Intersections in Health Care Accessibility and Person-Centered Care

HCBS Conference 2018
Access to Healthcare Services and Programs Under the ADA:

Lewis Kraus, Pacific ADA Center
HCBS Conference, August 2018
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
People with Disabilities Living in the Community as a Percentage of the US Population, by State, 2016

Data Source: 2016 American Community Survey, American FactFinder, Table B1810
Age Distribution of Disability in the US Population, 2016

Data Source: 2016 American Community Survey, FactFinder Table B1810

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

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

![Inaccessible weight scale](image1.png) | ![Accessible weight scale](image2.png)
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

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The Centene Provider Accessibility Initiative:

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

**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

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

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**

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
“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

Existing Accessibility Info overlay

Accessibility Legend

For specific criteria, please see the specific accessibilities for this provider.

Symbol: Meaning:

ASL: Signage with Braille and raised tactile text characters at office, elevator, stairwells and restroom doors. Rooms that are not likely to change function (like a restroom, kitchen, elevators, etc.) should be identified by name. Other rooms that may change function can be identified by a numbers or letters.

E: Exam Room, the entrance to the exam room is accessible with a clear path. The doors open wide enough to accommodate a wheelchair/scooter to turn around.

EB: There is an accessible ramp to the building. Curb ramps and other ramps to the building are wide enough for a wheelchair/scooter. Handrails are provided on both sides of the ramp. Doors are wide enough to allow entrance for a wheelchair/scooter and the doors have handles that are easily opened.

IB: Doors are wide enough for a wheelchair/scooter and have handles that are easily opened. There are interior ramps available and the ramps have handrails. If an elevator is present, it must be available for use by the public and patients. The elevator has easy-to-hear sounds and Braille buttons within reach. The elevator is large enough for a wheelchair/scooter to turn around. If a chair lift is present, it can be utilized without help.

ME: CMIS Medical Equipment Access. An accessible examination room has features that make it possible for
Revised Search on 49 Critical Disability Access Elements within 4 Domains
Drill Down into Each Domain
Example Provider Accessibility Screen

Accessibility For This Location

- Parking (P)  View parking details
- Exterior Building (EB)  View exterior building details
- Interior Building (IB)  View interior building details
- Programmatic Access (PA)  View programmatic access details

This provider is considered to have met some accessibility criteria. Learn more about these areas on your health plan website.

Legend:
- ✓ All criteria met
- ✓ Some criteria met
- X No criteria met
- P Some or all details pending

Accessibility information about this provider is self-reported.*

**When a provider reports their own disability access information, they are listed as "self-reported." In this case, the health plan cannot guarantee that this information is correct. This is because the information has not been "verified" yet by the health plan. The health plan verifies this information with an in-person Accessibility Site Review (ASR). It is a good idea to contact the provider before your visit to ask about disability access. If the self-reported information is not correct, please contact the health plan right away. Some providers are listed as "details pending." This means that the health plan does not have any accessibility details from this provider.

Confidential and Proprietary Information
Example Provider Accessibility Detail

Screen for Parking

Accessibility For This Location

Accessibility Details: Parking

- The right number of accessible parking spaces is given.
- Stops on any paths off of street public parking have ramps at the parking areas.
- Curbs on any paths off of street public parking have curb ramps at drop off areas.
- VAN accessible parking is given.

Please note: you can learn more about these areas on your health plan website.

Legend:
- Y: Yes (criteria met)
- N: No (criteria not met)
- NA: Not applicable
- D: Details pending Please contact provider for status.

Return to Provider Accessibility Overview.
Increasing Access to Healthcare for People with Disabilities - Let’s Get It Started!

• Please send any additional feedback or questions to:
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Children and Youths in Transition: Healthcare Accessibility, Disabilities and Race

Intersections in Health Care Accessibility and Person-Centered Care

Suzanne Rybczynski, MD
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We are all born with great potential. Shouldn’t we all have the chance to achieve it?
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.
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.
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.
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.
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.
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)

Aday and Anderson Model (1970s)

Characteristics of Health Delivery System
- Resources (volume & distribution)
- Organization (entry & structure)

Characteristics of Population at Risk
- Predisposing (mutable & immutable)
- Enabling (mutable & immutable)
- Need (Perceived & evaluated)

Utilization of Health Services
- Type
- Site
- Purpose
- Time Interval

Consumer Satisfaction
- Convenience
- Costs
- Coordination
- Courtesy
- Information
- Quality

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

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

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.
Model of Healthcare Disparities and Disability (MHDD) (2015)
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 to TARGET modifiable factors for intervention.

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?
“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.
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 (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
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.
Unmet healthcare needs include:
General healthcare - 73%
Mental healthcare - 70%
Mobility aids/devices - 67%
Dental - 61%
Specialty care - 57%
Vision - 46%.
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.
Children with Disabilities: Disparities in Quality and Access to Care

- 40,242 children (0-17 years)
- Addressed quality and access in children with single or multiple health conditions or disabilities.

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)
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.
• 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
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).

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.
• 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.
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.

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
POORER RESULTS

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

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.
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

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.
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.
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.

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.
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?
Case 3- IG

• IG: 6 month old African American girl
• 24 week premature infant.
• Severe seizure disorder.
• Ventilator dependent.
• Discharging to Baltimore City.
Model of Healthcare Disparities and Disability (MHDD) (2015)
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.
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.
Model of Healthcare Disparities and Disability (MHDD) (2015)

- Health Status
  - Health Conditions
  - Secondary Conditions

- Body Functions & Structures (Impairments)

- Activities
  - (Ability / Disability)
  - ADL / IADL
  - Work / Household Limitations

- Participation

- Environmental Factors
  - Transportation
  - Location
  - Natural / Built Environment
  - Policies
  - Health System (including structural factors, financial factors, provider attitudes, etc.)

- Access to Healthcare
  - Affordability
  - Availability
  - Accessibility
  - Acceptability
  - Accommodation
  - Quality of Healthcare
  - Utilization of Healthcare
  - Unmet Medical Needs

- Personal Factors
  - Race / Ethnicity
  - Gender
  - Marital Status
  - Health Beliefs
  - Education
  - Health Literacy
  - Insurance
  - Attitudes
  - Preferences
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.

• Accessibility: Had Cigna insurance. Had to use a clearing house (Care Centrix) to set up home health care support.
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.
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.
Model of Healthcare Disparities and Disability (MHDD) (2015)
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.
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.
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