

Citizens' Hearing and Panel Discussion
Home and Community-Based Care
March 29, 2007
Summary

Tying Nashville Together
HealthCare Action Team

Panel 1: The Need – Personal Testimony

PANEL MEMBERS are persons who deal with the elderly poor, the primary consumers of Home and Community Based Services (H&CBS). These are in-home personal care services that enable the debilitated elderly to remain in their homes.

TINA THOMSEN, Chair, TNT Health Care Committee

NATALIE NELSON, food bank coordinator, Edgehill Community

STEVE ZAGORSKI, Centennial Adult Day Care Center (provider of H&CBS)

FLOYD STEWART, The Accessible Builders, a nonprofit organization

TNT (Tina Thomsen):

Three different programs providing services are

1. Metro Social Services
2. State of Tennessee Options
3. Medicaid Waiver Federal and State program

The Greater Nashville Regional Council on Aging is the single point of entry for the above three programs for 13 counties in the State of Tennessee. There are considerable waiting periods gaining service from 1 and 2 above (1-3 years) and 3 above is largely underutilized.

Edgehill Food Bank (Natalie Nelson):

Seniors with whom she deals:

1. Face choosing between their medicines and food
2. Fear, if placed in a nursing home, they will be forgotten, mistreated, and die a slow and lonely death
3. Want help to enable them to live at home and receive quality health care

Centennial Adult Day Care Center (Steve Zagorski):

1. Options program
 - a. Well-structured and well-functioning program providing H&CBS
 - b. More state money will solve program's huge waiting list
2. TennCare is problematic due to need structural changes within the home- and community-based waiver on the bureaucratic side
3. Gaining services is a complicated bureaucratic process

The Accessible Builders (Floyd Steward):

1. I've learned that over 90 per cent of people who live in nursing homes don't want to be there but the reason they are there is because they don't have options
2. Tennessee is in violation of the Americans with Disabilities Act for failure to provide least restrictive environment for disabled
3. The nursing home industry has a death grip on our legislature and on our legislative dollars.

Questions and Answer Session

Steve Zagorski

1. Necessary reimbursement rates for providers to stay in business is \$20-\$25 per hour
2. Medicaid waiver rate of less than \$19 means many service providers cannot participate
3. Medicaid waiver for personal care attendant and home respite pay \$17/hour, a rate that I as a provider cannot participate in
4. Options program provides hourly assistance depending on need ranging from two hours per week to 5 days per week, 21 hours.
5. The problem really is, first of all, knowing who to call.
6. Medicaid waiver has many structural problems including limiting access to patients who are nursing home eligible and able to pass a preadmission evaluation (PAE)

Clara Kelley (Greater Nashville Regional Council):

1. Waiting list for enrollment in Options program goes back to 2004
2. "We need money. We need less bureaucracy through TennCare. And as long as the bureaucracy is there -- because if we could manage the Medicaid Waiver like we manage the Options Program, we would be through it so quickly."
3. "The solution is taking money from the nursing home industry and putting it over into the pot for home- and community-based services. That's the solution."

Audience member – "...the problem is not getting the services The problem is working with the various agencies we have to work with. We have to work with TennCare. They stipulate most all of our rules about requirements. Working with TennCare takes a long time. Once we finish with TennCare, we have to work with DHS."

Panel 2: Nursing Home and Home Healthcare Officials

Panel Members:

DIANE GRAMANN: Area Director-Alzheimer's Association

LEE STEWART: Metro Social Services, Planning and Coordination Division

STEVE ZAGORSKI: Centennial Adult Care Center

PAT WINGFIELD: Metro Social Services, Program Manager, Homemaker Program

KAREN ROBERTS: Martha O'Bryan Center, Senior Services Coordinator, Meals on Wheels

Alzheimer's Association (Diane Gramann):

1. Family Respite Fund:
 - * For people caregiving in the home
 - * Provides \$20 a month for families
 - * Use how they see fit: adult day care services, sitter-type services in the home, personal care services, homemaker services
 - * Currently serving 15 families over 22 counties; 25 on waiting list (some have been on list since 2001)
 - * Only for families whose income is \$35,000 or less
2. Partnering with Senior Citizens, Inc. to collaborate on providing senior companions at a lower rate.
 - a. Goal to provide more care in rural areas by teaming up with them and training senior companions
3. Looking for funding from United Way.
4. Currently: the cost is free for families
 - They access the program through an application.
 - Not accepting any more applicants because so many are on waitlist.
 - Alzheimer's in the home and income requirements.
5. Programs offered:
 - a. "Maintain your Brain" Workshops
 - b. "Partnering with your Doctor" program
 - c. Free Law Enforcement education [such as workshop at Nashville Police Academy]
 - d. Care consultations for family members
 - e. rigorous trainings on Alzheimer's disease
6. No training for the staff, but training provider for programs that Association funds people to partake in.

Martha O'Bryan Center/Meals on Wheels (Karen Roberts):

1. Caseload: 105 seniors
2. Many are unable to get out of their homes, immobile, no transportation, incomes of \$500 or less, very few resources, and cannot advocate for themselves ["Afraid to complain"].
3. All services are free.
4. A hot meal is delivered daily, Monday through Friday.

Centennial (Steve Zagorski), Metro (Lee Stewart) & General Info:

1. Aging and Disability Resource Connection of the Area Agency on Aging and Disability: **615-255-1010** Information for referral and assistance, access to government-funded programs
2. Council on Aging's "Magic Book": comprehensive resource on how to access all services in the aging field
3. Centennial Adult Day Care: 7am-6pm. Structured program with a registered nurse on part-time staff. Goal: Engage mentally, physically and socially. Focus on quality of life.
 - Not covered by Medicare, but by Medicaid Waiver
 - a. Transportation: Additional fee, access ride, free for veterans and most are brought by family members.
 - i. Veterans Administration pays for Veterans and have to pay interest after 45 days of nonpayment.
 - b. Both early and late-stage dementia, Alzheimer's and stroke victims etc.
 - c. Roughly a third the cost of nursing home care.
4. Options Program: will pay for Adult Day Care (Privately: \$62 a day.) Also paid for by Options: in-home care, personal care, respite care, homemaker services, meals (Privately: \$19-23 an hour).
5. Metro Social Service's Homemaker Program- call to be put on waiting list Approximately: 135 on waiting list
6. Stringent financial requirements
7. Not just for seniors, disabled persons in their 30's also utilize
8. 45 people going into 150 homes a day.
9. Look for people with CNT training but does not always happens, but more concerned with stability in employees.
10. Average Metro worker has been there for fourteen years
11. Metro is able to provide better wages because of their funding methods. Medicaid Waver programs pay Centennial \$18.50 an hour but it takes three months to obtain, it doesn't work.

Why does the Legislation not change when nursing home care is three times that of home based?

Lobbyists and legislators with vested interests in nursing homes.
AARP took a big part in what has been passed, such as the Options Program.

What needs to be changed:

Stewart:

Things that need to be changed:

1. Eligibility process for the federally-funded Medicaid Waiver Program. (No need for a doctor's prescription for a homemaker)
2. State should move some of the waiver responsibilities to the area agencies to that they could run the existing programs more expansively and efficiently.
3. Bring the rates for in-home services higher to match more closely to private rates so that private providers are more likely and encouraged to participate, this includes nursing homes providing in-home services.
4. Low pay and governmental training requirements produce high turnover. We need more appropriate training and better reimbursement.

Zagorski:

1. More money in the Options Program
2. Streamline the TennCare process
 - a. In two ways: for the consumer and for the providers.
 - b. Faster response times, more service
3. Emphasize a single point of entry
4. Cannot mandate a 147-page training book

Gramann:

1. People need to know what their options are.
2. Pool resources to make them more effective and efficient.
3. Need accountability.

Panel 3: Local Government Officials

Panel Members:

LYNNE O'NEAL: Tennessee Department of Health

GERRI ROBINSON: Metro Social Services

BRENDA GILMORE: Metro Council Member and State Representative, District 54

ADRIENNE LIPPARD: Senior Citizens, Inc., Living At Home Services

GORDON BONNYMAN: Tennessee Justice Center

MELANIE HOWELL: Greater Nashville Regional Council (GNRC) Area Agency on Aging and Disability

GNRC (Melanie Howell):

1. Plans and channels funds for different providers
2. Work with home-delivered meals, H&CBS, senior centers
3. Assess the eligibility of individuals that need to be assessed for services
4. Options for Community Living and the Non-Medicaid Waiver program

- a. Non-Medicaid Waiver program includes State Options for Community Living, including in-home services.
 - i. Non-Medicaid Waiver program does not have enough \$
 - ii. Only able to support 200 people in 13-county area under Options Program; 725 home-delivered meals
 - b. Works with Family Caregiver Respite Program & home-delivered meals
5. At last count, 1,910 people in 13 counties waiting for services
 6. Each plan of care averages \$3,100 a year for options; while a nursing home is over \$40,000.

Tennessee Justice Center (Gordon Bonnyman):

1. Non-profit public interest law firm that serves low-income healthcare consumers
2. 1 billion a year is spent in the state on institutional care; less than 100 million of that goes to long-term care for seniors and adults with disabilities (non-developmental)
 - a. “devalue personal autonomy, family integrity and humane care”
3. Two big obstacles:
 - a. Nursing home industry
 - b. Antipathy to personal legal entitlement
 - i. issue of political will
4. Medicaid and TennCare eligibility do not support those who need it *now*.
5. We have got to focus on where the money is, which is at the state level. It is controlled by a handful of state policy-makers. Metro and non-profit sector are just trying to ply catch-up.
 - a. policy is made with an “utter disregard” to impact downstream.

Senior Citizens, Inc. (Adrienne Lippard):

1. Private nonprofit organization serving Davidson and Williamson Counties
2. Primary goal: help people live independently for as long as possible with a high quality of life, promoting dignity and self-worth in aging.
3. Living at Home Services provides: care management, in-home counseling, adult day services, Meals on Wheels, respite and companion care, conservatorship and in-home support services for victims of crime.
4. Sponsored by Gov’t to provide services to address the inequities in financing of long-term care and to educate community about senior needs.
5. Care managers make referrals on daily basis to the Options for Community Living Program.
6. Housecleaning assistance, personal care and any other service that they offer go on Options list.
7. Metro Social Services also receive the referrals for those who need housecleaning.
8. Senior Citizens, Inc. will provide some (limited) services while they are on the waiting list.

Metro Social Services (Gerri Robinson):

1. Locally-funded department, largest providers of homemaker and nutrition services in Davidson county
2. Small privatization project with Mid Cumberland Human Resources Agency to provide some homemaker services.
3. Services to support seniors and relative caretakers.
 - a. Contract with Family and Children Services to provide training to surrogate parents
4. Metro Gov't supplements \$3 million to homemaker nutrition budget of \$6 million.
5. All Metro department heads are required to submit a budget to show a 10 percent decrease.
6. No such thing as the private sector as they are contractors to some public entity.

Metro Council (Brenda Gilmore):

1. Senior Citizen's board
2. There are 14 bills pending presently that have to do with the aged population
3. AARP is present at legislature on almost a weekly basis

Panel 4: Public Funding and Policy Associated with Home and Community Based Care and Nursing Home Care

JOHN ARRIOLA- Davidson County Clerk

BRIAN MCGUIRE- American Association of Retired Persons

CAROL WESTLAKE- Tennessee Disability Coalition

PATTI KILLINGSWORTH- Bureau of TennCare, Long-Term Care Operations

Davidson County Clerk (John Arriola):

1. Member of TN Commission on Aging and Disability
2. Served 12 years on TN House of Representatives, Assistant Majority Leader
3. Former hospital administrator
4. Worked on legislation beginning '98 to move state to give people ability to make choice between staying home or going into "an institution"
5. Biggest challenge in our state is funding; in particular, where to find it

American Association of Retired Persons (AARP) (Brian McGuire):

1. AARP has 38 million members nationwide; 685,000 in Tennessee; 70,00 active in contacting TN legislation, etc.
 - a. mostly on health and long-term care for last 7-8 years.

2. State could be doing a lot better than it is doing although there is a swing upward on long-term care which has typically been considered “nursing home care”
3. Nursing home care is really expensive, “50,60,\$70,000 a year”
4. Typical care in TN: Senior will enter nursing home on Medicare for 2-3 weeks then go on private pay until they spend all their money then they go on Medicaid.
5. Medicaid is primary long-term care for USA and TN where state spends over a billion per year for “about 27,000” patients.

Tennessee Disability Coalition (Carol Westlake):

1. Coalition formed over 20 years ago to persuade the state to adopt a balanced system.
2. confining the disable to a nursing home in many cases makes for a wasted life because you cannot work if you are in a nursing home, even if you are capable and wish to do so.
3. “Our goal is to figure out how to get a balance system, but we can’t just rely on Medicaid, we have to go to a ‘broad continuum’”.

Bureau of TennCare (Patti Killingsworth):

1. Assistant Commissioner and Chief of Long-Term Care Operations
2. TN spends almost \$2 Billion in Medicaid, institutional & home and community services
3. TN Spends \$800 million in home and community based services
4. But spends \$1.2 billion on institutional services
5. Waiver program for elderly and disabled, although expanded, is still less than 20% of dollars spent on home and community based services
6. We have dollars to serve 3700 in Waiver program but seeing only 1200 because of lack of application. So in order to argue for more dollars we need to first use the dollars we have.

Why is TN last in dollars devoted for Home Care?

Arriola: the major impediment is the idea of change..the whole mindset that the nursing home was the only option.

McGuire: Nursing homes were initially resistant, but gradually changing as they realize they must offer alternative services such as daycare, respite care. But state needs simple entry system and global budgeting system to reflect difference in cost of home care (\$15k) vs. nursing home (\$45k) to obtain faster change. We want to make the financial incentives real clear so they make the obvious financial decision; that is to help the person at home.

Westlake: Part of problem is resistance to change. Initial problem was belief that we needed to develop separate system with new money, separate from the nursing home system. You have to have an integrated system..global budgeting is a piece of that. But the state should spend some portion of money spent on Nursing Homes ,if a person wants to get out , and have those services provided in the community . It’s critical.

Other policy barriers involve access to the system, who provides service, how you pay for it, ..we have not put that infrastructure in place.

Killingsworth: State has created a system to mirror an institutional system and trying to do it in the community. That is not what home and community based care is. We have a medically focused system. There are a lot of hurdles and obstacles for qualifying for the program. How do we change the system ?

We have a lot of work to do, ..looking at not the way it's been, but the way it needs to be and how we restructure it to work for people,going forward.

Arriola Follow-up: Rest of USA uses a social model; not medical model that requires passing through so many hoops. Reimbursement rate must be reasonable.

What are problems facing rural areas?

Arriola: No services available but maybe with help of Nursing homes. They have a perfect platform as long as they move toward the social side more than the medical.

McGuire: No providers but maybe change with adult family homes, assisted living facilities. Nursing homes, senior ceteras can do adult day care. We've got to be more flexible. .

Westlake: Folks with disabilities need personal providers and. have transportation issues. Also, there are barriers that keep us from being able to use family members and friends as providers. Many activities that people with disabilities need , requires nursing intervention. This is very expensive. We need to look at how we set up barriers and find solutions .

What can be done to convince legislators to increase homecare?

Killingsworth: Increase enrollment and stress cost effectiveness plus integrated system and rebalanced budget. The challenge: change how we pay Nursing Homes from cost-reimbursement to like other states have done which is based on clinical acuity...the level of need people have. They have case rates. You pay for the people with higher levels of need to remain there.

McGuire: Enough money is in system- legislature has supported all remedies talked about. Decision is up to Governor to move forward. We must create financial incentive; current system makes no sense; to pay nursing homes for costs which do not relate to services; other states have contracts that deal with acuity level. TN is 30 years behind and despite political issues the Governor can require changes in payment system.

Westlake: Agrees with McGuire, but we need to give patients a way out of Nursing Home which they now do not have. Over 6,000 in TN report each year they want out (but no encouragement to do so).

What's available for middle class households?

McGuire: No adult daycare in 85 of 95 counties because Medicaid does not pay for it, only pays for Nursing homes; need to provide waiver program for home maker services, meals, etc. Options program serves less than 2,000; 4-500 on waiting lists.

Westlake: TN has small program called Family Support Program of \$7.5 million which serves adults with disabilities with children by providing funding for services up to about \$1300-4000 per year. Very popular program since 1992 but only serves about 2000 a year; has long waiting list.

Killingsworth: Income standards for home and community based care program (HCS) are much higher than Medicaid. So many people may qualify for HCS that might not qualify for Medicaid if they meet the level of need required. Second, TN is looking at provision that long term care insurance will not be counted against property/assets owned in terms of qualifying for Medicaid.

What needs to be done in 6-12 months to move campaign?

McGuire: TNT should get word out in Davidson County to apply for waivers and urge local providers to make some assisted-living beds for people on Medicaid; to start more adult day care centers. TNT should ask..where are the providers for the Waiver Program, where is the Area on Aging in terms of recruiting providers? We need to take ownership and make it happen; through local officials, i.e., Mayor and Councilmen.

Arriola: TNT should do inventory of what's available in Davidson County and what we would need to do to reach higher desirable goals that would be a model statewide.

Westlake: Agrees with Arriola that we need a coordinated effort to determine who are on waiting lists and whether they can use Waiver Program, Options, or Metro Social Services Program

To threshold eligibility level so high that people cannot qualify for Waiver Program?

McGuire: Financial and physical eligibility is essentially the same for nursing homes as for the Waiver Program. Deficit Reduction Act passed 2 years ago require every state by next year to offer easier way for physical eligibility to work without specifying how. So, we could develop different physical eligibility criteria now for people to receive care at home.

Killingsworth: TN has been working on developing new tool like used in other states for home care that TN does not look at today. TN is re-looking at what in keeping people from qualifying. It is maybe procedural which we will work to change.

Do we have any questions from the audience?

Stephanie Nitti (Area Agency on Aging and Disability): Agrees that many of the PAEs we send to TennCare are approved but we don't send over many applications because the persons are too functional. The present criteria with respect to actual

physical requirements are too difficult. Another problem is that many clients that do qualify have major medical problems that cannot be met by getting personal care and homemaking several times a week. Home health care in conjunction with a Waiver is designed to be a short-time service, not long-term, and I think therefore more clients that qualify need to receive private-duty nursing.

Audience: Other groups who can help us move forward are: adult children who have elderly parents . and their employers . They are concerned about the children missing work to take care of their parents. The children also are having to pay for their elderly parent's long-term care.

Westlake: I think the Olmstead case is very important because the Supreme Court held the TN state of Georgia could not deny two middle-aged women in a long-term care facility the right to leave the institution to be served with home and community-based services. The State would not allow them to leave on the ground that the state did not provide such home services. The Supreme Court held that under the Americans with Disabilities Act the state cannot lock people up if it is possible for them to receive the needed services in their home or community; that the state is obligated to offer such services in an integrated setting; and if they are not the state must have an active, working program moving in that direction. TN has never had an active Homstead plan. It's a legal obligation TN is not meeting.

Other Comments:

McGuire: Bill in legislature would create a department of aging and disability that would change system by creating a global budget and rational eligibility system. Bill is Senate Bill No. 308 and House Bill No. 2063 which the Governor supports.

[Note: bill did not pass before legislature adjourned for this session.]

Audience Member: Area Agency does not have several thousands on the Options Wait but there are 1,910 on wait list today because of fundings. But another obstacle is enrolling people in Medicaid Waiver is we have to explain to them up front about the Estate Recovery Act... when must people find out about this, they opt not to participate.

Killingsworth: Medicaid regulations require states to have an estate recovery provision so state cannot opt not to go back and recover assets to recoup the cost of home care services.

Why is there a difference in terms of financial eligibility between home-based care and Medicaid Waiver?

Killingsworth: Originally it was institutional only for people with higher incomes under-Medicaid. But people with enhanced income may qualify for home and community based waiver services at the same rates as nursing homes.

“We need to start to balance our system...to serve more people for less money. That’s been proved in other states, and that’s the direction we want to go” – Brian McGuire