

Challenging Diagnostic Overshadowing – One Community Health Center's Journey to create an IDD Integrated Care Gold Standard



Pamela Valenza, MD, MPH
Chief Health Officer, Tepeyac Community Health Center

Darla Stuart
Outreach and Education Coordinator, Tepeyac
Community Health Center, AmeriCorps VISTA Member

SESSION OVERVIEW

The session will include a didactic presentation and active participation through collaborative conversation, peer-to-peer learning, and small group discussion.

Session Participants will:

1

Begin to understand services through a lens of cultural humility that incorporates traditional beliefs and practices of patients within an evidence-based medical model

2

Learn to mitigate the challenges that the disability culture experiences when seeking health care and medical treatment by defining/practicing disability culturally competent gold standard medical care

3

Detail next steps in this continually evolving journey of excellence

WHO WE ARE

Tepeyac Community Health Center offers high-quality health services founded on the principle that healthcare is a human right. We proudly care for the whole body and the whole community with inclusivity at the foundation and compassion as our cornerstone.

Our Mission

Inspire health, wellbeing and humanity in our community, through all of life's stages.

Our Vision

We envision a healthy community with access to regular and ongoing health care. As we expand our reach and bring cultural responsiveness into the community, we strive for exceptional, trustworthy care that empowers our patients, decreases routine visits to emergency rooms, and creates healthier families overall.

OUR HISTORY



1995

Based on community need, Tepeyac opened its doors in a 2 bedroom bungalow on Kalamath St in Denver



2003

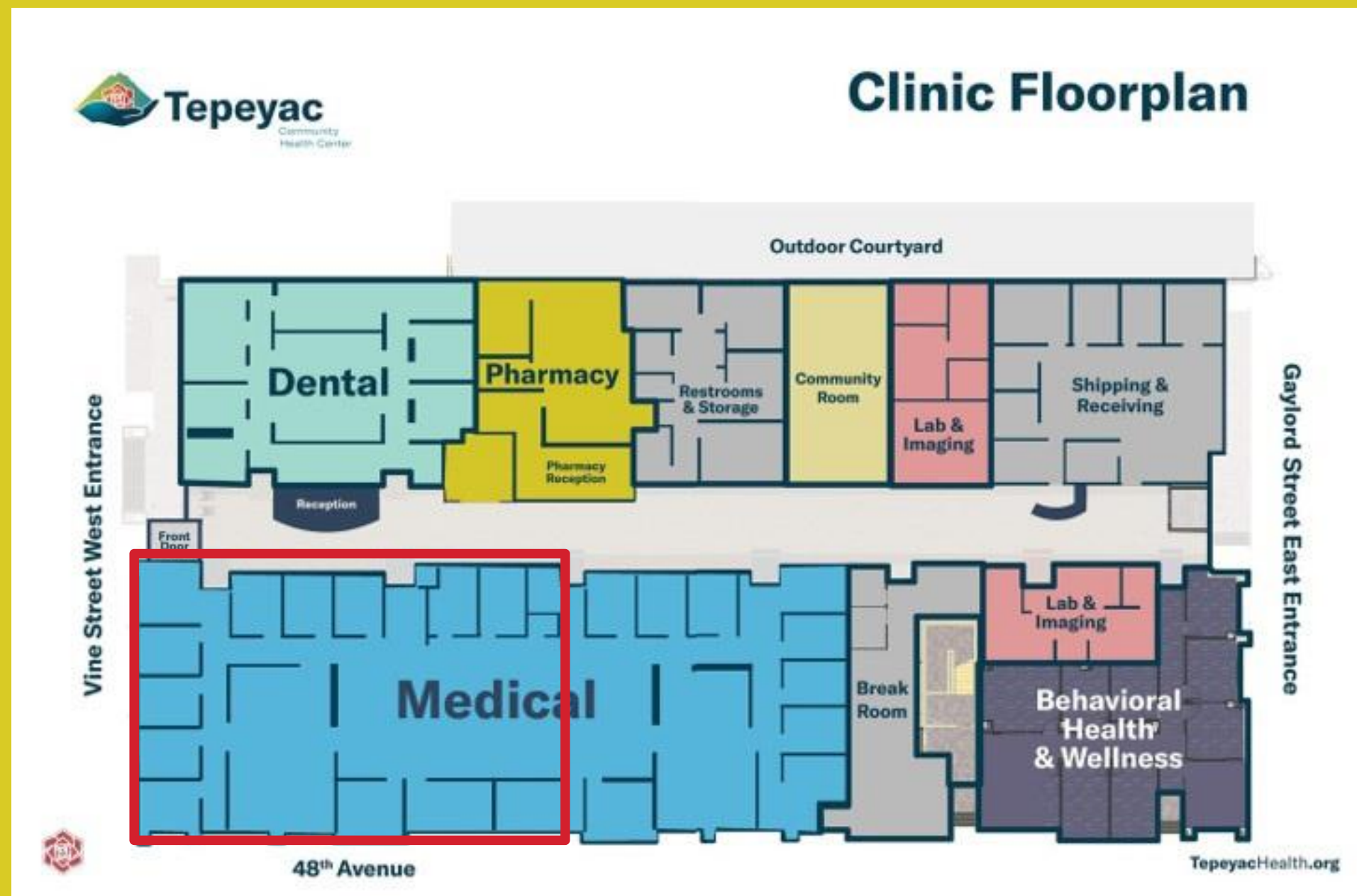
Patient demand soon exceeded the physical capacity of the clinic. Tepeyac expanded to 6,000 sq ft clinic on Lincoln St



2023

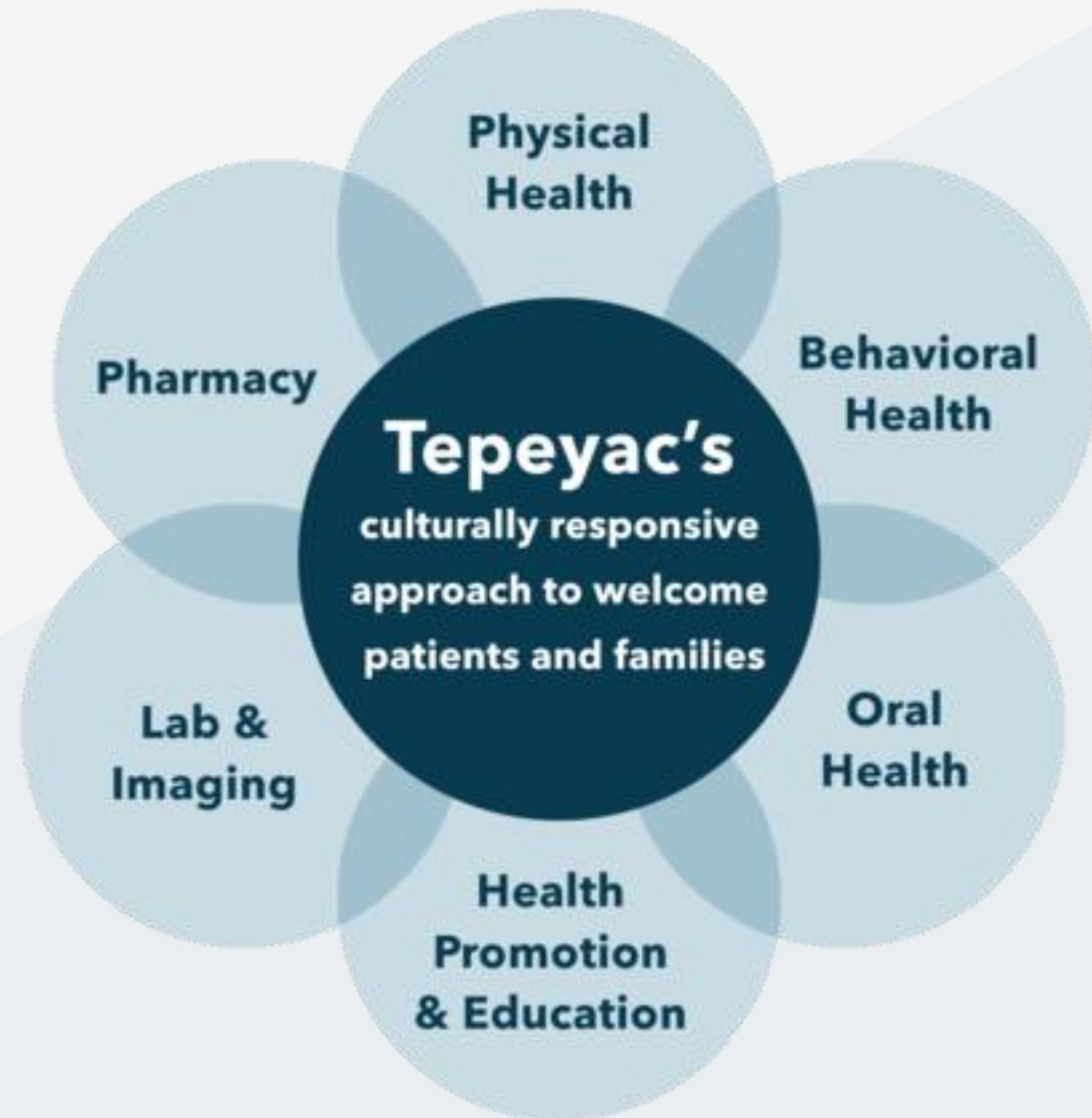
Tepeyac expansion to 24,500 sq ft clinic on Vine St, which will allow us to triple the number of patients we serve!

- On February 13, 2023, our new location at 48th and Vine in Denver, Colorado in the Globeville-Elyria-Swansea neighborhood opened to the public.
- 4x larger than our previous space, the new clinic has increased services and has more accessibility features!



OUR SERVICES

- Primary Care
- OBGYN
- Family Planning
- Pediatrics
- Dental Care
- Mental Wellness
- Addiction Medicine
- HIV Care
- Lab Tests, Ultrasound & Vaccines
- Wound Care
- Pharmacy
- Case Management
- Health Education and Promotion
- Enrollment and Financial Assistance





WHO WE SERVE

EVERYONE!

- At Tepeyac, all are welcome!
- 96% of patients are satisfied with their overall care and 94% were likely to recommend Tepeyac.
- We accept Medicaid, Medicare, private insurance, and offer a sliding fee discount.
- All staff receive training to provide care that works in alignment with patients' cultural beliefs and life experiences.
- In 2023, Tepeyac served close to 7000 unique patients. 1750 more patients than in 2022!
 - As of July 2024, we have already seen almost 6000 unique patients.

INSURANCES ACCEPTED



A sliding fee discount program is available for all qualifying patients. Patients without insurance are welcome! Our enrollment specialists are here to help you apply for Medicaid, Private Insurance, and the OmniSalud Program.



AWARDS

As a testament to the high-quality care provided, Tepeyac has earned the following recognitions, certifications, and awards:



- Tepeyac has been nationally ranked within the top 20% (2021) and 30% (2022) of all community health centers nationwide for quality. Additional HRSA awards include Health Center Quality Leader, Health Disparities Reducer, Access Enhancer, Health Information Technology Advancer, Addressing Social Risk Factors
- Colorado Academy of Family Physicians Family Physician of the Year, Pamela Valenza, MD, MPH, Tepeyac Chief Health Officer and Family Physician, 2023
- Migrant Clinicians Network Kugel & Zuroweste Health Justice Award, Paulina Segovia, Tepeyac Physician Assistant, 2022
- Gold Status Adolescent Centered Environment, 2022
- Minoru Yasui Community Volunteer Award, Joey Cleveland, Tepeyac Volunteer 2021
- Cesar Chavez Peace and Justice Committee of Denver Leadership Award, 2021
- Million Hearts® Hypertension Control Champion, 2020
- NCQA PCMH Recognition, 2019

BACKGROUND

- There is a **lack of disability competent providers**
 - Insufficient exposure/training in training programs across many disciplines
 - Only 40.7 % of physicians report being “very confident” in their ability to provide the same quality of care to patients with a disability
 - 56.5 % “strongly agreed” that they welcomed patients with a disability in their practices
 - Generational differences
- There is a **gap in access to appropriate care** for people living with IDD
 - An estimate of only 57.5 % of individuals with IDD receive an annual health examination
- Discussions with community partners led to an **initiative at Tepeyac to increase access to disability competent care and increase training of disability competent providers**
- Lots of resources out there but where to start?!
 - Volume of resources is overwhelming
 - Identified a need to develop a **disability competent care gold standard manual** that is accessible and easy to navigate for admin and clinical staff working at community health centers

OBJECTIVE #1

Understand health services through a lens of cultural humility that incorporates traditional beliefs and practices of patients within an evidence-based medical model

CULTURAL HUMILITY

Culture is an integrated system of learned behavior patterns that are characteristic of the members of any given society. Culture is the total way of life of groups of people. It includes everything that a group of people thinks, says, does and makes— its systems, attitudes, experiences and feelings. Culture is learned and transmitted from generation to generation.

–Robert Kohl

Cultural humility is active engagement in an ongoing process of self-reflection that informs deeper understanding and respect of cultural differences. Increased cultural humility can lead to behaviors, programs, policies, practices, and services that are more culturally appropriate (CDC).

IDD and the Primary Care Setting

- In the US, 1–3 % of the overall adult population are estimated to have IDD (approximately 7 million individuals)
- Primary care providers play an important role in screening and identification, and in providing interventions that are adapted to the needs of patients with IDD and co-occurring mental health problems.
 - Community health centers operate on an integrated care model that is well suited to meet the diverse needs of a diverse community
 - In 2022, over 1400 Community Health Centers served over 31.5 million patients across the country
- Prior research on primary care models for the IDD population have focused on adopting a relational and person-centred care framework in forming recommendations
- Feedback from the IDD community has identified the following top priorities with respect to primary care:
 - Having providers trained in caring for individuals with IDD
 - Increasing access to specialty services
 - Improving care coordination
 - Having intentionally designed space to meet the needs of the population
 - The need to have a “home” within the healthcare system

Lunsky and Lake. CAMH, 2016.

NACHC. America's Health Centers: By the Numbers, 2023.

Sullivan et al. Can Fam Physician, 2018.

Smith et al. Health Care Transitions, 2023.

Applying Cultural Humility in the Healthcare Setting

Power of Two! – combining evidence-based medicine and cultural humility

- ***Evidence-Based Medicine (EBM):***

- EBM emphasizes rigorous research evidence alongside clinical expertise
- By avoiding cognitive biases (like anchoring and premature closure), EBM encourages thorough symptom evaluation
- Clinicians consider alternative diagnoses, preventing tunnel vision and overlooking important conditions

- ***Cultural Humility:***

- Promotes self-awareness, openness, and respect for diverse patient backgrounds
 - Awareness of how people's culture can impact their health behaviors
- Use this awareness to cultivate sensitive approaches in treating patients
 - It encourages clinicians to recognize their biases and actively listen to patients
- By understanding cultural context, clinicians avoid presumptive diagnoses and consider multifaceted health factors

What is Diagnostic Overshadowing?

- Attributes a person's symptoms or behavior to their disability instead of looking for treatable underlying medical causes.
- Can be detrimental to quality of care and contribute to delays in diagnosis and treatment, unnecessary or unsafe care and inequities of care.
- Can affect future patient workups and how handoffs to other providers are framed.

Ask the Audience

Now that you know what diagnostic overshadowing is...

Have you personally experienced it?

Do you know people with IDD who have experienced it?



Case Scenario

Background: Dr. Smith, an attentive family physician, encounters Alex, a 30-year-old patient with cerebral palsy. Alex communicates using a communication board and has limited mobility.

How Diagnostic Shadowing Can Occur:

- Dr. Smith notices Alex's slurred speech and assumes it's related to cerebral palsy.
- She attributes Alex's recent fatigue and weight loss to the disability, overlooking other possibilities.
- Dr. Smith doesn't explore further due to diagnostic bias.

Utilizing an Evidence-Based Medicine (EBM) Approach:

- Dr. Smith reviews Alex's medical history and considers a differential diagnosis based on presenting symptoms.
- She orders blood tests, including thyroid function and vitamin levels, to rule out other causes.
- EBM prompts her to explore presenting symptoms related to conditions beyond cerebral palsy.

Cultural Humility:

- Dr. Smith engages Alex in conversation, respecting their communication preferences.
- She learns that Alex has been struggling with appetite changes and mood swings.
- Dr. Smith acknowledges Alex's unique experiences and considers emotional well-being.

Outcome Change using EBM and Cultural Competency:

- Blood tests reveal vitamin D deficiency and mild hypothyroidism.

Health Care Services through a Cultural Humility Lens

Objective #1

Understand health services through a lens of cultural humility that incorporates traditional beliefs and practices of patients within an evidence-based medical model

- Culture is an integrated system of learned behavior patterns that are characteristic of the members of any given society
- Cultural humility promotes self-awareness, openness, and respect for diverse patient backgrounds
- Utilizing an Evidenced Based Medical (EBM) model supports clinicians in considering alternative diagnoses, helps prevent tunnel vision and overlooking important conditions

OBJECTIVE #2

Learn to mitigate the challenges that the disability culture experiences when seeking health care and medical treatment by defining/practicing disability culturally competent gold standard medical care

Health Challenges

- People with IDD experience worse health outcomes than adults without IDD
- Challenges include:
 - Life expectancy – 20 year disparity in life expectancy
 - Limited access to appropriate health care
 - Higher rates of psychiatric disability
 - Mental health issues with potential psychotropic medication overuse
 - Obesity or overweight status
 - Increased fall risk
 - Undetected vision and hearing loss
 - Aging-related health issues due to disability or genetic syndrome
 - Black and Latino people with IDD experience worse health outcomes than white counterparts, even after accounting for income, education, and insurance status.

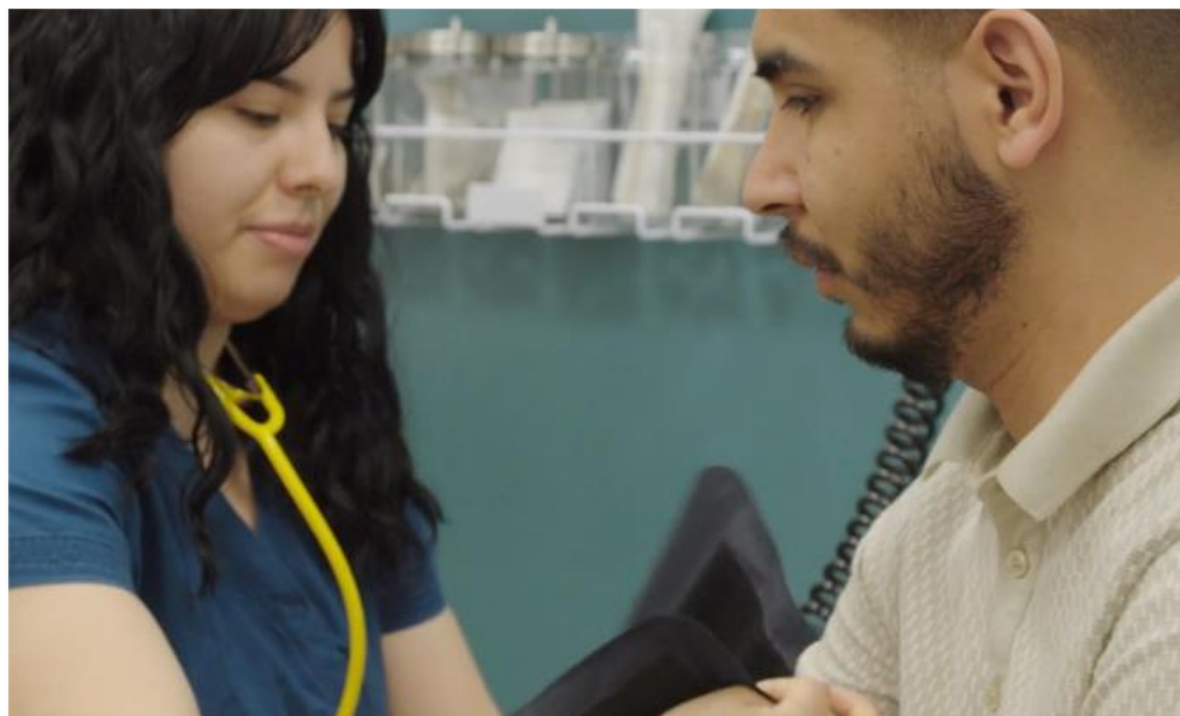
Access Challenges

- People with IDD report lower satisfaction and less quality of care than people without IDD
- For people with IDD access, issues are more than physical accessibility and include:
 - **Transition Challenges** pediatric to adult care
 - **Primary Care Difficulties** including finding primary care physicians
 - **Awareness Gap** leading to barriers in quality clinical care and sometimes discriminatory treatment
 - **Limited Patient-Centered Approach** with providers focusing on disability as the defining characteristic resulting in less aggressive treatment for acute problems
 - **Inadequate Clinician Training**
 - **Reimbursement Challenges** as few physicians are reimbursed for extended consultations

WHAT IS DISABILITY CULTURE?

People with disabilities represent a cross-section of communities and cultures including race, ethnicity, economic status, sexual orientation, and gender identities. However, the disability culture has evolved into its' own group identity from a range of issues that all people with disabilities experientially share, including perceived abnormality, illness and incapacity, as well as lived experience of exclusion, isolation, oppression and stigma.

Cultural humility is active engagement in an ongoing process of self-reflection that informs deeper understanding and respect of cultural differences. Increased cultural humility can lead to behaviors, programs, policies, practices, and services that are more culturally appropriate (CDC).



Ask the Audience

Shifting The Disability Culture Narrative

Identify how to shift attitudes from the negative to the positive below

“Abnormality” →

“Illness” →

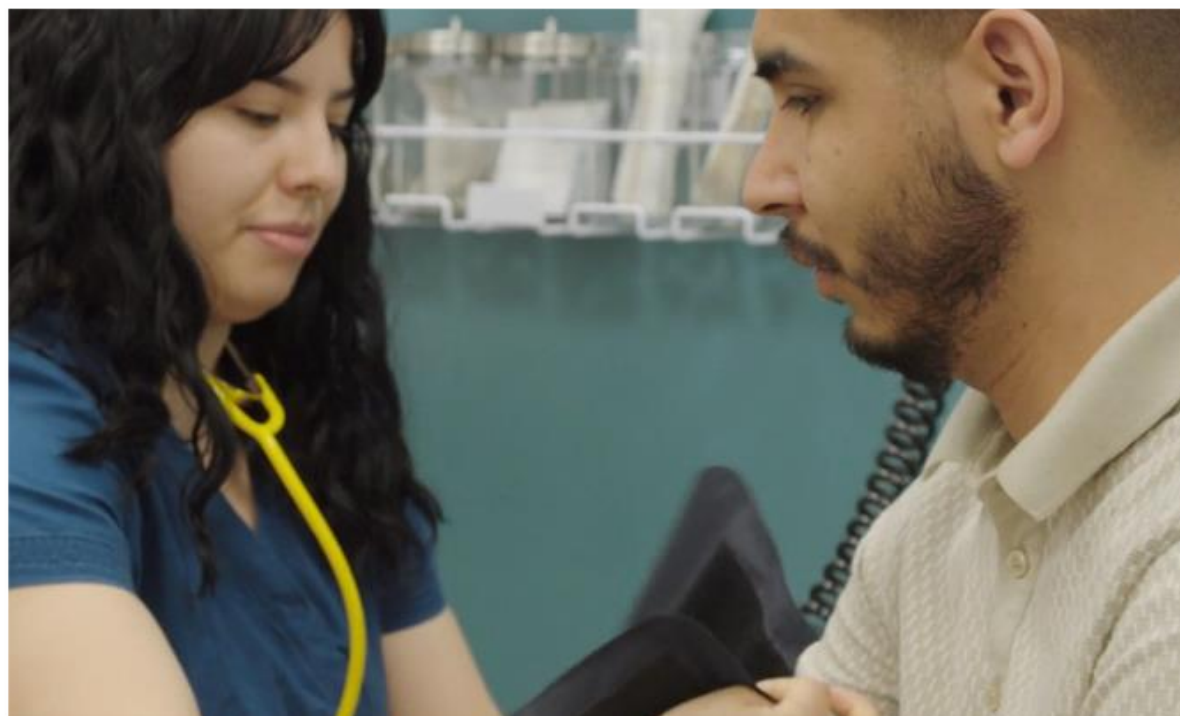
Incapacity →

Exclusion →

Isolation →

Oppression →

Stigma →



Ask the Audience

Shifting The Disability Culture Narrative

Identify how to shift attitudes from the negative to the positive below

“Abnormality” → Valuing Diversity

“Illness” → Patient-Centered

Incapacity → Capability

Exclusion → Inclusion

Isolation → Community

Oppression → Self-Determination

Stigma → Respect

DISABILITY COMPETENT CARE

Understanding
Disability Culture

Practicing Cultural
Humility

Challenging Diagnostic
Overshadowing

State Level Initiatives

- The Colorado Health Institute (CHI) is working with the Department of Health Care Policy and Financing (HCPF) to review access to disability competent care in primary care settings.
- Findings resulted in three distinct areas of proposed improvement:
 1. Ensure all Medicaid members have accessible care
 2. Increase capacity among providers for disability competent care
 3. Increase availability of disability competent care across Colorado

Tepeyac Health Center Initiatives

Disability Competency

- Intention to expand disability competent care
- Staffing
 - IDD Specialized Physician, Pediatrician with Developmental Training, Psychologist with additional ASD experience
- Training
 - All Staff
 - Disability Competency training with Dr. Barry Martin
 - PASCO
 - Medical, behavioral health, and dental providers
 - CCDC & NextFifty Initiative Disability Cultural Competency Training
 - Culturally and Linguistically Appropriate Services (CLAS) in Maternal Health Care
 - Webinar Series on Special Care Dentistry
 - ECHO series

Accessibility

- Depth-accessible and height-accessible check-in
- All exam tables are ADA-accessible and height-adjustable
 - Two are also bariatric-rated
- Wheelchair scales
- Hoyer lift
- Touchless wave to open (some) doors
- All services available in English, Spanish, and other languages including ASL
- Dimmable lights in the exam rooms
- Private dental rooms
- Flexible appointment scheduling, including telehealth
- Color-coded waiting areas

Ask the Audience

Is being disability competent and accessible enough?

What's missing?

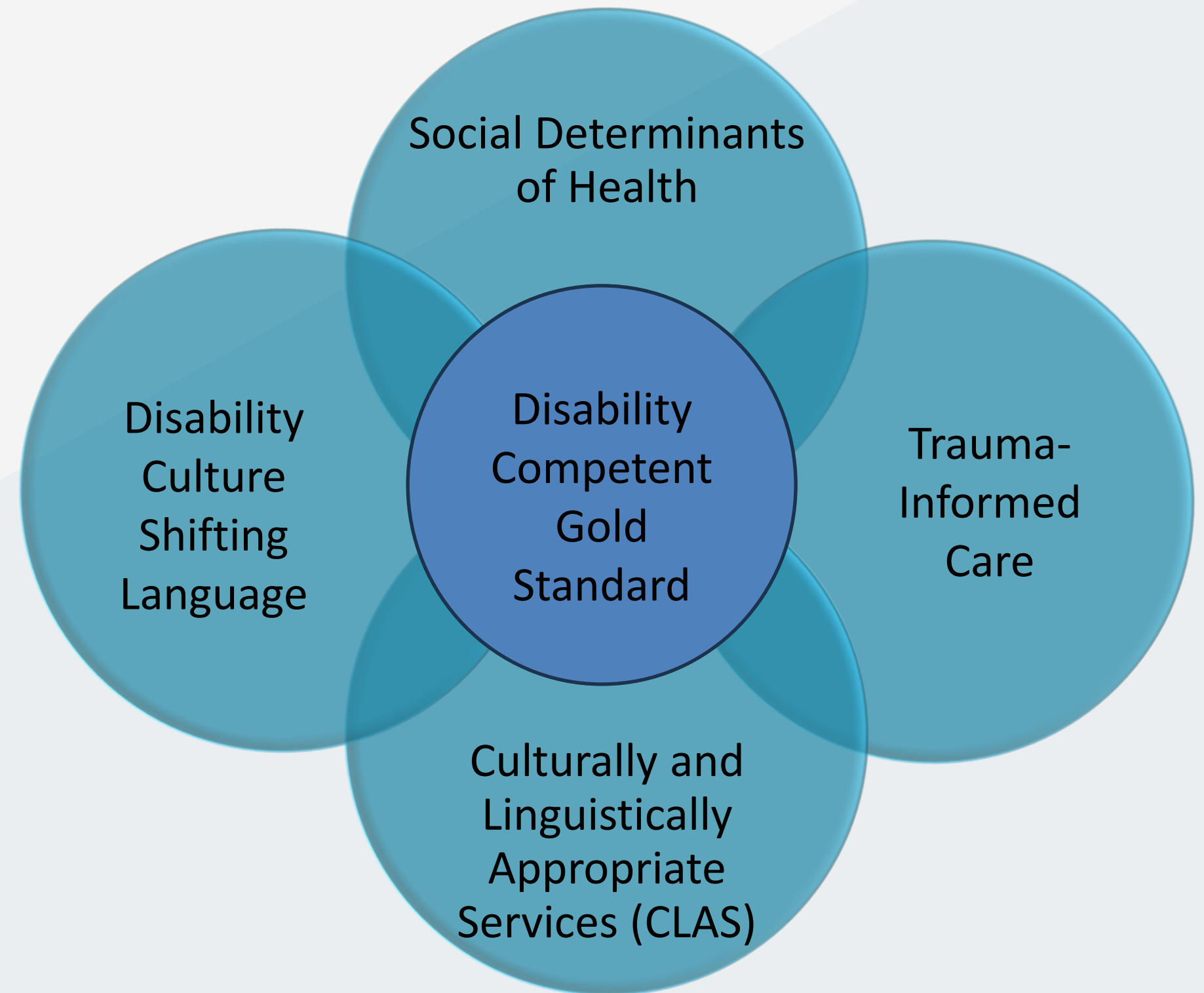


Research Focus – To know where you are going you must know where you are starting ...

- A search engine query was performed utilizing the following databases to systematically document and analyze relevant literature to gain a thorough understanding of existing research and development curriculums:
 - Google, PubMed, UptoDate
- Identify baseline literature and curriculum resources
- Identify gaps in approach to training for disability competent care
- Identify areas for synthesis of information and resources

Intersection of Care Standards

- Define principles-based contemporary ideology and training
- Integrate different established care standards
- Work on creating structure to support a center for excellence on disability competent care



Developing a Disability Culturally Competent Gold Standard

Objective #2

Learn to mitigate the challenges that the disability culture experiences when seeking health care and medical treatment by defining/practicing disability culturally competent gold standard medical care

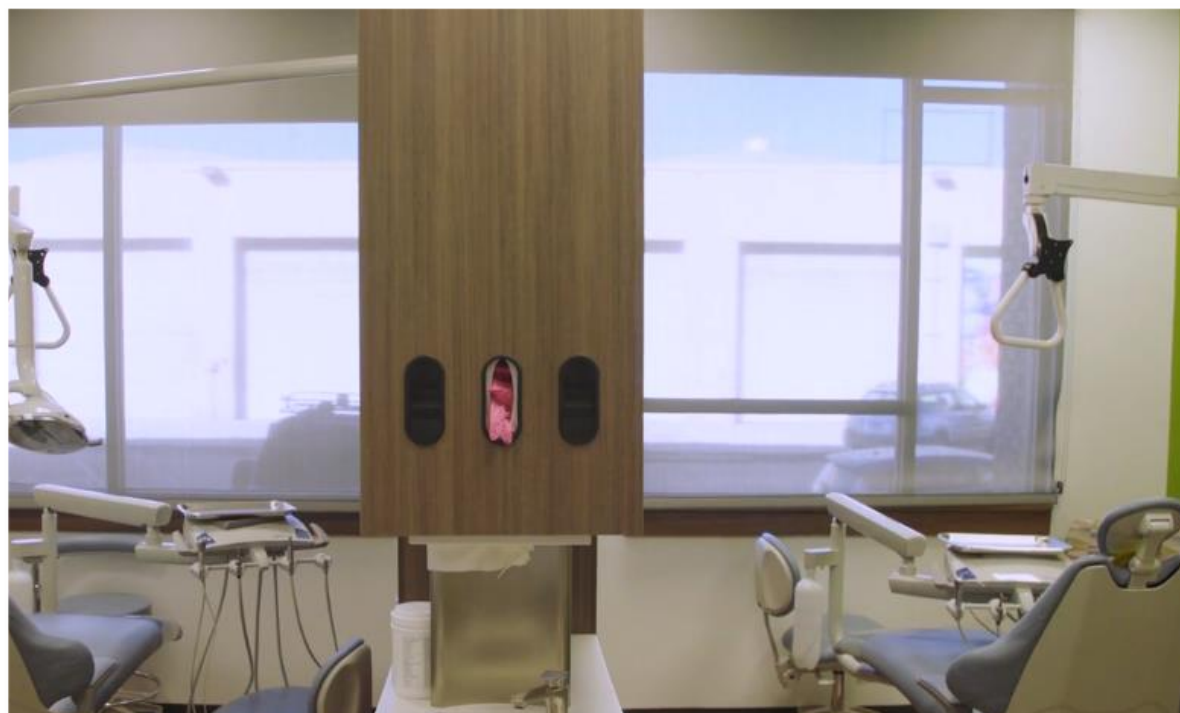
- Gold standard represents the best-known approach to addressing health-related needs in this specific population, ensuring that they receive the highest quality care available
- Develop digestible content from existing materials to move from theory to practice

OBJECTIVE #3

Detail next steps in this continually evolving
journey of excellence

NEXT STEPS

- Collate materials and resources based on intended audience/relevant at different levels of training
 - Administrative Staff
 - Clinical Staff
- Engage community partners, including people with IDD and their families, for feedback
- Determine evaluative process on how to assess outcomes once a Gold Standard is fully developed
 - Patient Outcomes
 - Staff Outcomes
- Implementation timeline
 - Responsible Parties
 - Estimated Costs
 - Success Indicators



Ask the Audience

What did we miss?

What is important?

How do we stay in touch?

REFERENCES

- Centers for Disease Control. *Embracing Cultural Humility and Community Engagement*. Guiding Principles for Global Health Communication. 2024 May 15. Available at <https://www.cdc.gov/global-health-equity/php/publications/cultural-humility.html>
- Prasad SJ, Nair P, Gadhvi K, Barai I, Danish HS, Philip AB. *Cultural humility: treating the patient, not the illness*. Med Educ Online. 2016 Feb 3;21:30908. doi: 10.3402/meo.v21.30908. PMID: 26847853; PMCID: PMC4742464.
- Lunskey Y, and J Lake. "Intellectual and developmental disabilities" in [Psychiatry in primary care](#). CAMH, 2019.
- Smith J, et al. *Freeman Center for intellectual and developmental disabilities: Patient-centered interdisciplinary care*. Health Care Transitions. Volume 1, 2023, 100003, ISSN 2949-9232. Available at <https://doi.org/10.1016/j.hctj.2023.100003>.
- The Joint Commission Sentinel Event Alert. *Diagnostic overshadowing among groups experiencing health disparities*. Issue 65, June 2022. Available at <https://www.jointcommission.org/-/media/tjc/documents/resources/patient-safety-topics/sentinel-event/sea-65-diagnostic-overshadowing-6-16-22-final.pdf>
- Brown, Steven E.. Independence Living Institute. *Disability Culture: Disability Fact Sheet*. 1996. Available at: Disability Culture: A Fact Sheet | Independent Living Institute
- Barth, Sarah; Taylor, Sharon; Simmons, Taylor. Health Management Associates. *Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences*, Report to the Medicaid and CHIP Payment and Access Commission. October 2020. Available at: Medicaid Services for People with Intellectual or Developmental Disabilities – Evolution of Addressing Service Needs and Preferences (macpac.gov)
- National Association of Community Health Centers. *America's Health Centers: By the Numbers*. 2023 Aug 7. Available at [America's Health Centers: By the Numbers – NACHC](#)
- Sullivan WF, Heng J, Salvador-Carulla L, Lukersmith S, Casson I. Approaches to primary care of adults with intellectual and developmental disabilities: Importance of frameworks for guidelines. Can Fam Physician. 2018 Apr;64(Suppl 2):S5-S7. PMID: 29650737; PMCID: PMC5906778.

CONTACT US



[\(303\) 458-5302](tel:(303)458-5302)



www.tepeyachealth.org



pvalenza@tepeyachealth.org
dstuart@tepeyachealth.org



2101 E 48th Ave, Denver CO 80216

FIND US ON SOCIALS!



/tepeyachealth

THANK YOU



Tepeyac
Community
Health Center

TEPEYACHEALTH.ORG

