

Integrated Health Services for Persons Living with Disabilities: "The Mayo Clinic for People with Disabilities"

Gavin Kerr 23 September 2011

Navigating America's health system can be a challenge for the most active, able-bodied among us. While our health system's capabilities are extraordinary, the system leaves even the most sophisticated consumers bewildered. For people living with physical, cognitive and developmental disabilities, the experience can be especially frustrating, traumatic and, in some cases, life-threatening.

People living with disabilities (also known as consumers) often live with complex chronic health conditions and have a greater need for care than most. Unfortunately, health services are often very difficult for them to access and use. Some of the barriers to high-quality, efficiently delivered care include:

- The 18" distance from a wheelchair up to an exam table can be an Everest-like climb for a person with quadriplegia. Unfortunately, barrier-free offices and equipment such as accessible exam tables, scales

and imaging equipment are rare. Moreover, consumers report that office staff often are unable—or unwilling—to assist with transfers from wheelchair to exam table.

- People with disabilities can be a bit scary if you don't have the experience to know what truly lovely people they are. As a result, healthcare professionals and office staff often feel ill-prepared to care for them and may have fears and attitudes that prevent them from giving (or being willing to give) appropriate care. This issue is exacerbated when caregivers must make extra time and extra office resources available to care for the disabled individual yet receive no greater reimbursement for their time and effort.
- Can you imagine having a 4+ hour journey for a 15-minute appointment? Now can you imagine not having the right test results available or having to reschedule for another specialist? That is a common occurrence for people with disabilities who depend on para-transit each day. For people with complex conditions, and especially those with disabilities, the lack of coordination can be devastating and life-threatening when information about medical histories, treatment plans and prescriptions is not available. This issue becomes even more critical when the consumer is unable to communicate for himself or herself adequately.

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Often, innovation is not creating something new, but applying an existing solution or solutions to a different problem in novel ways. I believe that a better healthcare solution exists for people living with disabilities (and for all people with chronic illnesses). Nationwide, frail elderly persons who are dually eligible for Medicaid and Medicare participate in PACE programs. The Program of All-Inclusive Care for the Elderly (PACE) features an interdisciplinary care team, consisting of professional and paraprofessional staff, who assess participants' needs, develop care plans, and deliver all services in a tightly coordinated, wellness-oriented model. Delivering all needed medical and supportive services, the program is able to provide the entire continuum of care and services to seniors with chronic care needs while maintaining their independence in their homes for as long as possible.

PACE services typically include:

- Adult day care that offers nursing; physical, occupational and recreational therapies; meals; nutritional counseling; social work; and personal care.
- Medical care provided by a PACE physician familiar with the history, needs and preferences of each participant.
- Home healthcare and personal care.

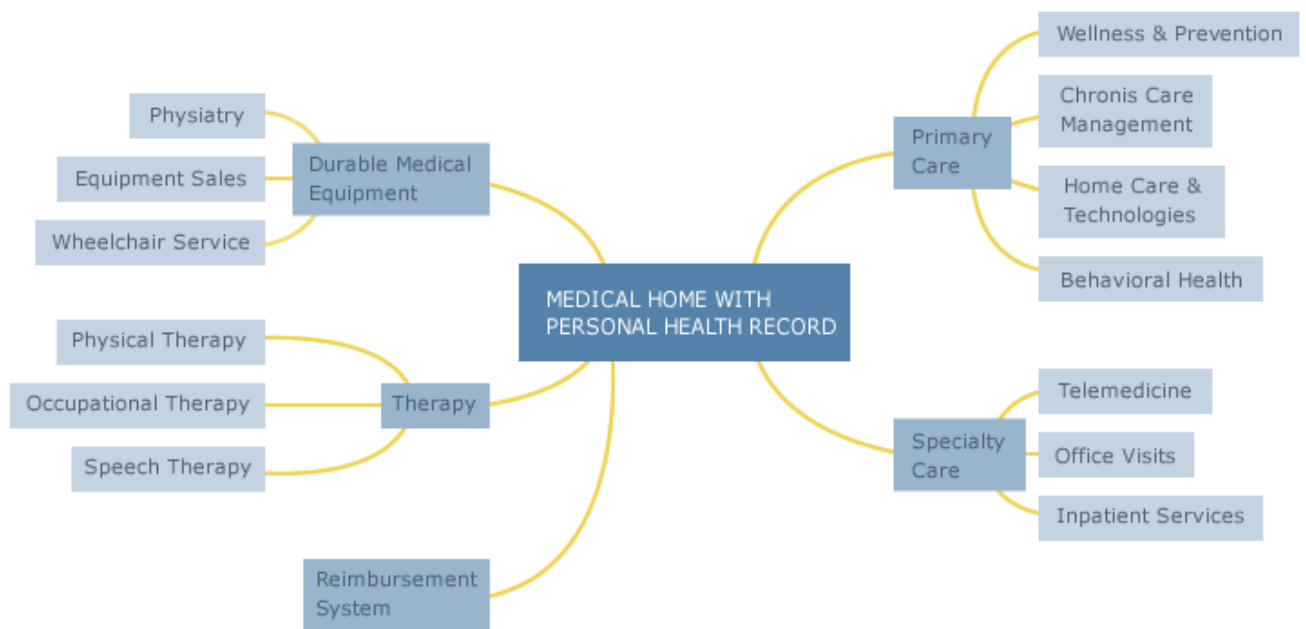
- All necessary prescription drugs.
- Social services.
- Medical specialists such as audiology, dentistry, optometry, podiatry and speech therapy.
- Respite care.
- Hospital and nursing home care when necessary.

And because PACE programs are capitated with a fixed monthly payment, PACE providers have a strong economic incentive to deliver care that is coordinated, caring and cost-effective.

Currently Pennsylvania PACE programs are limited to people 65 and older with incomes of less than \$14,500 who are eligible for both Medicare and Medicaid. At Inglis, we are working with Pennsylvania's Departments of Long Term Living, Public Welfare and Health and Human Services to adapt the PACE-like model to serve younger people living with disabilities. Key elements of a typical PACE program will be provided but with important enhancements to meet the needs of people with disabilities:

- A medical home with integrated preventative care and specialized chronic illness management.
- Accessible, barrier-free office environments including accessible exam tables, imaging and lab equipment, etc. and easy access to public transportation.
- Disability-friendly, specially trained staff including medical professionals, assistive personnel and office staff.

- An accessible, consumer-owned personal health record linked to adapted technologies for health management, prescription dispensing, care coordination, etc.
- Extensive use of home care and telemedicine to reduce transportation requirements.
- An integrated attendant care system that ensures appropriate, safe and dependable support with activities of daily living and chronic illness management.
- A capitated payment system, utilizing proven care management strategies to optimize health while minimizing utilization.



Critical Issues and Challenges

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As the nation and states struggle with massive deficits and seek to control Medicare and Medicaid spending, a PACE-like solution for individuals with disabilities provides

great promise to improve life while controlling healthcare expenditures across decades of care. Savings opportunities include eliminating unnecessary emergency care, reducing hospital admissions for chronic conditions and preventing hospitalizations typical of wheelchair users such as pressure wounds and urinary tract infections. In addition, the PACE-like model has the opportunity to reduce high-cost nursing home admissions and support consumers with higher acuity conditions to transition from nursing homes back into the community.

Several key challenges will need to be addressed to make this new approach successful. A critical economic challenge will be creating actuarial models and rates sufficient to address the complex health needs of people living with disabilities over long periods of time. This will be especially challenging for those with degenerative diseases such as Multiple Sclerosis and Lou Gehrig's disease (ALS). Moreover, the reimbursement system must be sufficient to incent a network of providers to participate and invest in accessible offices, equipment and special training for staff. Managing pharmaceutical costs will be important and difficult for diseases that often require exotic, small volume, high-cost drugs. A successful pilot will require developing care management protocols and electronic medical records that empower consumers to maintain their own health and enable caregivers to manage chronic conditions over periods of many years. And, perhaps most importantly, we must

build the confidence of consumers that this model will enable them to live with greater independence, more robust health and in ways that empower them to manage their own health and their own life.

Inglis is anxious to partner with the Commonwealth, healthcare providers and consumers in creating a demonstration project to test the viability of this model and, if successful, implement it broadly. I am confident that together we can enable consumers and their caregivers to achieve health and to live full, rich lives—cost-effectively.