Expanding the PACE Program: Challenges and Opportunities

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Background

- The Program of All-Inclusive Care for the Elderly (PACE) provides coordinated acute, chronic care, and long-term services and supports (LTSS) to:
  - individuals aged 55 or older,
  - who meet eligibility criteria for nursing home care, and
  - who are living in the community when they enroll.
- Key PACE model components:
  - Adult day health center
  - Interdisciplinary team
  - Capitated, per-member per-month basis payment
- The PACE Innovation Act of 2015 allows CMS to develop pilot projects using the PACE model, and to expand the program to individuals with disabilities who are aged 54 years or younger.

- Discuss the challenges and potential approaches to address those challenges when considering an expansion of the PACE model to include younger populations.

- Our study addressed the following research questions:
  - What are the key non-medical services needed for populations that might be served by an expanded PACE program?
  - How are those services currently provided?
  - How might an expanded PACE program collaborate with other organizations and resources to meet those service needs?
  - What modifications would need to be made to the existing PACE program to effectively meet the unique service needs and preferences of this population?

Methods

Reviewed published Medicare and Medicaid data to identify potential target populations of an expanded PACE program.

Conducted environmental scan of peer-reviewed and gray literature to learn about the potential target populations.

- Advocacy organizations that represent individuals with disabilities generally (e.g., American Association of People with Disabilities, National Council on Disabilities)
- Advocacy organizations that represent individual disability groups
  - Individuals with ID/DD (e.g., The Arc, Autism Speaks)
  - Individuals with mental health disabilities (National Alliance on Mental Illness)
  - Individuals with physical disabilities (National Multiple Sclerosis Society)
- U.S. Department of Health and Human Services agencies that focus on disabilities (e.g., Administration on Intellectual and Developmental Disabilities, SAMHSA).
- Information on services offered under state 1915(c) HCBS waivers.
- Reports on specific services (e.g., state data on vocational rehabilitation services) and federal programs.

- Younger adults (< 55 years old) who
  – Have physical disabilities
  – Have intellectual or developmental disabilities (ID/DD)
  – Have mental health disabilities

- **Intellectual disability (ID)** characterized by significant limitations both in intellectual functioning and adaptive behavior that originates before age 18 (e.g., autism spectrum disorders, Down syndrome, or fetal alcohol syndrome).

- **Developmental disabilities (DD)** is an umbrella term that includes intellectual disability but also other disabilities that are apparent before age 22 and are likely to be lifelong disabilities.

- Individuals with ID/DD represent a significant portion of the population receiving home and community-based services (HCBS) and of HCBS expenditures.

  – Accounted for more than 40% of total Section 1915(c) Medicaid HCBS waiver participants and 72% of all spending in fiscal year (FY) 2012

  – Average per-enrollee expenditure for an individual with ID/DD in Section 1915(c) HCBS waivers was $47,522 compared to an overall average of $27,232 among all enrollees in FY 2012

Individuals with Mental Health Disabilities

- Includes individuals with a serious mental illness (SMI), substance use disorder (SUD), or co-occurring SMI and SUD.
- SMI includes anxiety, trauma, and depression, as well as eating, personality, and psychotic disorders.
  - 9.8 million adults aged 18 or older in 2014
- SUD include recurrent use of alcohol and legal or illegal drugs that cause significant impairment.
  - 21.5 million people aged 12 or older in 2014, including 17.0 million with an alcohol use disorder and 7.1 million people with an illicit drug use disorder
- Among the 20.2 million adults aged 18 or older who had past-year SUD, 2.3 million (11.3%) also had SMI.
- Represent a very small share of population receiving HCBS
  - Accounted for 0.2% of total Section 1915(c) Medicaid HCBS waiver participants and 0.1% of all spending in FY 2012

- Physical disability may be the result of a congenital condition or due to illness or injury that occurred at some point in an individual's life.
  - Conditions may include such things as paraplegia, quadriplegia, blindness, deafness, multiple sclerosis, muscular dystrophy, traumatic brain injury, and spina bifida.
  - An individual's needs and preferences for support services will often vary by type of disability, age of onset, and stage of life.
- In 2014, 22.4% of people age 18 to 65 reported any physical difficulty
  - 4.9% among individuals age 18 to 44 and 17.5% among individuals age 45 to 65
  - Include high level of difficulty with ambulation, climbing stairs, standing, sitting for long times, stooping/bending/kneeling, reaching over head, grasping small objects, lifting/carrying 10 pounds or more, or pushing/pulling large objects

What Types of Non-Medical Services are Needed?

- Non-medical services help individuals with disabilities to live in the community, and to be as independent and engaged as possible

- Services may include
  - Residential supports
  - Employment supports
  - Education supports
  - Transition supports
  - Assistive technology
  - Support services
  - Care coordination
  - Transportation
  - Specialized treatment services

Residential Support

- Residential and housing supports, such as financial supports and home modifications, are needed to maintain community residence

- Residential needs may vary by population
  - Individuals with physical disabilities: Physical modifications to residence, such as ramps, widened doors, roll-in showers, raised toilet seats, or grab-bars
  - Individuals with mental health disabilities: Stable housing programs with access to case management and located near public transportation
  - Individuals with ID/DD: In-home support staff to assist with cuing and supervision

- Vocational rehabilitation services to help prepare for and engage in competitive integrated employment
- Supported employment services to provide ongoing support to people within integrated employment settings
- Employment support needs vary by population
  - Individuals with intellectual or developmental disabilities: Job training, on-site job coaches
  - Individuals with physical disabilities: Work environments that can adapt to physical needs, including access to assistive technology and physical restoration services
  - Individuals with mental health disabilities: Supported employment models specific to population, including Individual Placement and Support and Customized Employment models

Education Support

- Help individuals identify and support educational goals, including postsecondary education

- Link people to resources needed to overcome any barriers to completing education

- Education support needs vary by population
  - Individuals with physical disabilities: Supports to ensure mobility and accessibility to schools and assistive technology for individuals with physical disabilities

Transitional Support

- Assist individuals as they move from youth-based services to adult-based services to ensure they achieve education and employment goals to remain integrated in the community

- Transitional support needs vary by population
  - Individuals with physical disabilities: Supports that focus on how the postsecondary or employment environments can be modified to ensure mobility and transportation access
  - Young individuals with ID/DD: Specific services that focus on acquisition of daily living skills and functional vocational evaluation

- Technologies that can help individuals with everyday activities and enable them to maximize independence
- Assistive technology needs vary by population
  - Individuals with mental health disabilities: Therapeutic tools such as cuing devices, speech output devices, medication aids, and safety devices such as GPS locator systems
  - Individuals with physical disabilities: Tools focus on providing physical assistance such as motorized wheelchairs, robotic limbs, and voice and eye gaze–activated computer programs
  - Individuals with ID/DD: Tools that provide supervision and cuing assistance such as computer-aided systems providing pictorial task instructions to assist with housekeeping activities

- Services provided by another person to assist the individual with ADLs (e.g., walking, bathing, dressing) and IADLs (cooking, managing medication)

- Support services may be self-directed

- Support needs vary by population
  - Individuals with mental health disabilities or ID/DD: May be physically capable of performing everyday activities, but impairment prevents an individual from knowing when or how to carry out the task
  - Individuals with mental health disabilities: Peer recovery support services designed and delivered by people who have also experienced a mental and/or substance use disorder and are in recovery

- Coordination of the multiple services and supports needed to meet complex and unique needs is critical to ensure quality care.

- Care coordination can include assessment and service planning, accessing and arranging for services, and coordinating multiple services, including access to crisis services.

- For individuals with mental health disabilities, legal and organizational prohibitions on providers sharing information about mental health diagnoses, medications, and other features of clinical care can impede information exchange and effective care coordination.

Transportation

- Affordable and reliable transportation allows people with disabilities access to important opportunities in education, employment, health care, housing, and community life.

- Support needs vary by population
  - Individuals with physical disabilities: Require access to transportation that can accommodate physical impairments, which includes transportation with wheelchair access or support for other mobility aids; vehicle modifications
  - Individuals with ID/DD and mental health disabilities: Less likely to drive and may need aids to assist with navigating public transportation systems

Specialized Treatment Services

- Among individuals with mental health disabilities, specialized intervention treatment services are used to promote recovery.

- Many common treatment elements include medications, psychotherapy, psychosocial support, and crisis intervention.

  – Individual and group counseling or therapy, such as Cognitive-Behavioral Therapy or Motivational Enhancement Therapy

  – Community-based treatments, such as Assertive Community Treatment

  – Medications used in combination with counseling or psychotherapy.

How Are These Services Currently Provided?

A complex web of federal, state, and local agencies and funding sources

Federal Resources

Funding Source	Examples of Resource
Medicaid	• Residential care services, home modifications, or 1915(b)(3) authority for housing-related services • Current 1915(c) HCBS waivers and state plan options for other non-medical services, such as self-directed support services, transportation for non-medical activities
Other federal programs	• Social Security Administration (e.g., Ticket to Work Program, Plan for Achieving Self-Support) • U.S. Department of Housing and Urban Development (e.g., Housing Choice Vouchers Program)
Federal block and grant programs	• U.S. Department of Education grants for postsecondary education support • Community Mental Health Services Block Grant • State Grant for Assistive Technology

State Resources

Funding Source	Examples of Resource
State agencies	• Vocational rehabilitation agencies • State ID/DD agencies • State and county mental health agencies
Other local agencies or community-based organizations	• Centers for Independent Living • The Arc • National Alliance on Mental Illness

Adult Day Health Center

- ***Key Challenges:*** Attendance at the adult day center could conflict with employment opportunities and responsibilities, as well as a general emphasis on community integration

- ***Potential Approaches:***
  - Do not require attendance at a day center
  - Provide similar services through a different type of setting (e.g., vocational rehabilitation agency)
  - Consider a drop-in center

- ***Examples:***
  - CenterLight Healthcare PACE program
  - Rocky Mountain Health Services

Interdisciplinary Team

- ***Key Challenges:*** May be incompatible with self-direction and could disrupt long-standing relationships with usual service providers. IDT staff may need to build relationships with other organizations and funding sources.

- ***Potential Approaches:***
  – Revise required IDT membership
  – Allow and support self-direction
  – Emphasize care coordination over medical care provision

- ***Example:***
  – Community Care PACE program

Payment Structure

- ***Key Challenges:*** Rate-setting methodology needs to reflect the service needs of any new target populations and should consider how to pay for services outside of the usual benefit package

- ***Potential Approaches:***
  - New research is needed to build appropriate payment models for Medicaid and Medicare
  - Incorporate other funding streams, such as Social Services Block Grants

Eligibility Determination

- ***Key Challenges:*** Current PACE eligibility criteria relying on state nursing home level-of-care determination may not be an appropriate measure of need for expansion populations

- ***Potential Approaches:***
  - Individuals with physical disabilities: continue with nursing home level-of-care criteria
  - Individuals with ID/DD: State level of care criteria for intermediate care facilities for individuals with intellectual or developmental disabilities (ICFs-IDD)
  - Individuals with mental health disabilities: 1915(i) state plan option eligibility criteria

- An expansion of the PACE program to individuals under 55 could provide people with complex needs access to needed medical and nonmedical services in a coordinated setting
- Challenges remain with current PACE structure
  - PACE program should be attuned to desires for independence and community integration
  - Many nonmedical service needs are not generally used by population currently served by PACE (e.g., transitional, education, employment supports)
  - New relationships will need to be forged with public and private agencies that offer these services and which are known to adults with disabilities
  - PACE programs may need to learn about and develop methods for integrating funding streams outside of Medicare and Medicaid, such as those that provide employment or housing supports.

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