

INTEGRATED PROVIDER ORGANIZATIONAL MODEL:

Developing Consumer-Directed and Integrated
Care for Individuals with Disabilities



Background

Approximately, 62 million Americans experience some level of physical, cognitive, sensory or emotional impairment. For 30 million Americans, the impairment is significant enough to inhibit their ability to participate in society, maintain a household, work, or engage in activities and hobbies.ⁱ The current health care delivery system is ill-equipped to meet the needs of these individuals. Individuals with disabilities face physical, social, communication and attitudinal barriers to attaining quality health care and long term supports and services (LTSS). For example:

- 31% of individuals with disabilities rank their health as fair or poor, compared to 7% of people without a disability.ⁱⁱ
- Individuals with disabilities are at far greater risk for chronic diseases such as diabetes, HIV/AIDs and depression.ⁱⁱⁱ
- Women with disabilities experience significant physical and attitudinal barriers to routine gynecologic and reproductive health care. According to one study, women with disabilities were 24% less likely to have received a Pap test during the previous year than women without disabilities and were nearly three times more likely than women without disabilities to have postponed needed medical care.^{iv}
- Health care providers are poorly trained to meet the needs of individuals with disabilities. They often hold inaccurate or stereotypical perceptions about people with disabilities, make judgments about individuals' quality of life, or fail to make their facilities, clinics, diagnostic tools and exams accessible.

Vestiges of the traditional fee-for-service system often result in high cost, high utilization, and avoidable episodes of illness due to barriers to access, inadequate care coordination and lack of disability-competent solutions. Although states are implementing new initiatives to modernize care delivery, the managed care models under development typically provide a "one-size-fits-all" approach that is challenged to meet the needs of complex and vulnerable populations and offers consumers no choice of meaningfully different options. These approaches aim to enroll thousands of individuals served by large provider networks overseen by insurer-based health plans with care management functions added to facilitate coordination of care.

What is missing is a model that focuses on people with functional impairment and complex healthcare needs who require customized, coordinated solutions offered by a highly integrated and coordinated delivery system, either as part of a single provider-based organization or through a selected network of direct care providers. This approach to care is unavailable in either the traditional fee-for-service model or current managed care models.

The Program of All-Inclusive Care for the Elderly (PACE®) model is an integrated solution for older adults with complex chronic conditions and provides a starting point for developing a care model to better serve people with disabilities and complex medical care needs. PACE integrates LTSS with preventive, primary and acute medical care to maintain individuals in a community setting. As states develop and further refine new care models for frail populations, a demonstration to test and adapt the PACE model could provide customized solutions to those who struggle the most in obtaining much needed healthcare, while simultaneously delivering significant financial savings.

PACE Model of Care

PACE fully integrates all Medicare and Medicaid services through capitated financing to promote primary, acute, specialty and LTSS for frail older adults. The principle tenet of the model is the belief that it is

better for older adults who have functional limitations and complex chronic conditions to remain in the community as long as possible

In PACE care is provided by an interdisciplinary team (IDT) made up of 11 different professionals who oversee and provide all medically-necessary care for every PACE enrollee. Each PACE organization has at least one PACE center, a physical location where most enrolled participants receive services such as primary care, therapies and socialization.

PACE is a permanent provider under Medicare and a voluntary state option under Medicaid. PACE organizations receive a fixed monthly payment to provide all necessary care. Under this capitated payment system, PACE programs are able to provide the entire continuum of care and services to older adults with chronic care needs while maintaining their independence in their homes for as long as possible.

Currently, 114 PACE organizations provide care for approximately 35,000 people in 32 states. In order to be eligible for PACE services, an individual needs to be 55 years or older, reside in a PACE service area, be certified nursing home eligible and be able to live safely in the community with the help of PACE services. PACE leaders, policymakers, and consumer organizations have expressed a desire to expand eligibility so that more high-risk, high need individuals can access the high quality of care offered through PACE. Specifically, younger individuals with physical disabilities, intellectual or developmental disabilities, multiple, complex chronic diseases and other risk factors may be good candidates for the comprehensive care offered by PACE.

Because PACE eligibility is limited in statute, the National PACE Association, along with several other stakeholders, has proposed that the Center for Medicare and Medicaid Services (CMS) use its demonstration authority to test a "PACE-like" model with new populations. The PACE-like model would likely differ from PACE in some ways, but would offer younger individuals with disabilities and other complex populations a more integrated, direct care delivery system alternative to the current fee-for-service and managed care models.

Stakeholder Meeting

On March 10, 2015, the [National PACE Association](#), a member association representing the 114 independently operated PACE organizations across the country, and [Inglis Foundation](#), an organization serving adults with physical disabilities, convened a meeting to explore developing a care model that would adapt PACE to address the needs of individuals with disabilities. Attendees included representatives from national disability-related consumer and provider organizations, PACE organizations, state governments, and the Centers for Medicare and Medicaid Services (CMS).

The meeting provided an opportunity for the various stakeholders to consider how the PACE model could serve as a foundation for designing a delivery system and care model for people with disabilities who seek an alternative to uncoordinated fee-for-service care and remotely coordinated care by large, insurer-based health plans. In considering this question, the meeting aimed to:

- 1) Support the development of a PACE-like, Integrated Provider Organization (IPO) model for people with significant functional limitations and complex, chronic illnesses;
- 2) Determine the features of the care model needed to improve quality of care and quality of life for those the model would serve; and
- 3) Identify both a process and a timeline for implementing an IPO care model through a pilot or demonstration program.

Aspirations

Recognizing that a new model of care brings both hopes and concerns for the range of stakeholders, the meeting participants identified these at the outset. Meeting participants were randomly assigned to one of three groups to articulate the hopes and concerns for an IPO pilot from the perspectives of the government, providers, and consumers. The three viewpoints are highlighted in Table 1 below.

Table 1: Pilot Hopes and Concerns

Government Hopes	Government Concerns	Provider Hopes	Provider Concerns	Consumer Hopes	Consumer Concerns
Cost Savings	Higher cost without improving delivery	Adequate reimbursement	Insufficient reimbursement	System responsive to the needs of consumers	Access/Provider network inadequacy
Quality Improvement	Too small to make an impact	Improved pool of competent disability providers	Financial risk	Consumers in control and have the ability to make choice	Medicalization of LTSS
Increased Value	Administrative burdens	Ease of implementation	Too much regulation	Person centered	People don't want to be confined to a center
Improved affordability	Consumer/provider backlash	More integrated care	Monopoly of provider services	Disability competence	Quality of care may be poor
Reduced tax burden	Too many will use it	Innovation and providing services	Impact on choices	System responsive to the needs of consumers	Bureaucracy
Addressing gaps	Too few will use it	Serving more people	How to effectively coordinate care	Consumers in control and have the ability to make choice	Fear that disability groups would get lost
Increased access		Greater access to new population	Impact against HCBS rule	Person centered	Restrictive care model
Person centered		Creating flexibility/creativity in model	Insufficient funding	Increased access	No government bandwidth
Care coordination		Adequate reimbursement			Medicalization of LTSS

Government Hopes	Government Concerns	Provider Hopes	Provider Concerns	Consumer Hopes	Consumer Concerns
Improve consumer experience		Improved pool of competent disability providers			
Delivery system improvements					

With these hopes and concerns in mind, the stakeholders proceeded to address the following design elements for an IPO demonstration:

- Population – who would the IPO demonstration serve?
- Delivery System – what are the attributes and requirements for the IPO delivery system?
- Consumer Choice – how will the IPO support consumer choice and independence regarding access to and location of services?

Population

Currently, PACE serves individuals who are 55 years of age and require a nursing home level of care as designated by their state. The average participant is 76 years old, with multiple complex medical conditions, cognitive and/or functional impairments, and significant health and long-term care needs. This population requires the high degree of investment in assessing care needs, coordinating and delivering care. Due to the intensive nature of the PACE model, attendees agreed that a

PACE-like expansion should focus on individuals who have significant care needs, such as younger individuals who require help with activities of daily living, those diagnosed with multiple chronic diseases, and those whose health challenges and medical care needs are compounded by their disability and need for LTSS. The group agreed that healthy or well individuals with disabilities may not need a PACE-type



level of care. The following types of potential enrollees who have complex medical care needs and disabilities were identified:

- individuals with physical disabilities,
- individuals with cognitive disabilities
- individuals with intellectual or developmental disabilities,
- individuals with chronic care needs that result in functional impairment, and
- individuals with significant behavioral health needs.

In some cases, these individuals might not meet the state's definition of requiring a nursing home level of care. Further refinement of the eligible population, in conjunction with state policymakers, provider organizations, and consumers, will be necessary.

The group also agreed that one entity would likely be unable to meet the diverse and varying needs of all the subpopulations. Further specialization by subpopulation might be helpful in refining the care model.

Additionally, attendees noted that this model should be designed to meet the needs of individuals with disabilities across their lifespan. Individuals served under the demonstration - should it be successful - should be allowed to remain in the demonstration throughout their life, and not transitioned into PACE or elsewhere upon turning 55.

Delivery System

While insurers typically contract with large networks of providers who deliver services to a diverse group of patients (e.g., young and old, infirmed and well, public payers and private payers), PACE employs (directly or through contracts) providers who primarily serve PACE participants. This allows PACE IDT members to develop closer relationships with participants, increase their geriatric competence, and develop close working relationships across the IDT. Participants generally forgo their existing providers (e.g., primary care, therapists) to solely receive services from the PACE IDT.

Many consider the "provider-based nature" a key ingredient to PACE's success. At the same time, it has been known to restrict growth and deter individuals from enrolling, especially those who want to retain their primary care physicians. Further, it limits the models ability to leverage existing community resources that may be especially important in designing delivery system models for new populations.

Meeting participants discussed whether or not the IPO model should follow a similar approach. Specifically, the group raised the following questions and comments about organizations that would participate in the pilot:

1. Does the entity need to be in a position to directly provide all necessary services? Or would they be able to contract with community providers to establish small, highly coordinated and integrated networks focused on the high needs population they serve?
2. PACE uses a staff model of direct care providers to ensure coordination and appropriate expertise in the needs of its geriatric population. Are there other ways to assure coordination of care and disability competence for new populations?

Consumer Choice

The challenge will be to enable the participants as much choice and flexibility as possible while ensuring a well-coordinated and supported model of care. The group emphasized the importance of creating a

care model that facilitates independence, provides greater value than current options, ensures self-direction and – most importantly – appeals to consumers.

The group recognized the challenges of building such a model, especially given the diverse needs and preferences of various subpopulations within the disability community. For instance, younger individuals with intellectual or developmental disabilities may have vastly different expectations and needs than individuals with physical disabilities, or seniors who are at risk of a nursing home placement.

Likewise, some elements of the current PACE model may not appeal to certain potential target populations. Specifically, the use of the day center was problematic for many stakeholders. The use of congregate care settings is inconsistent with many of the goals of the disability rights community, who advocate for individually tailored services and supports that allow the individual to live, work, and socialize in communities of his or her choosing. A congregate care setting that exclusively serves people with disabilities is incongruent with principles of inclusion and self-determination, and is inconsistent with newly emerging LTSS regulations.

Others, noted that individuals with disabilities might benefit from daytime services that offer individuals the opportunity to socialize, participate in exercise or physical therapy activities, receive nutritional support through meals and counseling, explore employment options and receive other supports.

In offering day services, it is important to consider the individual preferences of those served through an IPO. While some individuals may avoid a congregate location or a facility that primarily serves individuals with disabilities, others might prefer the convenience and specialization that comes with a daytime setting devoted to their care. One example would be MS day programs, which have long waiting lists in many communities or Centers for Independent Living, which are run by and for people with disabilities, and offer support, advocacy, and information. Similarly, some individuals with disabilities would strongly prefer a model that allows them to visit the provider of their choice, while others might favor a PACE-like model where they are guaranteed a closely knit care team that offers high quality, disability-competent care.

The group grappled with how much to modify the PACE model to accommodate these multiple demands. While the participants did not reach consensus on all of these issues, they determined that an IPO could potentially address these concerns if it:

- Honors consumer self-determination;
- Offers consumers some choice of providers, especially personal care attendants;
- Complies with recent CMS regulations around Home and Community Based Settings;
- Assures choice on where services are delivered (i.e., not being forced to attend a day center);
- Balances medical care and social supports to reflect the holistic needs of the individual, including the need for independence and self-determination; and
- Collects and reports on quality and outcomes measures.

Furthermore, they noted that a PACE-like model should be one of many options available in a well-designed health care system that includes:

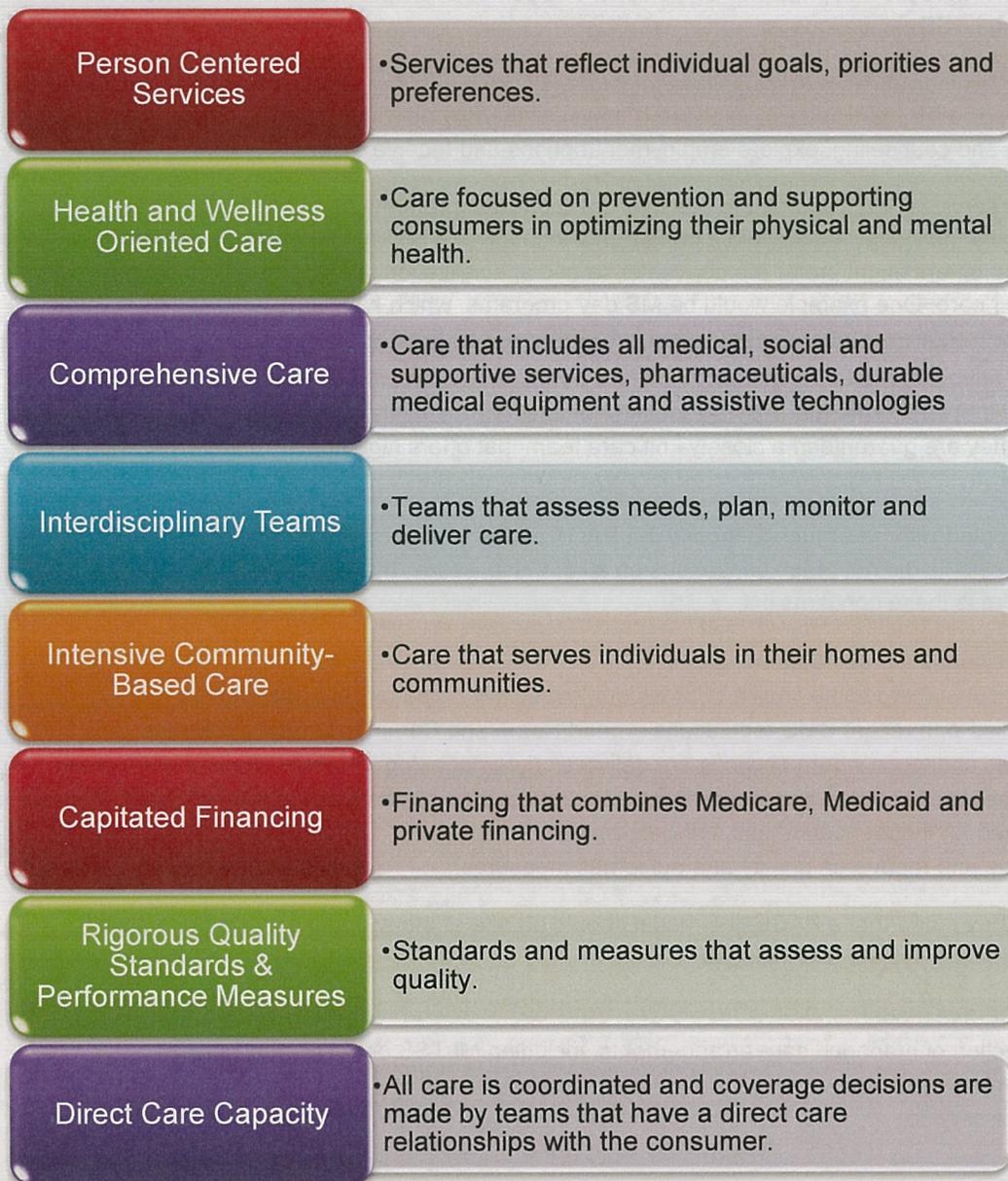
- A PACE-like model;
- A selection of managed care arrangements, including MLTSS or financial alignment demonstrations; and
- Fee-for-service

With these options in place, one stakeholder asserted, providers would have to compete for consumers' business. Providers that are able to provide better and higher quality services are arguably better able to draw in more patients. Further, individuals would be able to select the type of delivery system that best suits their needs and preferences.

Recognizing that a range of IPO care models is likely to offer the best path forward, the stakeholder group developed core elements that can be adopted to allow for flexibility within a framework for implementing the demonstration.

Core Elements of the Model

The group envisioned the following elements in an IPO, many of which are derived from the current PACE model of care:



There are some areas in which an IPO/PACE-like model may deviate from the PACE model. For instance, although PACE organizations engage in home modifications for seniors, the model does not provide housing. Additionally, PACE does not yet have a finalized set of quality standards and performance measures which would be necessary for the IPO.

Designing a Pilot

Acknowledging the diverse needs of people that could be served under an IPO pilot and the range of delivery system features that might be considered, the stakeholders considered the size and scope of the pilot. Questions raised during the discussion included:

1. Would the IPO be limited in enrollment size?
2. How many demonstrations should there be?
3. Should the initial demonstrations be restricted to specific states or geographic areas?
4. Will there be rules allowing for flexibility based on whether it is in an urban or rural area?
5. How long will the demonstration period last?

The group considered the experience of PACE in addressing these issues. The average PACE organization serves about 322 individuals; the median is approximately 183. Developing PACE-like IPO models that are of a similar size may prove challenging in managing financial risk because of the wide variation in costs of care and the limited ability to spread risk over a larger enrolled population. In developing the pilot, the group reflected on the lessons learned from the rural PACE experience. In the early phases of the rural PACE pilot, an outlier fund was created in which programs that experienced acute care costs in excess of \$50,000 per participant would be able to apply for outlier protection. In the history of the program, there were only a couple instances in which the funding was necessary. Providing a safety net similar to the rural PACE outlier fund would help mitigate risk and would further encourage providers to apply to participate in an initial pilot test.

In PACE, NPA has found that the investment in the interdisciplinary team (IDT) needs to be commensurate with the number of PACE enrollees. PACE organizations typically follow the guideline that there is one IDT for every 150 people. The same guideline may be applied to the PACE-like IPO model.

Since the IPO would be new, the use of technical assistance centers (TACs) would be helpful in promoting the success of a pilot test. TACs can offer organizations and providers the guidance and tools necessary to develop a PACE-like IPO model. Within the PACE community there are about 10 TACs that help interested organizations develop PACE and they have been instrumental in accommodating PACE growth.

Drawing on its earlier discussions and the consideration of a pilot's size and scope, the group concluded by recommending the attributes for an IPO pilot's populations served, scale and start-up. Table 2 on the following page summarizes these recommendations.

Table 2: Integrated Provider Organization Pilot Attributes

Population Served	<ul style="list-style-type: none">• Individuals with functional limitations• Significant healthcare needs• 18 through end of life<ul style="list-style-type: none">○ Scope and integration of benefit Medicare and Medicaid○ Collaboration with housing and employment agencies
Scale	<ul style="list-style-type: none">• Size needs to be sufficient to appeal to policymakers• Relationship between IDT size and populations served• Sufficient to evaluate across different programs• Proposal should be drafted to attract both large scale and small scale organizations
Startup Support	<ul style="list-style-type: none">• Initial capital investment funds - both for start-up and reserves• Risk management/reinsurance/outlier protection• Technical assistance/guidance

Summary

In closing, the group largely concurred that there is merit to a new care model and delivery system that would allow providers, or groups of providers, to assume risk for providing comprehensive health care and LTSS to individuals with disabilities. Additional conversations to reach consensus about the following elements of the pilot will be necessary:

- Specific populations served
- Care delivery model
- Consumer choice and independence

The pilot may need to allow for varying care models targeting several subpopulations. Accordingly, the pilot will need to be large enough to allow for some comparability across different care models/subpopulations in order to develop reliable and valid assessments to evaluate the variations.

Participants

Organization	Name
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Volunteers of America	Angela King

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Inglis – An organization that has been committed to helping people with disabilities since 1877. Inglis House serves people living independently in the community, as well as those living in residential long-term care community.

National PACE Association – An association that advances the efforts of Programs of All-inclusive Care for the Elderly. PACE programs coordinate and provide all needed preventive, primary, acute and long term care services so that older individuals can continue living in the community.

Christopher Duff – Former CEO of AXIS Healthcare, a Medicaid/Medicaid care management organization for adults with disabilities, Executive Director of the Disability Practice Institute, Chris Duff currently works as a disability policy and practice consultant, focusing on programs serving adults with disabilities who are largely on public programs.

ANCOR – The American Network of Community Options and Resources is a national trade association representing more than 800 private providers of community living and employment supports and services to more than 400,000 individuals with disabilities .(<http://www.ancor.org/>)

ⁱ Altman, Barbara & A. Bernstein, *Disability and Health in the United States, 2001-2005* (Hyattsville, MD: National Center for Health Statistics, 2008).

ⁱⁱ Seth Curtis and Dennis Heaphy, Disability Policy Consortium: *Disabilities and Disparities: Executive Summary* (March 2009).

ⁱⁱⁱ *Ibid.*

^{iv} National Council on Disabilities "The Current State of Health Care for People with Disabilities."
<http://www.ncd.gov/publications/2009/Sept302009#Health%20Status>

