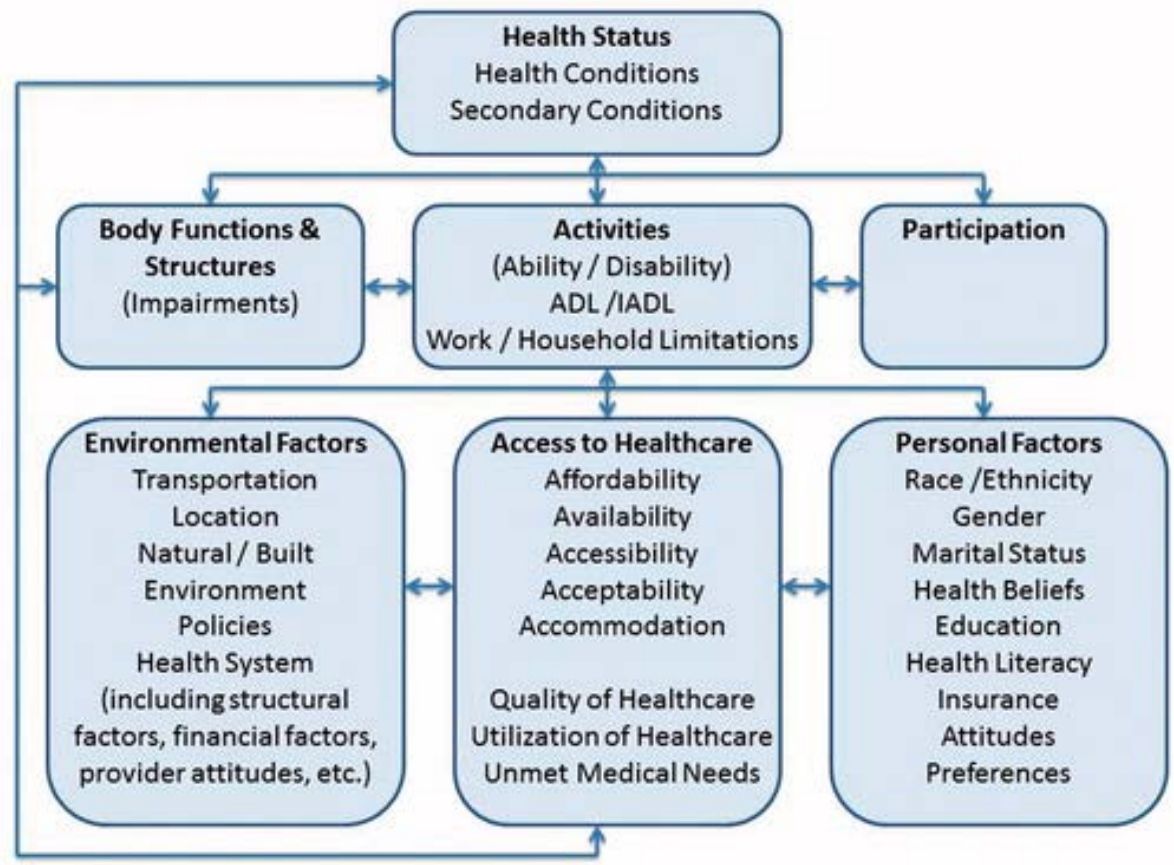
Model of Healthcare Disparities and Disability (MHDD) (2015)



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MHDD Model

- Provides a framework to help conceptualize health and healthcare disparities for individuals with disabilities.
- This can allow clinicians, researchers, policy makers, advocates and others involved in the provision of care to individuals with disabilities TARGET modifiable factors for intervention.

Meade MA, Mahmoudi E, Lee SY (2015) The intersection of disability and healthcare disparities: a conceptual framework, Disability and Rehabilitation, 37:7, 632-641

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What factors impact healthcare accessibility for children and young adults?

- What is the impact of disability?
- What is the impact of race?
- What is the impact of combinations of factors?

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AAP Technical Report: Racial and Ethnic Disparities in Health and Healthcare of Children (2010)

- "Racial/ethnic disparities in children's health and health care are extensive, pervasive and persistent, and occur across the spectrum of health and health care."
- Substantially increased risk for all mortality in all major US ethnic minorities.
- Increased risk of death from drowning, acute lymphocytic leukemia, following surgery for congenital heart disease.
- Significantly earlier median age of death for children with Down Syndrome.

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Flores et al (2016)

- Latino and African-American children account for 53 % of uninsured American children, despite comprising only 48 % of the total US child population.
- Examination of parental awareness of and the reasons for lacking health insurance in Medicaid/ CHIP-eligible minority children.
- Impact of the children's uninsurance on health, access to care, unmet needs, and family financial burden

Flores et al. A cross-sectional study of parental awareness of and reasons for lack of health insurance among minority children, and the impact on health, access to care, and unmet needs International Journal for Equity in Health (2016) 15:44

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Flores et al (2016)- continued

- For this cross-sectional study, a consecutive series of uninsured, Medicaid/CHIP-eligible Latino and African-American children was recruited at 97 urban Texas community sites, including supermarkets, health fairs, and schools
- >45,000 were screened for eligibility at various sites in TX.
- 267 participants

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Flores et al (2016)- continued

- Only 49 % of parents were aware that their uninsured child was Medicaid/CHIP eligible.
- 38% of children had suboptimal health.
- 2/3 had special healthcare needs.
- 64 % have no primary-care provider.
- 83 % of parents worry about their child's health more than others.

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Flores et al (2016)- continued

Unmet healthcare needs include:

General healthcare -73 %

Mental healthcare -70 %

Mobility aids/devices -67 %

Dental -61 %

Specialty care - 57 %

Vision - 46 %.

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Flores et al (2016)- continued

- Due to the child's health, 35 % of parents had financial problems, 23 % cut work hours, and 10 % ceased work.
- Higher proportions of Latinos lack primary-care providers, and higher proportions of African-Americans experience family financial burden

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Children with Disabilities: Disparities in Quality and Access to Care

- Review of 2009-2010 National Survey of Children with Special Healthcare Needs(CSHCN)
- 40,242 children (0-17 years)
- Addressed quality and access in children with single or multiple health conditions or disabilities.

Cheak-Zamora NC, Thullen M., Disparities in Quality and Access to Care for Children with Developmental Disabilities and Multiple Health Conditions Matern Child Health J (2017) 21: 36.

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Analysis: Groups of Conditions

- Physical Health Conditions (PHC)
- Mental Health Conditions (MHC)
- Developmental Disabilities(DD)
- Physical and Mental (PHC and MHC)
- Physical and Developmental (PHC and DD)
- Mental and Developmental (MHC and DD)
- Physical, Mental and Developmental (PHC, MHC and DD)

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Results

- Children with DD with and without additional conditions face significant disparities in quality of and access to healthcare services.
- 20-30% decreased odds of meeting quality indicators compared to children with PHC.
- If DD and another condition, 40% decreased odds of meeting community based service needs.

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Autism: Healthcare Disparities

- Vohra et al (2014) reviewed the 2009-2010 National Survey of Children with Special Healthcare Needs(CSHCN) with special focus on Autism Spectrum Disorder (ASD).
- Parents of children with ASD reported statistically significant difficulty accessing services and in quality of care.
- This resulted in financial impact on the family due loss of wages due to time burden of accessing services.

Vohra R, Madhavan S, Sambamoorthi U, St. Peter C. Access to services, quality of care, and family impact for children with autism, other developmental disabilities, and other mental health conditions. Autism. 2014. 18(7) 815-826

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Adults With And Without Disabilities: Health Risk Behaviors and Health Status

- Havercamp and Scott (2015) reviewed data from CDC 2010 Behavior Risk Factor Surveillance System which tracks health conditions and risk behaviors.
- Compared no disability (n=312,144), physical disability (n=132,812) and intellectual/developmental disability (n=20,395).

Havercamp SM, Scott HM, National health surveillance of adults with disabilities, adults with intellectual and developmental disabilities and adults with no disabilities. Disability and Health Journal 8(2015) 165-172.

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Adults With And Without Disabilities: Health Risk Behaviors and Health Status

- Overall Health: poor health status
  No disability 1%
  Disability 14%
  IDD- 5%
- Disability Group: more likely to be obese, smoke, be physically inactive and lack emotional support compared to no disability group.

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Adults With And Without Disabilities: Health Risk Behaviors and Health Status

- Both Disability and IDD groups were likely to be physically inactive.
- IDD group: less likely to have appropriate preventative health care pap tests, breast cancer screening and prostate screening but more likely to get flu shots and dental care.

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CSHCN with and without disabilities transitioning to adult services

- Lin et al Multivariate logistic regression study of data from 2007 Survey of Adult Transition and Health (SATH).
- Compared children with special healthcare needs (CSHCN) with or without disabilities.

Lin SC, Lee MT, Adirim TA. Transition outcomes for young adults with disabilities. J Ped Rehab Med 8 (2015) 23–30

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CSHCN with and without disabilities transitioning to adult services

BETTER RESULTS:

- Access to primary care
- Access to care coordination
- Better physician engagement in transition discussions
- Better connection to mentors.
- Increased odds of receiving Medicaid or other insurance

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CSHCN with and without disabilities transitioning to adult services

POORER RESULTS

- Control over personal finances
- Making friends
- Obtaining a HS diploma

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CSHCN and Race (Ngui, Flores 2007)

- Racial/ethnic disparities in unmet specialty, dental, mental, and allied health care needs among children with special health care needs (CSHCN) using data on 38,866 children in the National Survey of CSHCN.
- Compared with White CSHCN, Black CSHCN had significantly greater unmet specialty (9.6% vs. 6.7%), dental (16% vs. 8.7%), and mental (27% vs. 17%) health care needs.

Ngui EM, Flores G. Unmet Needs for Specialty, Dental, Mental, and Allied Health Care among Children with Special Health Care Needs: Are There Racial/Ethnic Disparities? J Health Care Poor Underserved. 2007. 18 (4): 931-949

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CSHCN and Race (Ngui, Flores 2007)

- Hispanic CSHCN had greater unmet dental care needs (15.8% vs. 8.7%).
- Black females had greater unmet mental health care needs than other groups (41% vs. 13–20%).
- Significant risk factors for unmet health care needs included un-insurance, having no personal doctor/nurse, poverty, and condition stability and severity.

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Unmet healthcare needs in adults

- Horner-Johnson and Dobbertin examined how racial AND disability interact in adults.
- Source of information: Medical Expenditure Panel Survey (MEPS) conducted by Agency for Healthcare Research and Quality (AHRQ) from 2001-2010.
- 165,028 adults 18-64 years

Horner-Johnson W, Dobbertin K. Usual Source of Care and Unmet Health Care Needs: Interaction of Disability with Race and Ethnicity. Med Care. 2014; 52: S40-S50

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Unmet healthcare needs in adults

- Usual Source of Care (USC) indicates access to healthcare and those without USC are likely to have unmet health needs. This includes delay in receiving medical care, unable to get needed medical care, delay in getting a prescription and unable to get needed medicine.

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Unmet healthcare needs in adults

Results:

- Across racial and ethnic groups, lower proportions of people with disabilities were without a USC.
- People with disabilities were more likely to have unmet healthcare needs, especially those with complex activity limitations.
- **Disability status combined with being part of an underserved racial or ethnic group did not have a compounding effect.**
- So, compared to whites with disabilities, all racial and ethnic minority groups had similar unmet needs.

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Intersection of Race/Ethnicity AND Disability

Peterson-Besse et al reviewed literature (2014) on barriers to care for adults with disabilities who are members of underserved racial/ethnic minorities.

- Screened >4000 articles
- Only 10 addressed both topics.

Conclusion:

NEED MORE RESEARCH.

Peterson-Besse JJ et al. Barriers to Health Care Among People with Disabilities Who are Members of Underserved Racial/Ethnic Groups. Med Care 2014; 52: S51-S63

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Future directions of research

- Many of the data sources for the papers discussed are in large national survey databases.
- It will be vital to compare how we have progressed, hopefully improved, in terms of healthcare accessibility in the last 10 years.

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Case Outcomes

Goal of Rehab: Return to home in the care of the family!

How were our outcomes in the context of research discussed?

Were we successful in mitigating factors that were barriers to successful reintegration into the community?

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Case 3- IG

- IG: 6 month old African American girl
- 24 week premature infant.
- Severe seizure disorder.
- Ventilator dependent.
- Discharging to Baltimore City.

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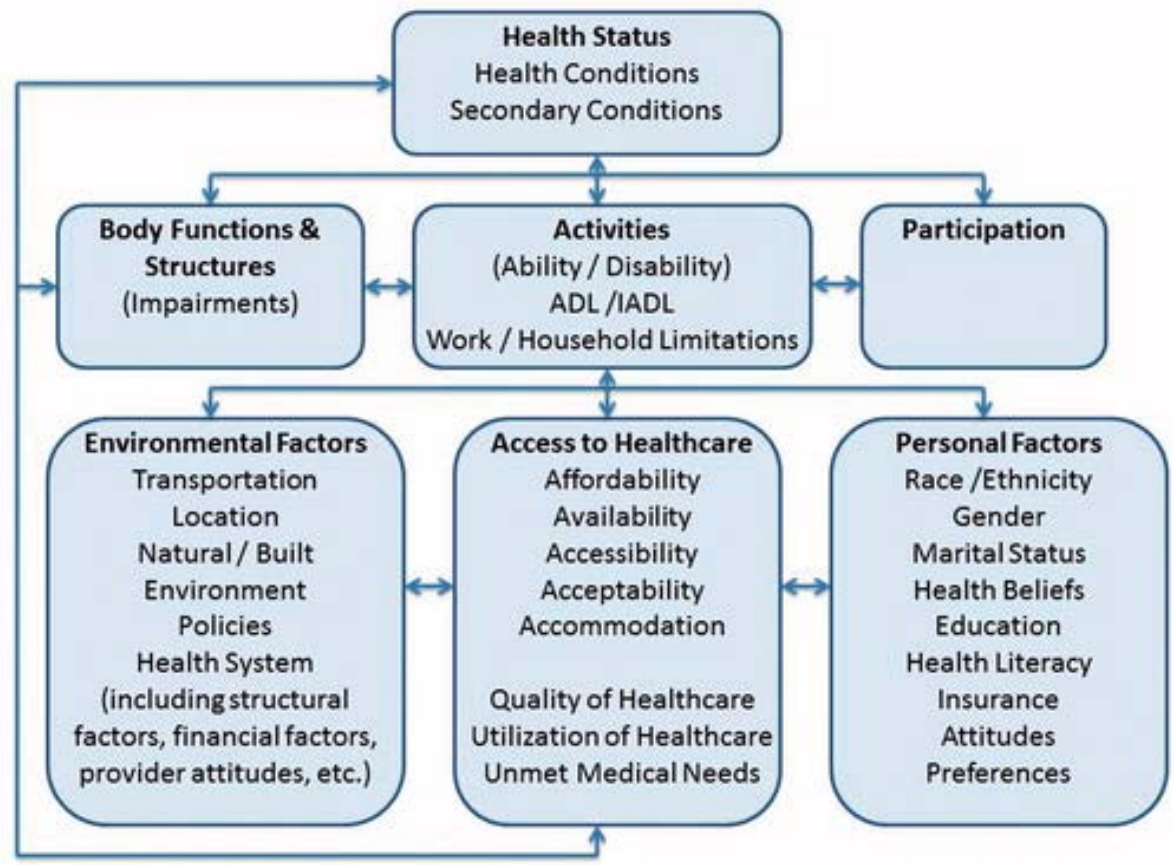
Model of Healthcare Disparities and Disability (MHDD) (2015)



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Discharge Barriers -IG

- Health Status: Medically complex with high medical needs. Needed 24 hour a day awake caregivers due to frequent seizures and ventilator status.
- Dependent for all ADLs (but all babies are).
- 5 As: Covered by MD Medical Assistance in Baltimore so able to find primary care MD to take her easily.
- Mom savvy on how to access health care as pt. was second child.
- Main issue was transportation. Mom did not have a car so dependent on Maryland Mobility transportation.

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Case 2 - JM

- JM: 12 year old Hispanic girl who attempted suicide by hanging and has severe anoxic brain injury.
- Gastrostomy and tracheostomy.
- Severe spasticity.
- Discharging to Rural Virginia.

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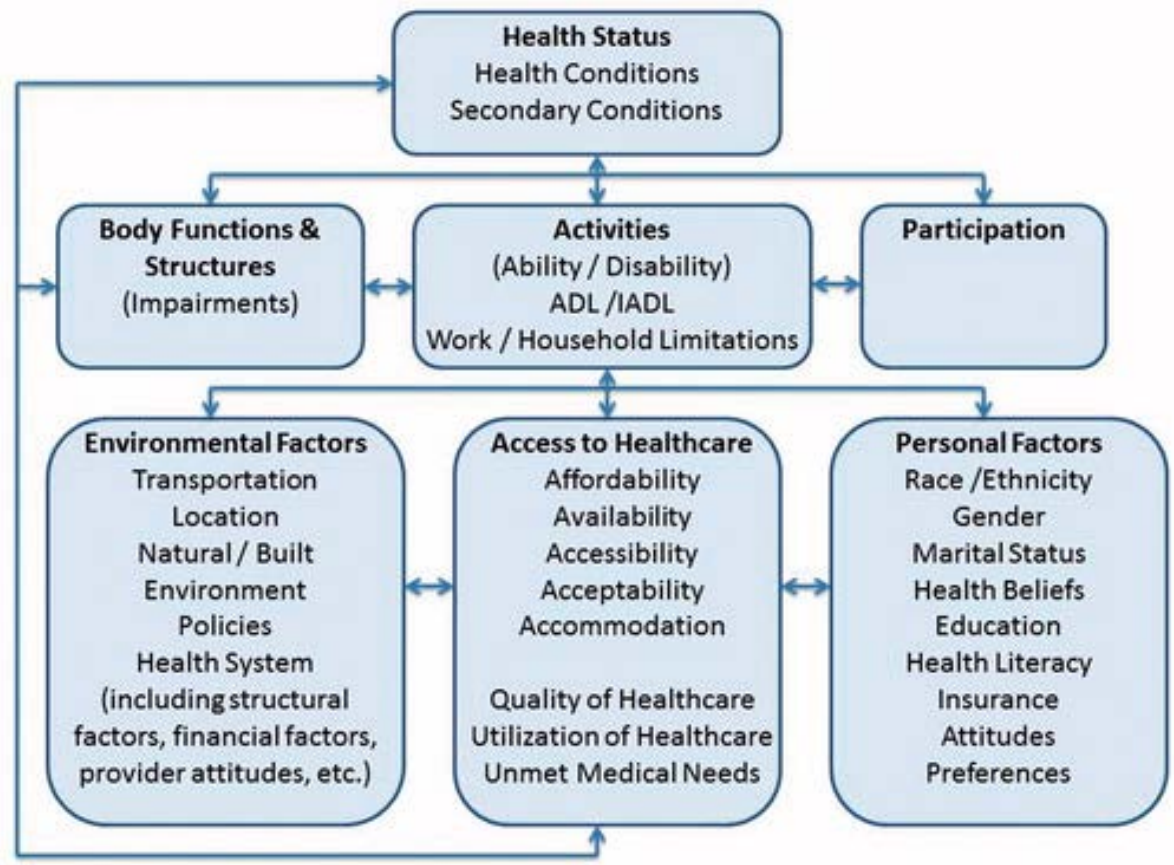
Model of Healthcare Disparities and Disability (MHDD) (2015)



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Barriers to discharge - JM

- Health status: function severely impaired Completely dependent for all ADLs. Non-verbal with tracheostomy.
- Race/Ethnicity: Parents did not speak English well and had difficulty accessing health care system. Calls were made but many misunderstandings.
- Accessiblity: Had Cigna insurance. Had to use a clearing house (Care Centrix) to set up home health care support

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Barriers to discharge - JM

- Availability: Could not get companies to provide complete coverage for discharge. One company cover suction tubing but no machine. Added 4 weeks to admission
- No nursing agencies for children in rural VA.
- Discharged home nursing with family rotating around the clock to care for pt for about 1 week when nursing was available.

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Case 1 - TH

- TH: 20 year old African American man with Spinal Cord Injury admitted to our rehabilitation unit following an acute illness.
- Tetraplegic and wheelchair dependent.
- BIPAP at night to prevent respiratory compromise.
- Needs assistance with catheterization and bowel movements.
- Discharging to Delaware.

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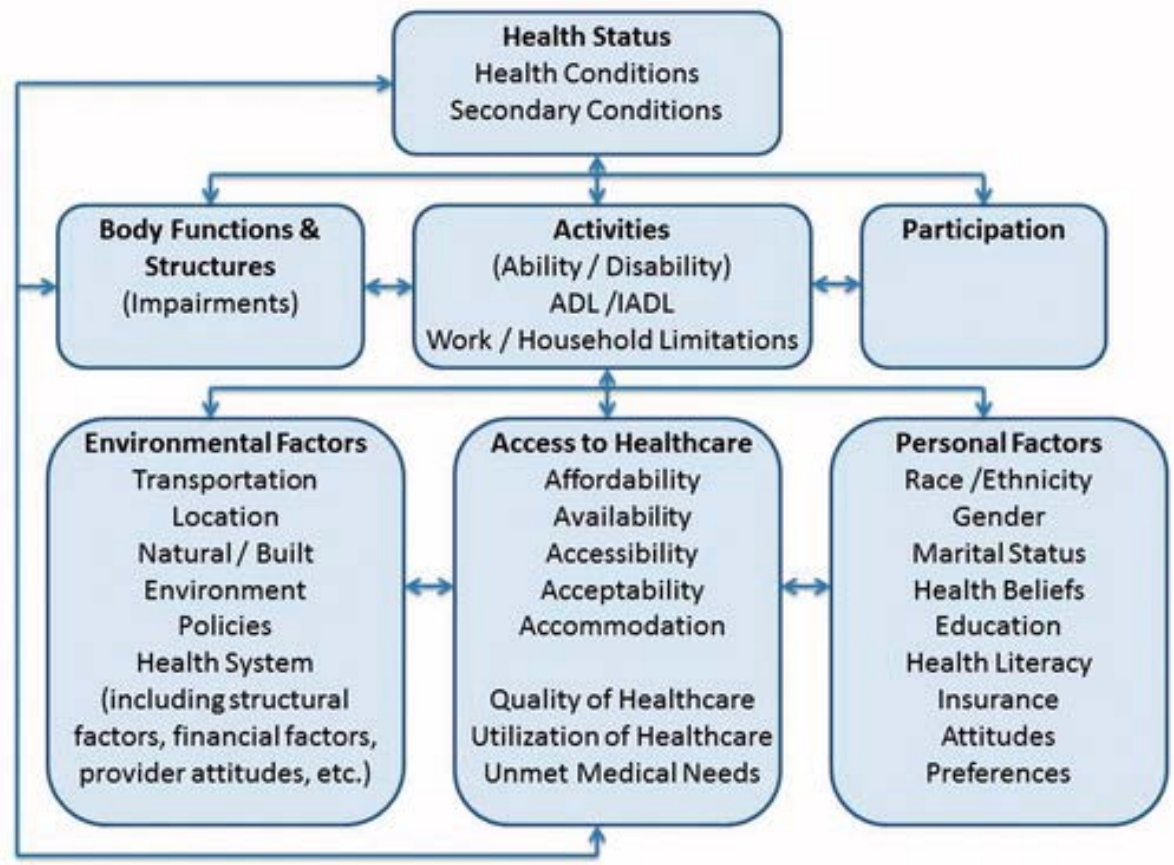
Model of Healthcare Disparities and Disability (MHDD) (2015)



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Barriers to Discharge - TH

Activities: Not fully dependent but with lots of needs. Tried to get home care aid but unsuccessful.

Transportation: Family did not have a reliable vehicle for transportation to appointments. Delayed discharge multiple times.

Accessibility: Had to find primary care MD who participates in DE Medicaid to write all orders including bipap machine, medications, supplies.

Environmental Factors: Home was not handicapped accessible. Mother tried to move to Maryland but was not successful. Remains at risk for more hospitalizations.

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Thank you for your attention

- Contact information: feel free to contact me at rybczynski@kennedykrieger.org
- Thank you to Sarah Triano, Lewis Krauss

and Daniel Davis.

Thank YOU:

- Meredith Raymond at ACL for inviting me to participate.

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Center for Disease Control's Disability and Access to Care Initiative

- Earlier this week the CDC's Division of Human Development and Disability released a feature on their website to provide resources that health care providers can use to assist with disability inclusion.

Q & A Session

HCBS Conference 2018

Administration for Community Living