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MEMORANDUM

To: Adela Flores-Brennan, Phoebe Hawley, Raine Henry, Colorado Department of Health Care Policy and Financing
From: Paul Presken and Sara Schmitt, Colorado Health Institute
Re: Best Practices in Disability Competent Care
Date: March 28, 2024

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. This memo is the first of five that CHI will provide by June 30, 2024. These memos cover:

1. Best Practices in Disability Competent Care
2. Disability Competent Care in Federally Qualified Health Centers (FQHCs)
3. Federal and State Accessibility Requirements
4. Barriers to Getting Disability Competent Care
5. Final Recommendations

This memo addresses the following objective and questions from the Data Collection Plan. Objective and question numbers correspond with the memo numbers listed above.

Objective 1: Identify best practices for providing disability competent care in primary care settings and FQHCs.

- Question 1.a: What does the literature say are best practices for caring for patients with disabilities?
- Question 1.b: How do people living with disabilities define and experience this type of care?
- Question 1.c: How do primary care providers and FQHCs define and provide access to care for people with disabilities?
- Question 1.d: What examples of these best practices are available in other state Medicaid programs?

CHI used the following sources for developing the findings in this memo: gray literature, peer-reviewed literature, and interviews with Colorado providers, individuals with disabilities, and disability advocates. Sources are cited below each reference.

Key Findings of Best Practices

- **Training and education** programs for providers and staff should be well-defined and test for disability know-how afterward.

- **Workflow and communication** practices should make the best use of electronic medical record (EMR) software and ensure that communications and systems are accessible.
- **Physical equipment and spaces** should be easy to access. Lighting should be suitable for people with disabilities.
- **Care models** should consistently coordinate care and provide a variety of related clinical services.
- **Virtual care practices** should include flexible ways to connect with providers online and be clear about the visits that require people to attend in-person.

Best Practices Common Themes

To improve care for people with disabilities, CHI found five areas on which to focus. Four of them were from literature sources. All were mentioned regularly as best practices during focus groups and interviews. Research and feedback also suggest that an approach that includes several or all areas would work best. The areas of best practice are:

- Training and education
- Workflow and communication
- Physical equipment and access
- Care model
- Virtual care

Question 1.a: What does the literature say are best practices for caring for patients with disabilities?

Articles about competent care for people with disabilities named four areas of best practice for primary care providers and facilities. These are training and education, workflow and communication, physical equipment and access, and care models.

Training and Education

Formal and informal training on disability care often does not exist or is cursory. So providers and staff are unprepared to recognize, respect, and help their patients with disabilities. Training and requiring proof of learned skills are core to improving competent care. Best practices for teaching this topic are summed up below:

- A paper in the Disability and Health Journal advises that training be adapted to the needs of people with disabilities, especially those with invisible disabilities. Courses should discuss the prevalence and effects of disabilities and should include communication strategies on managing complex chronic illnesses. Source: McClintock
- A publication by the Alliance for Disability in Healthcare Education recommends developing a standard disability training course that includes six core skills.
    - Relative and abstract frameworks on disability

  - Professionalism and patient-centered care
  - Legal aspects of caring for patients with disabilities
  - Teams and systems-based practice
  - Clinical assessment
  - Clinical care over the lifespan and during transitions
  - Source: Alliance for Disability in Healthcare Education
- Another paper in the Disability and Health Journal covers the workforce aspects of providing competent care to patients with disabilities. The article proposes that disability training be regulated and its impacts be measured. It also recommends that providers be trained and licensed in disability competence and its instruction. In addition, the paper suggests that methods be developed to evaluate disability competence after training. Source: Bowen

Workflow and Communication

Many articles talk about how to improve workflow and communication. They focus on how to best use electronic systems to document patients' disability status, prepare needed accommodations, and improve communication. These systems can be especially helpful to people who are hearing- or vision-impaired. The following articles provide best practices for improving workflow and communication.

- Develop and use EMR software to provide more effective care. Recommendations include:
  - Documenting disability status helps care teams identify potential disparities or differences in outcomes among patients with identified disabilities.
  - Staff can add patient needs to the EMR so that they can prepare early for the patient's visit and have accommodations ready.
  - Sharing information between systems (especially notes about accommodations) between scheduling staff and clinical staff can improve patient care.
  - Sending accommodation information along with referrals will allow specialists to prepare for patient needs without asking them to repeat their stories or needs.
  - Pop up alerts typically can let staff and physicians know of special accommodations that may not be obvious.
  - Letting patients add their needs on intake forms is important to complete before a visit.
  - Sources: Mudrick, Documenting Disability Status in Electronic Health Records
- The federal Office of the National Coordinator for Health Information Technology identifies standard sets of health data that are to be routinely collected and shared between health information systems. The third update in July 2022 identified disability status to be included in current and future software development. Source: United States Core Data for Interoperability
- This article shares communication challenges for people who are deaf or hard of hearing, are blind or have low vision, or have an intellectual disability. The

Americans with Disabilities Act (ADA) does not say how to reach the goal of communicating but does require that providers prioritize patients' preferences. Recommendations for improving communication include:
  - Make American Sign Language (ASL) interpreters available.
  - Make patient information easier to read, including using a larger font.
  - Use aids such as Braille, taped text, and qualified readers.
  - Write down notes on paper for patients, change voice and pitch, or talk slower to increase understanding.
  - Source: Agaronnik
- Another study in JAMA suggests that fewer than one in 10 U.S. doctors who care for patients with significant vision limitations provides information in a larger font. Tips for improving communication with people who are vision-impaired include describing clinic spaces to patients or providing large-font materials. Source: Iezzoni

Physical Equipment and Access

Primary care offices often do not provide access to the spaces or medical equipment needed to properly care for patients with disabilities. Several articles outline the barriers and best practices for improving such access.

- One study focused on the use of accessible exam tables and asked patients and providers about the use or lack of such equipment. Patients who were seen on an accessible exam table were more satisfied with their provider (better bedside manner and better perceptions of their work). Patients with disabilities rated their provider less favorably when they were not examined on such equipment. Source: Morris
- The Alliance for Disability in Healthcare Education recommends using universal design principles to create a respectful, accessible, and welcoming office environment. Using accessible equipment and techniques to diagnose and screen patients is essential to quality health care for patients with disabilities. Source: Alliance for Disability in Healthcare Education
- One article in Decision Making Advances is on wheelchair accessibility. The study considers physical infrastructure as well as attitudes, policies, and practices that promote social connections and equal opportunities for wheelchair users. The authors recommend:
  - Developing policies that prioritize wheelchair accessibility.
  - Adding ramps, accessible parking spaces, wider doorways, elevators, and tactile markers.
  - Creating awareness campaigns to address hidden assumptions.
  - Using assistive technology and innovation.
  - Training health care providers on wheelchair use, maintenance, and customization.

  - Source: Sahoo
- The Disability Equity Collaborative, located at the University of Colorado Anschutz Medical Campus, curated a list of disability-related accommodations that can facilitate equitable access to high-quality care. It includes accessible medical and diagnostic equipment, effective communication strategies, environmental modifications and accommodations, and policy/assistance needs for rooming and scheduling and staff availability. Source: Disability Equity Collaborative Accommodations List

Care Model

Literature sources also indicate a need to re-think care models to improve care for people with disabilities. In particular, care coordination focused on their needs and team-based care appear to improve care for people with disabilities.

- The Disability Studies Quarterly journal identifies that competent care teams use electronic systems to collect and manage patients' health and social needs. These systems improve communication across different service providers and monitor quality. Source: Disabilities Studies Quarterly
- Multiple sources recommend a care system like the Commonwealth Care Alliance (CCA) in Massachusetts. CCA emphasizes the use of teams made up of several different providers to treat all aspects of the patient. The team structure has evolved over time and employs many types of clinicians including physician assistants, nurse practitioners, registered nurses, and social workers to ensure that members receive complete care. Clinicians are expected to bring their clinical expertise and experience to the team and work together to help members get to the best outcomes. Given the complex conditions among people with disabilities, this team approach is critical to providing care to this population. Source: Mathematica

Question 1.b: How do people living with disabilities define and experience this type of care?

CHI interviewed over 50 stakeholders representing people with disabilities, providers, and advocates for disability competent care. They were asked what disability competent care means for them and what best practices achieve this type of care. The people interviewed consistently mentioned the five areas of best practice. A summary and examples of each are outlined below.

Training and Education

- Train everyone who interacts with patients, including doctors, office staff, and non-physician providers.

- Use learning groups for residents and faculty or similar types of care providers (such as health systems or FQHCs).
- Teach staff about trauma-informed care and approaches as well as how to understand individual biases.
- Train staff in safe transfers, wound care, and catheter changes.
- Offer training, such as how to communicate with individuals who read lips, on how to help hearing-impaired patients.

Workflow and Communication

- Document disability status and needs in patient charts.
- Set up EMRs to flag patients in need of accommodations, and alert providers and staff of these needs, especially when scheduling.
- Make patient forms, signage, and information available on paper, through accessible patient portals, available to screen readers, in large print, with color contrast, and written in plain language.
- Set up easy-to-use phone systems that require few buttons to press or allow a caller to reach a person with one button.
- Extend appointment times.

Physical Equipment and Access

- Make facilities wheelchair accessible. Build exam rooms, hallways, and waiting rooms large enough for people in wheelchairs or with walkers to get through easily.
- Add adjustable lights for people who are light-sensitive or vision-impaired.
- Create private spaces for completing paperwork.
- Purchase gowns with buttons or snaps rather than tie strings. This is an example of a small thing that matters to people with disabilities.

Care Model

- Hire care coordinators to set up accommodations, schedule visits, manage care among providers, and follow up to make sure care was received.
- Involve care coordinators in screening for social needs and in helping address patients' medical and non-medical needs.
- Dedicate staff to providing wrap-around, interdisciplinary care.

Virtual Care

- Make telehealth available for care that does not require an in-person visit.
- Make different telehealth options available, such as phone calls, for patients who are vision impaired.

Question 1.c: How do primary care providers and FQHCs define and provide access to care for people with disabilities?

Primary care providers and FQHCs do not have consistent definitions or experience with providing disability competent care for patients. In many cases, they want to provide such care, but they lack training, educational resources, or relevant care models. Most literature concedes that providers want to offer more competent care for people with disabilities, but they face multiple and complex barriers to providing such care. Several articles demonstrate this.

- A national study of outpatient providers revealed the following findings:
  - 48% said lack of time was a moderate or large barrier to caring for a patient with a disability.
  - 35% reported a lack of formal education or training as a moderate or large barrier to caring for a patient with a disability.
  - 21% provided incorrect answers for who pays for reasonable accommodation for patients with disabilities.
  - 36% reported knowing little or nothing about their responsibilities under the ADA.
  - 68% felt they were at risk for ADA lawsuits.
  - More than 70% gave incorrect answers when asked who is responsible for making decisions about accommodations.
  - Source: Iezzoni
- Another article that surveyed 714 physicians asked them about their perceptions of people with disabilities and their care. Findings in the article revealed:
  - Half of physicians "strongly agree" that they would welcome patients with disabilities into their practices.
  - Four in five physicians (82%) reported that people with significant disability have worse quality of life.
  - Two of five (41%) reported feeling very confident in their ability to provide equal care for people with disabilities.
  - Source: Lagu
- Interviews with providers in Colorado about disability competent care focused on the barriers they face to providing appropriate care for their patients (which will be detailed in another memo). However, the providers named common best practices that they have successfully implemented with positive results for their patients with disabilities:
  - Providing visits with extra time to properly address issues and communicate with these patients.
  - Investing in accessible medical equipment.
  - Providing additional or special virtual visits (video or audio) for patients.
  - Rearranging their waiting rooms and exam rooms for wheelchairs and walkers.

- Becoming, training, or hiring disability care champions in their offices to be aware of and improve processes and communication with patients with disabilities.

Research Question 1.d: What examples of these best practices are available in other state Medicaid programs?

Unfortunately, other state Medicaid programs offer few documented best practices in disability competent care in primary care. CHI made multiple attempts to engage with Massachusetts but was unsuccessful in setting up a meeting.

The only analysis of disability competent care Medicaid plans is from a Mathematica article that compares Medicaid plans in Massachusetts, Wisconsin, and New York. These are managed care plans for specific populations — such as those dually eligible for Medicare, those with long-term care needs, and/or people with developmental disabilities — not just primary care. A brief description of those plans is included below:

- **Massachusetts – Commonwealth Care Alliance (CCA)** has provided care to people with disabilities for over 30 years. It began in the 1990s as a stand-alone organization that contracted with the state's Medicaid program to provide care to working-age adults with disabilities. CCA was re-launched in 2004 and operates two plans, Boston's Community Medical Group and Senior Care Options.
- **Wisconsin – Community Health Partnership** operates two plans, the Community Health Partnership and the Community Family Care program. Both plans serve adults with disabilities in five counties in central Wisconsin.
- **New York – Independence Care System** began in 2000 and serves four boroughs in New York City. It coordinates all inpatient and outpatient care for members. Enrolled adults are eligible for Medicaid and require a nursing home level of care. Many enrollees have physical disabilities and need complex care.
- Source: Mathematica

Conclusion

Best practices for disability competent care offer multiple ways to improve quality of care and patient experience. While all best practices may not be feasible to implement at once, providers and facilities should look to multiple, proven, and recommended methods for improving their patients' care and contacts with the health care system.