Triple Threat: Managing Services for the Aging and Disabled in an Era of Unprecedented Growth

Dr. Jane Linder
October 2012
Helping senior and disabled citizens is the growth industry of human services. Many states already have long waiting lists with no obvious way to address today’s needs, let alone tomorrow’s. We asked human service executives how they are dealing with the triple threat: unprecedented demand, fiscal restraint, and increasingly complex service delivery. (See the Sidebar: Who Participated?)

### Who Participated?
We interviewed 13 human services leaders in 9 states. These included executives in departments of aging and disability services, and governor’s offices. The participants included, in alphabetical order:

- Denise Arnold, **Deputy Director of Programs, Community Development, Florida’s Agency for Persons with Disabilities**
- Hugh Eley, MPA, **Assistant Secretary, Louisiana Department of Health & Hospitals, Office of Aging and Adult Services**
- Kim Grier, **Livable Communities Specialist, Georgia Division of Aging Services**
- Jilienne Gunther, MSW, JD, **Legal Services Developer, Division of Aging and Adult Services, Utah Department of Human Services**
- Tony Kester, **Director of Lieutenant Governor’s Office on Aging, South Carolina**
- Nels Holmgren, **Director, Division of Aging and Adult Services, Utah’s Department of Human Services**
- John Holton, **Director of the Illinois Department on Aging**
- Duane Mayes, **Director, Senior and Disabilities Services, Alaska’s Department of Health and Social Services**
- Linda Rolfe, **Director, Division of Developmental Disabilities, Washington State’s Aging and Disability Services Administration, Department of Social and Health Services**
- Janice Sparks, PhD, **Director, Care Connection Aging and Disability Resource Center, Houston, Texas**
- Stephen Williams, **Director, Houston Department of Health and Human Services**

The leaders we interviewed agree: the future of aging and disabled Americans is cause for concern. The number of seniors will double by 2030—that’s right around the corner. Some states already have waiting lists for nursing homes, home services, and even meals. For some of the same reasons, and some different ones, the picture is similar for services for the disabled.

No one should be surprised. The country is crawling out from under four years of economic terror, and we are changed. Many of the good jobs that fled over the past few years are not ever returning. In their place we find lower wage jobs that keep people struggling to make ends meet for their nuclear
family, let alone their aging or disabled relatives. The looming responsibility for the aging and disabled will impose a heavy burden on the country’s workforce.

The boomers haven’t helped. Over the years we have repeatedly sold our future health for a burger and a plate of greasy French fries in front of the TV. Our own day-after-day lifestyle choices have made paying the Piper completely unaffordable. There are too many seniors, too much disease--much of it self-inflicted—and fractured families and communities that will struggle under the weight. John Holton, Director of the Illinois Department on Aging, says, “The daunting challenge of addressing the needs of seniors has quietly become what it is. What makes it unfortunate is that the problem wasn’t recognized as it grew. Arguably, it is still not recognized.”

As a result, the state executives responsible for services for the aging and disabled have come to a conclusion. Their job is overwhelming. Hugh Eley, Assistant Secretary of the Office of Aging and Adult Services in Louisiana says, “Waiting for more funding is not going to help. There will never be enough. We have to invent a whole new way of doing business.”

It almost seems as if Aging and Disabled Service leaders have hit a wall, or perhaps a springboard. From that place of “no way to satisfy everyone,” they have had to choose to give up or to operate with the utter freedom that being cornered evokes. The individuals we spoke to for this paper have all elected action. To a person, they stepped out of the box and are breaking new ground.

**What are leaders doing?**
Executives of services for the aging and disabled understand that they can’t do everything, so they are doing what they can. Not one of their stories could be mistaken for business as usual.

**Wading into the financial maelstrom**
When it comes to the aging and disabled, some states have experienced policy and financial whiplash. They have reduced the number of individuals in long term care facilities, only to see the savings more than eaten up in runaway personal care program costs. The allocation of resources was anything but fair: the demanding folks received the maximum allowable service and waiting lists of the underserved grew. No one wants this situation to continue, but it takes a tough leader to wade in and put order back into the system.

Hugh Eley and the Louisiana Office of Aging and Adult Services did just that. They faced off against advocates, providers, and beneficiaries and made some unpopular decisions to put programs on sounder and fairer financial footing. Eley explains, “The first priorities were to get the Medicaid waiver back to cost neutrality and slow spending growth. We grounded our new resource allocation model in an assessment of acuity.” Based on the assessment, individuals were assigned a budget or personal
care hours. As the system was rationalized, many people received reduced services. Eley and team weathered the public complaints, appeals, and lawsuits with equanimity.

The result? The average cost of each Medicaid waiver slot was reduced by 37 percent and more citizens have been served in spite of declining budgets. And Louisiana saw no increase in the rate of admissions to facilities, despite predictions that it would. Eley and team are continuing to push the financial envelope. They are implementing a new waiver that substitutes technology for hands-on workers. Eley says, “Our systems have depended heavily on personal care—someone in the house with you for extended periods. Well, that costs too much, and we can’t hire enough workers anyway. So we’re experimenting with electronic monitoring and telehealth. The biggest challenge will be convincing the recipients that they are comfortable and secure.”

Breaking through assumptions
When there isn’t enough money to go around, it’s imperative to focus what we do have on initiatives that work. Said simply, leaders have to get it right. Linda Rolfe, Director of the Division of Developmental Disabilities in Washington State’s Aging and Disabilities Services Administration, says, “What we build reveals our expectations for people.” She uses one guiding principle in prioritizing resources: “The more the system looks like the system for people without disabilities, the more successful it will be and the less likely we will have to tear it down and build something else.” She’s speaking about services for people with disabilities, but it applies to seniors as well. Her hard-won experience has taught her that group homes, sheltered workshops, and faux jobs don’t suffice. She says, “We have built lots of services that we have had to abandon because people want to live meaningful lives. What really works is for people to have real jobs, their own homes, and good friendships.”

“The problem starts with what believe about people,” says Rolfe. “No one asks whether people without disabilities are ‘job ready;’ we expect adults to work. Older people can contribute; folks with disabilities can contribute too. What stands in the way are dismissive expectations that the rest of us hold about their capacities. We all have to get over that. Meaningful work is better than any pill you can take.”

The organizations that help seniors with particular issues may think they know what seniors want and need. Think again. When Jilenne Gunther, a Legal Services Developer in the Division of Aging and Adult Services in Utah’s Department of Human Services, actually asked seniors what kind of help they wanted with legal issues, she received a surprising. For many of their legal needs, seniors felt they could be self-sufficient if they only had a book they could use as a reference for legal information. With a little bit of money, an entrepreneurial approach, and a lot of collaboration from the community, Gunther was able to provide just that.
With no budget, Gunther set out to create the book that seniors wanted. She knew she needed a strategy for attracting volunteers to the project. Through a series of seemingly flimsy network connections, Gunther was able to speak to the very popular former governor of Utah and convince her to write a forward to the book. That helped Gunther generate some buzz for the project and find a lawyer who was willing to provide the content pro bono. Says Gunther, “I was able to tell people, ‘You’re not just volunteering for me. This will impact thousands.’ I presented them an opportunity to do something meaningful.”

The volunteers were essential, but they did not, however, pay the bills. So Gunther approached the Utah-based Bank of American Fork with an offer. She had analyzed the bank’s charitable contributions to the community and found that very little was aimed at seniors, a very large segment of the bank’s customer base. She suggested that sponsoring the book, “Navigating Your Rights: The Utah Legal Guide for Those 55 and Older,” could help the senior community and the bank’s marketing effort at the same time. They agreed to pay for the printing, they introduced her to their graphic design firm which developed the book’s cover design for free.

Gunther summarizes, “This book is about miracles. It happened because we were able to tell a story that touches people. That’s what state government work is all about—finding the sticky factors and getting the greatest effect.”

Streamlining

Human services organizations are no longer willing to spend tight budgets on fractured, siloed, redundant structures. Leaders are consolidating organizations within their states and even pooling their resources across state lines to spread the costs. Nels Holmgren, the Director of the Division of Aging and Adult Services in Utah’s Department of Human Services, notes that Adult Protective Services shifted its regional structures to allow staff to be moved around as needed and similar changes are being made in the state AAAs. He says, “As we emerge from the economic mess, we are reaching out to other agencies to find out where we overlap and stop duplicating effort. We are also working with a local bank to develop a product that reduces fraud risk for seniors.” The product allows an observer on the account—perhaps a relative or trusted advisor. Jilene Gunther, who conceived of the product based on her study of financial exploitation of seniors, says, “The observer cannot access the funds, but they can keep an eye out for suspicious activity on the account. That way, any exploitation can be spotted immediately—before the senior, the bank, and the state have to bear the cost.”

Alaska is not running a deficit. However, that could change with the current decline in oil revenues. To leverage their resources, and provide the best service to citizens, Alaska’s Department of Health and Social Services is implementing a single web-based service plan system that crosses the entire department. Duane Mayes, Director of Senior and Disabilities Services in the department, says, “In many states, each organization has its own little system. We’ve gone a different direction. The
directors are working collectively to have one portal for the department—not just seniors and the disabled. It requires a lot of coordination, but we all know it’s the right approach.”

Pushing accountability to the community
Of course partners are essential. One Aging services executive says simply, “If my AAAs and service providers are not successful, then I am not successful.” But A&D Services executives are going one large step further. They are creating open spaces for collaboration that put community partners and seniors themselves in the lead.

Stephen Williams, Director of the Houston, Texas Department of Health and Human Services, advanced the city’s comprehensive agenda for seniors in a decidedly unique way. One of Williams’s human services targets was to get glasses for 18,000 Houston children who could not see well enough to learn. He started with contrarian assumptions. “Take a look at all the people who have retired. They have a lot to contribute, and they want to give back. So we took a multi-generational approach and pulled them into the mix.” He convened a discussion that included leaders from several government agencies, non-profit directors, school districts, private sector competitors in eye care, retired professionals and senior volunteers. Dr. Janice Sparks, the Director of the Care Connection Aging and Disability Resource Center in Houston, says, “We have been able to get glasses for 4,000 children a year, to include many seniors in this important project, and to strengthen the ties within our community. It’s a win-win-win for Houston.”

Some of the participants in Williams’s discussion came with understandable blinders on. They asked him to be the leader of the group and structure the initiative for them all. He took a different tack. He served as the facilitator and catalyst, creating a forum in which people could see the need clearly and decide for themselves how they wanted to fit into it. Says Williams, “The more structure you need, the less civilized you are. We proved we are civilized. Some of the folks at the table were surprised, but we now have a process that works. The next challenge we are tackling is air quality.”

Passing the baton to seniors, themselves
Tony Kester, Director of the South Carolina Lieutenant Governor’s Office on Aging tells people the truth. He paints a realistic picture for the state’s seniors to galvanize action. “Government is not your solution,” he states unequivocally. “There is not enough money going into the programs to take care of you. We have waiting lists in nursing homes and in home services as well. We have people in hospitals who cannot be discharged because they have nowhere to go. YOU need to figure out who is going to help you as you age. Don’t count on me.” Kester makes it his business to share this harsh message with as many seniors as he can. He recognizes that the crush of demand for senior services has begun, and he is powerless to stop it. So he takes the only realistic course open to him—he tells people they must be responsible for themselves.

Other leaders we spoke to are pushing participant-directed services to put control back in seniors’ hands. In the future they anticipate being able to add a little unobtrusive assistance here or there to
help seniors remain healthy and active in their communities. In times when financial resources are more and more limited leaders are exploring ways to serve as many elders as possible, without compromising their health and happiness. What better way to address both needs than with consumer-directed care. Seniors make their own choices, and it saves money. The results from these programs are overwhelmingly positive, providing recipients with more choice and control in everyday living, and producing a higher level of satisfaction and well-being.

**Thinking micro**

Thoughtful leaders advise us: Forget about finding one big answer to the looming service crisis. The only viable approach is a portfolio of smaller answers—micro solutions. Micro doesn’t mean simplistic. Solutions must still be comprehensive, but just on a smaller scale. They must still address health, transportation, housing, and so forth. One leader suggests, “We have to put everything on the table and explore every kind of option and model for taking care of people. We need to look seriously at every great idea that has come up—maybe a lot of little ideas.”

Georgia Division of Aging Services is investigating new operating models that rely more on neighborhood and community involvement. Kim Grier, Livable Communities Specialist in Georgia’s Division of Aging Services, explains, “We have all these activities spread all over the place—24,000 public and private services available in the state. We need to figure out how to bring them face to face in communities. We did an RFP for a ‘village concept of aging in place’ pilot and awarded it to the Northeast Georgia Area Agency on Aging.” Through the process, the community team will be looking beyond providing services to the most vulnerable seniors and instead trying to help as many people as possible. Grier continues, “We are thinking of it as a business model—how can we apply the lessons of businesses that grow successfully in lean times?”

One mindset shift that Grier and team have already made is toward “what can we offer you?” In the past, folks were knocking on doors to solicit help. Today they have adopted a more entrepreneurial attitude. For example, they are approaching private residential communities with vacancies to sell them on the merits of accepting seniors back into the community from nursing homes. With guaranteed incomes and social security, these individuals offer financial stability to the community. For some families caring for disabled or aging relatives, self-directed care can make all the difference. “It’s not unusual for the family to be in very tight financial straits, and bearing the additional burden of a dependent relative seems overwhelming,” says Denise Arnold, Deputy Director of Programs for Community Development in Florida’s Agency for Persons with Disabilities. “They may not be earning enough money to survive, cannot afford health care, or have given up their jobs to take care of their loved ones at home. Consumer Directed Care offers the option to pay family members a salary similar to what private agencies receive for the same kind of work.” This approach isn’t right for every family or situation, but it has proven to be an important part of a portfolio of options.
Stressing the relevant results
Kester gathers the statistics that show the crisis has already crept up on us. He uses these to argue for budget increases with the legislature. He may not be successful in the short run, but tracking outcomes will give Kester visibility into the best uses for his scarce resources.

Grier agrees. She recognizes she needs to be able to show how much her organization is saving by keeping people at home rather than putting them in nursing homes. Her ability to expand the most effective programs relies on analyzing outcomes. And Grier’s data environment extends beyond the individual to include the relevant support system. She points, for example, to Rhonda Montgomery’s research about caregivers and how to assess and address their needs.

The most affordable and long-lasting approaches to serving the aging and disabled involve prevention and early intervention. No ambitious public servant readily agrees to invest today’s money for returns that will accrue to successors. Says Utah’s Holmgren, “We do a great job of responding to crises, but we don’t often get in front of things. We’re trying very hard to be strategic.” That involves educating everyone about fitness and nutrition, focusing public health on prevention, and building longitudinal analytics that will compel more forward-looking investments.

8 Recommendations for Action
If you have a taste for leadership, our interviewees have some suggestions for action:

1. **Invite the “system” to the table.** Says Linda Rolfe pointedly, “Individual service planning is NOT the solution unless the system offers ready access to homes, jobs, friendships and family—in other words, meaningful lives. If the system is broken, we need to fix the system at the same time as we support individuals.” That means inviting stakeholders from across the system to the table. Take the lead by facilitating the discussion.

2. **Tell the story so it touches people.** We need to reach people in a different way than we have in the past. One leader recommends that we watch this video and learn to change our words. http://www.youtube.com/watch?v=Bf9WvEAXsIs&feature=fvwrel.

3. **Welcome others’ ideas.** Territoriality is out; open-mindedness is in. When there is no obvious solution to a problem, action-oriented executives eagerly look for answers from every quarter.

4. **Say what you want even if you don’t know how to get it.** Everyone’s concerned about trusting seniors being defrauded. Illinois’ Holton describes an “Angie’s list” of scam artists that alerts seniors to the risk. Putting good ideas out there can stimulate others to act.
5. **Make the most of the resources you have.** Entrepreneurial leaders think about what they have to offer others. They use limited funds to seed initiatives and attract more funding. They deliberately attract volunteers with the opportunity to make meaningful contributions.

6. **Amp up technology.** Scam artists will skate free as long as their technology runs circles around what’s available to government. Put technologies in place that give them a run for their money, then prosecute when you catch them.

7. **Get creative around incentives for health.** We can no longer afford the cost of unhealthy lifestyles; prevention and early intervention are the only viable solutions. We need to give everyone a reason to opt for healthy living, much as environmentally friendly companies get a financial benefit for being green.

8. **Send a message to the feds.** When the feds demand regular compliance reporting on irrelevant process measures that have nothing to do with outcomes, they waste everyone’s time and money. They need to get on board.

I’ve been interviewing public sector executives about various important topics for years—senior leaders from Singapore to London, San Francisco to Salt Lake City. But, I am completely blown away by the individuals who participated in this study. As a group, they epitomize leadership. They remain entrepreneurial in a rat’s nest of regulations, collaborative in a grid of siloes, and insistent on doing what really works rather than what is easy or convenient. They have taken what matters into their own hands, and I am inspired.

**About NWN**

NWN helps clients solve business problems through technology. The company has approximately 600 employees with professionals based in twelve offices across the country. For the past 25 years, NWN’s Smart Government practice has focused exclusively on public sector and education clients. Our professionals offer a combination of domain experience and deep technical expertise to help clients with custom application development and executive analytics.

For more information, please contact Jane Linder at 781-472-3498 (jlinder@nwnit.com).