

Primary Care Modernization Capability Summary

Individuals with Disabilities

Design group meeting notes are attached to the end of this document.

Definition of the Capability: Enhanced primary care for people with a disability that includes: access to preventive screenings and care, proper primary care provider training, accessible services, and home- and community-based services and care teams.

Goal of the Capability: Increase PCP capacity and resources to provide high-quality and comprehensive preventive, acute and chronic care focused on the needs of people with disabilities to support them in achieving their best health and quality of life.

Please go to the [survey](#) to rate this capability's impact as high, medium or low on the following criteria:

Aim
Health promotion/prevention
Improved quality and outcomes
Patient experience
Provider satisfaction

Consumer Input, Questions and Concerns

- Patients and families have equal choice of providers and care teams, based on their needs at the time
- Culture of care team is whole person centered care
- Care is equitable – people with disabilities get high quality preventive and routine care, especially those from historically underserved groups (e.g. people of color)
- Care is accessible:
- Accessible equipment in exam rooms and bathrooms for people with physical disabilities
 - o Communication devices for people with speech impairments, signers for people with hearing impairments, interpretation services for non-English speakers
 - o Practices accept patients with disabilities, including those with complex needs, regardless of their insurance
 - o Ways to get care outside of the office and office locations that are accessible via public transit or practice arranges transportation
- Clinicians and care teams are trained in and have experience caring for people with disabilities to reduce implicit bias and assumptions
- Training focused on “values-based” care, involves people with disabilities who speak from their perspective
- Clinicians and care teams understand unique needs of people with various disabilities (e.g. physical, neurologic, developmental)
- Clinicians and care teams establish how to work with “surrogates” and who to communicate with during encounters
- Establish validated metrics to measure patient experience and empowerment and health equity
- Avoid financial incentives to reduce care for people who have disabilities

People with Disabilities Design Group Approach to Recommendations

Design group members raised several concerns with the bundled payment model options under consideration by the PRC. The group agreed to make recommendations about best in class primary care

for people with disabilities, with the explicit provision that this group's recommendations do not represent an endorsement of the payment model options under consideration for the Primary Care Modernization initiative. The capabilities concept map and two-pager presented to the PTF incorporate principles and standards of care for people with disabilities based on information provided by participants in the design group process.

Note: As Task Force members are aware from a letter that was disseminated in December, a number of participants in the design group process ultimately objected to the recommendations, including the proposed concept map. They also objected to the characterization of this group as a Design Group for Individuals with Disabilities. Accordingly, unlike other skeletons and two-page summary recommendations, these recommendations are not a consensus recommendation of the participants in the design group process.

Principles for Primary Care

All primary care practices aim to achieve the highest standards of care through:

- **Expanded care team functions and members** (care coordinator, nurse care manager, community health worker, etc.) to better meet the needs of diverse patients and reduce burden on the primary care provider
- **Person-centered care:** PCPs and care teams are trained in how to care for and communicate with people with disabilities, how to engage surrogates, pre-visit planning and how to address the unique needs of people with varying types of disabilities; e.g., consider "able lives" programming.
- **eConsults between PCPs and subspecialists:** Electronic communications between primary care providers and subspecialists before or instead of referring patient to subspecialist
- **Phone, text, email encounters and telemedicine visits:** Allow patients to communicate with the PCP and care team without an office visit when appropriate, and to access more specialized care when needed
- **Exchange of disability information between PCPs and other services (with patient consent):** PCPs have access to patient personal health records and some DDS disability information and LTSS care plan information within their Electronic Health Record and other providers (e.g. LTSS) have access to person's medical information, with the person's consent
- **Accessible locations and/or practice arranges transportation**

A subset of practices/PCPs with enhanced expertise and experience in caring for people with disabilities, with the following provisions:

- Providers and practices with specialized expertise see all patients, not just those with disabilities. They are recommended based on how their unique expertise enables them to provide person-centered care for patients' with a variety of disability related needs.
- Specialized practices are not "disabilities only" clinics and they do not restrict access to certain clinic dates/times based on disability type or status.
- Patients, families and caregivers choose which provider and practice they go to (who may or may not be specialized)
- Provider expertise and experience in complex care for people with disabilities is supported by additional capabilities:
- Home-based primary care services: Physician supervised care teams provide primary care services in the home for patients who cannot leave the home or who have difficulty getting to

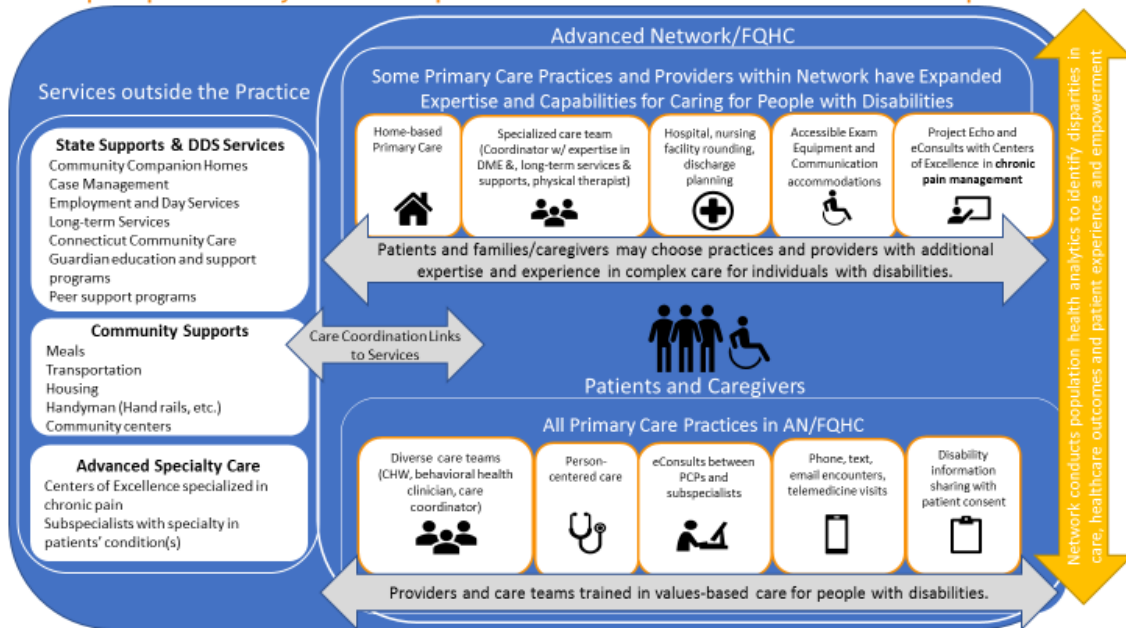
the office due to acute medical issues, which may include following discharge from a hospital or nursing facility

- Specialized care team: Care coordinator has expertise in long-term services and supports and Durable Medical Equipment coordination, physical and occupational therapists, other care team members based on practice population.
- Established clinical liaisons between primary care team and facilities: Primary care team communicates with hospital and nursing facility staff, rounding by primary care providers with support from the care team for care transitions
- Enhanced accessibility with respect to exam equipment and communication accommodations: Supports such as hi-lo tables, wheelchair scales, transfer equipment, lifts, specialized mammography equipment, and communication devices when needed
- Project Echo and eConsults with Centers of Excellence in chronic pain management: Specialized expertise in chronic pain management and treatments

Additional Design Group Recommendations

- Measuring Patient Empowerment
 - Current patient experience measures (e.g. CAHPS) do not adequately capture person-centered care
 - Important to measure that person feels in control of their health decisions and is leader of their care plan
 - Aim to align with Dept. of Developmental Services research on validated measures to capture this
 - Public Scorecard for primary care practices that includes accessibility score
- Health Information Technology
 - Sharing personal health record between primary care providers, specialists and LTSS providers, with person's consent
 - Sharing DDS information with primary care provider, with person's consent
 - Gets at what person's capabilities are, not just what they can't do
 - Get the person's vision for the future
 - Includes information important to primary care team that wouldn't otherwise be captured in Electronic Health Record
 - E.g. Timing for changing and dressing a wound based on who is in the home and care plan or understanding when a person takes their medications

PTTF Concept Map for Primary Care for People with Disabilities: Network/Practice Level Requirements*



Proven Strategy

Name: Enhanced primary care for people with disabilities.

Definition: Enhanced primary care for people with a disability that includes: access to preventive screenings and care, proper primary care provider training, accessible services, and home- and community-based services and care teams.

This section provides a detailed description of the services and supports envisioned in PCM. As an overview, the Concept Map above summarizes the components of the capability. Patients, families, caregivers and primary care clinicians are at the center of the modernized practice. Patients, families and caregivers may select any primary care practice or may choose to obtain care from a subset of practices with specific expertise in the complex care for people with disabilities or the patient's condition. All practices will offer diverse care teams, eConsults between PCPs and subspecialists, options to engage via phone, text, email and telemedicine. Primary care teams will be trained in care for people with disabilities. The Advanced Network/FQHC will provide access to home-based care, coordination with home and community services and supports and discharge planning. The AN/FQHC and practices will have care coordination links to state supports and DDS services, community supports and advanced specialty care.

Understanding the Need

The Problem:

People with disabilities experience higher rates of disparities in care, especially preventative care, when compared to other populations. A 2013 National Institutes of Health (NIH) study investigated the experiences of health care for physical needs from the perspective of people with a disability. Several patients felt they were discriminated against or treated differently because of their disability (NIH, 2013). Some of these experiences were due to negative staff attitudes towards patients and a failure to treat patients respectfully (NIH, 2013). Other experiences were due to indirect discrimination arising

from lack of staff awareness of patient needs, and health services failing to accommodate the needs of people with a disability (NIH, 2013). As a result, many patients with disabilities do not receive the care they need. According to the Centers for Disease Control and Prevention (CDC), people with disabilities are more likely than people without disabilities to report having poorer overall health, having less access to adequate health care, and engaging in risky health behaviors like smoking and physical inactivity (CDC, 2018).

People with disabilities are more susceptible to preventable health problems that decrease their overall health and quality of life. Certain conditions strongly associated with individuals with a disability include a higher incidence of dental disease, functional decline and/or musculoskeletal disorders, mental illness, bowel obstruction, gastrointestinal cancer, and obesity (Tinglin, 2013). Hearing impairment and vision loss are common in older adults with a disability due to preexisting undiagnosed pathologies. Secondary conditions such as pain, fatigue, obesity, and depression can also occur as a result of having a disabling condition (CDC, 2018). In fact, pain is commonly reported by people with many types of disabilities. For some, pain can affect functioning and activities of daily living (CDC, 2018).

Capability Requirements:

All Primary Care Practices have the following capabilities for people with disabilities:

- **Training for all Primary Care Providers:** There are few national standards when it comes to provider training and education in people with a disability (FPH, 2014). Yet, people with disabilities look to general practitioners and family physicians for their continuing, comprehensive primary medical care. Some medical schools are beginning to offer undergraduate curriculum content for conditions commonly associated with disabilities, usually found in psychology, psychiatry, or pediatrics programs, and are often community-based. The Connecticut Department of Developmental Services offers ongoing training sessions for Connecticut healthcare providers. The September 2018-November 2018 schedule can be found [here](#).

The disability curriculum in Connecticut should be expanded to train care team members to screen for, recognize, and manage common problems for people with disabilities. Programs should include improving the knowledge, skills and attitudes of health care providers of people with disabilities. Providers should be trained to accommodate people in their visits by providing accessible information and having health passports or communication books on-hand. Additionally, providers should learn to effectively manage a patient's pain and distress, medication intake, and vaccination history.

- **Operation House Call (OHS)** is a good example of how providers should be trained. OHS teaches young medical professionals essential skills to enhance the health care of people with disabilities through home visits. Offered by The Arc of Massachusetts, OHS turns to families, parents and individual self-advocates as educators in a health care field. The program provides medical students the opportunity to grow comfortable working with people with disabilities and learn more about the complex conditions associated with having a disability.
- **Diverse Care Team:** Care teams include a diverse set of roles and their membership can vary depending on the program, needs of the patient population, and services offered. Care team members are integrated within primary care and provide services during in-office, telemedicine, or

home care visits. Care team members most applicable to the needs of people with disabilities commonly include:

- **Behavioral Health Clinician:** Licensed clinicians provide mental health, clinical and case management services, conduct evaluations and assessments, provide ongoing counseling, treatment and interventions, conduct individual, group, and family psychotherapy, and provide consultation to other care team members on treatment needs and behavioral plans for people with disabilities.
- **Pharmacist:** Conducts comprehensive medication reviews that target specific conditions, conduct medication reconciliation, provide comprehensive medication management for people with multiple chronic conditions, provide medication monitoring and care coordination across multiple prescribers and pharmacies, and tailored medication action plans. Pharmacist services may be provided in-office, through telephone interviews, home visits, or a combination of methods (Stratis Health and KHA Reach, 2014) (Reidt, Morgan, Larson, & Blade, 2013).
- **Care Coordination:**
 - **Care Coordinator:** The RN/Care Coordinator performs a care continuum process that assesses, plans, implements, coordinates, monitors and evaluates the options and services required to meet a patient's health needs, using communication and available resources to promote quality, cost-effective outcomes.
 - **Community Health Worker:** The patient and/or guardian works with their community health worker or care coordinator to connect with community-based services identified through the state and local community. Whenever possible, community health workers with a disability should be employed to allow better understanding of the needs of the patients being served. These services may fall under the category of health and wellness, schooling and/or employment assistance, self-advocacy, and others. Some specific examples include connecting with a nutrition and/or exercise program or an initiative that connects people with disabilities to employment opportunities. Connecting people to resource teams at the Connecticut Department of Developmental Services (DDS), or having practices create their own, would better a patient's connection with community-based services. Such DDS-provided services include community living services, financial services, and quality of life services like day camps and vacation opportunities. A list of DDS-provided community services available to people with a disability can be found [here](#).
 - **Advanced Specialty Care:** Centers of Excellence specialized in chronic pain; Subspecialists with specialty in patients' condition(s)
- **Person-centered preventative care:** Preventative screenings can improve health outcomes and overall quality of life for people with disabilities. In-office, preventative screenings are to be conducted by the patient's primary care physician. The assessment may include a review of the patient's medical history, current conditions, medications, social support, and care preferences. Based on the assessment results, and after speaking with the patient's guardian (if applicable), the physician determines if the patient would benefit from home-based care. If so, the physician may use the current appointment, or schedule a follow-up, to introduce the home care provider. Training providers to screen for and monitor key health issues commonly seen in people with disabilities,

such as dental diseases, musculoskeletal disorders, and gastrointestinal cancer, is important, and it is equally imperative that people with disabilities receive routine primary care screenings such as mammograms, pap tests, and colonoscopies. It is imperative for providers to know how to communicate effectively with their patients about these screenings. Regularly scheduled screenings and assessments (yearly or every six months) are recommended, partnered with a multidisciplinary approach to health maintenance.

- **eConsults between Primary Care Providers and Subspecialists:** Primary care providers have access to eConsults with subspecialists inside and outside of the network. eConsult is a telehealth system in which PCPs consult with specialists using asynchronous electronic communications before referring an individual to a specialist for a face to face visit. Subspecialists provide clinical guidance to primary care providers on routine management of conditions. With eConsults, PCPs and subspecialists have access to and share patient data across the same platform.
- **Access to Non-Visit Based Care through Phone/Text/Email:** Primary care offices provide expanded access to care team members through non-office- based communications, including secure phone, text, and email encounters and advice lines for minor medical issues and questions instead of requiring in-office visits.
- **Telemedicine Visits:** Telemedicine visits are between clinicians and patients through virtual real-time communications such as video conference. These interactions may involve remote patient monitoring and other digital technologies (such as smart phones) to support provision of care. Telehealth visits are provided for the following types of interactions:
 - Urgent care or same day visits outside of a practice’s normal business hours, or when an in-office visit is not available.
 - Routine care that can be provided outside of the office setting for identified individuals.
 - Behavioral health needs.
 - Remote or home patient monitoring for chronic conditions or after an acute care episode, with a virtual visit to connect with the patient to discuss an issue, provide medical guidance or education, or adjust the treatment plan.
- **Accessibility to data for providers:** The Department of Development Disabilities (DDS) supports approximately 15,350 patients that have a Medicaid number, 1,049 patients that have no Medicaid number, and 5,775 patients that are considered dual eligible (Medicare and Medicaid) (DDS, 2015). The Department of Developmental Disabilities maintains a database of intake information from patients they support that should be available to providers to better inform them of patient/care team decisions. This would allow providers of people with disabilities to better identify health issues, prevent new issues from forming, and manage existing conditions.

A subset of primary care practices within the network have experience and expertise to provide all specialized services listed below for high-risk people with disabilities:

- **Home-Based Primary Care (HBPC):** Utilizes physician supervised care teams by providing health services in the home of identified high risk people with disabilities who are experiencing acute problems that interfere with ability to attend an on-site visit (may be the patient’s own home, a family home or community home).

- **Risk Assessment:** The in-office risk assessment is conducted by the patient's primary care physician. The assessment may include a review of the patient's medical history, current conditions, medications, social support, and care preferences. Based on the assessment results, the physician determines if the patient would benefit from HBPC. If so, the physician may use the current appointment, or schedule a follow up, to introduce the home care provider. The patient's primary care provider and home care provider work together to create and implement a patient-centered care plan that addresses all the patient's health-related needs.
- **Home Visits:** Patient-centered health care services are delivered in the home by the home care provider. During the initial visit, medical care is provided based off the patient's history and individual needs. A home visit is typically scheduled following an unexpected hospitalization. During this visit, the provider assesses what caused the hospitalization and determines what can be done moving forward to prevent future hospitalizations.
- **Specialized Care Team:**
 - **Expert Coordinator:** Care coordination and patient long-term services coordination involves deliberately organizing patient care activities, sharing information among all members of the care team, and coordinating long-term services for those patients who need it. Care coordination may be performed by a member of the primary care team and/or a member of the home-based primary care team. The care coordinator meets routinely with the care team to review patient problems and develop solutions. This ensures patient needs are prioritized and communicated to the right care team members. The care coordinator also coordinates with subspecialists and connects patients with other agencies that provide care to people with disabilities. For example, the expert coordinator is well-versed in Durable Medical Equipment (DME) coordination, as described in Case Study #1, and works closely with rehab specialists and DME vendors to ensure that patients can use and maintain their equipment, and to assist them in accessing repair services if needed (CCA, 2018).
 - **Physical/Occupational Therapist:** Physical and occupational therapists are ATP-certified and have extensive experience in seating and equipment evaluation. Rehab therapists will take the time to ensure a complete and accurate assessment of each patient's needs. Therapists communicate with the patient's care team and participate in joint evaluations with equipment vendors or other therapists at seating clinics in the community (CCA, 2018).
- **Hospital, skilled nursing facility, nursing home rounding, and discharge planning:** A primary care clinician (physician, physician assistant or advanced practice registered nurse) makes hospital rounds and provides care for high risk individuals with disabilities identified by the network who have been admitted. This clinician communicates back to the primary care team and works with the care coordinator to manage the patient's care following discharge. A patient follow-up visit is then scheduled, ultimately reducing the chance of readmission (Jackson, 2015).
- **Accessible Exam Equipment and Communication Accommodations:** Issues of physical accessibility are common amongst people with disabilities, and providers may need different tools and office setups to meet patient needs. For example, according to the CDC, obstacles can be steps and curbs that block a patient with a mobility impairment from entering a primary care office building or using the adjacent sidewalk, mammography equipment that requires a woman with a mobility

impairment to stand, and the absence of a weight scale that accommodates wheelchairs or others who have difficulty stepping up (CDC, 2018).

Intended Outcomes:

- Keep people with disabilities in the home, avoiding facility placement
- Increase knowledge of caretakers for family members with a disability
- Reduce disparities in care for people with disabilities
- Improve provider training of how to effectively treat people with a disability
- Reduce avoidable Emergency Department visits
- Reduce hospitalizations, length of stay and readmissions
- Identify new and/or worsening conditions sooner
- Ease care transitions to the home following hospitalizations
- Increase coordination/access to a range of services for people with disabilities
- Increase patient engagement
- Increase patient and primary caregiver satisfaction

Consumer Needs:

- Phone, text, email and telemedicine visits could be very helpful to people unable to drive and in need of transportation.
- Exam rooms must have sufficient equipment to allow for a full exam including scales and lifts to support the patient onto the exam table. If not financially feasible to have all offices set up with this equipment, have some.
- Providers need sensitivity and compassion. One way to show that sensitivity is by documenting the patient’s disabilities, so they are not asked to stand when they cannot or do other activities they cannot do.
- Providers need to recognize that a patient’s disability might not be their sole concern, and that a patient with disabilities may have many other health concerns.
- Many people with disabilities need medication management (perhaps from a pharmacist). Other important capabilities include pain management expertise and coordination with providers of various services and community resources.
- All care team members need to understand behavioral health issues, social issues, and how they intersect with medical issues. Just adding a behavioral health team member is insufficient.

Health Equity Lens:

- Transportation barriers make it difficult for people with disabilities to access primary care in office-based settings.
- High costs of care can limit the resources available to low-income people with a disability.
- People with disabilities may not be able to retain employment, leaving them reliant on others and unable to obtain their own care.
- According to an Institute of Medicine report, “race and disability together may have a previously unaccounted cumulative impact on creating health disparities.”¹
- Inadequate focus on health promotion and prevention (i.e. health disparities in screenings).
- People with disabilities are often more susceptible to preventable health problems that decrease their overall health and quality of life.

¹ <https://dredf.org/healthcare/Health-and-Health-Care-Disparities-Among-People-with-Disabilities.pdf>, page 2

Implementing the Strategy

Annette has a 31-year old son named David. David has a disability. Annette is her son’s caregiver and has been taking him to the same primary care physician for years. This primary care team knows her son well and has taken training sessions with the Connecticut Department of Developmental Services to be able to better serve people like David. Annette and David recently underwent a routine primary care check-up, where David’s care team screened him for various conditions highly associated with having a disability. The screenings showed that Annette and David should make an appointment with David’s dentist and speak with a nutritionist about David’s diet. The in-office patient navigator helped David and his mom set up these appointments within their community, David was given information on optimal dental care and dietary choices, and a follow-up appointment was scheduled with David’s primary care team.

HIT Requirements:

- Access to Electronic Health Records for all care team members, and from remote locations
- Scheduling system accessible to all members of the patient’s care team
- Remote patient monitoring technology as needed for patients (tele-rehabilitation)
- Accessibility technology to improve patient care, such as computer and/or robotics technologies in electric-powered wheelchairs (i.e. the iBOT) and computer-aided seating or cushion designs for ulcer prevention (Cooper, 1999).

Implementation Concerns:

- Frequency/distance of home visits decreases the number of patients care teams can manage.
- Need to clearly define and document communication channels.
- Appropriate selection of high-risk patients.
- Risk of overtreatment due to increased patient provider interaction time.
- Overload of primary care team caseloads.
- Multiple surrogates can lead to complications in treatment.

Impact

Aim

Summary of Evidence

Health promotion/prevention

In a 2006 study, patients with a disability were identified within primary care teams and structured health checks were performed by primary care team members. 51% had new needs recognized, of whom 63% had one health need, 25% had two health needs, and 12% had more than two. Sixteen patients (9%) had serious new morbidity discovered. Management was initiated for 93% of the identified health needs. The findings reflect a concern that current care delivery leaves individuals with disabilities at risk for both severe and milder illness going unrecognized. Health checks present one mechanism for identifying and treating such illness in primary care for patients with a disability. (BJGP, 2006)

Improved quality and outcomes

In a recent study of a Special Olympics Wisconsin (SOWI) program that provides healthcare screenings, dietary and dental services, and wellness activities and information to athletes with a disability, most were considered in “good” or “very good” health (49.01% and 41.72%, respectively) post program. Additionally, many athletes and guardians who responded to the survey indicated they understood the athlete’s conditions and knew what medications the athlete takes and why they take those medications. (AADMD, 2013)

Patient experience

The 2013 study first mentioned in the problem statement of this skeleton investigated the experiences of health care for physical needs from the perspective of patients with a disability. Many study participants reported examples of good care and improving practice, such as being invited for health checks, suggesting that some of the initiatives to improve health care access have been successful, although further progress was required. Several suggestions were made about improving care, including the provision of more training for staff in communication and awareness of the needs of patients with a disability.

In the Special Olympics Wisconsin (SOWI) study, 98.66% of athletes and parents believed that their athlete received all the primary care services that were needed. The percentage of athletes who received adequate dental, vision, specialty, and preventative care services ranged from 48% for preventative care to 81% for dental care (AADMD, 2013). When questioned as to what limits the athletes’ ability to access care, the most common response was insurance (21.85%) followed by cost (17.22%). When asked what could be done to improve the athlete’s experience with healthcare providers, the most commonly indicated answer was “More health care providers willing to see me/my athlete” (25.17%) (AADMD, 2013).

A 2017 report by the Bureau of Health Information provided survey responses from almost 9,000 adults with a disability who were admitted to a public hospital in 2015. 17% of patients with a disability said they were not given the right amount of information about their condition compared with 13% of patients without disability. 25% of patients with a disability said doctors did not always explain things in an understandable way compared with 20% of patients without disability. 23% of patients with disability who needed help to eat their meals said they did not get enough help from staff compared with 20% of patients without disability. (BHI, 2017)

Provider satisfaction

In the recent Special Olympics Wisconsin (SOWI) study, 60% of providers indicated that they do not feel they are able to provide the same quality of care to patients with a disability compared to their other patients. Common reasons were communication barriers (54.39%), complex social or family situations (47.37%), and complicated or multiple medical conditions (31.58%). Other factors that were shown to limit the provision of care to patients with a disability were insufficient appointment time and challenging appointment dynamics (38.60%).
 (AADMD, 2013)

Lower Cost

In a 2018 report by the Commonwealth Fund that focused on creating better systems of care for adults with disabilities, it was noted that an independent evaluation of a Minneapolis-based rehabilitation center for patients with disabilities (described in the Case Study section of this skeleton) found a significant reduction in total costs of care for Medicaid beneficiaries in 2016, mostly through lower use of acute care. This trend continued in 2017, where a marked reduction in hospitalizations was seen in 198 Medicaid beneficiaries.
 (Hostetter, Klein, McCarthy, 2018)

**Please complete the survey on this capability [here](#).

APPENDIX

Learning from Others

State and National Scan:

Case Study #1: Commonwealth Care Alliance (CCA) is a Massachusetts non-profit, community-based healthcare organization dedicated to improving care for those who are dually eligible for Medicaid and Medicare with complex medical, behavioral health, and social needs, including those with disabilities (CCA, 2018). CCA offers two health plans: Senior Care Options (HMO SNP), for individuals ages 65 and over who have Medicare and Medicaid, and One Care, a Massachusetts program for dual-eligible individuals ages 21 to 64. These comprehensive health plans provide all the services covered under Medicare and Medicaid, and other benefits as determined necessary by an inter-professional care team in conjunction with CCA's preferred provider network (CCA, 2018). CCA has four primary care, disability-competent Commonwealth Community Care (CCC) centers, and its CCA One Care health plan has close to 20,000 members. 48.3% of these members have four or more chronic conditions, 72.3% have a physical and/or behavioral health disability, and 8.3% have a major disability (such as paralysis, multiple sclerosis/muscular dystrophy, or cerebral palsy) (CCA, 2018).

Best Practice: Within every Commonwealth Community Care practice, each patient has a primary care team, led by a nurse or physician assistant, that is focused on preventative care and responding to new conditions (CCA, 2018). The team actively coordinates all needed care and services, and patients and their families are involved in the development of their care plans to meet individual needs and

preferences (CCA, 2018). The primary care team may include a primary care physician, a nurse practitioner, a social worker, a health outreach worker, a behavioral health specialist, a physical or occupational therapist, a long-term services and supports coordinator, a durable medical equipment coordination team, and/or an administrative services coordinator (CCA, 2018).

The CCC social work team works closely with primary care providers to help with housing, family issues, and access to community services (CCA, 2018). The behavioral health team provides assessment and diagnosis of behavioral health conditions, connects patients to therapists, and ensures that people with complex health conditions receive the full care they need. The Durable Medical Equipment (DME) coordination team works closely with rehab specialists and DME vendors to ensure that patients can use and maintain their equipment, and to assist them in accessing repair services if needed (CCA, 2018). Whether at home or in a day program, group residence, or other community setting, CCC clinicians provide care where the patient needs it (CCA, 2018). For those patients who can travel and receive in-office primary care, CCC examinations include hi-lo tables, wheelchair scales, transfer equipment, and lifts for people with physical disabilities. CCC care teams also offer translation and communication assistance when necessary, and in the event of a serious episode requiring inpatient care, the behavioral health and primary care team consult specialist providers on each patient's discharge plan and transition to home and recovery (CCA, 2018).

Results: Medicare Advantage and Prescription Drug Plan CAHPS surveys conducted by the U.S. Centers for Medicare and Medicare Services found that between 2015 and 2017 (CCA, 2017):

- Acute admissions per 1,000 CCA One Care members were down 3.3%
- 30-day hospital readmission rates were down 6.7%
- ED visits were down 2.1%

Case Study # 2: The Courage Kenny Rehabilitation Institute is part of Minneapolis-based Allina Health, and has a primary care clinic that services roughly 325 adults (mostly under the age of 60) who have a spinal cord injury, traumatic brain injury, or musculoskeletal conditions. Primary care clinicians meet with patients for hour-long appointments to monitor their chronic conditions and identify and address secondary conditions (Hostetter, Klein, McCarthy, 2018).

Best Practice: Primary care providers refer patients to on-site specialists, including psychiatrists and psychologists, who offer treatment for those who have behavioral and mental health needs (Hostetter, Klein, McCarthy, 2018). Providers prescribe exercise plans and have patients partake in support groups. Additionally, nurses and a trained peer (a clinic patient) lead a six-week course for all new patients on living with mobility limitations, including evaluating potential treatments, getting good nutrition and exercise, and coping with frustration and fatigue (Hostetter, Klein, McCarthy, 2018). The institute also employs social workers (paid for through a Medicaid waiver) to visit people in their homes to ensure they are equipped to care for themselves and help them secure better housing, go back to school, or find employment opportunities (Hostetter, Klein, McCarthy, 2018).

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Appendix

Design Group 1 Meeting Notes: October 5, 2018

Design Group 2 Meeting Notes: November 2, 2018

Design Group 3 Meeting Notes: December 7, 2018

Primary Care Modernization Persons with Disabilities Design Group Meeting 1

10/05/18

Building the Primary Care System We Need

-What problems do you see in primary care today?

- Lack of coordination convenience
- Too little support between visits
- Depression, anxiety, substance use often can't be treated within the same office
- Not always good at connecting patients to community resources
- Too little money spent on primary care and providers are only paid for office visits

-What if we had...

- Care teams, instead of just doctors, with more skills and functions to keep people healthy, catch problems early and manage conditions
- Technology to connect providers with each other and their patients
- More money for primary care and payments not tied to office visits
- More convenience like options for email, phone, text

Practice Transformation Task Force Report Key Takeaways:

-Add new staff to primary care teams-pharmacists, care coordinators, community health workers

-Allow access outside of a traditional office visit-phone, text, email, home visit, telemedicine

-Double investment in primary care over five years through more flexible payment options

Discussion:

- Dr. Schaefer: The Lieutenant Governor has a steering committee, one of the workgroups is the PTF and focused on medical home capabilities, and addressed SDOH and behavioral health issues, the task force is made up of consumers, providers, and includes health plans like anthem, and state agency representatives

Care Delivery Goal: Increase the Ability of Primary Care to Meet Patients' Needs

- Participant asked what genomic screenings are being considered as part of the model. Dr. Schaefer is working with Yale on 3 conditions (BRCA, lynch syndrome, and hyperlipidemia)
 - In primary care, there aren't genomic screenings for any conditions, so we are starting with those 3 conditions to implement the infrastructure.
- Talking about having a dedicated behavioral health specialist and care coordinator, and looking at different areas of specialization
- Dr. Schaefer: Alyssa used the term networks→85% of care providers out there are a part of a network (unlike 20 years ago). So, most primary care is part of an organized network to be able to provide decision support or care coordination services (we should talk about practices being supported by those larger organizations)

Payment Model Goal: Increase spending on primary care, reduce total cost of care, prevent underservice

- Attendee: You used the word bundle twice, what does that mean?
 - Dr. Schaefer: The bundle is one of the more important features of payment reform it's also the most controversial
 - Dr. Schaefer: Fee-for-service means primary care providers get paid for everything they do and focuses their attention on seeing people in the office and time with patients (whether they need to or not) (what's billable is the revenue stream that supports the practice)
 - Dr. Schaefer: Primary care is something that should be continuous. The bundle provides a level of support and purchases primary care support that might not be a doctor visit, but a care coordinator or nurse practitioner. So, by bundling a payment upfront (i.e. 4 payments of a ¼ of a million over a year) means doctors don't have to worry about how much money is coming in to support the practice. All interactions with patients are recorded, but it's still a lot less documentation for physicians.
 - Dr. Schaefer: So, primary care practices would be going from being paid for each patient to this lump sum payment.
 - Dr. Schaefer: The downside of the bundle is: what if doctors lose the incentive to see patients? So, you must have a way to measure that you're getting better outcomes and supporting and bettering patient experiences.
 - How do you measure that?
 - Dr. Schaefer: Electronic health records can capture interactions with the care team, and anyone participating in this model is reported.
- So, you have people with significant disabilities that must see doctors much more. How do you account for those who need more services?
 - Dr. Schaefer: The actual payment amount varies based on the patient's needs. So, people with high SDOH would get the practice a larger payment (risk adjustment: payment amount varies on the risk of the patient)
 - So, when Medicare does this they also have disability status.
 - Dr. Schaefer: So, this means practices are as interested in seeing complex patients as they are in seeing noncomplex patients.
- So, how do providers reevaluate when a patient's needs have changed?
 - Dr. Schaefer - we have a Payment Reform Council working through those parts of the model and if this group is interested, we are happy to come back and explain.
- Patty Richardson: United Health Care has inflated the risk level of individuals to increase the reimbursement
 - In the Medicare world, there is a lot of problems related to inflation of reimbursements

- Having an independent entity assessing might be the only way to stop this.
- Dr. Schaefer: So, what you're describing is a type of fraud.
- Or conflict free, so the people providing the services are not the ones billing the patient.
- Dr. Schaefer: Then you have payments based on a level of risk, but people can try and inflate the risk.
- Dr. Schaefer: In fee-for-service, you have a different problem (i.e. unnecessary medical procedures).
- Dr. Schaefer: The risk of providers gaming the system is the same for every system.
 - So, you have an audit to ensure the patient's needs match what was billed.
 - Where risk scoring is important → it makes sense to have an audit process to ensure the diagnosis were real
 - There must be some method of ensuring, but some methods are pricier than others.
- Dr. Schaefer: This initiative is just about primary care
 - In a Medicare fee-for-service, the model is also based off risk adjustment.
 - They focus on physician productivity measures by volume and the other is risk scoring
 - The risk scoring is a bigger issue. We just need methods of ensuring accountability
- Tom Fiorentino: Is there bundling in Medicare like what you're proposing for Medicaid?
 - Dr. Schaefer: At some point in the middle 80s, they went to bundle groups and it solved an access problem. Hospitals were very eager to get patients admitted and weren't concerned about readmissions. So, the bundle payment fixed that.
 - Dr. Schaefer: You see them now for things like cardiac procedures (Commonwealth Care Alliance started taking bundled payments as well)
 - Dr. Schaefer: Getting away from fee-for-service is key
- Patty Richardson: Bundling payments allotted for home care, but now it's the same amount of money for less care received. We must look carefully at the total picture or else you can miss the adverse effects to beneficiaries.
 - The problem with Medicare is that there have been so many initiatives in reimbursement models.
 - Reductionists services for most people under the Medicare benefit.
- There is a disconnect from the beneficiary/patient and we need to get that consumer perspective back in.
- People are concerned this is going to be a capitation system.
- Dr. Schaefer: We are also working on consumer experience measurement.
 - Unsure whether the group agrees that primary care is underfunded, but it's the thing that everyone relies on for basic care needs.

- Dr. Schaefer: This relentless focus on volume, billing and having report cards on encounters is what is burning physicians out.
- Dr. Schaefer: I totally get downside risk of bundling, but the question is, are there enough protections?
- Everywhere across the state, patients have SDOH needs. Patients with PTSD and depression are more likely to have chronic diseases. Patients with language barriers have providers who can't understand them and their needs (or vice versa). Pharmacies might be better equipped to do this. The people who cannot speak English, don't know how to access proper primary care. The community health worker must have access to the community that really needs them (communities with high SDOH patients). These people are isolated. Other patients come from violence and trauma from other countries, and we must be aware of that issue as well.
- Judy Levy: Part of the goal is to have care teams who can speak their language. So, people that go into the homes, meet them where they are with feet on the street. With the disabled population, we must try to move away from the medical model. Maybe they need a social worker to better obtain access to services in the community? With the bundled payment, there are many more options and its more flexible. This should be the goal: for it to happen for everyone.
- Michelle Jordan: Where does the money come from to create this? (Coming from someone who has worked in the community)
 - Dr. Schaefer: One of the reasons we have health plans, employers, Medicaid is that they must be persuaded to pay more initially to get a system that is less costly long-term.
 - The avoidable use will be the offset. We are already one of the most expensive states for Medicare and Medicaid. Reallocating how we spend the dollar overtime combined with a staged expansion of primary care.
- Patty Richardson: Stressors on physicians→ the networks that have developed are driving that pressure. I have a feeling that the stressors will still be there if you just change the system and do not address the network.
- A lot of folks who have Medicaid **only** don't necessarily have that access. The folks who have Medicare are getting the access to those groups, the folks with Medicaid aren't (they're only 5% because they're **not** going to the doctor)
- What groups are we talking about?
 - Dr. Schaefer: The universe.
 - Dr. Schaefer: If you're a practice, you can't completely reinvent primary care for just that population.
- Dr. Schaefer: What should primary care look like tomorrow and what should it look like in five years?
- Quality care means caring about who the patient is.
- Dr. Schaefer: How does primary care fall short for yourself or the consumers you represent?

- Attendee: My practice is not part of network (we serve a geriatric population and oversee people with disabilities). People have frustrations with office-based visits and want to jump into telemedicine. We have increasing requests for home-bound patients, and patients are worried about not being cared for in the community (so they chose nursing homes/ care facilities)
- Attendee: When we are talking about a care team, the individuals we work with often have frequent stays. Supporting patients throughout their need for care is so important. A lot of patients travel far (costs issues). Telehealth and care teams can better connect patients to care.
 - Dr. Schaefer: I hear two principles: **relationship-based medicine** and **continuity in care**
 - Dr. Schaefer: We can keep these principles at the center of it.
 - Attendee: That and value of care.
- Dr. Schaefer: We can come back and talk about what's emerging from the Payment Reform Council
- Attendee: Cost of care is an issue. Transportation: when you've missed too many visits, and practices can no longer hold a spot for you. Practices are turning down patients in the community and a lot of these folks are Medicaid patients. So, the issue is not just that practices are not taking new patients.
 - Dr. Schaefer: The new patient problem is going to get worse since workforce in primary care is going down.
 - Having other members of the care team doing things the physician doesn't want to do will help alleviate this problem.
 - Cutting down in person visits would cut down costs and alleviate transportation issues.
 - The-fee for-service price is not necessarily the barrier, but it's probably attached to some of the other patient's characteristics.
- Dr. Schaefer: We solve for some of the issues around missing visits (this is a practice revenue challenge). If you miss a visit under pay-for-service payment model, its big deal. If you miss a visit under a bundle, you just want to make sure that patient received the care owed to them.
- Within a primary care network, self-specialized practices became very good at this treating their chosen specialty disease (and they had an expert coaching them too).
 - Dr. Schaefer: Dr. Rebecca Andrews said we should find enough folks who really want to see a patient with chronic pain receive the training to become an expert in pain management. We are thinking of something similar with older adults (like Commonwealth Care Alliance)
 - Pain is something a lot of practitioners are not interested.
- Mary Ann Langton: I have had negative experiences with providers who did not know a thing about my disability.

- Dr. Schaefer: You don't think it's a good idea because? Where did you experience this?
 - Hartford, Connecticut
- Attendee: You worry they wouldn't have the expertise that they're saying they have?
 - Yes.
- Patty Richardson: I would be in support of having care right from diagnosis of a disability. It's challenging to make sure the nursing home is communicating with doctors for patients in homes.
 - There are not a lot of specialty areas who know how to work with special populations (i.e. spinal cord injuries, neurological issues). There are just not enough long-term in specialty service entities in our state.
- Patty Richardson: Transportation for Medicaid patients right now is a real problem. SDOHs are a barrier, and it's the system that is the problem. Telehealth is good only if it's not being used to replace a real physician's assessment. I would love to see specialty care teams, too.
- It would be good to have specialists in Connecticut that are able to virtually connect with primary care doctors → then you're expanding this coordination of care.

Next steps:

- We have one upcoming webinar meeting and one in-person meeting in November
- Dr. Schaefer: We are hoping to do a reform over the course of next year and are working hard to identify the definition of advanced primary care → so we can begin the conversation with Medicare early next year.
- Attendee: Are we assuming that Medicaid would already be experimenting with this or what?
 - So, we make the proposal to Medicare, and Medicaid would have to have its own design process. When you do a multiplayer demonstration, you have to have Medicare, and secondly, we can't make decisions with Medicaid (our goal is to describe as much of the model by December, and not finalize a report until March)
- This is the first meeting of disabilities of this group, but we did another one in September of consumer engagement (this is our second conversation regarding this, but this is the main group we were hoping to enlist)
- Attendee: Is this process televised?
 - FHC: We can send out information on how to attend/call in to future meetings (i.e. PRC, PTF)
- FHC will be in touch about scheduling the next session between this meeting and the November meeting

Primary Care Modernization People with Disabilities Design Group 2

11/02/18

Participants: Tom Fiorentino, Mary Ann Langton, Robin Wood, Sheldon Toubman, Karyl Lee Hall, Kevin Brophy, Siobhan Morgan, Dawn Lambert, Patricia Richardson, Mark Schaefer, Maggie Ewald, Michelle Jordan, Robin, Judy Stein, Marie Porter, P-something, Julie Peters, Stephanie Burnham, Alyssa Harrington, John Freedman

Notes

The group discussed the purpose of the design group. Several participants had thought the purpose was to discuss payment models and voiced concern with the bundled payment model options that the Task Force recommended, including:

- Capitation did not work for Medicaid. The FFS system in Medicaid is working much better than the capitated system.
- Many of the capabilities being proposed such as telemedicine and Community Health Workers are already reimbursed under FFS.
- There is a crisis in home care and people with disabilities do not have access to needed services. Changing payment models in the midst of this fraught environment will not solve the problem but make it worse.
- The capabilities should define the payment model, not the other way around.
- People with disabilities are being consulted too late in the process of development payment model options.

The group discussed that the purpose of the design group was to discuss how primary care can better serve people who have disabilities through enhanced care delivery capabilities, rather than the payment model. Several participants expressed difficulty divorcing the capabilities discussion from the payment model options.

Several participants discussed how the current payment and care delivery system is fragmented and broken and does not work for people who have disabilities. The people that they work with who have disabilities do not get the same level of care as people who do not, care is not equitable, and there are huge gaps in preventive care. Not all participants agreed. They expressed that this group being involved in this discussion was an opportunity to define ways to make care better and more equitable for people who have disabilities. The group agreed that everyone had this goal, but there were questions about how to get there. Some participants felt a bundled payment model would not do anything to improve the system and would instead make it worse.

The group discussed how to define “disabilities”. Some participants noted that it is difficult to define services without a defined population. Others felt that having specific definition contributed to the fragmentation of the system – the point should be to include everyone rather than requiring people to meet certain qualifications to be eligible for certain services, which is part of the current problem.

After more discussion, the group agreed to make recommendations about care delivery capabilities to improve primary care for people with disabilities, ***with the explicit provision that this group's recommendations in no way support an endorsement of the payment model options under consideration for the Primary Care Modernization initiative.***

The group discussed opportunities to improve primary care for people with disabilities, including:

- There is a lack of knowledge in primary care about how to work with people who have disabilities.
- People with disabilities often travel long distances to see specialists who understand their condition. Being able to access these specialists via telemedicine would go a long way. A successful, out-of-state telemedicine consultation for patients with Prader-Willi syndrome was given as an example.
- Issues go beyond just access – people with disabilities do not receive the same quality of care as people who do not have disabilities.
- Primary care for people with disabilities should be person-centered. There are measures of shared decision-making that can help measure whether care is person-centered.
- The patient and their circle of support (e.g. families, caregivers, designees, etc.) should be at the center of the care team.
- If there are practices that specialize in care for people with disabilities, they should be accessible via public transportation such as bus lines. Consider incentives to have these practices in certain areas.
- People with disabilities may use subspecialists as their primary care providers depending on their needs at the time. Consider fluidity in who the primary care provider is at any given time.
- Restrictions in eligibility for home care when people return to the community from facility settings are affecting access to these very needed services. Consider waiving eligibility requirements for home care.

The group discussed having a four hour meeting on December 7th to continue defining the primary care capabilities for people who have disabilities.

Primary Care Modernization People with Disabilities Design Group
12/07/18

Participants: Mary Ann Langton, Maggie Ewald, Mark Schaefer, Deborah Migneault, Siobhan Morgan, Stephanie Burnham, Velandy Manohar, Lesley Bennett, Dawn Lambert, Mairead Painter, Michelle Jordan, Sheldon Toubman, Alyssa Harrington, John Freedman, Kelly Sanchez, Nadine Repinecz, Maria Dwyer

Reviewed the goals for primary care

- Ms. Mary Ann Langton:
 - Need more training for the primary care providers.
 - Need to know how to communicate with people.
 - Need to know about the specific disabilities that a person might have.
 - Make assumptions about patients that are not always true.

- Ms. Siobhan Morgan
 - The word I use is surrogate.
 - Mary Ann needs her mom to be at the doctor, to be able to deal with different surrogates is important.

How does that doctor talk to that person and make it a person-centered experience?

What would help facilitate that?

- Ms. Siobhan Morgan: Training
 - Dr. Gerry Kerins who is teaching ppl how to do an assessment and he has the expertise
 - Department of Developmental Services were talking about a training program
 - It's allowing the person to make their own decisions and not putting our own values on them
 - There is a curriculum out there
- Ms. Mary Ann Langton:
 - To be trained by people with disabilities themselves.
- Ms. Michelle Jordan:
 - Shared an experience where her friend with a disability told her, "When you're there with me, they treat me differently."
 - Change our own biases and attitudes -to have a nonjudgmental approach to people
- Able lives programming-DD Council did it→give a different perspective of what life is like
- We must see where patients live and what the impact is like (their environment)
- FCH: Training is what makes a practice better suited
- Ms. Siobhan Morgan: Equitable care
 - Friend had two hours on disabilities training at UConn medical school
 - Friends dreaded going to the doctor, the doctors were the ones who directed the parents where patients/their kids should be living

- Ms. Lesley Bennett
 - My daughter has a severe neurological impairment
 - Knows a patient who hates going to the doctor because she can't speak and due to her neurologic impairment, the PCP and his staff treat her as though she has BH issues
 - Genetic disorders end up with severe impairments and a lot of training is needed
- Dr. Manohar:
 - My team looks at the schedule, and ensures transportation is lined up if needed
 - Someone will alert the physician if a mental health professional is needed in certain appointments as well
 - We do not want that first floor person telling patients your bills are not being paid
 - All of that must be managed
- We can send staff to the home.
- Look out for the caregiver.
- FHC: Training is crucial.
- Ms. Siobhan Morgan
 - Dr. Manohar is really talking about culture
 - People want to go in there and feel they're the most important person at that time
- Subgroup under equitable care-from slide for Goals for Primary Care- would be persons of color
 - Are there ways to measure why people of color that are disabled get less quality care?
 - Are those the kinds of things that you look at?
 - FHC: Measurement framework is not yet fully developed. However, if you're looking at data, you can ensure people are getting the level of care that they need.
- Dr. Schaefer: The knowledge and training is not enough.
 - We need to get schooled in what is effective
 - Calling out that implicit bias-the health equity outcome-is key

How much of this have you measured, Dawn?

- Ms. Deborah Migneault:
 - Spent the last couple days doing a literature review to measure person-centered care
 - Lack of measurement in person-centered care, there are scales, but the scales do not measure what we need.
 - There's a lot about quality but getting at that choice; being in control of your health decisions does not currently exist.
- FHC-CGCAPS is a standardized questionnaire meant for ambulatory visits and it works terrific generally
- SIM uses a version of it
- Ms. Dawn Lambert:

- The question must get at improved experience of care and reduced utilization through the empowerment of the individual.
- Making patients the leader of their care plan team.
- Talking about person-centered care and the person has the power to make those choices.

FHC: Are there any leading researchers out there that have validated this?

- Ms. Dawn Lambert:
 - Just came from a meeting in Washington talking about this and I can tell you people aren't doing it
- Ms. Mary Ann Langton:
 - I don't want to have to retell my life to every provider.
 - Ms. Dawn Lambert
 - There's a flip side to that → You don't want providers to look at data and make decisions before they meet you.
- Ms. Bennett: We have standards in medicine that don't always apply to disabled patients.
 - Ex. A friend with a disability went in for a drug test and they didn't have a lift.
 - We need different accommodations for this.
 - We prepare a cheat sheet for our daughter to give providers.
 - Little things at Boston Children's Hospital are different than in CT.
 - When our daughter's PCP Pediatrician retired last year, we had to work with Dr. Zavowski to find a new local PCP who would treat a patient with multiple/neurologic impairments.
 - When I called, Stamford Health asked if she had BH or was physically disabled. Went to one that was very well-trained to treat patients with neurological impairments. They (Physicians at Stamford Health) were the ones that recommended we add this to the PTF. We really do need these accommodations for the physically disabled.

Dr. Schaefer: What did they do with that information?

- Ms. Bennett: They put it in her record. They started training physicians a little bit differently.
 - People with autism, some doctors don't know how to handle.
 - Started training physicians in how to deal with that at Columbia Univ
- Ms. Siobhan Morgan
 - All doctors' offices should have the equipment to work with those with disabilities.
 - Creating these groups of doctors must be flexible and inclusive.
- Dr. Manohar: In the room, one-on-one with a patient is where all the action is. Makes sure to ask every patient:
 - What is my main problem? What do I need to do? And what is important?
 - Gives website of choosing wisely.

- Also asks cost questions.
- One other discussion on goals:
 - Don't want to have any financial incentive not to provide care for those with disabilities
 - Appts take longer
- Dr. Manohar: We need to do something about the reimbursement system

FHC: Let's start with a tangible example of what's happening elsewhere...

- Commonwealth Care Alliance
- Mr. Sheldon Toubman:
 - The only example you have is a fully capitated model.
 - The price of these capabilities is a capitated model.
- Ms. Siobhan Morgan:
 - I don't agree. I don't see that.
- Ms. Dawn Lambert:
 - Washington has a managed fee-for-service system
- Ms. Bennett: We are trying to get to what people with disabilities want to see in primary care
- FHC: Not focusing on payment model. They have great care team functions, a durable medical equipment coordination team, address SDOH needs, provide care at different settings (in the home and the community), etc.

Concept Map for Primary Care for People with Disabilities: Network/Practice Level Requirements

(See provided meeting materials.)

- Ms. Siobhan Morgan:
 - We used to have those clinics (referring to concept map), the primary care teams train in person. These specialties must be connected to them, they can't be a separate practice.
 - Take the top five boxes and lay them over the bottom
 - We have a lot of the support and services under Medicaid for these folks, but they are at different places
 - We have a lot of these things in CT, but they're in different places
- Ms. Bennett:
 - DSS and DDS do not always talk or share services
 - Had difficulties moving from pediatric care to adult care.
- Ms. Siobhan Morgan:
 - Have a PCP group with a specialist in there, or they can bring someone in, so they don't have to refer out
 - That person being able to be there, via in-person or Skype
- Ms. Bennett:

- Stamford Health asked if my daughter had BH issues because they would have recommended a different provider and that helps the patient be a little more comfortable
- Dr. Schaefer: Did they tell you they must go to this?
 - Ms. Bennett: No, the recommendation came from Dr. Zavoski's office
- Ms. Siobhan Morgan:
 - If you don't have doctors taking Medicare and Medicaid, patients can't find affordable care
 - A lot of ppl we treat are on one or both.
 - And these are people that have insurance!
 - How do we get people in the door?
- FHC: Networks would need to have some practices that are trained to work with disabilities and have that specific expertise.
- Dr. Schaefer: This is an important practice, are you a practice or a clinic with kids with down syndrome and what's your experience with that?
 - The rationale for the graph is worth understanding (referring to provided materials) when you're talking about conditions that need a lot of care.
 - If you're a provider, folks that do things the most tend to be the best at it.
 - Take all practices and make them equally capable. It's the expertise that comes from lived experience.
 - Ex. Provider asked folks who were interested in working with patients with hepatitis C, and then trained them to provide expert care
 - Is it realistic to expect we are going to create this level of capability without that experience?
- Dr. Manohar: Agrees. Specialization is key
- Ms. Mary Ann Langton
 - A warm hand off works the best when the two doctors talk to each other
 - Ms. Siobhan Morgan: Individuals who get the best care, the nurse is calling the doctor's office; that warm hand off is crucial.
- Attendees son has down syndrome:
 - He sees all the same doctors that everyone else in the family sees.
 - Attendee is his legal guardian, he chooses to have her or her husband there with him.
 - The family goes to specialists just like everyone else. It's not terribly wrong having providers that specialize in individuals with disabilities.
 - Knows several people with down syndrome with lots of questions and are not getting any answers.
 - Providers can tap into each other learn a lot from each other.
- Ms. Siobhan Morgan: If you're showing signs of dementia, you should be able to get an appointment. We must have specialties.
 - You want those with disabilities to be included
 - If you're a specialist, you serve everyone, and it doesn't matter if they have a disability or not.

- Dr. Schaefer: Want to follow the usual care route for all family members that makes sense.
 - Mother was deteriorating looking for primary care doctor to be helpful and was struck by the lack of support.
 - Took her to the University Michigan Center and they have deep compassion for an older adult who was suffering tremendously, to have the option of a place substantially more competent.
- It's about choice: she had the option to stay with her PC who knew her or to change
- And the concern is some don't always have the option to choose
- You're never going to find one cookie cutter that everyone is going to be happy with
- Other people are going to be challenged in different ways
- Can't have doctors rushing through patients who can't speak well. When we talk about payment and coverage, make it so that nurses and other service providers take the time with each patient.
- We must be careful just looking at the medical model.
- Should be up to the individual because it's their risk also, its not just the providers risk.
- Dr. Manohar: Transportation services need to be provided.
 - Not everyone needs to come face-to-face and not everyone needs 4 hours of transportation.
 - Ms. Mairead Painter: Doing it telephonically is just as good.
- Dr. Manohar: Home visits helps those with disabilities
- Mr. Sheldon Toubman: DSS is working on a state amendment specifically for telemedicine
 - It's a good model and its paid on a fee-for-service basis.
 - It's funded by the Feds.
 - Have it as an option and have fee-for-service reimbursement.
- Dr. Manohar: Somebody who lives far away doesn't have to come to me if there's a camera. We can do a very good evaluation through video.
- FHC: If practices have specialized expertise, its providers have more experience working with people with disabilities and additional care team support.
- Dr. Schaefer: It's been an enlightening conversation and the model may evolve around choice. These are places where literally everyone can go, and the experience is essentially for everybody.

Capabilities for All Primary Care Providers (See provided meeting materials.)

- Whose forming these care teams?
- FHC: Care team environment decides what functions are needed.
- The practice has hired a nurse and a pharmacist to assist the primary care provider, individual can go to the pharmacy they always go to but there would be this resource in the practice if a person needs it.
 - Mr. Sheldon Toubman: Unsure if the pharmacist part is needed.

- Someone on multiple medications for multiple providers-it's the care coordination piece of it.
- The pharmacist wouldn't have to be on site at every practice.
 - Dr. Manohar: Could have access in the network.
- Ms. Mary Ann Langton: Once or twice a year, primary care physician reviews all medications.
- FHC: We don't envision that would go away, to Sheldon's point, not every practice would need to have a pharmacist.
- Patients have all these places they can go that may not be tied to their physician.
- Could see this as a benefit in more urban settings.
- Dr. Schaefer:
 - Study found Medicaid patients were on a lot of medication, identified problems and then worked with the pharmacists to review these medications. They tune the recommended medications to get the optimal result.
 - If a network has enough support to meet those needs, a PCP may be comfortable to spend more time with complex patients that they might otherwise not be able to do.
 - The pharmacists are an essential part of the care team even if they aren't colocated in a practice.
- Mr. Sheldon Toubman: May not be needed that often; wouldn't want to adopt anything that can only be done through a network.
 - Don't want to do this for a capitated payment but drug reactions are a huge cost.
- Ms. Bennett: We are doing this for diverse care teams.
 - Patients who do use a lot of drugs are prone to drug reactions. It's expensive and can have life-long consequences.
- Mr. Sheldon Toubman: Would prefer it be done under the existing payment system.
- Ms. Bennett: Let's focus on what these patients need.
- Ms. Mary Ann Langton: When I get a new medication, they have me flagged on the computer.
- Ms. Bennett: Some of them aren't recorded.
- Ms. Siobhan Morgan: Warm hand off to a pharmacist, not necessarily have someone in the office.
 - Doctors and all the other specialists in that group should form relationships with DD agencies or private providers in the community.
- Mr. Sheldon Toubman: The function is important.
- Ms. Siobhan Morgan: How can we work together?
- Dr. Manohar: False overdoses and deaths are very common; need consultation support.
 - Physicians must look at the PMP before consulting.
 - A bi annual review of the medicines is needed.
 - One pharmacy for the patient and family.
- Ms. Siobhan Morgan: Over-the-counter conversation for medication is important.
- Ms. Mairead Painter: What is the role of technology in this?
 - Dr. Schaefer: Physicians can already see the medications, but we can look into this.

- Dr. Schaefer: Systems can be relied on to identify known interaction effects, however, won't always know the unknown effects.
- Sometimes, it's going to take the physician to know the interaction.
- Side effects are not going to be captured by the HER.
- Pharmacists trained to provide that level of consultation can be a great asset to the team.
- If a pharmacist can take 5% of time → frees up the physician to be available in different ways.
- Pharmacists can be a part of the team to enable the physician to practice at the top of their training.
- FHC: Sounds like people recognize these functions are important.
- Mr. Sheldon Toubman - Not agreeing that a pharmacist must be on a care team it could be a consultant
- Ms. Dawn Lambert: What we want, we can agree, but how we do it is the key.
- Why couldn't it be virtual?
 - Dr. Schaefer: As opposed to face-to-face?
 - Still a human being, but once removed.
- Dr. Schaefer: So, for BHCs, the panel size may not warrant that fulltime person. The question is: should networks get their own pharmacists and are pharmacists interchangeable?
- Looking at teams, if a person has difficulty with a care giver, there should be some option to move to someone else.
- Dr. Schaefer: Goes back to that choice.
 - No restriction in freedom of choice.
 - Nothing about what we are proposing would put additional restrictions on patient choice.
- Choice versus apparent choice is the reality.
- FHC: How you form a team to give the best care.
 - Not having to reexplain your life story every time you go to the doctor.
- Ms. Siobhan Morgan: The level of need assessment-important.
- Dr. Schaefer: When we propose a capability in primary care, is there something that could happen to enable the info to be where it needs to be? Is there data that EDS has that you can envision a patient might want? Should the information be solicited only to the care team or should there be other sources of data
 - Ms. Mairead Painter: Should be the patient's choice
 - Ms. Dawn Lambert: That's what a personal health record is
 - Ms. Dawn Lambert: I would never feel comfortable sharing non-medical information.
 - Ms. Mairead Painter: Non-medical info is important for my physician to know but I would want to control it.
 - Ms. Siobhan Morgan: The consent must be signed off. Part of it is educating the doctor that there is this information available.
 - Ms. Siobhan Morgan: There must be some education because just having the information is one thing, understanding what it means is different.

- We prepare advanced care directives for elders, are those conversations standard?
 - Ms. Mairead Painter: Not necessarily.
 - The advanced directive information might be collected by a specialist for example.
 - Ms. Siobhan Morgan: That goes back to the education of the doctors, are they getting a DNR just because they have a disability?
 - Ms. Siobhan Morgan: Everyone going into a nursing home gets a DNR. Those are important things for doctors to know.
- Ms. Mairead Painter: Some patients with high SDOH have separate needs, having those kinds of records would help give a holistic view of the patient.
- Dr. Schaefer: There's often an uncertainty of whether to follow the DNR.
 - The goal is to think about advanced care planning.
- Ms. Deborah Migneault: I work with MD interns and we have whole conversations around DNR.
 - Dr. Manohar: These are tough decisions.
- Ms. Siobhan Morgan: Would highlight some of the capabilities on the person, not focused on what you can't but also what you can do
 - That information identifies some of the risk areas for the person.
- Ms. Dawn Lambert: The healthcare system is more than just medical services, it exists in the community.
 - You can't have a whole person perspective if you don't see that person's support system. How do all these supports help the individual in achieving their goal? I would argue for all systems but would likely not win. The personal health record -a person can choose to share that now.
- Ms. Mairead Painter: Efficient home care depends on knowing the patient's home life and schedule.
- Dr. Schaefer: Would be good for us to have a few examples to see a need like that.
- Ms. Siobhan Morgan -The timing of medication is so important. Must ensure patients are not kept waiting.
- Ms. Dawn Lambert: I don't want to drive by a practice and be able to say, "that's a practice that serves patients with disabilities."
- Ms. Mairead Painter: Should be a general accessible doctor's office.
- Ms. Siobhan Morgan: Not every doctor's office is equipped.
 - Ms. Mary Ann Langton: Agreed.
 - Ms. Dawn Lambert: Newer equipment is excellent, but it costs money
 - Ms. Dawn Lambert: Best practice is accessibility, make it the standard.
 - Dr. Schaefer: We can take this as a general principle of expectation for all practices.
 - Dr. Schaefer: How do you achieve that goal of 100% compliance?
 - Ms. Dawn Lambert: Demand. If new patients are shopping for doctors, their business model won't be able to survive.
 - Dr. Schaefer: Putting up a public score card in January of ACOs.
- Mr. Sheldon Toubman: There's a letter from 32 advocates saying we can stick with fee-for-service payments, but I agree this should be a policy for practices, not networks.

- Ms. Mairead Painter: If I'm a pediatrician, depending on my practices, I may need less of this, but if I'm a very large practice, I may need 3 or 4 people working on accessibility services. I can see where the specialized care team might go to that practice.
- Whoever a patient's chosen community physician is should have access to them in the hospital
 - Keeping the person connected to their identified care provider.
- Dr. Schaefer: How does that effect the current system?
 - FHC: You don't want the hospitals to play that role because you then have too many cooks. The problem with the old rounding system was providers round in the morning before seeing patients and then are not available all day, it's a tradeoff.
 - Ms. Mairead Painter: People want to be able to move to that next level of care and the hospital doesn't know that.
- Many patients trust physicians even when they don't know everything about their background.
- Nursing homes very rarely communicate with physicians
- Ms. Mairead Painter: Must connect with community care.
- Dr. Schaefer: At a minimum, anyone with complex needs, a care team should establish a liaison arrangement for the patient's goals and if there's a need for a hospitalist.
- Dr. Manohar: I would want to know what happened to my patient, so I would want communication.
- FHC: You see a direct representative of your doctor.

Next Steps

- FHC: Came out with a lot of good things and will circle back.
 - Will let everyone know what the PTF group discussed
- Mr. Sheldon Toubman: Are we already doing this in Medicaid, or we are about to?
- Dr. Manohar: Want to make sure cultural competence is dealt with.
- Healthcare disparities are huge.
- Would like to discuss the recommendations from the Payment Reform Council.
- What has worked in the past and what hasn't?
- It's important not to overlook history.
- Mr. Sheldon Toubman: Want to make sure this wasn't brought back as if we were endorsing it in any way.
- Ms. Michelle Jordan: It's important to tweak the system to make it better and not reinvent anything.