

## USING THE OPPORTUNITY OF HEALTH CARE REFORM TO IMPROVE CARE AND MANAGE COSTS FOR PEOPLE WITH PHYSICAL DISABILITIES

Individuals with disabilities who are entitled to Medicaid and/or Medicare benefits consistently report their health care is abysmal. Disregard, disrespect, and ignorance on the part of providers and their staff abound. People with disabilities seeking care thus find an appalling lack of understanding, awareness and expertise. The current fee-for-service system fails them on multiple levels, including providing even the simplest of preventive measures, such as proper wheelchair cushions or screening for infections. Moreover, there is no way to obtain timely care for foreseeable complications -- such as pressure ulcers, urinary tract infections, or depression. Nor for that matter, are there systematic, effective processes in place to anticipate any of the normal, daily medical/emotional/social needs that exist for people with disabilities. As a consequence, these individuals are amongst the Medicare and Medicaid beneficiaries whose care (or lack thereof) may cost \$10,000 per person per month. A large percentage of these costs consist of missed opportunities to keep people from being hospitalized unnecessarily, and then being sent to institutions following extended hospitalizations. All of these variables - and many others - contribute to increasingly poor health and barriers to living independently for people with disabilities resulting in forced - and unnecessary - dependency.

### **A New Model: Disability-Competent Care**

Three not-for-profit disability care programs - Commonwealth Care Alliance/Boston's Community Medical Group (CCA/BCMG) in MA, Community Health Partnership (CHP) in WI, and Independence Care System (ICS) in NY, which together care for some 8,900 individuals with disabilities - have created an informal alliance to share ideas, practices, and experiences. Their goal is pioneering systems of disability-focused care that build on the current models that each organization provides separately. These systems of care are driven by member self-determination and are designed specifically for the medical, physical, social and emotional health and well-being of adults with disabilities eligible for Medicaid and/or Medicare.

Together, the leaders of these three organizations, the Disability Care Practice (DCP) Alliance, have outlined a model to deliver member-directed/member-centered individualized care referred to as a "Disability Care Practice" model.

This DCP model includes five unique components that differentiate it from the status quo health care delivery system. They are:

1. **Team-based multidisciplinary primary care services provided in the community** that includes home visits and care, when needed, in offices that are accessible for motorized wheelchairs and scooters. The centerpiece of this model is the individualized plan of care (IPC), designed with the member (along with family members, assistants, and whomever else they choose to include in their care planning), and focused on both the health and well-being of the member and on the goals members choose for themselves; such as, "being able to go to church," or "being able to attend and enjoy my weekly poker game on Wednesday nights."
2. **Coordination of all care needs** to bring an end to the constant battles to receive fundamental services, such as obtaining needed physical or occupational therapy, wheelchair seating, personal care assistants (PCAs), transportation, special adaptive devices – with primary/medical care in order to remain living independently (if a person so chooses). The model ensures that all caregivers and clinicians remain in communication about the member's medical/social/emotional care needs and preferences.
3. **Combined/coordinated medical and behavioral health** services with home and community-based services.

4. **Provision of personal care services** (including PCAs) based on the **needs and preferences of each individual** member.
5. **Provision of mobility and durable medical equipment (DME) and supplies**, especially wheelchair evaluation, purchase, repair (including teaching repair to individuals) and maintenance, to enable people to participate fully in community life based on the **needs and preferences of each individual** member.

This new disability-competent model of care will provide both a showcase and a testing ground for combining primary, acute, long-term care and behavioral health services across all settings of care and sources of funding for people with disabilities. The DCP Alliance members will first expand the three existing Disability Care Practice programs in Massachusetts, New York, and Wisconsin to cover an additional 7,000 people. Putting the DCP model into practice via local programs on an expanded basis in the three states where the DCP programs are currently operating (MA, NY and WI) will also shine a light on where the model needs further study and refining in order to be replicated in local communities across the country.

### **The Disability Practice Institute**

The DCP Alliance members have created the Disability Practice Institute (DPI), whose role is to define, refine, and document the Disability Care Practice model. The DPI will serve as the critical foundation of knowledge, training, quality measurement, consumer involvement, and outcomes evaluation for replication of the DCP model in additional communities across the country. The Institute will provide Learning Collaboratives to capture and share best practices, and work with health information technology (HIT) experts to create and expand electronic health records, so that all members of the care team, and members as well, can communicate information seamlessly, easily and immediately. The organizations will also propose the creation of a formal “Demonstration program” by the Centers for Medicare and Medicaid Services (CMS), with the expanded programs of CCA/BCMG, CHP, and ICS as the participants, showcasing this model of disability-competent, integrated, member self-directed care for Medicaid/Medicare eligible individuals with physical disabilities, and replication of the model in other states.

### **We need your help.**

As persons with a disability, you and your allies know best what isn't working for you; you have probably created unique solutions to get your needs met. Your experience and perspective are needed to guide the development and ongoing refinement of this new model of care. Instead of being frustrated and having to use your anger to be heard, join us in your local community and nationally to be a part of the solution. Give us your ideas... tell us your concerns... help us make sure you are in charge of your health, choices, and health care.

For more information, write to us at: [info@DisabilityPracticeInstitute.org](mailto:info@DisabilityPracticeInstitute.org)

### **Team-Based Care: How it Works**

Here's an example of how team-based care works for a person currently enrolled in BCMG, one of the existing DCP programs, based in Boston, Massachusetts: Jane, who is 29 years old, was born with cerebral palsy and diabetes; she doesn't have control of her arms or her legs, and she needs the assistance of a keyboard and machine to be understood when she speaks. She needs help with her insulin injections, and also requires a feeding tube to get enough nutrition. Because Jane is enrolled in a DCP program, she gets care in her home. Jane has made it clear to her nurse practitioner that she only wants to live at home, and does not want to live in a nursing home. The nurse practitioner, who is the leader of the care team, wrote up a plan of care for Jane (the IPC), with this overarching goal in mind, including orders for a personal care assistant (PCA), a physical therapist, and an occupational

therapist to go to Jane's home on a regular basis; she also wrote orders for a nurse to visit Jane to check on her tubes and work with her, her family, and her PCA, to make sure Jane eats properly and gets the right injections of insulin. Jane works as a partner with her nurse practitioner to do everything she (Jane) can to keep herself healthy. The nurse practitioner visits Jane at least every six months, and more frequently if Jane gets sick and needs help. Since Jane depends on her keyboard to communicate with others, and needs her motorized wheelchair to get around, she alerts her primary care team if something goes wrong so it can get fixed as soon as possible. Nurse practitioners or physicians are on call 24/7, and will always reach her that same day when she's sick and needs help. So far, Jane is doing well, and is living in her home with the assistance of the primary care team, and the services and supports she needs to live her life.

## THE DISABILITY PRACTICE INSTITUTE



## THE DISABILITY CARE PRACTICE (DCP) MODEL

### Frequently Asked Questions (FAQs) for Advocates and Policy Makers

#### *What is the Disability Care Practice (DCP) Model?*

The Disability Care Practice model, as currently conceived of, provides for **all the care and services a person with disabilities needs to function with maximum independence and self-sufficiency at home and in the community**. The DCP program (the implementation of the DCP model) is responsible for care and services covered by Medicare and Medicaid, including medical and mental health care, physical and occupational therapy, preventive care and community support (including durable medical equipment such as wheelchairs, and their maintenance; individualized seating and cushions for wheelchair users; transportation; personal care assistants when they are needed, etc). **The DCP program is not an insurance plan; it is a care provider.**

#### *What is unique about the DCP program?*

Unless someone with physical disabilities is enrolled in Commonwealth Care Alliance's Boston's Community Medical Group (BCMG), Independence Care System (ICS), or Community Health Partnership (CHP), s/he will likely not have access to a team of healthcare professionals whose job it is to listen to her/his choices and goals, and to provide the best possible care in a timely manner. Instead, the status quo means having to make multiple telephone calls, and go from place to place to attempt to get care and support. **In the DCP program, however, primary care team members work together to plan, coordinate, and deliver care.** This includes home visits (at least every six months; more often if there is a significant change in health status); development of an Individualized Plan of Care (IPC), and care coordination and management via computerized health and medical records (that can also be accessed by the member). Disability-competent episodic care will be available 24/7, with the goal of same day home visits for members as needed, to keep people as healthy and independent as possible for as long as possible.

#### *Who will be eligible for it?*

Adults with physical disabilities who are Medicaid and/or Medicare beneficiaries who qualify for nursing home level of care, and are either living in the community, or are making arrangements to live in the community are eligible to enroll. There are no changes for individuals in terms of any co-pay.

#### *How is the program financed?*

The DCP programs will receive payment from state and/or federal government for the provision of Medicaid and/or Medicare covered services and supports, as modeled by the three pioneering disability-competent care programs at CCA/BCMG, CHP, and ICS. The program has been proven to work by these three care systems; all have experience in providing the kind of member-directed, team-based, individualized care that we have been describing, and in ensuring that each beneficiary gets all the care and services s/he needs to maintain health and independence. Currently, the three programs provide care for an aggregate 8,900 adults with disabilities who meet eligibility requirements.

***How do the DCP programs pay for care coordination and home-based primary care in addition to all the other Medicaid and Medicare services?***

This new DCP service model does provide new services not currently covered under the current Medicare and Medicaid regulations. These enhanced services (care coordination) and increased access (24/7 home-based primary care when needed) are financed from the cost savings associated with avoidable hospitalizations. The obvious example is that the monetary cost of hospitalization and/or (skin-flap) surgery for skin breakdown averages between \$50,000 - \$70,000 (for hospital-based costs alone; post-hospital/follow-up costs are additional). Add to this the personal costs to beneficiaries of the discomfort, and disruption of many months of lost productivity and independence. By contrast, when individuals receive timely and appropriate care at any sign of skin breakdown (and of course, prior to this, all preventive care), costs (of all kinds) to everyone are dramatically reduced. The DCP program requires no additional governmental support; instead the care system utilizes the Medicare and Medicaid payments to provide all needed care, services and supports, all of which are allocated by the primary care team, and driven by the goals and choices of the individual.

***To which states will the DCP programs expand?***

The first step is to expand the three existing DCP programs in the states where they currently operate--Massachusetts, New York, and Wisconsin-- to provide care for an additional 7,000 people. Putting the DCP model into practice via local programs on an expanded basis will also shine a light on where the model needs further study and refining in order to expand it to other communities across the country.

***When will this new program be up and running?***

The three programs expect to begin expanding to additional areas within their three states by the beginning of 2012. They then expect to expand to additional local communities in certain states by the end of 2013 or beginning of 2014.

***What is the Disability Practice Institute?***

The DCP Alliance members have created the Disability Practice Institute (DPI) to serve as the nexus of innovation in disability care. The DPI's initial role is to define, refine, and document the Disability Care Practice model. The DPI (or "Institute") is the place where matters such as quality, training, and analysis of "how we're doing" for its beneficiaries, will be housed; the DPI will help us determine how to bring this model of care to people in additional communities across the country.

***Why is the Disability Practice Institute (DPI) needed?***

The Disability Practice Institute (DPI) is critical to the theme of "Getting it right and bringing it to scale;" it is newly established by the three pioneering DCP programs. The DPI will also serve to create the Demonstration platform on which to scale, evaluate, and replicate the DCP model, and serve as a clearinghouse of the model; it will further the development, evaluation and refinement of disability-competent care standards and practices, and facilitate the codification/defining and sharing of best practices through self-assessments and Learning Collaboratives.

***How do the organizations share information and decide what works, and then make changes?***

The DCP programs will be required to track and report on a wide range of data and measures. These data elements will be used to assess measures such as clinical care, quality improvement, financial performance, member satisfaction, ease of access to care for members, and other elements to determine program performance and member outcomes. All personally identifying information is removed to ensure privacy and to ensure compliance with confidentiality regulations. In addition to providing data as required by Medicare and Medicaid, anonymous data are also provided to other oversight organizations and other key stakeholders. The DPI will maintain a data warehouse of longitudinal, personally de-identified data for purposes of program evaluation and refinement. For example, the data may be used to evaluate the performance of varying treatment modalities used with participants at all DCP program sites with Stage IV skin breakdown. This information will subsequently be used to build best practices.

***What is the Vision of the DCP?***

The vision of the three DCP pilot programs is that in 10 years, persons with disabilities will be able to choose to participate in DCP programs in multiple local communities across the country, choose and/or direct the health care services and supports they need, access timely and appropriate care when they need it (thus preventing hospitalizations), obtain needed, individualized, and appropriate wheelchairs and equipment ASAP, and make choices on ways to contain their health care costs to minimize needless cuts in service and maximize support, so they are able to pursue their hopes and dreams.

We welcome your input. For more information, or to send us ideas or best practices, write to us at: [info@disabilitypracticeinstitute.org](mailto:info@disabilitypracticeinstitute.org)

**THE DISABILITY PRACTICE INSTITUTE**



## CREATING THE DISABILITY CARE PRACTICE (DCP) MODEL

### Frequently Asked Questions (FAQs) for Consumers

#### **What is the Disability Care Practice Model?**

The DCP model, as currently conceived of, provides for **all the care and services you need to function with maximum independence and self-sufficiency at your home and in the community.** The DCP program (which is the implementation of the DCP model) is responsible for care and support covered by Medicare and Medicaid, including medical and mental health care, physical and occupational therapy, preventive care and community support (like wheelchairs and their upkeep; individualized seating and cushions for wheelchair users; transportation; personal care assistants or “PCAs,” when they are needed, etc). **The DCP program is not an insurance plan; it is a care provider.**

#### **What is unique about the DCP Program?**

If you aren't currently enrolled in a program with BCMG, Independence Care System, or Community Health Partnership, you probably don't have access to a team of healthcare professionals whose job it is to provide you with the best possible care and in a timely manner. Instead, you are likely calling and/or traveling from place to place to attempt to get the care and support you need. **In the DCP program, however, your primary care team members all work together to plan, coordinate, and deliver your care.** This includes home visits determining what your needs are (at least every six months; more often if you experience a significant change in your health); development of your Individualized Plan of Care (IPC), and management of your care, using computerized health and medical records (that you can access on your own if you so choose). Someone who knows about your health and needs will be on call all the time, and will try to get over to see you when you call if you are sick and need help. They work with you to decide what you need, and to make sure you get whatever you need to remain independent.

#### **Who will be eligible for it?**

You will be eligible for the DCP program if you have a physical disability, are 18 years of age and older, eligible for Medicaid and/or Medicare, would qualify for nursing home level of care, and are either living in the community, or are making arrangements to live in the community. Nothing changes for you in terms of what you pay; whatever you pay for your Medicaid (and/or Medicare) is what you will pay for this new DCP program.

#### **What does “team-based care” mean, exactly?**

Team-based care means that you receive basic medical care (“primary care”) from an actual, multidisciplinary team of healthcare professionals who are there to work with you for your physical, medical, emotional and social well being in partnership with you, to have control over the care and services you need. Care team members usually include: nurse practitioners, physicians, social workers, mental health professionals/therapists, physical therapists, occupational therapists, and others, depending on your needs. The team members work together (and will be connected via computerized records); they will work with you to prevent problems before they happen, such as bedsores (pressure ulcers), and urinary tract infections. When you

enroll in a DCP program, one of the people assigned to your care team (usually the nurse practitioner, perhaps with a social worker) sits down with you (and family or other caregivers you want to have there) to create what is called an “Individualized Plan of Care” (IPC). This is exactly as it sounds: a written plan for all the team members to make sure you get the care and services you need based on your choices, preferences and goals for yourself. For example, you may want to make absolutely certain you can stay in your home, and not move to a nursing home or other group home; you may want to be able to go to your place of worship each week; you may also want to be able to go to a friend’s house on a regular basis, out to dinner, or to the movies, and be able to take advantage of other opportunities in your community. Your team will work with you to determine what you need to keep you safely and comfortably in your home.

**What if I have to go to the hospital?**

The DCP Model covers all care and services across all sites of care -- hospitals, medical offices, residential -- medical as well as mental health care (therapists, family/informal and paid/formal caregivers). Again, the goal of the program is to prevent the need for hospitalizations by **providing all the care and services you need to keep from becoming ill.**

**I have heard that the new program is supposed to be “consumer-directed.” What does that mean?**

Commonwealth Care Alliance/Boston’s Community Medical Group (CCA/BCMG), Community Health Partnership (CHP), and Independence Care System (ICS) are currently operating disability-competent programs in Massachusetts, Wisconsin, and New York, respectively that resemble the DCP model as it has been described. Although each one is slightly different, they all are based on the same goals and principles of providing care for people with disabilities. One of these principles is being “consumer-directed.” This means that your health care and life care goals and preferences shape your individual plan of care; there are checks and balances in place to ensure you get what you need to live as you choose to live. They will respect your right to make your own choices and decisions; for example, if you chose to smoke, even though you know it is bad for your health, that is your decision. If you ask for help to stop smoking, you will get help. That goes for all choices. All people working in these programs are trained in working with persons with disabilities and consumer self-direction and determination. “Member-directed” also means that you can get involved with the way the organizations runs and is managed, if you so choose; all three of the existing DCP programs have ways to involve their members.

It also means that if you have a complaint about someone or something, your complaint will be heard and acted on as quickly as possible; if you use equipment/technology to assist you in any way, you will get quick responses on fixing that equipment/technology immediately if something goes wrong; the focus is on you and your needs, and the people working with these DCP programs know they need to respond as quickly as possible.

**What if I’m unhappy with the program and want to complain or disenroll?**

Of course, the first step is to talk with your team. If you aren’t satisfied in this discussion, you can talk with an ombudsman within the program or call your local Disability Service Center or the Medicaid office. **Remember that these care providers have chosen to provide care that is “disability-competent,” and they want to hear from you. So please speak up. You are a valued expert in meeting your care needs.** If you continue to be dissatisfied, you can disenroll at any time. Disenrollment will be effective the first of the following month, after transition plans are in place to ensure your care following disenrollment.

**How can I get in touch with the existing disability-competent care providers?**

Boston's Community Medical Group (MA): **617.426.0600**

Community Health Partnership (WI): **715.838-2900**

Independence Care System\*\* (NY): **212.584.2500**

For more information on the Disability Care Practice model and programs, write to us at:  
[info@disabilitypracticeinstitute.org](mailto:info@disabilitypracticeinstitute.org)

\*\*Please note that Independence Care System right now provides care coordination – such as helping you find a personal care assistant, working with you to prevent bedsores and urinary tract infections, making sure you have transportation, etc – and manage only long-term care benefits for adults with Medicaid and/or Medicare with physical disabilities in Manhattan, the Bronx, and Brooklyn.

**Is there anything I can do to help make sure this happens?**

Yes. Your experience and perspective is needed to guide the development and ongoing refinement of this new model of care. As persons with a disability, you and your allies know best what isn't working for you; and you have probably created unique solutions to get your needs met. Give us your ideas... tell us your concerns... help us make sure you are in charge of your health choices, and health care.

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