

# Health Elevations



A Quarterly Journal on  
Health Policy in Colorado

Fall 2015

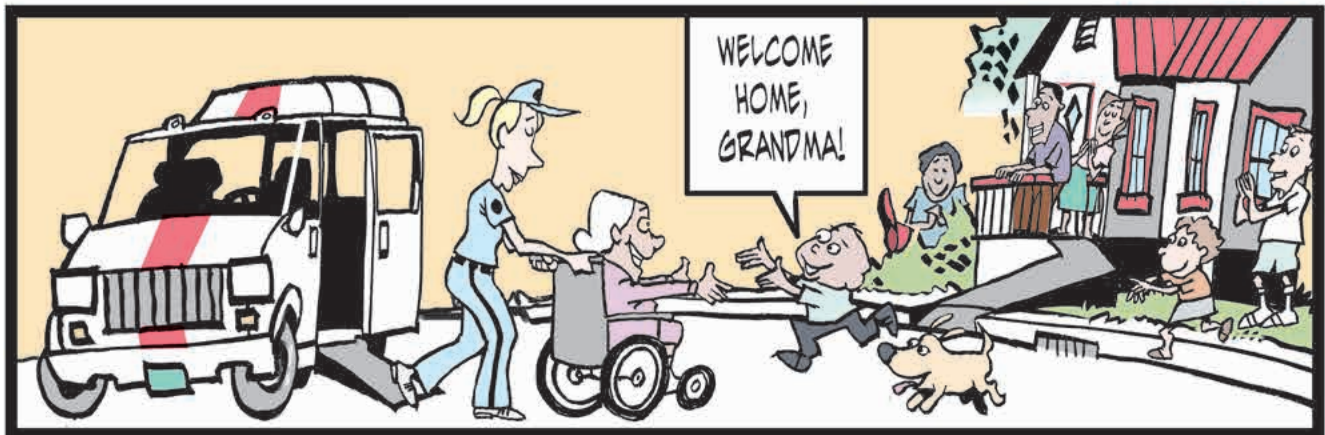
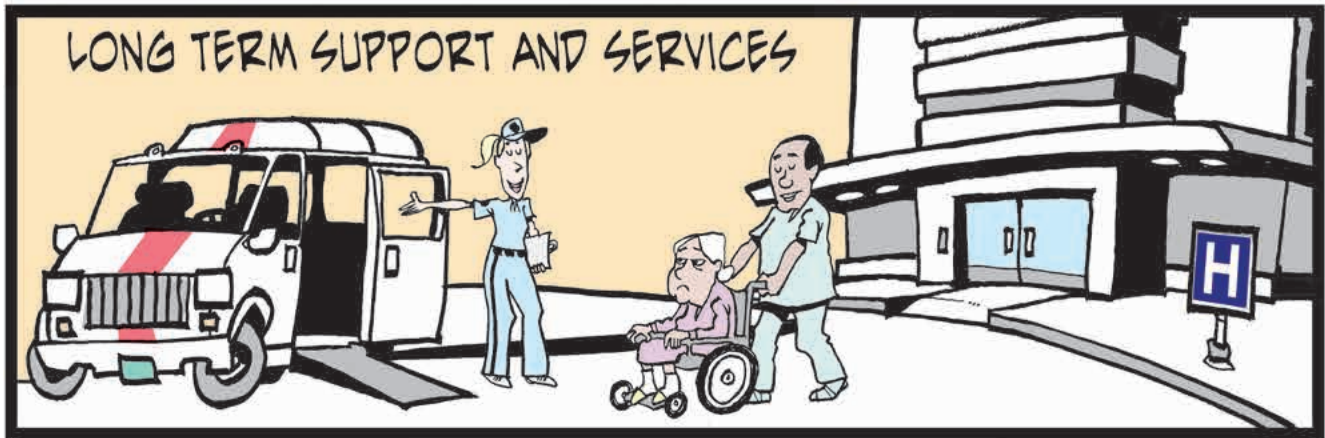


## A Colorado Conversation ...

**... on Working Together to Live  
Independently at All Stages of Life**

A Turning Point for Long-Term Services and Supports

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# Health Elevations



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Fall 2015

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# About the Colorado Health Foundation

**HEALTH ELEVATIONS** seeks to further the goals of the Colorado Health Foundation by highlighting problems that can be solved, illuminating the people who are making progress in solving them and provoking a new way of looking at complex health issues. The journal will report on and synthesize a variety of sources to provide information that can further the work of policymakers, grantees, providers and the engaged public in advancing better health care, health coverage and healthier living. Useful information presented in a memorable way is indispensable to the complex field of health policy.

**THE COLORADO HEALTH FOUNDATION** works to make Colorado the healthiest state in the nation by ensuring that all Colorado kids are fit and healthy, and that all Coloradans achieve stable, affordable and adequate health coverage to improve their health with support from a network of primary health care and community services. To advance our mission, the Foundation engages the community through grantmaking, public policy, investing in evaluation, private sector initiatives and strategic communications. For more information, please visit [www.ColoradoHealth.org](http://www.ColoradoHealth.org).

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## Walking the Talk



# Working Together for Independence

**A** truth of our era is that when your life needs a little support, you can feel isolated anywhere: Living alone high up a mesa in western Colorado, or surrounded by hundreds in a high-rise apartment in Denver, knowing where to turn is a challenge.

A balancing truth of the modern age is that you can feel connected anywhere. An app can call you a ride to a senior center for a yoga flexibility class. Texting can keep a wheelchair-bound patient at Craig Hospital in touch with high school friends 10 states away.

It's imperative to our goals at the Colorado Health Foundation that state residents are connected – no matter where they stand, sit or yoga-pose – with the long-term services and supports they need to live independent and live healthy, whenever possible.

Even to a relative newcomer, it is clear that Colorado has been at the forefront of the independent living movement. The state is well past the crucial tipping point of spending more money on home health services and supports than it does on institutionalized care.

Yet it's also clear the state now faces unprecedented challenges maintaining and improving those services. A high volume of aging residents will move into support categories in coming years. Alongside them may come a growing population of younger people with disabilities who desire independent living, and a wave of Latino residents who may face barriers to state services over documentation and other issues.

This edition of *Health Elevations* explores all these issues and more, asking how to keep the state at the forefront of long-term services thinking. Can we shift Medicaid spending even further toward self-directed care that bolsters independence? Can we expand successful models of transportation, day centers, nonmedical daily living aid and other services, without breaking the bank? How are Medicare experiments transforming the future of coverage and care? How do we take advantage of technology to promote ability and adaptability, without giving up our humanity?

We hope you will dive deeply into our take on the state of long-term services and supports in Colorado and send your reflections back to us. Working together for independence is not a contradiction, it's the solution. As the new Chief Executive Officer of the Colorado Health Foundation, I look forward to learning how Coloradans are working to improve those long-term supports.



Karen McNeil-Miller, President and CEO  
The Colorado Health Foundation



## The LTSS Issue

Demographic challenges and policy opportunities present a unique moment for long-term services and supports in Colorado. This edition of *Health Elevations* explores the rapid growth in demand for independent living among elderly Colorado residents and an accomplished, activist community of younger people living with disabilities. We also dig into some good news about Medicare, efforts to tie together naturally occurring retirement communities, the needs of Latino elders, and how Colorado's housing-price boom threatens independent-living movements.

Please send your thoughts on this issue via Twitter to @COHealthFDN or @MBoothDenver.

# A Golden Age for

## And a Challenge to Long-Term Supports for All Ages

*By Michael Booth, Editor in Chief  
Photography by James Chance*

**Colorado Faces Stunning Demographic Challenges Even as It Celebrates Success in Community Living for Elderly and Younger Disabled**

Candace has just turned 65. She says she has had some issues, including missing teeth, which made her self-conscious about being out in public, even in the sparsely populated towns in Grand Mesa country. Some of the teeth that weren't missing were loose, making her shy about eating in public.

Her extreme introversion and anxiety when away from her house made driving a challenge – stress that was exacerbated by the need for new eyeglasses for better road vision.

But Candace was also quite far from being a burden on society and prided herself on that. She lived independently and well, if modestly, taking her camper up onto the mesa for weeks at a time in good summer weather. What she needed to stay independent was a little help, once in a while.

“On my income, I can only afford one big surprise a month, and for me, a surprise means a hundred dollars,” she said.

Enter the Region 10 Area Agency on Aging, the six-county western Colorado office charged with helping seniors and the disabled through those moments when living independently feels overwhelming.

Eva Veitch, community living services director at Region 10, and her staff found the money for Candace to get a loose tooth pulled and a new bottom dental plate made at a time when Medicaid didn't offer adult dental services. When a local service club's red tape delayed getting new glasses for Candace so she could drive, Region 10 found a way to acquire them within three weeks. Steady encouragement bolstered her to make the drives to unfamiliar communities, small medical offices and sprawling discount stores to finish the errands.

By July she was packing up her camper for her next foray up to the mesa and its 11,000-foot altitude grandeur.

“It's good for me to see there are kind people in life,” Candace said, calling Veitch someone who “shines on the inside.”

“The teeth and the glasses and the driving – it all helped come together to keep me taking care of my own needs,” Candace said. “I don't know what else might come up for me, but at least I know there are people who can help.”



# Aging Planning

## Staying Independent

Veitch shrugged off the personal praise and said that practical orientation – finding a way to keep people independent, to heck with the bureaucracy – has become the default mode of all Colorado agencies and assistance sites working on long-term services and supports.

Colorado's nursing facility census has held remarkably steady at about 16,000 residents since 2005, while the state population over the age of 65 has risen by more than 250,000 in that time.

"That's what people really want, to stay at home in their community, and oftentimes just a little bit of support can make that happen," Veitch said. "So we assess people and partner with those consumers on their strengths and what information they need so they can make well-informed decisions on what their lives should look like. Then we help them build on those strengths."

The new mantra, Veitch said, is what resources can we give people so they can be successful in whatever they are trying to do?

That attitude increasingly permeates the levels of government facing a wave of aging and disability services demands throughout Colorado.

The surge of baby boomers hitting 65 began in 2011, and now, 10,000 to 11,000 Americans hit the official Medicare age every day. That massive demographic sea change is deepened by wavelets of growth in other categories of people needing long-term supports, including individuals with disabilities favoring community rather than institutional living; large numbers of military service members coming home with traumatic brain injury, lost limbs or other disabling conditions; and better medical care resulting in longer life spans for many with disabilities.

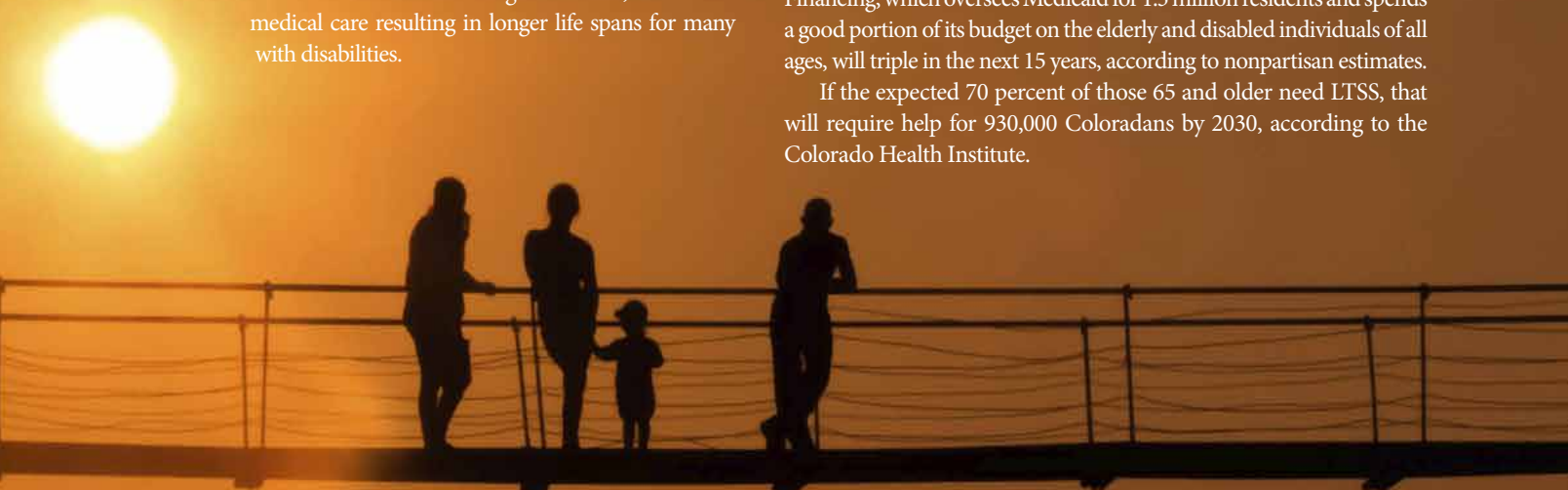


Colorado already spends a large portion of public health funds on long-term supports for the elderly and disabled. The next wave will be staggering.

Colorado's population over age 65 will nearly triple by 2030 – from 420,000 to more than 1.3 million, according to the state demographer – and become nearly 20 percent of the overall state population. That will be the fourth-largest growth in that age group for the whole nation.

The budget for the state Department of Health Care Policy & Financing, which oversees Medicaid for 1.3 million residents and spends a good portion of its budget on the elderly and disabled individuals of all ages, will triple in the next 15 years, according to nonpartisan estimates.

If the expected 70 percent of those 65 and older need LTSS, that will require help for 930,000 Coloradans by 2030, according to the Colorado Health Institute.



**I don't know what else might come up for me,  
but at least I know there are people who can help.**

*Candace, a senior living independently on the Western Slope*

...

## We're facing this unprecedented demographic shift. We've never seen anything like it.

Bob Semro, health policy analyst, Bell Policy Center

...

The movement to provide that help at home and in the community rather than a group institution has not only become a moral imperative in the last two decades, it is increasingly seen as a financial necessity. The cost of an assisted living facility is \$45,000 a year, while skilled nursing facilities average \$84,000 a year; the state's cost for home- and community-based waivers for one person is close to one-quarter of that amount.

Thus the fiscal push – parallel to the evolution of a more humanistic care philosophy – to get people support services where they already live.

"We're facing this unprecedented demographic shift. We've never seen anything like it," said Bob Semro, a health policy analyst with the Bell Policy Center, who is helping direct the work of the new Strategic Planning Group on Aging. The planning group is charged by the state Legislature with delivering a comprehensive framework for state, local and private sector initiatives by fall 2016.

"Number one, consumers want to age in place for as long as they can," Semro said. "The numbers of people wanting to do that are nonambiguous. And institutional long-term care is extremely costly – not only to the consumer but to the state in terms of Medicaid."

### LTSS: Replacing Outdated Institutions

One piece of bedrock good news for Colorado planners is that the mindset of looking to the community first for helping every individual with a disability is now the default mode instead of a revolutionary idea.

"The institutions we had created had very little personal control and tailoring, or sense of home; they evolved into a medical model, focusing on the disease and the treatment of the disease, not on the quality of life," said Sara Honn Qualls, a psychology professor and director of the Gerontology Center at the University of Colorado

Colorado Springs, and an advisor on aging services in El Paso County and nationally. "That old, old system had to be shattered, and I think we've made good progress in shattering that."

"The trends are very clear," said Eric Carlson, an attorney with Justice in Aging, a watchdog and advocacy group based in Washington, D.C. "Institutional spending is going down, down, down, and community spending is going up, up, up. And that's been consistent for 10 to 15 years."

In this edition of *Health Elevations*, we will explore more modern interpretations of LTSS while pointing out the policy challenges ahead in extending services to those hundreds of thousands of potential customers, clients and patients.

We will look at the Colorado Latino Age Wave initiative three years in, designing services and policies for a fast-growing minority population in Colorado that has demographic, cultural and budgetary demands all its own.

We will click deeper into technological changes that pose both opportunities and challenges for the elderly and younger disabled: If everyone operates their lives from a smartphone, for example, how do we adapt the buttons, the voice controls and the screens to best suit users with different abilities? Ride services like Uber could be a major boon for immobile populations, but not if vehicles aren't adapted and not if they don't open employment opportunities to a willing disabled workforce.

We will ask whether so-called "naturally occurring retirement communities" are a viable way to support at-home services and vital links of friendship and informal assistance for daily needs.

We will also explore with experts the reasons behind Medicare's improved financial outlook, a major improvement in the long-term viability of a key pillar for LTSS. A technology engineer and disabled rights activist takes us through the overlooked issues that drive conversations between disabled clients and state Medicaid officials.

And finally, Colorado families allow us into some of the most intimate and difficult moments they will ever face, as they talk with loved ones about the care they want – and do not want – at the end of life. Part of long-term support is asking when people want that support to quietly end.

### Outlook for Long-Term Care Benefits

In exploring these topics, leaders in aging and disability acknowledge that one tool they hoped to have by this point has been pulled back, likely for good: While the Affordable Care Act in 2010 promised a new government-backed structure for previously exorbitant long-term care insurance, the idea is now dormant if not dead.

Though authorized in a portion of the ACA called the CLASS Act, an affordable long-term care plan



Fully activated senior centers, as in Montrose portrayed in these photos, are one key to promoting independence and community engagement. At left, bingo is always popular; at right, Charles Sanden "racks 'em and cracks 'em" at a Montrose pool match, encouraged and heckled by his wife, Joanne.





that still had useful benefits was no longer feasible to design by the fall of 2011, according to the Obama administration. Long-term care advocates were disappointed but not surprised, saying the sweet spot of utility and affordability has proven impossible to find.

Even those boomers now joining Medicare will be confused when they learn the federal insurance covers some short-term home care after a hospital stay, but not ongoing home or institutional care, Qualls said. (The joint federal-state Medicaid program does cover long-term home or institutional care, but only for income-qualifying clients who have spent down nearly all other assets.)

“The lay public still doesn’t understand the difference,” she said. “The model we’re in is untenable, but people don’t have the stomach for the price tag to fix it.”

A key decision for state planners in LTSS for the coming year is whether Colorado’s Medicaid program should join Community First Choice, a federal option many activists see as a major step forward in independent living and self-directed care.

CFC provides a larger federal match for covered services – 56 percent instead of the usual 50/50 split with state funding – and allows states to simplify the complex Medicaid waiver system usually needed to approve nonmedical services like home attendants or job transportation. Under a provision of the ACA, states must study and choose whether to join CFC.

The option is highly attractive for many of the same reasons Colorado has made progressive disability policy moves in the past, said

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## The model we’re in is untenable, but people don’t have the stomach for the price tag to fix it.

*Sara Honn Qualls, director, Gerontology Center,  
University of Colorado Colorado Springs*

...

Jed Ziegenhagen, director of the Office of Community Living for the Department of Health Care Policy & Financing, which oversees Medicaid.

“It’s unusual to have a government service so innately connected to how people live their daily lives,” said Ziegenhagen, noting that LTSS provides for the most intimate of services such as feeding, showering, grooming and other daily needs. “We certainly do a lot of positive things most states are just getting around to. But there’s a sense the system as a whole just needs to be better. People aren’t satisfied with the way it is, and as career civil servants, we’re not satisfied either.”

The problem, he added, is that CFC dictates services that Colorado doesn’t always pay for under its current compartmentalized waiver system and also mandates those be provided for everyone who qualifies, with no waiting lists. An early group study estimated the CFC option could cost up to \$80 million in new state matching share, a tab even the advocates felt was too high to take to the Legislature for approval.



*LTSS experts want to see growth in comprehensive day centers like Denver’s InnovAge on South Broadway, offering medical services, social supports and a neighborhood contact for those living independently. Here, Arline Bonetti arrives at InnovAge with the help of driver Cesar Chavez Ontiveros.*



“The new CFC budget doesn’t have to be zero, but it can’t be \$80 million if policymakers are seriously going to chew on that,” Ziegenhagen said.

A working committee regrouped to see how CFC costs could be lowered while still taking advantage of the new services.

Nationally, disabled advocates will continue to push to make the services embodied in CFC mandatory in all states, not optional. “We believe it is a civil rights issue,” said Joshua Winkler, an engineer and activist who sits on multiple local and state disability policy boards.

Advocates for improved LTSS in Colorado will also be watching developments in two other federally sanctioned programs: Money Follows the Person (MFP) and PACE (Program of All-Inclusive Care for the Elderly).

States that take advantage of MFP look for Medicaid-eligible patients in an institutional, long-term care setting who would be able to live more independently if they gained access to the right services. MFP can go outside traditional Medicaid boundaries, for example, to help pay a housing deposit or make a dwelling accessible to a wheelchair.

Colorado’s MFP program, called Colorado Choice Transitions, has moved slower than hoped. It has helped just over 100 people move to more independent living in three years rather than the goal of 500 people over five years, Winkler noted. The primary barrier has been fast-rising housing costs in the state’s booming economy: The support available in government housing vouchers can’t keep pace with rental rates.

PACE, where nonprofits provide home and day-center support for seniors with health and behavioral needs under both Medicare and Medicaid, is poised for new growth. A handful of nonprofits currently serve a few thousand Coloradans under the program, which pays nonprofits like InnovAge a “capitated” per-person fee to handle all their health and personal needs.

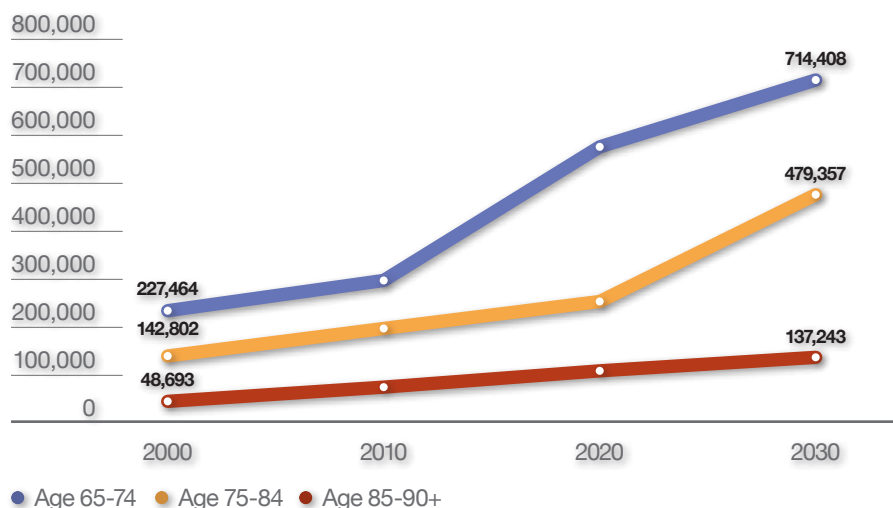
InnovAge, which manages multiple centers in several states, operates the second-largest fleet of buses to RTD along the Front Range. The vehicles fan out across Denver each morning and bring seniors of different abilities to the South Broadway location for services and activities.

The seniors might have a medical appointment with InnovAge’s full on-site clinic, take a hot noon lunch, get help with a bath or sit in on a geography game. The idea is to keep people in their preferred homes or apartments as long as possible, with InnovAge providing needed health care and a vital link to sustaining mental and physical activity.

Backers of the concept want to expand services, in part to see if a higher volume of clients can produce savings over more traditional home-based Medicare and Medicaid services. A bill passed in the 2015 Colorado legislative session was aimed specifically at allowing InnovAge to convert to a for-profit, which could allow it to issue debt or stock to build more centers.

Now Colorado policy and disability groups are planning how to weigh in. They are not necessarily against the conversion concept, but want to make sure of two things: that the nonprofit’s assets continue to benefit the community after enjoying years of tax-advantaged status, and that services to the elderly stay at a high level after the conversion.

## Colorado’s Population Distribution Ages 65 Years and Older



## Finding Solutions to Cultural Shifts

More and more prominent in the minds of those shaping the future of LTSS in Colorado are workforce demands and pressures. Hundreds of thousands of more elderly and younger disabled clients in Colorado will require more of everything – from highly skilled nurses and gerontologists, to certified nursing assistants, to jack-of-all-trades personal assistants, to craftspeople who can fashion physical adaptations.

That potential workforce now shrinks each day as boomers leave it for retirement. Among younger workers, societal pressure to raise wages in fast food and other service industries means home-health jobs with stagnant wages might look less attractive.

“If our economy continues to improve, it’s going to be an even bigger problem,” Qualls said. “If I have a choice of working at Kohl’s for \$15 an hour or lifting people and cleaning up incontinence for \$8 or \$9 an hour, that’s a fundamental problem.”

As state leaders and local activists work to design new LTSS plans for Colorado, they will confront cultural changes within the demographic reality of population growth.

In younger disabled needs, for example, Montrose and other Western Slope communities are confronting challenges they never imagined. Long-term drug abuse has damaged some young adults to the point they will need various levels of institutional supports for decades to come, Veitch said.

“What happens with a methamphetamine addict who lives long enough to age? We are starting to see some of that now in nursing homes – 20- to 30-year-olds who have destroyed themselves with drugs, and there’s nowhere else to go. There are unique challenges everywhere I look,” Veitch said.

In El Paso County, the Pikes Peak Area Agency on Aging sees all forms of fascinating and contradictory cultural shifts. The boomer who retires at 65 may have a decade or more of good health before seeking out any support services, noted Guy Dutra-Silveira, director of the Pikes Peak AAA. On the other hand, because of better medical care that boomer may live to 95 and need 20 or more years of assistance.



Mary Seely enjoys one of the frequent craft classes at the Montrose senior center. The classes are often packed with enthusiasts.

And when boomers do seek services, their needs and requests might be very different. The generation that fought World War II tended to wait to ask for help and take what was given, Dutra-Silveira said.

"I think my generation will say there should be services and will be very vocal if they are not there. And I think my generation will ask for a lot more choice. The model of the meal site, where you walk in and get a tray, is not terribly appealing to the younger senior. Changing that is going to be a big challenge," said Dutra-Silveira, 62, who himself planned to retire at the end of the summer.

The Pikes Peak AAA scrambles to meet rising demands; Colorado Springs alone adds nine assisted living sites a year, Dutra-Silveira said. The agency covers three counties (El Paso, Teller and Park) and is striving to improve transportation and meal coverage throughout the area.

The agency funded 117,000 congregate meals and 18,000 home-delivered meals last year. New agreements with partner Silver Key will add hot delivered meals to rural areas like Monument, where only frozen and shelf-stable meals had been available before.

One statistic troubles the Pikes Peak region: Colorado Springs has only one senior center for an area of 600,000 residents, Dutra-Silveira noted. With the city's well-documented financial problems after the 2008 recession, "[Colorado Springs has] trouble supporting even one," he said.

Still, the elderly assistance sites prefer to focus on what's working. They feel their emphasis on adaptable, creative programs outside of Medicare and Medicaid can provide the little things that keep community living possible for the elderly and disabled.

Veitch said her colleagues view the overall drop in nursing home use as a moral and financial victory.

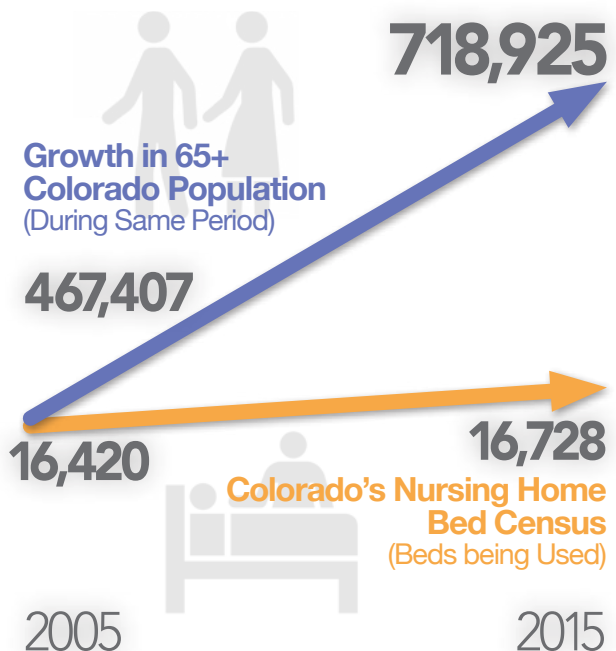
"Because it's what people want. And it's so much less expensive. For about \$4,000 a year, we can provide enough support for most people to live at home, like Meals on Wheels, homemaking support a couple of times a month," she said.

"We have many families ask, 'What about assisted living for my mom?' When we really drill down on what's working and what's not, it's really just a few services they might need: a few rides a month, personal care and homemaking, four or five hours a month for heavy lifting and cleaning and laundry.

"It all makes me feel hopeful because there are things we can do," Veitch said. "There are definitely days it just feels so big, I wonder how we can address all these challenges. But every day it seems as if we come up with solutions, too." •



## Staying Out of the Nursing Home



Sources: State demographer and Colorado Medicaid office

# What Saved Medicare?

## The Core of Long-Term Health Care is Getting Healthier **A Look at Why Things Changed**

By Michael Booth

**Editor's note:** A stable and progressively designed Medicare program is clearly one key to supporting the long-term health and lifestyle needs of Coloradans. More than 775,000 people in Colorado – mostly seniors, but some younger people with qualifying conditions – get their health coverage and care through the federal Medicare program. For years, analysts sounded deafening alarms about the retirement of baby boomers pushing Medicare into insolvency and destroying the federal budget. In 2014 and 2015, updates from actuaries showed a stunning turnaround: Medicare was getting healthier. Per capita Medicare spending not only flattened out in 2009, it actually dropped slightly after 2011 – an unprecedented development in a program accustomed to the buffeting of high medical inflation. In real dollars, the savings are in the hundreds of billions: Actual Medicare spending in 2014 was \$580 billion, while as recently as 2009 the projection for that year foresaw \$706 billion in spending. We asked Kaiser Family Foundation health care analyst Juliette Cubanski to walk us through how and why Medicare's outlook has changed. Cubanski, of Menlo Park, Calif., is associate director of the Program on Medicare Policy at KFF.

**Before the recent, more optimistic analyses of the Medicare spending slowdown, what had been the worries and the predictions about the program and its supposedly untenable costs?**

It boils down to a simple fact of demographics of the population aging: the sheer number of people coming onto the program, aging onto Medicare eligibility when they turn 65. The growth in that population has been a cause for great concern; holding everything else constant, if there were more people coming onto the program and the per capita costs were growing at the rates they had historically, there were real concerns about Medicare having a shortfall in financing. The problem is that the rate of population aging is outpacing the rate at which we are growing the worker base. So there have been some pretty serious and dire projections of Medicare not having enough money to pay for all the hospital benefits that would come due in a relatively short period of time.

In 2009, just six years ago, the Medicare trustees were projecting that the Medicare hospital insurance trust fund, where all these payroll benefits go, was going to basically run out of money and not have enough money to pay current hospital bills as soon as 2017. That was really just right around the corner then. That was the big picture.

**We keep hearing the statistic that boomers are turning 65 at the rate of 10,000 to 11,000 a day. Shouldn't that alone threaten the system?**

That started in 2011, when the baby boom generation started turning 65. Prior to then, the population growth had been a coming concern, but it hadn't come yet. After 2011 is when that number you tossed out became a reality. This baby boom population that is going to last for 20 years is really just now coming into Medicare eligibility.

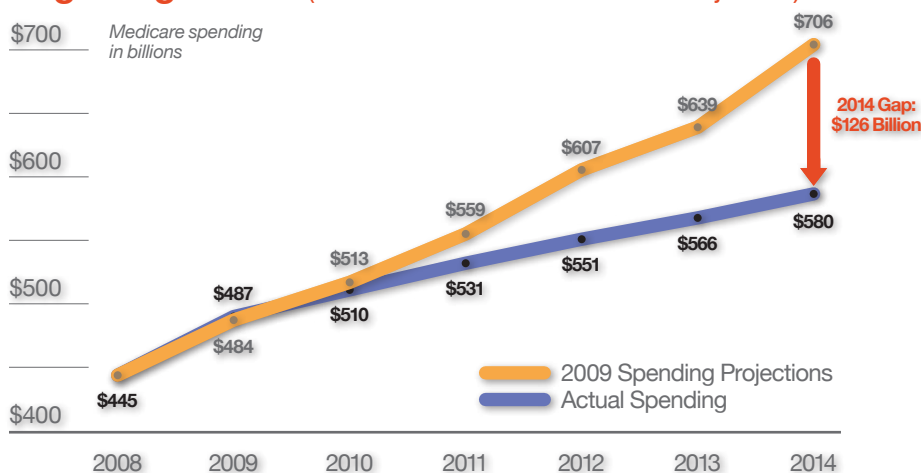
**And so financially for the Medicare system, what has happened instead of those more dire projections?**

One point of comparison: I mentioned in 2009 the trustees were projecting the date of insolvency would be 2017; now in their most recent report for 2015, they are projecting the insolvency date is pushed out to 2030. That's one clear indicator of Medicare's improved financial health.

**So instead of eight years of solvency, we have at least 15 years of solvency.**

That's right. So there we have a clear indicator that Medicare spending projections are not completely under control, but certainly more under control than they were five or six years ago.

### Medicare Spending Trajectory Flattened Beginning in 2010 (\$126 Billion Lower Than 2009 Projection)



Note: Medicare spending equals payments for benefits, net of recoveries from providers for improper payments, adjusted for shifts in the timing of capitated payments. Years are federal fiscal years, which run from October through September.

Source: RAND/Kaiser Family Foundation

### **So what have you and other analysts found as you've dug into the numbers? Why are costs not rising as fast as predicted?**

In our 2014 paper, we tried to look at what happened that year. There are some obvious explanatory factors, some not so obvious and some residual results which we cannot explain. The obvious reason is that the (Affordable Care Act) passed, and that included many provisions affecting the Medicare program and Medicare spending. They were implemented as early as 2011; others rolled out over time. There were basically provider payment cuts and the rate at which those payments were allowed to grow over time. That was one obvious and immediate way to bring Medicare spending under more control – by cutting them now and building into legislation future constraints on the rate of growth going forward.

Another big factor is the reduction in payments to Medicare Advantage programs, the managed care counterpart to traditional Medicare. Historically they have been paid more to provide the same benefits; that plan got paid more than if the person had stayed in traditional Medicare. Some legislators had been bothered by this for years, and they were finally able to restructure and level the playing field. It's phasing in over time.

## **The hope among supporters of the reforms is that these efforts will take hold and more people will get behind them ... and that the system will change in such a way that we don't need a full-scale restructuring of the Medicare program.**

*Juliette Cubanski, health care analyst, Kaiser Family Foundation*

### **Can any of the flattening of growth be attributed to various spending and care experiments going on around the nation in Medicare?**

There are some other provisions in the ACA that might be contributing factors, but we can't assign dollar savings to them because it's too early to tell what role, if any, they are playing. Things like (accountable care organizations), Medicare Shared Savings, bundled payments, independence at home programs – a lot of these initiatives and demos and pilots are being rolled out in various places. It's really hard at this relatively early stage of the game to evaluate how successful these are. I would say some have showed modest signs of promise, but it's tens or hundreds of millions in savings versus an overall program that spends hundreds of billions. They would have to be rolled out on a much larger scale in many more parts of the country.

### **The chart on the first page of your 2014 report shows the flattening of per capita patient spending in recent years. Is that significant?**

It's definitely a big deal. Historically, per capita spending has just gone up, and I think people expected that as a fact and not something you could really do much to change. So the fact that spending trend has been relatively flat is really unprecedented in Medicare. There are some other changes, besides the experimentation I mentioned, that could

be significant. For example, growth in prescription drug spending has been much lower per person than it had historically. While prescription drugs are only about 10 percent of Medicare spending, that trend line does have an effect on the overall Medicare trend line. More people were shifting to generic drugs; fewer blockbuster brand name drugs (were) being introduced. And a lot of the more popular brand name drugs lost patent protection and had generics become available.

There are some other things possibly related to delivery system reform. There have been large relative reductions in the hospital readmission rate. Hospital spending is roughly about one-quarter of annual Medicare spending, so there's a lot of money involved, and clearly Medicare would be happy to see a successful effort in this area.

What is commonly referred to as waste, fraud and abuse – (Medicare has) tried a lot of things in recent years. One area is home health spending, some pretty egregious examples of fraudulent providers; (Medicare's) efforts have been pretty successful, according to the Office of Inspector General and others.

### **I'm sure lawmakers want to know if all of this tightening of the screws has changed consumer satisfaction or quality ratings for the worse.**

We don't focus on that so much at Kaiser, but I'd say the quality measures that have been around for a while, I haven't seen any indication that quality of care has suffered as a result of these initiatives. If anything, Medicare may be sorting out the good from the bad in these integrity efforts. It's very difficult to find evidence that access to care has been affected negatively by any of these efforts. Most people say they are very satisfied with Medicare and that really hasn't changed much at all over the history of Medicare or the history of us asking that question.

### **Has the flattening of costs changed the tenor of the long-term debate about Medicare?**

Yes and no. I think it depends on who you are listening to. There are some policymakers who are paying more attention to recent news about what's happening with Medicare spending and see this as evidence of the effectiveness of the ACA and payment reform, and many people want to double down on those reforms and go bigger and go bolder with those initiatives. But other policymakers seem to not be paying much attention to Medicare's recent history and are talking about raising Medicare's eligibility age and benefit design and shifting to the premium support model. Those ideas are designed to address what might be seen as Medicare's long-run problem: The aging of the population is happening. No matter what you do to Medicare now, the fact is we are going to have upwards of 80 to 90 million people on Medicare in a few decades. And that is the reality that I think many people feel has still not been addressed.

The hope among supporters of the reforms is that these efforts will take hold and more people will get behind them, and as providers get more used to living with bundled payments and the experiments take hold, that the system will change in such a way that we don't need a full-scale restructuring of the Medicare program. There are still some people who are very philosophically opposed to Medicare as it exists today and want it to be a different program in the future.

There are kind of two realities going on for policymakers, depending on which side of the aisle you're on: the vision you have for the health care system overall and where you see Medicare fitting in. ●



# 'Networking' Seniors to Cement NORCs

By Kelly Pate Dwyer  
Photography by James Chance

In 2007, Ada Menzies met a social worker who helped her elderly parents living in Edgewater. After her parents died, the social worker encouraged Menzies to attend a therapy group for caregivers.

"After I got rested enough and ready to face things, she said, 'Make the leap for me, girl,'" Menzies recalled, referring to Alison Joucovsky of Jewish Family Service of Colorado. Menzies, now 64, took Joucovsky's advice and sought counseling.

*Encouraging contact and support between generations is part of the philosophy of "naturally occurring retirement communities". Here, Colleen O'Reilly learns to make tamales with granddaughter Oriah Rumley, age 9, at the Wheat Ridge Active Adult Center.*

Joucovsky also encouraged Menzies, a chef, to teach a cooking class to seniors. She does that, too.

After weaving ties with Joucovsky and JFS for the past eight years, Menzies has earned a reputation as "the go-to person for friends with senior-type questions," she said. "It's turning into this little network. It's about sharing information."

Count one huge win for JFS and Joucovsky, who coordinates social services programs for the naturally occurring retirement communities, or NORCs, in Edgewater and Wheat Ridge, where Menzies lives.

Joucovsky builds relationships with seniors who may need help and fosters connections among seniors to decrease social isolation, build community and make aging in place a comfortable way to live. That's what makes a healthy NORC tick.

"It's all about trust," she said.

## A Model for Aging in Place

A NORC is any area home to a significant share of seniors ages 60 and older, which develops naturally as residents enter their senior years and remain living in their homes – often because they are close to family, friends, their doctor's office, and favorite stores and restaurants – or because they

cannot afford to move. NORCs also attract new seniors or evolve because younger residents move away.

Most NORC residents are women and many live alone. Only some are retired. One NORC may consist of two apartment buildings (a vertical NORC), while the next is a neighborhood filled with single-family homes or an entire small town (a horizontal NORC).

Because they are naturally occurring, NORCs exist at both ends of the economic spectrum. Typically, a NORC is affiliated with a supportive services program (NORC SSP), like those in Wheat Ridge, Edgewater and Denver's Capitol Hill, where need is strongest for the types of services offered.

These programs vary in size and scope but follow a similar design: A nonprofit partner, such as Denver-based JFS, coordinates core social services, including medical care, housing help and transportation, and also facilitates social, recreational, educational and volunteer activities.

Working together, JFS and its partners, including Seniors' Resource Center, HealthSET and Jefferson Center for Mental Health, aim to "close the loop" for Wheat Ridge seniors who otherwise are left to navigate a fragmented system.

When a senior first makes contact with JFS or one of its partners, details about his or her specific needs are entered into a shared database, which triggers outreach efforts within the partner agencies that serve those needs. JFS circles back with clients twice a year to monitor how well their needs are being met.

JFS also works with city governments and community organizations such as Brothers Redevelopment, which helps seniors with home remodeling, maintenance and repairs.

That teamwork, along with visibility and availability of trusted sources like Joucovsky, who spends 75 percent of her time in the field, makes aging in place both doable and desirable for many seniors.

## Lack of Funding Slows Growth

In the mid-1980s, a collaborative effort was organized to provide medical and social services to a cluster of seniors living in a cooperative housing development in New York City. That program laid the groundwork for today's NORC SSP model.

In 2001, the Jewish Federations of North America sought federal funding to introduce NORC programs in other communities,





*June Gallegos, right, discusses tamale-crafting techniques with instructor Yolanda Duran at the Wheat Ridge Active Adult Center.*

said Rob Goldberg, JFNA's senior director of legislative affairs. Between 2002 and 2008, the federal government awarded grants to 45 NORC communities in 26 states as part of a national initiative to test innovative, aging-in-place programs. A decade later, Congress cut that funding.

Yet many of those original NORC programs and others continue operating. United Hospital Fund in New York and various loosely affiliated Jewish-run organizations across the United States lead most NORC SSP programs.

These programs frequently rely on private funding except some in New York, which still receive some government funding. In Colorado, the Colorado Health Foundation, Rose Community Foundation and Daniels Fund are the biggest benefactors of NORC programs. Grant amounts vary; for example, JFS and its partners are working under a three-year, \$900,000 grant to serve the Wheat Ridge NORC, which encompasses about 10,000 seniors in 9 square miles. (The Edgewater and Capitol Hill NORCs are significantly smaller.)

According to Jucovsky, some of the Wheat Ridge grant funding is earmarked for sustainability plans, and she and her colleagues recently began working with a consulting firm to help map out the future of the Wheat Ridge NORC program.

## Healthy Community, Healthy Individuals

That large organizations continue to fund NORC programs is a testament to the strength of the model, which holds promise for improving seniors' health and, in turn, reducing health care costs.

In a 2006-2007 survey of seniors living in 24 NORCs that receive supportive services, 70 percent "agreed" or "strongly agreed" with the statement that they "feel



healthier than they used to as a result of their participation in a NORC SSP.”

Most of these seniors also said they leave their homes more often for various activities than they did before a NORC program launched in their area, according to the survey, conducted by JFNA.

Menzies is a case in point. She has homebody tendencies but along with cooking classes, she also teaches warm water therapy, which she credits for helping her recover from a near-fatal car accident in 2003.

Besides the obvious benefits of exercise and social interaction, these activities are opportunities to make friends, build trust and share information. Menzies said that she recently connected two women, one seeking affordable transportation and the other having used a discounted taxi service.

“NORC programs formalize a structure where you can derive these informal interactions with all sorts of value to them,” said Emily Greenfield, associate professor in the School of Social Work at Rutgers’ Institute for Health, Health Care Policy and Aging Research. “Health is about housing, (avoiding) social isolation, nutrition, feelings of inclusion.”

Volunteerism also is a critical piece. Social workers in NORC areas cultivate relationships with senior residents and other trusted adults in the area such as church clergy, who may encourage seniors they know to get involved in specific activities and know how to connect them with medical and social services.

The informal interactions weave a web of awareness so that if a neighbor doesn’t show up for a routine activity, someone notices and calls for help, Greenfield said.

## Housing Prices Challenge Stable Retirement

Lack of housing is one of the greatest obstacles that seniors face, and it threatens the ongoing success of NORC programs nationwide and in metro Denver, where both the senior population and total population are exploding, driving up the price of rent.

“If your Social Security is \$1,300 a month and your rent is \$900, you’re barely making ends meet,” Joucovsky said.

And affordable housing units are well short of the need. For instance, in Wheat Ridge, 700 people are on the wait list for a subsidized senior building with 85 units. Another 55 units are under construction, she said.

## There are seniors who have lived in this area for decades, paying affordable rents. Then things fall off a cliff.

*Johanna Glaviano, program coordinator,  
Capitol Hill Care Link*

“Half the calls I get are for housing issues,” said Johanna Glaviano, program coordinator for Capitol Hill Care Link, a NORC program launched earlier this year by The Center – Denver’s hub for the gay, lesbian, bisexual and transgender community – and its affiliation with SAGE of the Rockies. CHCL serves all seniors living in the area.

“Many buildings are turning their apartments into condos,” Glaviano said. “There are seniors who have lived in this area for decades, paying affordable rents. Then things fall off a cliff.”

For seniors who own their homes, maintenance and access present hurdles.

“People are growing old in an environment that was not designed for them,” said Andrew Scharlach, author and professor of aging at the University of California, Berkeley’s School of Social Welfare. For instance, their bathrooms

may lack grab bars, the sidewalks are narrow or lack curb ramps, or seniors can’t cross the street fast enough on a green light.

The growth and continued success of NORCs and aging in place generally also depend on building awareness within the community at large – among business owners, politicians and younger people who don’t know their older neighbors or don’t realize they may be struggling.

“One of the key things NORC SSP programs do – and villages do a better job – is engage older adults themselves in answering these questions” about aging in place successfully, Scharlach said. (Villages resemble NORCs in terms of lifestyle, but they are grass-roots, membership-driven organizations.)

On a recent weekday in August, a small group of grandparents and grandchildren gathered for a tamale-making class that Joucovsky arranged at the Wheat Ridge Active Adult Center. None of the participants were clients of JFS or its medical and social service partners. That’s OK with Joucovsky.

“You need a lot of entry points” into the community, she said, including reaching people before they develop health problems. “If you fall, then you remember you’ve been coming to activities and events and think ‘I’m going to call Alison.’” ●

**NORC Results** JFS surveys all seniors who receive direct services (medical, care management and homemaker services) through the NORC program, both before they start a service and again six months later. The following results are based on surveys completed by 60 seniors who use the NORC services in Wheat Ridge.

**75%** report fewer hospital visits.

**100%** report increased confidence accessing community resources.

**63%** report fewer ER visits.

**75%** report improved confidence aging in place.

**67%** feel more connected to their community.

**100%** report feeling satisfied or very satisfied about the services they’ve received.



# Easing the End of



*The Shepherd family has now had “the conversation” about end-of-life choices, though not everyone started at the same comfort level. Retired physician Carolyn Shepherd, center, and husband, John, have talked things over with daughter Hana, right; son-in-law Diego Matamoros, left, holding baby Esti Matamoros; and Carolyn’s sister, Susan Parsons.*

# Life with Conversation

## A Unique Project Encourages Families to Talk about the Unmentionable

By Sharon Sullivan  
Photography by James Chance

**A**s ethics consultants, Constance Holden at Boulder Community Hospital and Jean Abbott at University Hospital in Aurora are often called on to help resolve conflicts that arise when family members disagree on how to care for their loved ones who are nearing the end of life.

"I have witnessed many difficult situations that might have been averted or been less difficult if the patient had had a conversation with family about their wishes," said Holden, a retired registered nurse and co-founder of The Conversation Project in Boulder County, whose mission is to foster meaningful and effective conversations about end-of-life care.

According to the Institute of Medicine, many people may not be able to physically or mentally communicate their wishes regarding care when they are nearing the end of life. And while 82 percent of Americans say it is important to put end-of-life wishes in writing, only 23 percent have actually done it. Patients, moreover, often end up in the hospital with a physician who they have never met.

Designating a medical durable power of attorney before a crisis – choosing an agent who is locatable and can speak on the patient's behalf at those crucial moments – can eliminate these conflicts. "That person is key because of the fragmentation of the health care system," said Abbott, a retired physician and co-founder of The Conversation Project in Boulder County.

Partnering with the Community Foundation Serving Boulder County, The Conversation Project encourages people to think about, document and, most importantly, talk to family members about their values and wishes regarding end-of-life care. A starter kit (available at [theconversationprojectinboulder.org](http://theconversationprojectinboulder.org)) includes questions that address emotional, medical and practical issues to help guide people in having those conversations.

### State – and National – Outreach

The Conversation Project in Boulder County is based on the work of Pulitzer-prize winning journalist Ellen Goodman, who founded the organization in 2012 after the death of her elderly mother. The Conversation Project is supported by the Institute for Healthcare Improvement.

"Jean brought Ellen Goodman's work to my attention. We both looked at each other and said, 'This is what people should be doing,'" Holden said.

They believed similar programs across Colorado could improve end-of-life care for people in many communities and prevent the types of conflicts they often deal with as ethics consultants. They asked Goodman if they could use "The Conversation Project" name for their local endeavor.

Goodman agreed, requesting that the Boulder project become a model for other

communities, which it has done. There are similar efforts in Weld and Larimer counties and several groups in metro Denver, Abbott said. She and Holden regularly hear from people from across the country seeking information about what's happening in Boulder County.

"We are hoping this will become a statewide initiative," Holden said. "We're willing to share everything we have."

In Boulder County, Abbott and Holden along with a dozen trained volunteers have given nearly 200 presentations about The Conversation Project. They estimate that they have reached at least 2,200 people by speaking at rotary clubs, libraries, senior centers and other venues.

In Grand Junction, Rocky Mountain Health Plans Foundation has twice invited Abbott to speak on the Western Slope to groups that include clergy, social workers, hospice employees and other community members about how to start their own Conversation Project. "Our foundation is looking at taking The Conversation Project into the workplace," said RMHPF executive director Lisa Fenton Free. "Starting in the fall with our (450) employees, we will hold sessions at workplaces on work time and before and after work."

In July, RMHPF met with the Coordinating the Coordinators Committee, a Grand Junction group working to coordinate patient care among physicians, agencies and case managers, and bring The Conversation Project into their various worksites. RMHPF also plans to reach out to the Mesa County Health Department to learn about other places in the community where they might introduce The Conversation Project. "We're excited about promoting these conversations, which will add more meaning to life versus having a fear-based approach to end of life," Fenton Free said.

### Starting the Conversation

For the past two decades, the Mesa County Advance Directives Task Force, represented by Grand Junction's two hospitals, the county Department of Human Services, RMHPF and other organizations, has sought to educate community members about advance directives, said task force chair Mary Watson. "This year we focused our attention on The Conversation Project" by giving presentations at HopeWest hospice, assisted living centers, nursing homes and Montrose Memorial Hospital.



The Conversation Project is particularly timely since the Centers for Medicare & Medicaid Services recently announced a new policy: The government will reimburse doctors for having voluntary conversations with their patients regarding values and preferences for end-of-life care. The policy is set to go in effect January 1, 2016, after a 60-day public comment period. A similar provision was initially included in the Affordable Care Act until opponents likened it to “death panels,” claiming, falsely, that the government would be rationing actual health care.

“Frankly, the majority of people who come to our presentations fear they’re going to get too much medical care – life-prolonging procedures they may not want,” Holden said. “The default is that if you don’t tell anyone your thoughts, you will get everything (resuscitation, ventilator, feeding tubes) regardless of quality of life afterward.” The Conversation Project helps people identify what they want, whether that’s aggressive, “do everything” medical treatment or signing a do not resuscitate order.

The Patient Self-Determination Act requires physicians and hospitals to ask patients if they have advance directives or would like information about making end-of-life decisions. “It was supposed to spark those conversations, but it hasn’t happened” because physicians are often uncomfortable broaching the subject, Holden said. “We want the public to have these conversations with family, and then go and talk to their doctor. We’re preparing people to do that.”

## Frankly, the majority of people who come to our presentations fear they’re going to get too much medical care – life-prolonging procedures they may not want.

*Constance Holden, ethics consultant, Boulder Community Hospital*

Sandy Younghans downloaded the starter kit after her brother Jeff was diagnosed with a rare, degenerative brain disease. The retired Boulder attorney initiated the conversation with her brother by using the starter kit questions to help Jeff identify his goals and wishes for his approaching end of life.

“He was very clear about not wanting any feeding tubes,” Younghans said. She discovered her brother’s biggest fear was loss of mobility, which explained his plans for knee replacement surgery – a high-risk procedure that would have still left him with tremors, speech problems and prone to falling as well as a lengthy rehabilitation period. After talking with his sister and palliative care professionals, Jeff was able to identify what was most important to him – spending time with family. He canceled the surgery. The conversation with his sister paved the way for subsequent conversations with his wife and daughters.

Retired Boulder physician Carolyn Shepherd learned about The Conversation Project when she heard Goodman speak at an Institute for Healthcare Improvement conference on the East Coast. Shepherd and

her husband downloaded the starter kit and answered the questions separately. Though they found the majority of each other’s responses not surprising, there were issues that “became clearer for both of us – if ever we’re in that position,” Shepherd said.

“For example, my husband was adamant about having his loved ones follow his wishes exactly, even if it makes them uncomfortable,” Shepherd said. As a physician, she said she expected to make some decisions about his care; but her husband was most comfortable with her promising to not deviate from his wishes. “The degree of importance of this to him surprised me and was something that was critical for me to understand,” Shepherd said.

Next, the couple had a conversation with Shepherd’s sister. A third conversation is planned with the family’s two children.

“One daughter is very uncomfortable (with the topic), but she’s going to do it,” Shepherd said. “It’s very helpful to have a small template to put the conversation into. (The starter kit) is a useful tool.”

The conversation may need to be repeated as plans may change, and the chosen agents may also undergo a switch, Holden said. She emphasizes the importance of having the conversation “upstream” – before a new diagnosis or other medical crisis, when the topic may be more difficult to talk about with loved ones.

“In our capacity as ethics consultants at our respective hospitals, we are often called upon when families are in conflict about the course of action to take when their loved one is unable to participate in decision-making,” Holden said. “Too often we hear, ‘We really don’t know what Dad would want; we never talked about such things.’ Values-based discussions can offer families critical guidance at the bedside. Avoidance of confusion, conflict and heartaches are the goals of The Conversation Project.” ●







# Long-Term Supports

## May Start Young, But Needs are the Same for All

A Q&A with engineer and activist  
Joshua Winkler

*Josh Winkler speaks for many Coloradans living with disabilities on a variety of policy and advocacy boards, while also running an adaptive-technology business from his self-engineered garage shop behind his house.*

By Michael Booth  
Photography by James Chance

**Editor's note:** Colorado has a deep history of disability activists encouraging – and sometimes forcing – change in state and federal policy to better serve the long-term services and supports needs of state residents. Joshua Winkler is a longtime activist who now sits on numerous government advisory panels and community boards, including the Community First Choice Development and Implementation Council, which is advising the state Department of Health Care Policy & Financing as it considers launching a CFC program for Colorado. He also is on the board of The Arc of Colorado, the Colorado Cross-Disability Coalition and other activist groups. Winkler, a mechanical engineer who works in adaptive technology, overcame a childhood disability only to suffer a spinal cord injury in his teens. We met recently in Winkler's high-tech garage workshop to speak about where Colorado's disabled services need to go next.

**It sounds like you had the mentality from the beginning of your injury to do whatever you needed to do to get back to what you wanted, which was working with your hands.**

I'm 34 this year; I was hurt when I was 17. When I broke my neck, it was something new, but life deals you these things and you move on. I was hurt in Pennsylvania and did my rehabilitation at Craig Hospital. I was thinking, I'm going to need a degree; I'm going to need a piece of paper to get a decent-paying job. Originally I had the thought, if I'm ever going to get off Medicaid, I have to have enough money to pay for my services – roughly \$30,000 to \$40,000 a year in out-of-pocket expense even with a good insurance policy. That's the home health aide that private insurance doesn't pay for. I came out with a degree in engineering in 2005. I'd wanted to work for NASCAR because motocross was my thing before I got hurt. I got lucky and got involved with the Furniture Row racing team here in Denver – an internship and then got a full-time job. Then the economy dropped, and furniture sales and advertising also dropped, so they had to cut back on the team.

Colorado didn't have a Medicaid buy-in program. I started looking for states that did. California did. I wanted to work; maybe I needed to move. Well-educated, 29, I wanted to work and run my own company. I stumbled on the fact that Colorado was actually working on a Medicaid buy-in, though it took three years of meetings to do it. I contacted (the Department of Health Care Policy & Financing); they said they were working on it. What I wanted was consumer direction, because then you can get the home health aides you can hire yourself and get to show up at your house at 6 in the morning so you can get to work by 7 or 8. That was 2012.

**Where do you think Colorado, in general, sat at that time in terms of its policies for long-term services and supports?**

Our LTSS were probably in the top three or four in the country at that point. We had a pretty solid home health system here. Rural areas are decently covered; we have full consumer direction under Consumer-Directed Attendant Support Services. Those pilots started in 2005 for people under the Elderly, Blind, and Disabled Waiver, and it's been extended to other waivers.

**When the activist community started pushing the state hard in about 2012 to formalize its long-term services plan and respond to Olmstead Decision mandates, at that moment where would you say Colorado's services were in comparison to others? You said we were maybe among the three or four best states in the nation. Can you elaborate on what we were doing well at that time and what still needed to be done?**

Colorado is the Medicaid waiver king. At our peak I believe we had 13, and from 1981 when they were authorized under Reagan until the Affordable Care Act, they offered the best way to provide LTSS to the various populations who needed them. The downside to the waivers is that the targeting criteria force segregation of services based on

diagnosis. This has left individuals with developmental disabilities wanting services folks with physical disabilities get, and folks with physical disabilities wanting services only brain injuries get, etc. One well-known example is access to consumer-directed service delivery through In-Home Support Services and Consumer-Directed Attendant Support Services, which are great for the folks who have access to them and are desperately needed by many of the people on the IDD waivers.

**What exactly was pushing the activist community at that time to take over meetings and be more vocal in its demands from the state agencies?**

Complacency. Several state agency directors were happy to be one of the best states at providing LTSS, but advocates knew we could still do better.

**In general, has Colorado been successful in emphasizing home- and community-based services over institutional care? You had mentioned some states were one-third/two-thirds on that split of spending, and Colorado was the opposite.**

Absolutely. And this goes back to the birth of the independent living movement and the birth of ADAPT in Denver. *(Editor's note: ADAPT has been a prominent and widely effective advocate of independent living for people with disabilities.)*

**While Colorado is moving forward on waivers and reformulating its programs to better meet community needs, there is one larger need you have mentioned that is a tough challenge for all in this state: housing costs.**

The current rental market has created a big challenge: The housing vouchers all have a cap on what the apartment market rate is, and currently, apartments are renting for 150 percent or more of the market rate. We need more affordable, integrated, accessible apartments to be built, and that will require incentivizing builders in some manner. Until the Democrats in the Legislature back off on construction defects liabilities for condo developers, the Republicans are refusing to pass any low-income rental incentives, so we are at a stalemate until the housing market in Colorado crashes again. Colorado was recently awarded funding for 411 units under Section 811 rules (federal money specifically for housing for the disabled); these aren't as good as Section 8 (federal vouchers allowing more freedom in choosing units), but are better than nothing, if the state can get builders to take the money to create the units.

**What is Community First Choice and why could it be helpful to users of long-term services who want to direct more of their own needs?**

Community First Choice is an optional Medicaid program authorized under the ACA. CFC would move services that assist with activities of daily living and instrumental activities of daily living from waivers to the state Medicaid plan. In order to be eligible for these services, clients would still be required to meet level of care requirements. One example of a "pro" in CFC is that it opens up the delivery model to allow for the clients' needs and gives them more ability to direct services. The clients receive services outside of their homes – if you need an attendant to help while you are at work or at school, at the park – so that you can continue to go to all of those places. It's a big step to simplifying the waivers.

**What's the barrier to the state in joining the optional CFC? Too high a bill for the Legislature?**

The biggest barrier is the projected cost to the state general fund. CFC services would receive an enhanced 6 percent match from the federal





government, but early cost projections indicated it would still cost Colorado more money as services are expected to be utilized at a higher level under CFC due to the availability across disability types. The CFC Development and Implementation Council is working with HCPF and contractors to ensure cost estimates are accurate and to find ways to reduce costs without gutting the services offered under CFC.

### How have we done on the seemingly innovative Money Follows the Person? Can we meet those targets?

MFP is a great program, but delays in getting it rolling in Colorado combined with a tough housing market will likely cause us to miss the target of 500 people transitioned out of institutions in five years. Momentum has picked up, but we are barely over 100 in three years.



### From an outsider's perspective, it might seem that the needs of a younger disabled person who wants to live alone would be very different from those of a 78-year-old person who may be on the verge of a nursing home decision. Are there common needs that make your activism apply to everyone in Colorado?

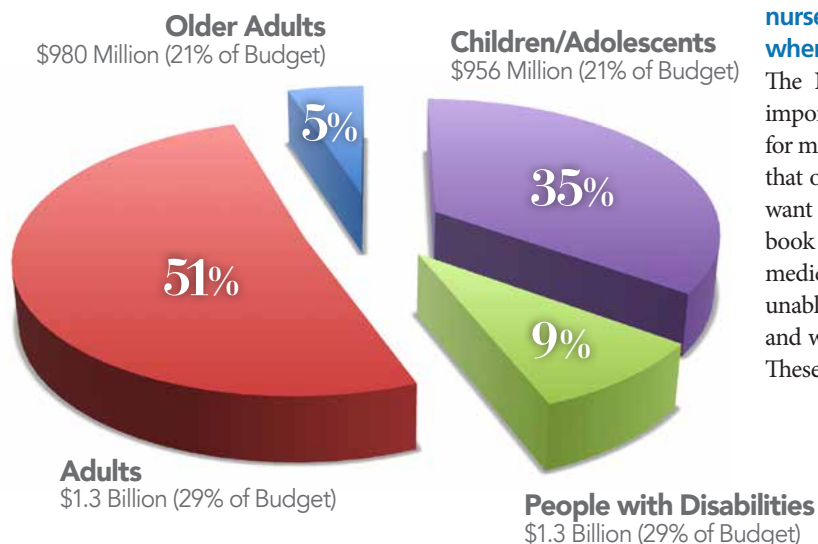
Absolutely. Maslow's hierarchy of needs applies to all of us. People want to feel safe (housing and medical insurance), healthy (medical insurance and good living environment), loved (access to community, friends, family, church, etc.), mobile (ambulatory, with wheelchair/scooter/walker/crutches and by car/taxi/bus/paratransit) and free to make their own decisions (which institutions take away). The biggest area where older and younger folks differ is on employment, and Colorado is making concerted efforts to improve employment opportunities for younger folks with disabilities. Nobody wants to be a burden on their parents, their children, or their friends and extended family.

### Disruptive technologies like Uber would seem to offer potential for many disabled people – both as a rider and as a potential driver – for earning income. Can you talk about Uber and Lyft from both a rider's and a potential driver's perspective?

Unfortunately tech startups have a history of ignoring or directly discriminating against people with disabilities. In recent years, Google and Apple have instead seen the disability market as a huge customer base and put effort into meeting our unique needs. Uber and Lyft have done everything they can to get around the laws that govern public transit, including laws that prohibit discrimination. Many media outlets have covered it. Wheelchair-modified vehicles are extremely expensive – around \$50,000 – so it is a difficult issue to solve. The idea of folks like myself who already have adapted vans becoming Uber drivers often comes up. But my inability to strap down a passenger's wheelchair would make it unsafe, and Uber's "our drivers are independent contractors" stance would open me up for personal liability.

### Medicaid: Enrollment vs. Spending (FY 2013-14)

A demographic group's share of enrollment (percentage of pie, below) may differ greatly from what Medicaid spends on that group (text next to each pie slice)



### As the baby boomer population ages and more young disabled people are living longer and healthier lives, will we face a shortage of workers who can help make LTSS better? You have mentioned the need to loosen rules on whether a nurse, for example, is required to do a certain assistance job when someone with other training might do as well.

The Nurse Practice Act and Nurse Aide Practice Act both are important in acute care settings and in long-term care facilities. But for most of us receiving LTSS in the community, it is more important that our attendants are trained to perform specific tasks the way we want them done rather than being able to pass a test about how a book says things should be done. Much of the LTSS work done is not medical in nature, but rather daily activity assistance we as clients are unable to do ourselves. Getting attendants who listen, are trustworthy and who will stick around as employees for years is very important. These folks know every detail of our lives. •

# Family-Centered Care at the Heart of Latino Elder Initiative

By Buffy Gilfoil  
Photography by James Chance

In July 2014, 83-year-old Catalina Gonzalez was in a tough situation: A paperwork glitch left her without Medicaid and without benefits through the Medicare Savings Program, which helps income-qualifying seniors with their premiums. Her daughter, Wendy Evangelista, tried to get the coverage reinstated but online applications were rejected twice.

Later that year, with help from the Colorado Latino Age Wave initiative, the Colorado Gerontological Society hired Leslie Ojeda, who not only has a solid background in human services but also speaks Spanish.

About the same time, Gonzalez, who speaks little English, heard about the society through a

friend. She contacted the organization and was put in touch with Ojeda, who visited Gonzalez at her home and completed a hard-copy application in less than a week. Evangelista hand-carried the application to the county, and Gonzalez's coverage resumed weeks later.

Gonzalez is typical of the quickly growing group that the Colorado Latino Age Wave initiative seeks to help.

The initiative was begun in 2011 after national research by Hispanics in Philanthropy identified unique needs and challenges facing the elderly. With past support from the Colorado Health Foundation, the initiative currently relies on a partnership among Hispanics in Philanthropy, the Rose Community Foundation and the Latino Community Foundation of Colorado.

The first action taken by the initiative was to conduct a community assessment. It found

the number of Latino elders in Colorado increased by 76.9 percent between 2000 and 2010 compared with a 51.9 percent increase for all races in the same age group. By 2030, the Latino population of all ages is expected to grow by 174 percent compared with a 31 percent projected growth for the white non-Hispanic population.

"We're the fastest-growing minority elderly group – nationally and in Colorado," said Cec Ortiz, project manager of the Colorado Latino Age Wave initiative.

Compared with other older Denver adults, Latino elders face additional challenges, according to the assessment. But "they also possess cultural values and assets that can enrich the aging experience for Latinos as well as enhance the new narrative of aging that is currently being written by all older adults at this time in our nation's history."

*Leslie Ojeda, right, visiting with Catalina Gonzalez at her Aurora home, helped Gonzalez straighten out Medicaid issues. As Colorado's significant Latino population ages with the rest of the state, planners are identifying both advantages and challenges in finding services.*





## Access to Resources in Latino Communities

One important lesson the assessment highlighted, according to Ortiz, was a disconnect between agencies providing services to Latinos and those providing services to older adults. Latino-serving agencies have historically had little access to resources dedicated to older adults, while service providers for seniors have not had training in providing culturally appropriate services to Latinos.

To address this and other findings, the initiative funded a grantee cohort to understand and improve practices.

The cohort comprised three agencies that serve Latinos – Colorado Impact: Center for Economic Prosperity, Latino Task Force of Boulder County and Sisters of Color United for Education – and two that serve older adults – Catholic Charities of the Archdiocese of Denver and the Colorado Gerontological Society.

These agencies completed more than 50 hours of structured cultural competency training and participated in more than 300 community events that marketed services to 1,762 Latino elders, their caregivers or both. They continue to work together and learn from each other.

In addition, three fellows, all over age 55, studied a different issue. Transit and mobility expert Mary Young focused on access and affordability. Among other achievements, she examined leveraging family and community assets. Vietnam veteran Jose Aguayo worked on veteran awareness, appreciation and services. His actions in support of Latino veterans included producing a 32-page resource guide. Michael Cortes, clinical assistant professor at the University of Denver's Graduate School of Social Work, supported the initiative's policy work by testifying before legislative committees on the consequences of poverty on older Latinos and other issues. His accomplishments included a presentation at the American Society on Aging's annual conference.

As the grantee cohort and the fellows gathered information, they heard about the importance of family among Latinos and the challenges of caregivers.

"For Latino elders, the family is the nucleus of care," said Lori Ramos Lemasters, adding that Latino caregivers have the same challenges and struggles as other caregivers, but the two groups are affected differently. Lemasters, a

caregiver herself, conducted seven two-hour focus groups with 84 adult caregivers of Latino elders. She left her job in the mortgage business when her mother, now deceased, had a stroke.

Service delivery providers sometimes think language is the only barrier to delivering care to Latinos, Lemasters said. "It's so much deeper than that."

Lemasters said she met many naysayers when she was planning the focus groups. "When we first started and decided to hold focus groups, they said caregivers wouldn't come, especially not Latino caregivers. And if they would come, they wouldn't talk."

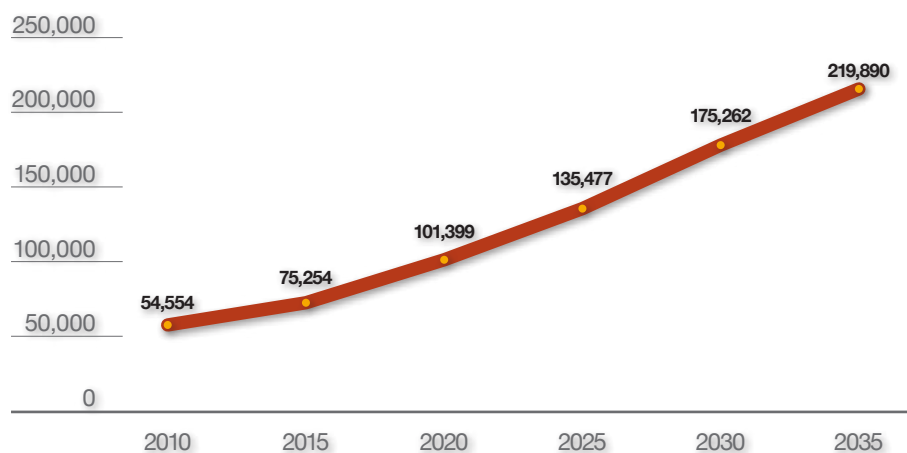
But she worked with organizations that already had ties to the Latino community and conducted outreach through churches, doctors' offices and other trusted sources. She followed up by mail and phone. Caregivers not only came, but they opened up.

to find their own resources, understand their stresses and give themselves permission to take care of themselves."

The program was organized into two groups with five caregivers each. All received resource kits with books on caregiving, resource lists, chocolates and blank care plans. For one group, all the help they received was in the kit; the second group received support from caregiver mentor Josephine Bachicha, who cared for her now-deceased mother and continues to care for her adult son Dominic, who has Down syndrome. Bachicha had initial and ending visits with members of her group and a few phone calls in between. They talked about care plans, which included identifying challenges. She also administered before and after assessments of the caregivers' ability to access resources.

Results of the pilot are not yet available, but Bachicha observed that caregivers are fully

## Colorado's Latino/Hispanic Population Ages 65 Years and Older



Source: State demographer

Trust is an important factor among Latinos, Lemasters said. A caregiver may tell outsiders she loves taking care of her parents, that she's doing fine and feels no pressure or stress. "In a different setting, she might admit she cries herself to sleep she's so tired," Lemasters said.

Lemasters also worked with a naturally occurring retirement community in Wheat Ridge to increase the involvement of Latino elders. "We did lots of community engagement," she said.


Last summer, Lemasters oversaw a three-month peer-to-peer pilot program that focused on resources in three areas: access to services, respite and transportation. The ultimate goal, Lemasters said, was "to empower caregivers

dedicated to caring for loved ones but minimize their own needs and pressures. "(Caregivers) almost feel selfish if they feel a need to ask for services for themselves," she said.

Ortiz said the initiative will build on its successes to date to further develop models that help Latino elders thrive in their communities with the support of family-centered care. It will also continue to focus on the needs of caregivers.

Meanwhile, Gonzalez described the treatment she received from the Colorado Gerontological Society as "excelente."

Ojeda said of Gonzalez, "She's very dear to my heart. She has a dynamic personality. I feel good knowing she's getting the help she needs." •



# Technology

## Can It Ease Disability Instead of Add Confusion?

By David Cogger

**E**very morning when Mary Johnson climbs out of bed, she turns on her Samsung Galaxy tablet and touches a large green app with a white checkmark in the middle. The app sends a message to the front desk at Clermont Park, a retirement community in Denver where Johnson lives. The message notifies the front desk that Johnson is fine and ready to start her day.

Johnson, along with 167 other residents, has embraced the tablet technology to communicate within the community and to keep in touch with friends and family living elsewhere.

“At first, I thought there was too much information and the instructions were too complicated,” Johnson said. “I am a one-two-three person, so I worked through the instructions and came up with a simpler way to teach it.” She soon became Clermont’s go-to person for tablet instruction and later delivered a speech about the program at the LeadingAge conference in Denver.

While technology can improve the lives of seniors and younger people living with disabilities, constant changes in equipment and machinery can leave people frustrated and sometimes overwhelmed. Helping people find clarity and utility from technology is a constant challenge for the long-term services and supports community.

Clermont launched its tablet program with a pilot group of 10 in the fall of 2012. Although success did not happen overnight, the program was implemented throughout the entire facility in the spring of 2013. Today, Clermont has 200 residents in its independent living facility, and it boasts a 90 percent participation rate in its tablet program.

“It was a major undertaking because some had never used technology or a computer,” Johnson said. “I had used a computer, but I am not a tech person. My phone is an emergency device, and it isn’t ‘smart,’” she added with a smile.

Elsa Wysick uses her tablet to keep tabs on her children and grandchildren.

“One of the things that is so great was the opening up of another world,” Wysick said. “My children talked me into it.”

Before adopting the tablets, Clermont used a ring system much like do not disturb signs found in hotels. The concierge staff monitored the rings that residents placed on their doorknobs every night and checked in the morning to see that they had been removed, indicating that residents were awake and fine. If a ring had not been removed, the concierge would knock on the door.

The app has eliminated the concierge and some of the human touch, but Clermont has created a virtual community by adding other apps, including a message board, activities, a staff and resident directory with photos, a slideshow and a program that enables residents to schedule maintenance and work orders. In addition, residents have unrestricted access to the Internet.

Johnson uses her tablet to Skype with her sister who lives in St. Louis. She also has a Facebook page to keep in touch with her grandchildren and uses the tablet search engine to research topics that interest her.

For Wysick, Facebook takes too much time. “I really do not care if my grandchildren have brushed their teeth in the morning,” she said. “I would rather spend my time talking to my friends.” Wysick said that although she likes the technology, she does miss the personal touch and the knock on the door when she left her ring on the doorknob.

“When we got people to be unafraid of the tablet, it changed the attitude,” Johnson said. “The community became an ‘I can’ place, where we thought if we can manage the tablet, there is nothing we cannot try.”

According to Clermont staffer Kayleen Gibson, the tablet program is part of a long-term plan to prepare for the next wave of residents, the baby boomer generation.

“Our CEO is always on the edge and asking what we are going to do next and how do we prepare for the next generation for whom technology is a must.”

## Adapting for All Generations

In another part of metro Denver, a printer arm turns quickly inside a clear box retracing the same pattern, laying strand upon strand of thin blue plastic the diameter of fishing line. As the printer motor hums, a business card holder takes shape. The finished piece is a duplicate of the universal symbol used to designate handicapped access in parking lots and other public places, in 3-D miniature.

The holder was designed by Joshua Winkler, whose work focuses on solving problems for people confined to wheelchairs, a world he has known for much of his life.



Winkler was born with a defect in one of his legs that left him with a limp. An automobile accident in high school resulted in a broken neck and confinement to a wheelchair. After completing a master's degree in mechanical engineering and work on a NASCAR team, he launched Cripple Concepts, a company that designs and manufactures adaptive equipment that makes the lives of people in wheelchairs a little easier.

"I want to make everyday devices more user friendly," he said as he rolled his chair out from under a milling machine atop a retrofitted bench.

His workshop, located in an oversized garage behind his home in Aurora, includes computer-controlled lathes, milling machines, a router, a modified hydraulic pipe bender and the 3-D printer. Winkler described the equipment as "high-end hobby and low-end professional" tools.

Winkler redesigned and retrofitted the entire shop. Machines that normally would sit on the floor have been placed on benches, allowing Winkler to roll his wheelchair underneath. Hydraulics and computerized mechanisms that can be programmed to cut, bend, saw and mill large pieces of metal assist with work usually done by hand.

He brings the same engineering skills to his work designing and building adaptive devices, including user-friendly USB charging ports that attach to the arm of a wheelchair. The port's prototype was built with the 3-D printer and mass-produced in China.

Winkler replaced the flimsy rubber control stick knob on his own chair with a metal one turned on his lathe. Word-of-mouth eventually led to production of several more for friends. And he redesigned the leg rest on his chair to include a rubber bumper to protect his legs and feet.

A bird nest of thin clear tubing is the makings of a cooling system called the Cripple Cooler. It is a work in progress that sits on a bench next to the printer. "Sweat is a problem for people with paralysis," Winkler said, because nerve damage alters the body's ability to regulate temperature. His earlier work with NASCAR's driver cooling system was the inspiration. Winkler also plans to make a modified backrest using a network of cooled tubing.

"All of the machines and tools are designed to make things reachable. My whole life works that way."

## Giving Voice (Recognition) to the Injured

On a sunny afternoon at Craig Hospital, a young boy belts out a tune before a crowd of spectators attending the annual Craig Talent Show, while patients in wheelchairs maneuver in and out of customized vans to attend appointments or to work out in the gym.

Meanwhile, in a sun-drenched lab on Craig's fourth floor, assistive technology specialists Jill Baldesarri and Erin Muston-Firsch work to make technology like smartphones, tablets and voice recognition devices a little easier for patients using wheelchairs.

Baldesarri demonstrates a voice recognition product called Echo, developed by Amazon. She instructs the small desktop tower, which the staff has named Alexa, to "play Pandora." Soon, blue lights begin to glow atop Alexa and the Disney station starts to play.

"Just by talking to it, you can create shopping lists, listen to audiobooks, create music playlists and save things to a calendar," Muston-Firsch said.

"What used to be super expensive has evolved and become more reasonable," Baldesarri explained. "The tower costs under \$200."

• • •

**When we got people to be unafraid of the tablet, it changed the attitude. The community became an "I can" place, where we thought if we can manage the tablet, there is nothing we cannot try.**

*Mary Johnson, resident, Clermont Park retirement community*

• • •

In some case, this technology can cut back on the need for round-the-clock caregivers, allow for greater access to hobbies and creative activities, and contribute to longer independent living situations.

In addition to Echo, the lab at Craig offers adaptive technology that can control doors, open and close window shades, and turn lights and appliances on and off. Technology known as the Nest allows people to control household thermostats remotely. And voice recognition available on iPhone, Android and Google devices can open email and enable hands-free application of services like Siri.

Apple has also created technology to provide warning systems for those with spinal cord injuries, for whom weight shift is extremely important. Long periods of sitting in the same position can cause skin sores. "The app can be customized for individual injuries, and intervals can be set to account for the time between weight shifts and the time it takes to shift your weight," Baldesarri said.

Some apps offer photos of different meds to make sure a patient is taking the right pill. And sip-and-puff joysticks attached to wheelchair arms not only allow patients to maneuver their chairs, when paired with phones using Bluetooth, different durations of sips and puffs can control applications on a smartphone.

The lab is beta-testing infrared technology like that used in TV remotes to eventually control more practical household apps through a smartphone. For now, this technology is for recreational use only. Products like the Griffin Beacon, RedEye and the Flipper work through home Wi-Fi, Bluetooth or cable boxes, allowing users to control television program lists or games, and then watch with just a tap on an on-screen guide.

Voice recognition tools, including Dragon for email, word processing and Internet navigation, are also available through the lab.

"If someone wants to pursue a hobby, we try to help," Baldesarri said. This includes adaptive gaming apps with modified controllers. "Games have proven to be a great activity for those confined to a wheelchair. They are a great way to connect with friends and others in the community."

One patient who had been a pianist wanted to play a keyboard. Craig created a mouth stick enabling her to play. Eventually she became proficient enough to play and record music. She then mixed the piece on an app known as GarageBand using hands-free technology.

"We want to make it easier for people to control their environments with technology, and we have come a long way," Baldesarri said. •



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## A Long-Term Support Party in Montrose

Building a community of long-term services and supports, the focus of this issue of *Health Elevations*, can be as much play as it is work. The senior center in Montrose is a vital core of the community, with active dancers, pool players, crafts aficionados and more. Join us at [www.coloradohealth.org/journal](http://www.coloradohealth.org/journal) for a video portrait of the Montrose family of seniors.

