

# Creating Better Systems of Care for Adults with Disabilities: Lessons for Policy and Practice

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## PROGRAM AT A GLANCE

**KEY FEATURES:** Some health plans and clinics have created customized approaches for people with disabilities. These programs share key features including ensuring accessible care, proactively identifying and treating secondary conditions, engaging and building trust with patients, and integrating long-term services and supports to improve health and promote independence and social inclusion.

**TARGET POPULATIONS:** Working-age adults living with physical disabilities, intellectual and developmental disabilities, or serious mental illnesses.

**WHY IT'S IMPORTANT:** Americans with disabilities often have difficulty finding physically accessible practices or providers with expertise in their conditions. Compared with other adults, they receive less preventive care and have a high incidence of potentially preventable medical conditions stemming from their disabilities.

**BENEFITS:** Engaging patients in managing their conditions and offering them a variety of support services can help avoid medical complications and improve quality of life.

**CHALLENGES:** Ensuring adequate funding. Programs that serve adults with disabilities often rely on private and public grants to cover their costs. More closely managing medical and long-term services and supports for people with disabilities — as a growing number of states are doing through managed care — may lead to higher rather than lower spending, at least in the short term.

## TOPLINES

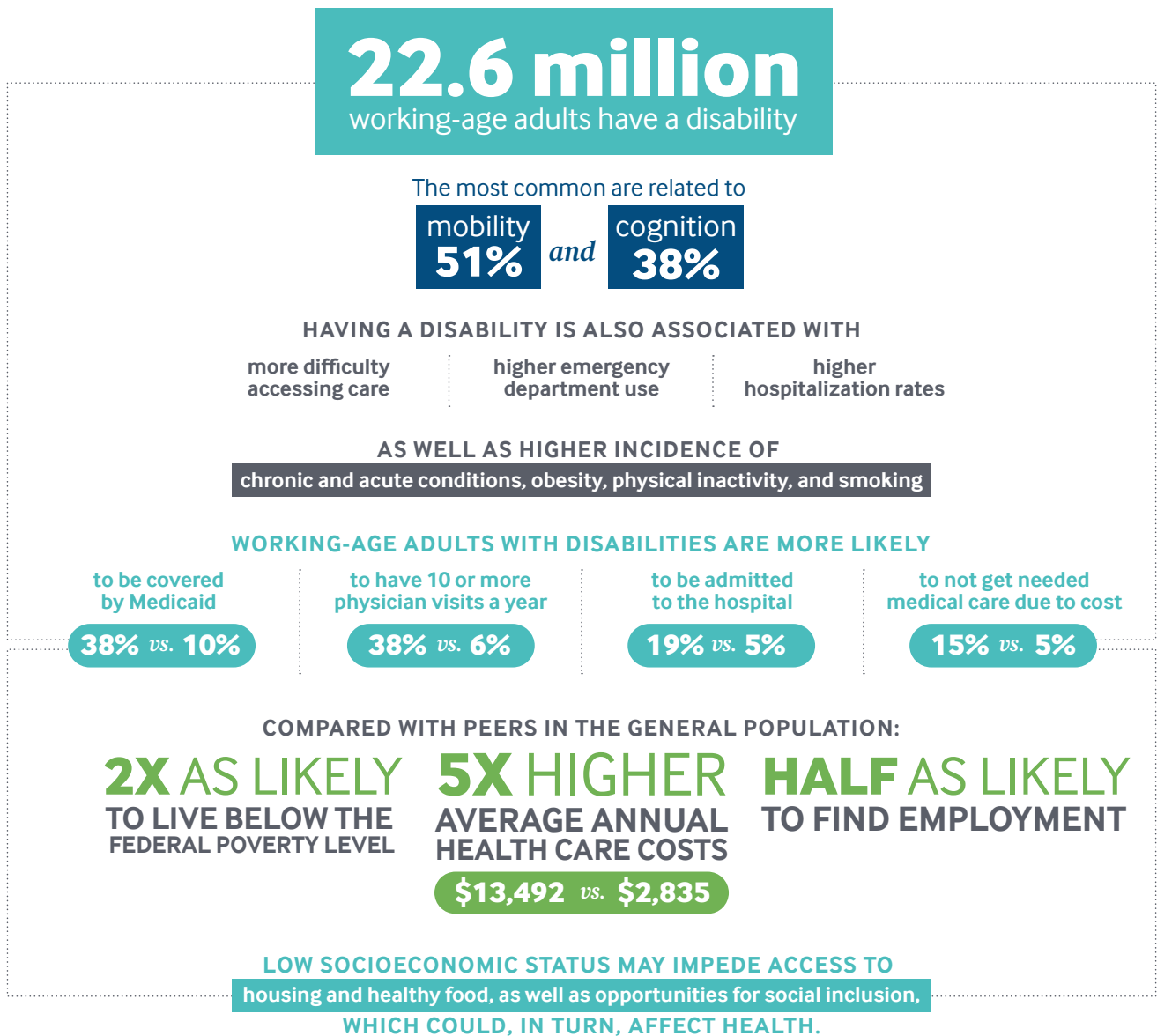
- ▶ **Proactive, comprehensive care for adults with disabilities can help them avoid medical complications and improve their quality of life.**
- ▶ **Model care programs for adults with disabilities share a focus on prevention, trust-building, and integrated supports and services that promote independence and social inclusion.**

This case study is available on the Commonwealth Fund's website at: <https://www.commonwealthfund.org/publications/case-study/2018/sep/systems-care-adults-disabilities>.

## INTRODUCTION

As a young psychiatrist working in Ohio’s state psychiatric hospital, Julie Gentile, M.D., found none of her training had prepared her to help a patient with a severe intellectual disability admitted because of aggressive, possibly psychotic behavior. Because the patient was nonverbal, her usual diagnostic approach — taking a history and conducting a mental status exam — wasn’t effective, but Gentile wasn’t comfortable prescribing antipsychotics based on little information. After reviewing medical records and carefully observing her patient,

she noticed he tended to become agitated after meals and when he lay down in bed. Gentile guessed he had gastroesophageal reflux disease, something she later learned was common among people with intellectual and developmental disabilities and a possible contributor to their higher prevalence of stomach cancer.<sup>1</sup> When Gentile prescribed an acid blocker, his aggressive behavior went away. “This experience really made me think we are probably missing medical issues right and left for patients with intellectual and developmental disabilities who can’t always tell us what is wrong,” Gentile says.



Data sources: Alissa C. Stevens et al., “Adults with One or More Functional Disabilities — United States 2011–2014,” *Morbidity and Mortality Weekly Report* 65, no. 38 (Sept. 30, 2016): 1021–25; Jae Kennedy, Elizabeth Geneva Wood, and Lex Frieden, “Disparities in Insurance Coverage, Health Services Use, and Access Following Implementation of the Affordable Care Act: A Comparison of Disabled and Nondisabled Working-Age Adults,” *Inquiry* 54 (Jan.–Dec. 2017): 1–10; Stephen P. Gully, Elizabeth K. Rasch, and Leighton Chan, “The Complex Web of Health: Relationships Among Chronic Conditions, Disability, and Health Services,” *Public Health Reports* 126, no. 4 (July/Aug. 2011): 495–507; and Lewis Kraus et al., *2017 Disability Statistics Annual Report* (University of New Hampshire, 2018).

In fact, there is copious evidence the health care system is not serving many Americans with disabilities well. Those living with physical disabilities, for example, face enormous difficulty finding medical practices with wheelchair-accessible equipment or clinicians who are cognizant of their unique risks, like pressure ulcers, which can lead to life-threatening infections. Those disabled by mental illnesses such as schizophrenia and bipolar disorder tend to develop chronic diseases earlier and die younger than others, in part because their conditions may not be diagnosed or treated in a timely way.<sup>2</sup>

Many studies have documented these and other problems: in general, Americans living with disabilities receive less preventive care, have a higher incidence of chronic conditions, and visit the hospital and emergency department more often — leading to much higher health care spending than for adults in the general population.<sup>3,4,5,6</sup> People with disabilities also face higher out-of-pocket costs for their medical care and are twice as likely to live below the federal poverty level.<sup>7</sup>

Despite the high levels of need, most health care providers receive little training in how to take care of people living with disabilities, and some focus to such an extent on the disability that they miss other medical conditions.<sup>8</sup> “Adults with disabilities are assumed not to be having sex, for instance. So they don’t get tested for sexually transmitted diseases, and there’s no discussion of their sex lives or

pregnancy,” says Lisa Iezzoni, M.D., a professor of medicine at Harvard Medical School.

In this study, we profile health plans and clinics that are the exceptions, ones that have created custom models for people with different types of disabilities: physical, intellectual and developmental, and those related to serious mental illnesses.<sup>9</sup> The health plans and clinics were selected based on the recommendations of researchers, industry representatives, and advocates for people living with disabilities. While these programs, and others around the nation, often focus on serving people with just one type of disability, they share key components:

- a focus on prevention and proactive identification of secondary conditions
- efforts to engage patients and build trust
- integration of long-term services and supports to improve health and promote independence and social inclusion.

We focus on working-age adults with disabilities, since their goals and needs are distinct from those of older Americans who lose physical or cognitive function because of aging, and there has been less attention paid to this younger group to date. And we offer lessons about the policy and payment modifications that may be needed to support innovative care models.

## DEFINING DISABILITY

The term “disability” is imprecise and may refer to a wide range of functional limitations.\*

Common Disabilities	Examples
<b>PHYSICAL</b>	Acquired brain and spinal cord injuries, spina bifida, cerebral palsy, stroke, sensory disabilities including vision and hearing loss
<b>INTELLECTUAL/ DEVELOPMENTAL</b>	Down syndrome, Fragile X syndrome, autism spectrum disorder, fetal alcohol syndrome
<b>SERIOUS MENTAL ILLNESS</b>	Schizophrenia, bipolar disorder, obsessive-compulsive disorder, post-traumatic stress disorder

\* The Americans with Disabilities Act defines disability as a physical or mental impairment that substantially limits one or more major life activities. See U.S. Department of Justice, *A Guide to Disability Rights Laws* (DOJ, July 2009). Income support programs (SSI/SSDI) use a narrower definition, defining it as physical or mental impairment expected to last at least one year or result in death with inability to engage in any substantial gainful activity. See Social Security Administration, *Disability Evaluation Under Social Security* (SSA, n.d.).

## PROGRAMS SERVING PEOPLE LIVING WITH PHYSICAL DISABILITIES

Henry Claypool was a 19-year-old college student in Boulder, Colorado, when a ski accident left him paralyzed from the chest down and in excruciating pain from a nerve injury, akin to “someone dragging razor blades back and forth across my right hand,” he said. Although he eventually finished college, he was a wreck: “I don’t think I was really able to deal with the trauma, and the change, and the chronic pain. I used alcohol to self-medicate.”

Claypool’s life improved dramatically when nerve surgery relieved his pain and gave him back use of his arm. With the help of Medicaid, Medicare, disability insurance, and other supports, he was able to live on his own and finish college. He then made a [career](#) advocating for access to personal assistance services, transportation, and other supports that promote health and resilience for people with disabilities. Eventually, he developed enough self-care skills and financial independence that he no longer needed public support.



Henry Claypool

During his recovery and over the next 16 years, Claypool had regular visits with the clinicians and therapists at Denver’s Craig Hospital, a rehabilitation hospital for patients with spinal cord or traumatic brain injuries.

But when a new job brought him to Washington, D.C., in 1998, he left behind this support system. Claypool had to search out clinicians with expertise in issues like skin breakdown and neurogenic bladder problems, which are common among people with paralysis. “At Craig, I could go in for an evaluation and get a comprehensive look at all my body systems. In D.C., it was more piecemeal,” he said. “I was fortunate that I had some basic understanding of how my body worked and was able to cobble together a network of specialists that has given me the basic support I need.”

Claypool’s experience is common: people with physical disabilities who don’t live near top-tier specialty facilities struggle to find well-coordinated care and knowledgeable

providers. This section describes health plans or clinics that have created customized models for people living with physical disabilities. Some programs are using evidence-based models, including integrating behavioral and physical health care, while others have developed homegrown approaches. When available, we offer evidence of their impact on patients’ experiences, health outcomes, and costs.

### Independence Care System

Since 2000, [Independence Care System](#) (ICS), a nonprofit Medicaid managed long-term care plan, has coordinated the medical care and long-term services and supports for adults with physical disabilities in New York City. Ninety percent of its 2,400 members with physical disabilities use a wheelchair or other assistive device, and 30 percent require 12 to 24 hours of assistance every day.

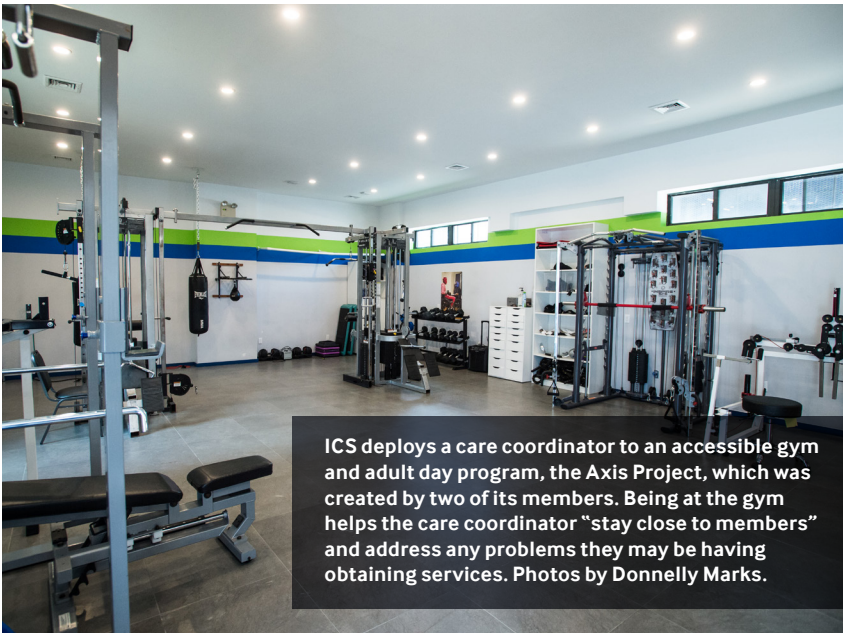
ICS president Rick Surpin says members routinely encounter physical barriers (e.g., inaccessible medical equipment or facilities) and bias in their interactions with health care providers. Because of a lack of access to primary and preventive care, many receive only episodic medical care, often in emergency departments, or require hospitalizations for conditions that could have been treated in the community if addressed earlier. As a consequence, they may experience delayed diagnoses, improper treatment, and premature death, Surpin says. To help, the plan has taken a “center-of-excellence approach” — offering disability awareness training to staff at a handful of clinics, helping them modify their processes and facilities to accommodate members, and then directing members to those providers.

It has, for example, coached staff at five women’s health facilities, which then made simple modifications, like adding Velcro straps to mammography machines to hold women’s arms in place if they are unable to do so themselves. ICS also sends a nurse educator along during members’ visits to offer clinicians tips on how to enable accurate and comfortable exams.<sup>10</sup>

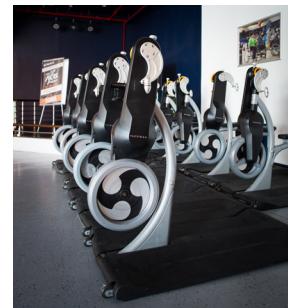
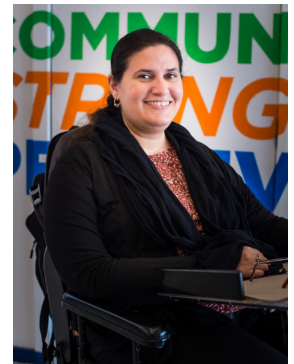
As part of New York State’s Medicaid requirements, ICS nurses assess members’ functioning and physical and behavioral health at least every six months, or when their conditions change, and social workers then help members develop plans to meet their near- and long-term needs. About a fifth of ICS members make use of Consumer Directed Personal Assistance Services, a Medicaid program that allows them to hire and train their personal care attendants, home health aides, and nurses.<sup>11</sup>

To identify members who may need additional support, ICS developed a risk-prediction system that combs through data from the nurses’ assessments. Leaders have found that members are at higher risk when they cannot name their primary care providers (suggesting they haven’t established a good relationship with them), report poor health, or have had a recent and potentially avoidable hospitalization. When someone appears to need help, members of a complex care team (a nurse, social worker, and behavioral health specialist) are deployed to offer support, sometimes through home visits or counseling to address signs of depression.

The flexibility afforded by managed care enables ICS to offer services that are not reimbursed by Medicaid but nonetheless contribute to members’ health, independence, and quality of life, including a wheelchair purchasing, evaluation, and repair clinic; free membership to an accessible gym and adult day program; and group art and other classes.



ICS deploys a care coordinator to an accessible gym and adult day program, the Axis Project, which was created by two of its members. Being at the gym helps the care coordinator “stay close to members” and address any problems they may be having obtaining services. Photos by Donnelly Marks.



On New York's *2017 Managed Long-Term Care Report Card*, 90 percent of members (including older adults as well as those with physical disabilities) rated ICS as good or excellent. Seventy-four percent demonstrated improvements in locomotion and 92 percent remained stable or had improvements in terms of shortness of breath. In both cases, these percentages are significantly higher than the statewide average among managed long-term care plan members.<sup>12</sup> Eighty-two percent of members said their pain was controlled and 89 percent were not lonely or distressed — both statistically lower proportions than the statewide average.

### Courage Kenny Rehabilitation Institute

Courage Kenny Rehabilitation Institute, part of Minneapolis-based Allina Health, has a primary care clinic that services about 325 adults, most under age 60, with 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. Patients have an average of nine conditions, including hypertension, heart conditions, and arthritis. Primary care providers are able to refer patients to on-site specialists, including psychiatrists and psychologists who offer treatment for those coping with depression, anger, and other emotions. “Many experience depression when they receive their life-altering diagnoses,” says Kyle Grunder, the clinic’s director. “We prescribe an exercise plan, have them see our

psychiatrist and therapist, and take part in group support to help them understand there is optimism and hope despite their current state of health.”

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.<sup>13</sup> The institute also employs independent living skills workers (typically 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 a job.<sup>14</sup>

An independent evaluation of Courage Kenny’s model found a significant reduction in total costs of care for Medicaid beneficiaries in 2016, mostly through lower use of acute care.<sup>15</sup> Courage Kenny reports this trend continued in 2017: among 198 Medicaid beneficiaries, there was a marked reduction in hospitalizations.<sup>16</sup> There was, however, an increase in emergency department (ED) visits; the program’s leaders say ED visits are often for emergent medical issues, and that the uptick may be a function of the decline in hospitalizations. This is because prior to enrolling at Courage Kenny, many such patients would have been admitted to the hospital from the ED, which would then be counted as a hospitalization, not an ED visit. Leaders say that local ED staff feel comfortable sending Courage Kenny’s patients home after treatment, given the level of follow-up and support the clinic will provide.



Many Courage Kenny patients are prescribed exercise or other therapeutic classes. Photos courtesy of Courage Kenny.



Courage Kenny uses the Patient Activation Measure to assess patients' confidence and ability to care for themselves. In 2016, 61 percent of patients had achieved higher levels of activation after a year. Seventy-three percent of patients with moderate to severe depression improved during the year.<sup>17</sup>

### University of Pittsburgh Medical Center Adult Spina Bifida Clinic

The [Adult Spina Bifida Clinic](#) at the University of Pittsburgh Medical Center is one of a handful of facilities specializing in ambulatory care for adults with spina bifida rather than children. Spina bifida is the most common permanently disabling congenital condition in the U.S.<sup>18</sup> People with spina bifida are, on average, living longer than they used to thanks to improved medical, particularly urologic, care. The clinic treats more than 250 patients a year, many coming from hours away. The Pennsylvania Department of Health provides grant funding for the clinic for care coordination, mental health screening, and nutritional consultations.

Brad Dicianno, M.D., a rehabilitative medicine physician and the clinic's director, has led research projects on how to support patients between visits. In one pilot, a nurse visited patients in their homes to offer education on preventing complications and encourage them to set short-term goals (e.g., drink more clear fluids), long-term goals (e.g., complete

an adaptive driving course), and maintenance goals (e.g., take all medications as prescribed). Nurses met with patients every quarter and were available via telephone to answer questions and help arrange medical visits and support services. After two years, the 65 patients had on average improved their physical functioning, mood, and self-reported quality of life. Cost of care for preventable conditions increased significantly during the first year, likely because of greater detection and treatment of conditions. Costs declined during the second year, though not significantly.<sup>19</sup>

To create a sustainable and replicable wellness program, Dicianno and colleagues are piloting digital tools. The [Interactive Mobile Health and Rehabilitation \(iMHere\)](#) platform — developed with patients and accessible to those with cognitive, motor, or sensory impairments — helps people manage their conditions and allows them to securely communicate with their clinicians via smartphone. It includes a module that tracks medications and reminds users to take them, and one that prompts users to perform catheterization and bowel management and report problems. Another module prompts users to conduct inspections of insensate skin and send photos of wounds or other potential problems, while another reminds them to complete a survey that detects depressive symptoms. Case managers and clinicians can review patients' responses and respond to problems.

### Interactive Mobile Health and Rehabilitation (iMHere) platform



The Skincare app (far left) allows patients to track the progress of skin ailments by taking photographs with the smartphone's digital camera. The MyMeds app (near left) keeps track of the patient's medications, providing reminders to take them as prescribed. Screenshots courtesy of iMHere.

During a yearlong randomized control trial, people who were frequent users of the tool said it improved their ability to manage their spina bifida. Participants in the intervention group experienced fewer medical problems (e.g., urinary tract infections or wounds) and fewer ED visits and hospitalizations than before the trial, while those in the control group had more medical problems and service use.<sup>20</sup>

## Inglis

Since 1877, Philadelphia nonprofit **Inglis** has provided housing and medical care for adults with physical disabilities including multiple sclerosis, cerebral palsy, ALS disease, and spinal cord injuries. Today, it serves nearly 1,000 adults in the community and about 250 adults in Inglis House, its long-term care facility designed for people who use wheelchairs.

In 2016, Inglis launched an 18-month pilot involving 23 people who wanted to transition from Inglis House to independent living in accessible apartments built adjacent to campus.<sup>21</sup> Many of the apartments are equipped with smart home technology that allows paralyzed or mobility-impaired residents to unlock doors and control lights, as well as heating, cooling, and entertainment systems.

Inglis enlisted primary care clinicians, social workers, rehabilitation therapists, home care attendants, and others to form a care team for these residents, coordinating their work mostly through phone calls. But unlike in the long-term care facility, residents were responsible for managing their own care, including making appointments and arranging transportation, a process that left some overwhelmed. “The approach worked well for patients who were driving their own care,” says Lea Frontino, vice president for information and adapted technology. But about a third became less engaged — missing appointments and, in some cases, developing complications like urinary tract infections that brought them to the ED. “We’ve learned it’s one thing to coordinate care and another to help someone get a sense of what they are about to experience and ensure they have the skills to live independently,” says Dyann Roth, Inglis’ president and CEO. “That’s critical work that has not been funded.”

Inglis’ leaders say the experiment has pointed to the need to train residents in independent living skills, and to add behavioral health specialists to their care team to offer greater emotional support. Residents also may benefit from more advanced training in recognizing the signs of medical problems.

Inglis administrators had hoped to use the Program for All-Inclusive Care for the Elderly (PACE) model to support residents who wanted to live on their own. PACE combines Medicaid and Medicare dollars to offer flexible, capitated funding for all needed medical and long-term services and supports to people age 55 and older. The model is for those deemed frail enough to need nursing home–level care, but who prefer to live in the community.<sup>22</sup>

The PACE model has been around since the 1970s, but 2015 legislation allowed pilots of programs that combine medical care and long-term services and supports (LTSS) for younger people, including those with permanent disabilities. Pennsylvania approved Inglis’ proposed pilot for the Medicaid portion of funding, but the Centers for Medicare and Medicaid Services has not yet done so for the Medicare portion. “We decided we weren’t going to wait any longer,” says Roth. “We wanted to test the coordination of the care, even though we didn’t have a capitated payment model.” Private grant funding paid for the clinically related services not reimbursed by Medicare or Medicaid, such as care coordination among providers.

Inglis also runs an adaptive technology lab, where people with limited mobility use tools such as eye-gaze software to control computers. Other creative applications of technology include use of 3D printers to make custom supports and virtual reality software that allowed a quadriplegic member to dance with an avatar. “He cried and said, ‘You know I never thought I could dance,’” Frontino says.



## PROGRAMS SERVING PEOPLE LIVING WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

Heather O'Connor, age 46, of Cleveland, remembers the name of every person who has helped her in her decades-long struggle with autism and mental illness: the teachers and principals who handled her outbursts and encouraged her to stay in school; the therapists who helped her find ways to cope; and the college students and professors who “looked past the weird” and became friends.

Like many others with comorbid conditions, O'Connor went for years without a clear diagnosis. Given her difficulties in school, some teachers suspected she had attention deficit hyperactivity disorder. Her parents were hesitant to have their daughter tested (and likely medicated) for what was then a newly recognized condition, and opted instead for therapy, which helped a bit, O'Connor says.

But as she got older she “got more stubborn,” she says. An expulsion from high school for fighting led to a stint at a boarding school for troubled teens and, later, a psychiatric hospital. There, O'Connor received a diagnosis of depression and a prescription for medication that, she says, helped her feel calmer and better able to focus.

After high school, O'Connor enrolled in Cleveland's Magnolia Clubhouse, a place where adults with mental illnesses come to socialize and take part in job training. Eventually, she found a temporary job, but when that ended, O'Connor fell into a major depression. “When I was working I had stopped taking my medication because I was feeling so good,” she says. A clash with a clubhouse staffer led to thoughts of suicide, and another visit to the psychiatric hospital. There, she was diagnosed with bipolar disorder and prescribed a medication that has gone a long way to help stabilize her emotions.

Just last year, at a behavioral health clinic in Washington, D.C., O'Connor was diagnosed as high-functioning autistic. “Even though the diagnosis is another thing to deal with,” she says, it has helped her make sense of some of her behaviors, including her intolerance of loud and crowded places. It also might explain her uncanny recall for names and dates.



Heather O'Connor (left) celebrates her college graduation with family members.

A few years back, O'Connor set three goals: take better notes in school, graduate from college, and learn to drive. She's worked diligently on the first one, and this May she graduated from Cleveland State with a 3.0 GPA and a degree in anthropology. Recently, she's found a driving school that works with people with autism.

In the following profiles, we describe efforts to ensure people like Heather — those living with intellectual and developmental disabilities — receive appropriate medical care and support to achieve their goals.

### Mental Illness/Developmental Disabilities Coordinating Center of Excellence

In 2003, Julie Gentile, M.D., founded Ohio's [Mental Illness/Developmental Disabilities Coordinating Center of Excellence](#), which she helps run through Wright State University's Boonshoft School of Medicine, where she is a professor and chair of psychiatry. Through public speaking and training of medical residents and providers,

Gentile — who became a specialist in mental health treatment for those with intellectual and developmental disabilities (IDD) after her early experiences treating such patients — helps primary care clinicians and others who care for those with IDD understand relevant related syndromes, engage with patients, and provide good medical care.

According to Gentile, effective medical visits start by creating an alliance with patients, no matter how limited their communication skills, to elicit as much diagnostic information as possible. Patients with IDD often come to the doctor's office with their assistants and caregivers, and clinicians may be tempted to address them for the sake of expediency. Gentile urges clinicians to speak directly to their patients, paying attention to nonverbal cues; using simple yes/no questions; and offering clear guidance about what will and will not happen during visits (e.g., you will not be getting a shot today, which she says is often a worry).<sup>23</sup> It's also important to make patients feel safe during medical visits because many have experienced trauma — abuse or neglect from family members or caregivers. Gentile reassures patients by saying: “First, this is your appointment. We’re going to talk about what you’re comfortable with. The more information I have, the more I can help you, but that’s on your terms.”

Gentile urges clinicians to rule out physical health problems before looking to psychiatric causes of behavioral changes like mood swings or aggression that often bring IDD patients into contact with doctors. Clinicians also should be aware of the heightened medical risks among those with IDD, including the risk of developing heart disease and obesity as well as seizures and hearing or vision problems. Patients may be unable to accurately report symptoms, and medical problems may present differently in this population, leading to missed or delayed diagnoses.<sup>24</sup>

Polypharmacy is also a problem: antipsychotics and/or mood stabilizers that are often used for their tranquilizing effects may result in metabolic side effects, movement disorders, or other neurologic problems.<sup>25</sup> “I’ve had many patients come to me with 30 to 35 prescription

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*Individuals with IDD are typically very genuine . . . they tell it like it is. And working to get their story, earn their trust — it’s a challenge and when it works, it’s quite rewarding.*

**Julie Gentile, M.D., Chair and Professor,  
Wright State University Boonshoft School of  
Medicine**

medications,” Gentile says. “And you really don’t even know what you’re treating until you take some of those away.” She also notes that medications are often overused and nonpharmaceutical treatments like speech and occupational therapy may be underused.

Gentile sometimes uses video visits to help her most complex patients. Since 2012, she and seven colleagues have provided care for 1,300 patients with dual IDD and mental health diagnoses from more than 70 Ohio counties via a secure videoconferencing system. With this and other support, some 300 of her patients have moved from institutional to community living — saving Ohio an estimated \$88,000 per person per year.

### **Tennessee’s Employment and Community First CHOICES Program**

In 2016, Tennessee tasked managed care companies with coordinating long-term services and supports for Medicaid beneficiaries living with IDD, with a goal of helping them find employment and live as independently as possible in the community. Tennessee has been one of only handful of states to do this.<sup>26</sup>

In many states, Medicaid beneficiaries with IDD have not been moved from fee-for-service to managed care for long-term services and supports, as have beneficiaries with physical or other types of disabilities, in part because of family members’ concerns about disrupting their existing

relationships with providers.<sup>27</sup> In Tennessee, families asked the state to offer a managed long-term services and supports program after seeing the positive effects it had for other disabled groups. Tennessee's **Employment and Community First CHOICES** program has become a model for other states considering a transition from fee-for-service to managed Medicaid for beneficiaries with disabilities, in part because it includes **detailed expectations** for how plans should support beneficiaries.

For example, plans must engage people in a planning process to help them identify their goals and the supports they need to achieve them. If a person is institutionalized, the plans must perform comprehensive assessments to determine beneficiaries' interest in and capabilities for living outside of institutions, create transition plans, ensure all supports are in place, visit their new homes, and make regular follow-up visits. Plans also must assess family caregivers' abilities and offer them training and support. As of early 2017, there are no Medicaid beneficiaries with intellectual and developmental disabilities living in large institutions in Tennessee.

Tennessee also has partnered with its managed care plans to build the capacity of physical and behavioral health providers to treat people living with IDD. In partnership with Vanderbilt University researchers, the state has created a **toolkit** to help primary care providers communicate effectively with IDD patients and their caregivers, secure informed consent, and keep in mind relevant physical and behavioral health issues. For example, there are tips for dentists on how to reduce the use of sedation.

To control the inappropriate use of psychotropic medications among people with IDD, the state offers prescribers free continuing medical education on other nonpharmacological approaches. It also instituted prior authorization requirements for these medications unless there is evidence of a co-occurring serious mental illness.

The state also requires managed care plans to support people in finding work if they desire — and requires beneficiaries with IDD to explore their employment options before receiving certain other services, such as independent living skills training.<sup>28</sup> It relies on an

**evidence-based approach** to “supported employment” in which specially trained staff help people with IDD identify their employment goals, find jobs that provide competitive wages, and maintain their employment. More than 80 percent of people completing the process have opted to pursue employment, according to Patti Killingsworth, an assistant commissioner of TennCare, the state's Medicaid agency, and chief of long-term services and supports.

The managed care plans contract with providers who specialize in preparing people to work and supporting them in working. These supported employment providers are reimbursed based on achieving certain milestones: exploring and documenting employment goals, creating an employment plan, and gaining and retaining a job or self-employment. Preliminary data show outcomes that are exceeding national averages for similar programs, according to Killingsworth.

“Medicaid health plans and their network of providers really have to go beyond typical expectations if we expect to help people have good quality lives in the community,” says Killingsworth. “They have to think about how to support people to not just live in the community, but to work and actively participate in their communities, increase their independence, and develop and build relationships — the things that bring meaning and purpose to all of our lives.”

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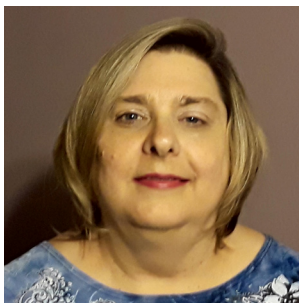
***I don't think there's a day that goes by that we don't talk with our health plans. We also go out to people's homes with them so that we can observe things up close and personal and understand how it's working from the member's perspective.***

**Patti Killingsworth**  
Chief of Long-Term Services and Supports  
and Assistant Commissioner for the Bureau  
of TennCare, Tennessee's Medicaid program

## PROGRAMS SERVING PEOPLE LIVING WITH SERIOUS MENTAL ILLNESSES

Mary Tolle, 52, was in her late twenties and working as a computer programmer in San Antonio, Texas, when a divorce and diagnosis of a mental health condition disrupted her life. At her lowest point, she was unable to work, go to school, or socialize. The first psychiatrist she saw prescribed medications that reduced some symptoms, but didn't help her understand what she was going through. "He didn't even tell me my diagnosis, even though I asked," she says.

Forging a trusting relationship with a provider was further complicated by her insurance status. When she was employed and had insurance, she saw clinicians in the private sector. When she lost that coverage, she turned to the Center for Health Care Services, the county mental health provider for San Antonio. Over the years, she worked with counselors and psychiatrists at several different clinics, splitting her time between treatment, work, and caring for her aging parents. Eventually, Tolle learned she had schizoaffective disorder, a rare mental health condition that affects thinking and mood.



Mary Tolle

In time, Tolle felt ready to go back to work full-time. An employment specialist from the Center for Health Care Services helped her apply for jobs, and she landed a position as a math teacher at a junior college. She also developed a steady relationship with a

psychiatrist, leading to mutual trust and shared decision-making. When her doctor suggested adding a medication for attention deficit hyperactivity disorder, she agreed. "I noticed improvement in my driving and ability to perform math calculations in my new position."

Eventually, Tolle became a certified peer specialist and began working at the Center for Health Care Services, where she helps others in recovery. The most important advice she offers them is that "there's hope." Before she came to the Center she hadn't heard that; her previous providers told her "you'll be in care for the rest of your life," she says.

Tolle helped create the Center's drop-in clinic, known as the Recovery Zone, where peer specialists use music, art, and other activities to foster connections among participants. "A lot of people have social anxieties, they're tired from their depression and the medications, and it's hard for them to get out," she says. "Having a safe and nurturing place to socialize is crucial to their recovery." She also leads group discussions about coping, self-management tips, and exercise and nutrition, given that many people with mental health conditions experience weight gain as a result of taking psychotropic medications.

When people with serious mental illnesses don't feel welcome in clinics or trustful of their providers, they may avoid care or not follow treatment. In the following profiles, we describe health plans or clinics that have created customized models for people living with serious mental illnesses that focus on earning patients' trust and integrating behavioral and physical health care.

### Center for Health Care Services' High Utilizer Program

In 2012, the [Center for Health Care Services](#) turned one of its 15 clinics into a High Utilizer Program for people who frequently visit emergency departments because of their medical and substance use issues. Many are homeless patients with schizophrenia or other untreated mental health conditions that make it hard for them to receive care in traditional settings. "If you have a 20-minute appointment and have competing voices in your head, and then your doctor wants you to succinctly say what's going on, you can see how that's not going to work," says Ruth Morgan, M.D., a family medicine physician who is helping the High Utilizer and other clinics integrate physical and behavioral health services.

The High Utilizer Program offers an array of services: free transportation; trauma-informed counseling; group classes to help people quit smoking, lose weight, or meet other goals; and referrals to find supportive housing or employment. Clinicians offer substance use disorder treatment and counseling, psychiatric medication management, and primary care, but it may be some time before patients are willing to comply with medication and other treatment recommendations. “Over time we see that as people participate in group activities then they will come back to treatment because they feel connected in some way,” says Morgan.

Among 154 patients seen at the clinic during one year, there were 40 percent fewer emergency department visits, saving Bexar County an estimated \$4.3 million.<sup>29</sup>

### **UPMC Insurance Services Division’s Models for Integrated Care**

The University of Pittsburgh Medical Center (UPMC) Insurance Services Division, which oversees an array of health plans, has fostered collaboration between two of its Medicaid managed care organizations to improve the health of beneficiaries with serious mental illnesses and concurrent medical conditions.

The Integrated Care Program enables the two managed care organizations — *UPMC for You*, which covers physical health services, and *Community Care Behavioral Health Organization*, which covers behavioral health — to exchange information about members’ hospitalizations, emergency department visits, lapses in medication refills, and treatments for mental health conditions. (Limited information about substance use disorders is shared with members’ permission.)

Care managers use electronic health records and claims data to identify those at risk of developing serious health problems and offer support and education, often over the telephone, with support from care managers at clinical sites. Care managers, pharmacists, and providers hold monthly meetings to talk through the needs of patients with complex conditions and develop shared plans. “Often care managers in one setting might know something

about patients’ transportation issues or housing or their relationship with a physician that other providers aren’t aware of,” says James Schuster, M.D., vice president of behavioral integration and chief medical officer for behavioral and Medicaid services for the UPMC Insurance Services Division. “So it’s a chance for them to get a holistic view and think together about how they can best support someone.” UPMC for You and Community Care have similar programs with other Pennsylvania Medicaid managed care organizations.

This model is derived from Connected Care, a pilot organized by the state of Pennsylvania in which the managed care plans received financial incentives for providing certain services and reducing acute care use. Over two years, this approach led to a decrease in mental health hospitalizations from 41.1 to 39.6 per 1,000, compared with an increase of 33.8 to 37.2 per 1,000 in a control group. Among the subset of members who gave consent to share their behavioral health information, the mental health hospitalization rate decreased by 20 percent (74.7 to 59.4 per 1,000).<sup>30</sup>

In another novel program, Community Care responded to requests from rural behavioral health providers for help in improving the physical health of those with serious mental illnesses. The health plan experimented with two approaches. In one, patients were given access to online portals with their health information, customized wellness interventions, and tools to help them track progress in efforts to quit smoking, lose weight, eat better, and get more sleep. The other approach added a nurse to clinics to educate staff about ways to promote wellness, and to help patients coordinate their care and track their progress in meeting goals. In both models, case managers and peer support counselors, who typically help patients with behavioral health problems, also coached patients to help them improve their physical health.

A study found that both increased patients’ level of activation, their engagement in primary and specialty care, and perceived mental health status.<sup>31</sup> Community Care has spread a combined version of this model, using self-management tools, wellness coaching, and nurses, to 49 clinics in 39 counties across Western Pennsylvania.<sup>32</sup>

## Resources for Human Development's Assertive Community Treatment Program

[Resources for Human Development](#), a national human services provider, runs 13 assertive community treatment (ACT) programs, which deliver and coordinate intensive mental health care services for people whose lives are too unstable to be treated in a clinic setting.

In Iowa, for example, a nurse, mental health counselor, substance use specialist, and peer support counselor make home visits to help people living with mental illnesses often compounded by substance use disorders. The ACT team visited one man on the day he was released from jail, finding him temporary housing and making daily trips to deliver his medication for bipolar disorder. After a few months, he had moved into permanent housing and no longer required the daily visits. With intensive support from ACT staff, he has remained stably housed for 10 months, without hospitalizations or incarcerations.

The field team is supported by a psychiatrist and psychiatric nurse practitioner who offer virtual visits to clients via iPads or laptops. While nurses monitor clients'

health status and liaise with their primary care providers, peer support specialists offer them advice based on their firsthand experiences, says Gina Hiler, Resources for Human Development's Midwest regional director. "They might talk to clients about practical strategies for their diet, activity, and medication regimens while they're in recovery. They also connect people to natural supports in the community, whether that involves going with them to AA or NA meetings or going out for pizza," she says.

Iowa's ACT teams are supported by Medicaid, supplemented by county funding to make up for the fact that Medicaid services are billable only on weekdays but "ACT is a seven-day-a-week, 365-day-a-year program," says Hiler. Among the 50 people receiving ACT services in the Waterloo, Iowa, region during the program's first year, 23 percent have had psychiatric hospitalizations, compared with 40 percent in one large study of ACT participants.<sup>33</sup> Nearly all (93 percent) have remained stably housed during their first year of engagement with the program, and 83 percent have had no arrests or other law enforcement involvement (compared with 67 percent in the large study of ACT participants).

In Iowa, staff from Resources for Human Development make home visits to help people living with mental illnesses. Photos courtesy of Resources for Human Development.



## SHARED FEATURES OF PROGRAMS SERVING ADULTS LIVING WITH PHYSICAL DISABILITIES, INTELLECTUAL AND DEVELOPMENTAL DISABILITIES, OR SERIOUS MENTAL ILLNESSES

While the programs we profile here are customized for particular groups, they share certain features that appear to be central to their effectiveness. Most prominently, all of the programs proactively identify and address the unique risks and needs of people living with disabilities, including complications stemming from those disabilities as well as chronic conditions like diabetes and depression.

The programs take steps to earn patients' trust, as people living with disabilities may be wary of a health care system that often makes it hard for them to get care and in which providers may see them only in terms of their disability. They do so by including patients in care planning, and by offering opportunities for them to socialize with providers and other patients.

Many also incorporate counseling and other services to identify patients' trauma, depression, or other problems that may occur among those living with disability, particularly among those who lose function from a progressively disabling condition or catastrophic accident.<sup>34</sup>

### Leveraging Long-Term Services and Supports to Promote Independence

The programs serving adults with disabilities also integrate medical care with long-term services and supports (LTSS), a broad range of benefits provided to disabled and other Medicaid beneficiaries. Services and supports may include transportation, help with bathing or cooking, wound management, or other complex care, as well as supports like home modifications and adaptive technology to make it possible for people living with disabilities to pursue education, work, or develop relationships.<sup>35</sup> LTSS also covers care provided in institutional facilities or day programs.

LTSS have become more important in recent decades as more adults with disabilities live in the community — a product of their wishes and the Supreme Court's 1999 Olmstead decision, which held that people should

not be confined to institutions if their needs can be accommodated outside of them. In 2015, spending on LTSS made up 30 percent of Medicaid program expenditures.<sup>36</sup> Since the Olmstead decision, the proportion of LTSS spending for services to allow people to live independently has surpassed that spent on institutional care.<sup>37</sup>

Medicaid and other health care payers may save money by moving people out of institutions and supporting them in the community. According to Aetna, which oversees LTSS in 10 states, the savings generated from managing care of an individual in a home or assisted living facility as opposed to an institutional residential facility range from \$2,000 to \$5,000 per member per month.<sup>38</sup>

Disability advocates welcome this trend, which could further their efforts to shift from the medical model of disability, which defines people in terms of their deficits, toward the social model, which emphasizes their well-being and social inclusion.<sup>39</sup>

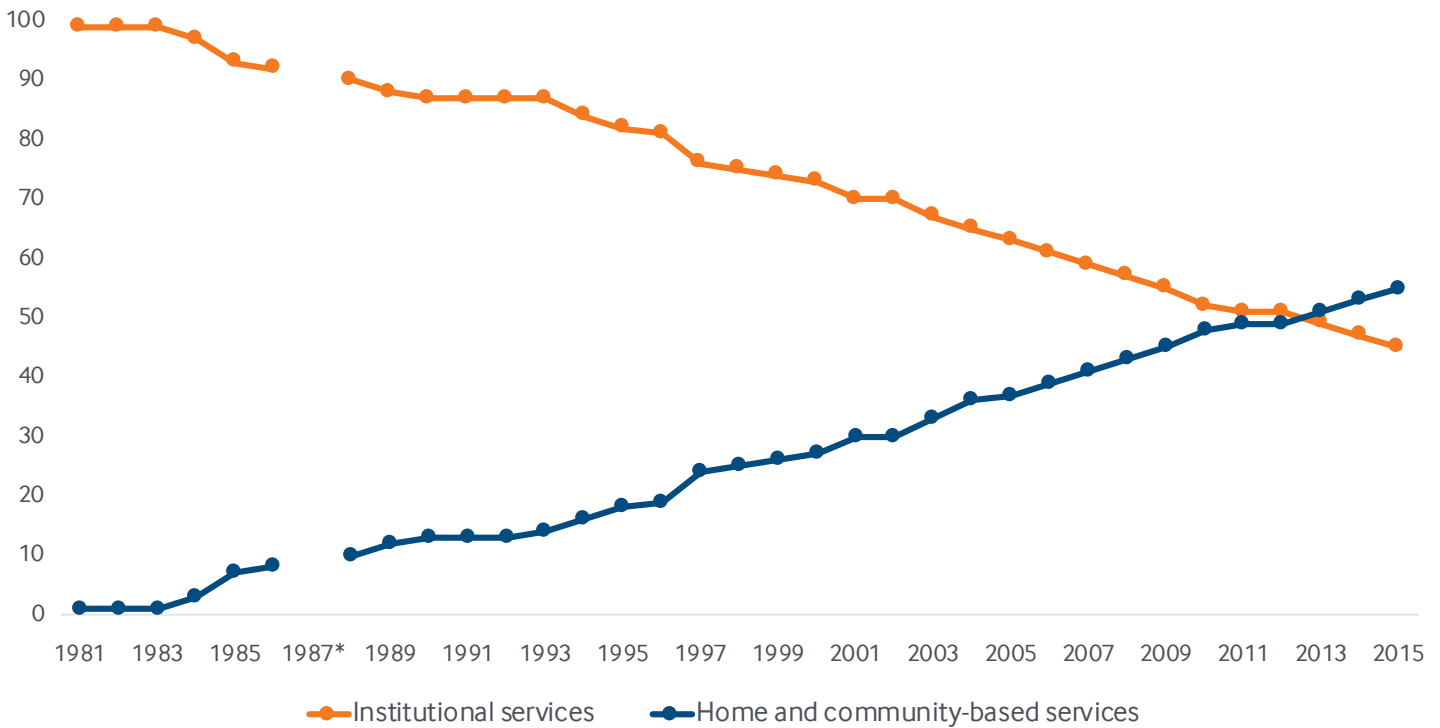


***While still maintaining a role in protecting individuals they serve from serious, avoidable harm, LTSS systems must balance that responsibly with the individual's right to take risks and sometimes experience adverse consequences as a result.***

**Steve Kaye**  
**Cochair of the Committee and Professor,**  
**Department of Social and Behavioral Science,**  
**University of California, San Francisco**

## Medicaid Expenditures for Home and Community-Based Services Now Exceed Spending for Institutional Services

Percent of Medicaid expenditures



\* Because of an anomaly in the data, Truven Health Analytics did not report 1987 figures.

Note: The 2017 *Long-Term Services and Supports State Scorecard* found variation in states’ spending on institutional vs. community-based care for older adults and those with disabilities. Minnesota and Washington State spent 65 percent or more of their Medicaid LTSS dollars on home and community-based services, while Alabama spent just 13.6 percent.

Data source: Steve Eiken et al., *Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2015* (Truven Health Analytics, April 14, 2017).

To oversee the transition of people with disabilities from institutions to community housing, and to coordinate the array of supports they need to live independently, nearly half the states have turned to managed care plans.<sup>40</sup> Advocates have expressed concerns that assigning the supervision of LTSS to managed care plans, especially those unfamiliar with the unique needs of people living with disabilities, may lead to stinting on crucial services, including hours allotted for direct support staff.

But others say managed care when done well can promote health and independence among populations that have been poorly served. “The biggest increment of benefit comes from the fact that there is an organization, and a care manager in that organization, with responsibility

for what happens to you,” says G. Lawrence Atkins, executive director of the MLTSS Health Plan Association, an association of managed care organizations administering LTSS on behalf of state Medicaid agencies.

### CHALLENGES TO SPREADING EXEMPLARY PROGRAMS

Despite the benefits of customizing care models for Americans with disabilities, few health plans and providers have done so. Outside of urban areas, people living with disabilities are often geographically dispersed, reducing the incentive for an organization to specialize in serving them.



The Veterans Health Administration, which provides care to the hundreds of thousands of veterans disabled by traumatic brain and spinal cord injuries, has overcome the problem of geography by using a hub-and-spoke model to extend the expertise of multidisciplinary teams at regional centers to primary care practices around the country. It also relies on telehealth to provide mental health care to patients who live a long distance from its facilities.<sup>41,42</sup>

Another limiting factor is funding, as people living with disabilities are disproportionately covered by Medicaid, which varies from state to state in the extent and type of services covered.<sup>43</sup> Many providers struggle to stay afloat or look to philanthropy to supplement their reimbursements. In addition, Medicaid and other payers may not adequately account for the complexity and severity of need among people living with disability when setting reimbursement rates, and health plans serving disabled patients may not have enough members to spread risk.

Through home and community-based services waiver programs, some health plans have been able to use Medicaid funding to cover services such as peer supports (Pennsylvania), employment services (Tennessee), and remote monitoring equipment (Ohio). These waivers have enabled states to direct funds to new programs (and, in the case of Tennessee, to clear waiting lists for services for the physically disabled). But states' budgets for home and community-based services are tied to historical spending levels, which experts say likely underestimate the demand.

## CREATING OPPORTUNITIES FOR EMPLOYMENT AND SOCIALIZING: BROOKS REHABILITATION CLUBHOUSE

In 2008, Jacksonville, Florida–based Brooks Rehabilitation opened a day program to help patients with acquired brain injury (ABI) after their medical and therapeutic treatment ends to help them continue to improve their physical and cognitive functioning as well as their social and psychological function. “We found as we discharged these people home, if there’s not something to keep them engaged, there can be declines that lead to not only bad quality of life but higher medical cost,” says Doug Baer, Brooks’ CEO.

The [Brooks Clubhouse](#) offers social opportunities, adaptive sports and recreational activities like aquatics, fitness training at the local YMCA, music therapy, and arts and crafts, as well as vocational evaluation and training. Members, who can join for life, can visit the clubhouse up to five days a week, with most paying about \$10 a day. While Brooks accepts payments from the Florida Division of Vocational Rehabilitation for its supported employment services, it subsidizes the bulk of the clubhouse’s \$300,000 annual budget. “It’s pennies on the dollar” to run the clubhouse, compared with formal neurological rehabilitation services, says Kathy Martin, a cognitive rehabilitation therapist who founded and manages it. There are fewer than 10 [clubhouses](#) for people with acquired brain injuries in the U.S. and hundreds of [clubhouses for people with mental illnesses](#).<sup>44</sup>

Though not a formal rehab program, the clubhouse has helped people reclaim their lives. One man joined 30 years after his stroke, which had left him with severe aphasia, or speech loss. “Now, he can express 80 percent of what he’s trying to say, compared with about 5 percent before,” Martin says. “That speaks to the value of putting people in an arena where there’s constant communication and stimulation.”



Brooks Clubhouse members help prepare shared meals. Photo courtesy of Brooks Clubhouse.

While many states have entered into managed care arrangements with the expectation that closer management of medical and long-term services and supports will lead to savings, that may be unrealistic, at least in the short run, as long unmet needs are recognized and addressed. “Where you can save money is in reducing hospitalizations and lengths of stay. Will that pay off in a given year? Absolutely not,” ICS’s Surpin says. “Might it in three, five, or 10 years? Probably, but no one has run the experiment.”

Some also caution there may be limited ways to reduce spending on the services needed to support people with serious disabilities. “People don’t get any ‘less’ Down Syndrome, or get any less on the autism spectrum, for example,” says Mark Davis, president of the Ohio Provider Resource Association, which represents for-profit and nonprofit organizations serving Ohioans with developmental disabilities. “These are chronic conditions for which people will need a lifetime of support.”

### Measuring What Works

Experts say developing fair and sustainable payment models will require getting a better handle on the quality and adequacy of medical and LTSS services. Current assessment methods, for instance, don’t track things that have a bearing on resource utilization, such as the safety and accessibility of people’s homes.

A committee convened by the National Quality Forum has called for a standardized approach to quality measurement and reporting to assess whether LTSS needs are being met and to enable comparison of different models. Among other proposals, the committee recommends greater attention to whether and how health systems and plans honor patient choice.<sup>45</sup>

### Workforce Shortages

Another impediment to spreading exemplary programs is the national shortage of direct support professionals who help with basic activities like eating and bathing. People living with disabilities often face challenges finding, training, and keeping personal aides. These



## NATIONAL QUALITY FORUM: Recommended Performance Measurement Domains for Long-Term Services and Supports

- Service delivery and effectiveness
- Person-centered planning and coordination
- Choice and control
- Community inclusion
- Caregiver support
- Workforce
- Human and legal rights
- Equity
- Holistic health and functioning
- System performance and accountability
- Consumer leadership in system development

workers typically receive low wages despite the rising demand for their services.<sup>46</sup> In Minnesota, some 8,000 home health care jobs are unfilled, forcing some people with disabilities to live in nursing homes rather than apartments — a costlier option, in the long run, and one that runs counter to most people’s preferences.<sup>47</sup>

“Direct support staff pay is below the poverty level for many,” Davis says. His organization works with youth at risk of dropping out of high school to prepare them for careers as direct support aides.

There are also problems recruiting clinicians to work with disabled groups. Resources for Human Development, which runs assertive community treatment programs in Iowa and elsewhere, has found it particularly hard to recruit mental health counselors and other trained staff in rural areas. “We have learned that we must be willing to invest resources and time to train and appropriately credential staff who desire to serve in their communities,” says Gina Hiler, regional director for Resources for Human Development.

### **A PATH FORWARD**

Ultimately, reducing health disparities and enabling those with disabilities to live their lives with dignity and independence will require a constellation of policy and health system changes. Chief among these are ensuring sufficient funding to support medical and long-term services and supports providers, direct support staff, new forms of technology, and clinical education. Demonstration programs that test the effectiveness of new models could help. “I would love to see a huge pot of federal money for experimentation to determine if we can build meaningful subcapitation models for a disability population — combining primary care, social work, and home visits so we can figure out what that buys in terms of short-term and long-term savings,” says John Tschida, associate executive director for research and policy at Association of University Centers on Disabilities.

## NOTES

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27. There are other reasons that people with physical disabilities are often moved into managed care ahead of people with IDD, according to Patti Killingsworth: people with physical disabilities often have medical needs that

make a more compelling case for integration of physical health and LTSS and health plans have less experience coordinating the kinds of supports that people with IDD may need, including employment and community integration services, 24/7 residential supports, and behavioral supports. In addition, the IDD advocacy and provider communities have been more vocal opponents of managed care.

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