# CT Primary Care Payment Reform
# Draft Capabilities Skeleton: Persons with Disabilities
*This Draft: October 24, 2018*

**Understanding the Need**

**The Problem:**
Persons 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 patients 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 also have higher incidence of certain diseases. Certain conditions strongly associated with adults 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). Pain is commonly reported by people with many types of disabilities and can affect functioning and activities of daily living (CDC, 2018).

## Proven Strategy

**Name:** Enhanced primary care for people with disabilities.
**Definition:** Person-centered, comprehensive quality preventive, acute and chronic care for people who have disabilities that supports improved long-term health outcomes and quality of life.

**Capability Requirements:**

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

- **Training for Primary Care Providers:** Primary care providers and care team members participate in training on care for people with disabilities to screen for, recognize, and manage common problems for patients with disabilities. Programs usually include improving the knowledge, skills and attitudes of health care providers of patients with disabilities and how to accommodate people in their visits by providing accessible information and having health passports or communication books on-hand. For example, the Special Olympics Healthy Athletes program provides health screenings for athletes with intellectual disabilities at Special Olympics events using volunteer providers. The events are designed to educate athletes on health lifestyle choices and identify health problems that may need additional follow up (CDC, 2018). Through this program, they have trained over 100,000 healthcare

professionals in the US on how to provide care for people with intellectual disabilities in their practice.

- **Diverse Care Team**[1]: 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 patients with disabilities commonly include:
    - **Behavioral Health Clinician:** Licensed clinicians (LCSW, APRN, psychologist) provide initial screenings and assessments, brief interventions, consultations, medication and episodic care, and provide consultation to other care team members on behavioral healthcare needs for patients with disabilities.
    - **Clinical Pharmacist:** Conducts comprehensive medication reviews that target specific conditions, conduct medication reconciliation, provide comprehensive medication management for patients 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 Coordinator:** The 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. The care coordinator helps link patients to community-based services and coordinate with state-based services through the Connecticut Department of Developmental Services (DDS). A list of DDS-provided community services available to patients with a disability can be found here. The Care Coordinator would also help coordinate care between PCPs and subspecialists.
    - **Community Health Worker:** Connects patients and caregivers to relevant community resources and aims to address social determinants of health needs and support the patient in adopting healthy behaviors. These services may include health and wellness, legal assistance, health insurance assistance, meal delivery, home maintenance and others. They also support home care providers by ensuring patients are transported to in office visits and provide emotional support to patients and caregivers.

- **Person-centered preventative care**: Primary care providers conduct in-office, preventative exams and screenings based on the person's age, gender and medical history. The assessment may include a review of the patient's medical history, current conditions, medications, social support, and care preferences. Preventive care includes physical exams and routine primary care screenings such as mammograms, pap tests, and colonoscopies. Regularly scheduled screenings and assessments (yearly or every six months) are recommended, partnered with a multidisciplinary approach to health maintenance. Patient-centered approaches emphasize treatment of the whole person, not

[1] The Diverse Care Teams design group is defining care team member functions and roles for expanded care teams in primary care, as well as what cross training is needed for special populations like older adults with complex needs. Definitions will be aligned based on their recommendations.

just the disabilities, engaging caregivers while respecting individuals' rights and decision-making abilities, and developing expectations for habilitation and rehabilitation together.

- **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. PCPs still make referrals to subspecialists for patients' specific conditions as needed.

- **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. Telemedicine 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:** Primary care providers have access to information about a patient's disability and health status within their Electronic Health Record to better identify health issues, prevent new issues from forming, and manage existing conditions. This would also help the provider be sensitive to the patient's abilities and limitations during the visit.

**A subset of primary care practices** within the network have experience and expertise to provide all specialized services listed below for patients with disabilities who have complex needs:

- **Home-Based Primary Care (HBPC):** Utilizes physician supervised care teams by providing health services in the home of identified high risk patients with disabilities (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 of 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.
- **Care Coordination and Patient Navigation**: Care coordination and patient navigation involves deliberately organizing patient care activities and sharing information among all members of the care team. 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 specialist physicians, hospital staff, rehabilitation therapists, mental health professionals, and others who are outside the patients care team.
- **Transportation**: Transportation services are provided to patients who have difficulty getting to in-office appointments or community services. Transportation services may be owned by the health network or contracted to a third party. A member of the patient's care team, most likely the home care provider or a community health worker, schedules and coordinates transportation services ensuring continuity of care between all providers.

- **Specialized Care Team:** Members of the care team have specialized expertise to support patients with disabilities who have complex needs.
  - **Specialized Care Coordinator:** The care coordinator has expertise in long-term services and support and Durable Medical Equipment coordination. As described in Case Study #1, the care coordinator would work 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 complete an 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 patients with disabilities, and providers may need different tools and office

setups to meet patient needs beyond the accommodations required by the Americans with Disabilities Act. For example, this may include hi-lo tables, wheelchair scales, transfer equipment, lifts, specialized mammography equipment, and communication devices and assistance for non-verbal patients (CDC, 2018).

- **Specialization in Chronic Pain Management:** Practices have access to Project Echo guided practice in pain management and eConsults and technical assistance from Centers of Excellence in pain management to care for patients with disabilities who suffer from chronic pain.

**Intended Outcomes:**

- Keep patients 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 patients 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 patients with disabilities
- Increase patient engagement
- Increase patient and primary caregiver satisfaction

**Consumer Needs**:

- Phone, text, email and telemedicine visits could be very helpful to patients 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 patients 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 patients with disabilities to access primary care in office-based settings.
- High costs of care can limit the resources available to low-income patients with a disability.
- Patients with disabilities may not be able to retain employment, leaving them reliant on others and unable to obtain their own care.
- 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.

**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 patients 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 |
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| *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 |

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| | reflect a concern that current care delivery leaves adults 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.<br><br>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).<br><br>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 |

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| | 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 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 with a primary care clinic 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) |

**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 patients 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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