FACT FINDING SESSION
COMMENTS FOR TAX COUNCIL
August 26, 2010

NAME	ORGANIZATION	PHONE NUMBER	EMAIL
Pat Puckett	GA Independent Living Council	770 270-6860	ppuckett@silcga.org

COMMENTS FOR TAX COUNCIL

Please consider ways to enhance revenue streams to meet growing human services needs - especially those who need long term services and supports.

The Price of Neglect:
Long-Term Care in Georgia

There is a substantial hidden cost of caring for people with disabilities…. An estimated 33,000 Georgians are not in the labor force because they are caring for a disabled person in their household. This translates to over $900 million in lost wages each year.[1]

Who Needs Long-Term Care? Who provides it?

Depending on which data source one uses, the percentage of the population with a self-care difficulty ranges from 2.8%[2] to 4.8%[3]. Using the lower, more conservative percentage, this means that **230,000 non-institutionalized Georgians age 5 and over have difficulty performing one or more self-care activities such as dressing, bathing or getting around inside the home.** Of those with a self-care difficulty, 129,000 are working age adults age 18 to 64 while 88,000 are 65 years or older.[4]

Research shows that in 2004, approximately 44 million men and women in the United Sates provided unpaid care to a family member, friend or neighbor. This is 21% of all U.S. households with an economic value of this unpaid labor force at approximately $306 billion.[5] Without a doubt, the vast majority of Georgians who need human assistance on a daily basis receive it from the informal, unpaid network of family and friends.

While "taking care of our own" is a valuable part of our Southern culture, we rarely acknowledge the human cost. Many people who encounter those with long term service needs have often heard: *"I had to quit my job to take care of her."* Or *"We lost everything after my husband was injured and could no longer work."*

At present, our state and our nation invest very little in helping friends and family with this important work. Instead, people with disabilities and those who care about them exhaust themselves - and often their bank accounts - until their reserves are gone and "going into a home" is the only choice left.

---

[1] August 2007 Policy Brief by Kevin Fortner & Catherine P. Slade

[2] Tabulations by the Center for Personal Assistance Services from the 2005 American Community Survey. www.pascenter.org/state_based_stats

[3] Americans with Disabilities: 2002. Household Economic Studies, U.S. Department of Commerce Economics and Statistics Administration, U.S Census Bureau

[4] Tabulations by the Center for Personal Assistance Services from the 2005 American Community Survey

[5] McGuire, L. C., Anderson, L. A., Talley, R. C., & Crews, J. E. (2007). Supportive care needs of Americans: A major issue for women as both recipients and providers. Journal of Women's Health (15409996), 16(6), 784.

What Happens to People?

When the informal network falls apart and finances are depleted, people with self-care disabilities have two choices: Institutional (nursing home) services OR Home and Community - Based Services. Federal and state policies make the institutional option readily available and the community option nearly impossible. Federal and state policies put most of our tax dollars into the places where people would rather die than go - a rather clever cost-containment strategy! In FY 06, Georgia invested 70.2% of the state's Long-Term Care funds in institutional services.[6]

Institutional Services: A Mandate

Nursing facility services are, by Federal law, "mandated" for all states that participate in Medicaid. This means that anyone who is Medicaid eligible and meets nursing facility level of care criteria must be served if they ask for nursing home services. In Georgia, there are roughly 39,500 beds in 372 nursing facilities located in every county in the state. While the bed occupancy for the state averages 83%, some metro areas have well over 90% occupancy.[7] No new beds have been added over the past 10 years nor are any additional beds expected in the near future. While most people served in nursing facilities are frail elderly, the percentage of younger Georgians confined to nursing facilities is increasing. **In 2006, there were almost 9,000 people under age 65 living in nursing facilities.** From 2002 to 2006, the percentage of nursing facility residents under age 65 grew from 11.6% (7,211 people) to 13.6% (8,846 people).[8]

Home and Community - Based Services: An Option

Home and community - based Services are "optional" services, meaning that the Federal government does not require the state to provide these services to all eligible applicants. Changing this reality is agonizingly slow. For nearly 20 years, people with disabilities and their allies have advocated for a reversal of this cruel policy. In 1989, ADAPT changed its name and its focus from "American Disabled for Accessible Public Transit" to "American Disabled for Attendant Programs Today." In May of 1995 the Olmstead case was filed and in June of 1999, the U.S. Supreme Court ruled that unnecessary institutionalization is a violation of the Americans with Disabilities Act. In 1996, Georgia advocates launched the Unlock the Waiting List! Campaign in an effort to address the needs of people fighting to stay out of institutions. In 2001, the Georgia Department of Community Health together with the Centers for Independent Living applied for and received a Real Choice Systems Change grant in an effort to re-settle unnecessarily institutionalized people. In 2007, the Georgia Department of Community Health applied to the Federal Centers for Medicaid and

---

[6] Georgia Department of Community Health, Office of Long-Term Care, Money Follows the Person Operational Protocal

[7] Data from Georgia Nursing Home Association.

[8] Centers for Medicaid and Medicare, Nursing Home Data Compendium 2007. Tables 2.5 (a) and (e), pps. 33 and 36.

Medicare for a Money Follows the Person grant to "re-balance" the state's Long-Term Care budget. Despite these efforts, Georgia still has a system dominated by institutional care. *From FY 2001 to FY 2006, the increase in Medicaid spending on nursing homes was nearly eight times as great as the increase in spending on HCBS. In fact, the increase in nursing home spending ($526 million) was more than three times the total HCBS spending for older people and adults with physical disabilities ($157 million) in FY 2006.*[9]

Can the existing Long-Term Care budget be re-balanced?

There is no doubt that Georgia has slowed the pace of institutional placement. The rapid growth of the SOURCE program is clearly an effort to use Medicaid resources more effectively. SOURCE program data clearly shows that access to primary and preventive care reduces emergency room visits and prevents unnecessary hospital or nursing home placements. While these are significant results, it is questionable if more effective and efficient use of existing Medicaid resources is enough.

The summary table below provides a point-in-time picture of the number of non-institutionalized people over the age of 5 who receive daily assistance from the publicly funded Home and Community - Based service system. Based on national studies and surveys, we know that a conservative estimate of Georgians needing these services is at least 230,000 non-institutionalized people. The table below shows the number of people served in each of the Home & Community - Based programs as of 5/15/08.

Table 1. Home & Community - Based Services

Program	People Served
1. Independent Care Waiver	840
2. Deeming Waiver (Katie Beckett)	3,826
3. CHHS	1,054
4. MRWP	9,367
5. CCSP	12,259
6. SOURCE	13,312
Total	40,658
Georgians age 5+ with need for daily assistance	230,000
Remainder -	**189,342**

The data shows that the informal network - family and friends - are the "mega provider" for almost 190,000 non-institutionalized Georgians who need assistance with one or more activities of daily living.

[9] *A Balancing Act: State Long-Term Care Reform.* AARP Public Policy Institute. Authors: Enid Kassner, Susan Reinhard, Wendy Fox-Grage, Ari Houser and Jean Accius.

Table 2 on the following page provides more detail on each of the Home & Community - Based Waiver programs. Please note that people served in the pediatric programs (GAPP) are not included in Tables 1 or 2 primarily because the census data source does not include people with self-care disabilities age 5 and under.

Table 2.

Home and Community-Based Services in Georgia

Program	Population Served/Eligibility Requirements	Services Provided	#'s Served	#'s Waiting	Average Cost per person per year HCBS/Average cost per person other health services	Department Managed By and Contact
Independent Care Waiver Program for Physical Disabilities and Traumatic Brain Injury (ICWP)	Adults with physical disabilities or traumatic brain injury ages 21-64 must be able to direct their own care and are at risk of nursing home or hospital placement	Medical equipment and supplies Personal attendant care Home modifications Behavioral Management	840	175	$45,121/$53,182	Department of Community Health. Apply through Georgia Medical Care Foundation. Contact Mark Trail
Deeming Waiver (Katie Beckett)	Children under 18 with chronic medical conditions. Waives only the parental income requirements in order to receive Medicaid health care services.	Medicaid health care insurance	3,826	No Waiting List	$4,039 (just health care related)	Department of Community Health. Apply through Georgia Medical Care Foundation. Contact Mark Trail
Community Habilitation Support Services Waiver (CHSS)	This waiver was created to serve individuals who were moved out of Brook Run State Hospital. It has the same eligibility requirements as the MRWP.	Has one bundled service which includes services such as residential, day habilitation, supported employment	1,054	No Waiting List. Nobody is being put on this Waiver.	$55,136/$10,820	Department of Human Resources through Division of Mental Health, Developmental Disabilities, Addictive Diseases. Contact Gwen Skinner
Mental Retardation Waiver Program (MRWP)	People with mental retardation or developmental disabilities (e.g. cerebral palsy, autism, downs syndrome, spina bifida) who require the level of care provided in an intermediate care facility for people with mental retardation (ICF-MR) and are at risk of institutionalization	Personal supports Day habilitation Supported employment Family Support Residential supports Medical Equipment Home Modifications	9,367	Short Term Planning List 2,884 Long Term Planning List 2,628	$29,961/$7,469	Department of Human Resources through Division of Mental Health, Developmental Disabilities, Addictive Diseases. Apply for Services through 5 Regional Offices. Contact: Gwen Skinner
Community Care Services Program (CCSP)	Covers Elderly and People with Disabilities who qualify for the level of care provided in nursing homes and need regular nursing care and personal care services, but can stay at home with home and community-based services	Care coordination Home health Adult day care Alternative Living Services Respite Care Personal Support Services Home Delivered Meals	12,259	620	$8,968/ $7,267	Department of Human Resources through Division of Aging Services Apply for Services through Area Agencies on Aging Contact: Maria Greene
Service Options Using Resources in a Community Environment (SOURCE)	Frail elderly and people with significant disabilities who are Medicaid or SSI eligible	Intensive Case Management/Primary Care Physician Services Any Service Provided through CCSP	13,312	No Waiting List	$6,716/ $16,175	Department of Community Health. Apply by contacting the site serving their county. Contact Mark Trail

Questions to Consider

If there are more than 230,000 Georgians age 5 and over who have a self-care disability, why are so few people on the waiting lists for services?

Based on the experience of those who encounter people needing services, the following are educated guesses:

1) Many people think it is their responsibility to care for a loved one who needs assistance. They don't ask for help because they do not see it as a burden but as "giving back" to those they love. This is especially true of parents caring for an offspring, regardless of how old their child is and it is often true for children caring for their elderly parents. "It's no big deal…it's just what you do."

2) When people do need outside help, they purchase it if they can afford it. Sometimes, the help is the same type many of us buy - a lawn care service or a housekeeping service. When personal care is needed, they find paid workers through word of mouth or through a growing industry of home care companies or senior day care centers. The reality is that people of financial means have a much better chance of avoiding the unpleasant fate of a nursing facility existence. Healthy retirement accounts, reliable health and Long-Term Care insurance, reverse mortgages and so forth allow people who need regular support and assistance to purchase necessary services as long as they have the money to do so. Therefore, it is important to recognize that poverty is a significant risk factor for institutionalization. National AARP confirms this truism in a recent report that details the "risk factors" for nursing facility placement. A significant risk factor for seniors is lack of home ownership.[10]

3) **Many people who might be eligible for publicly financed home-based care do not know about the programs listed above.** People who come from the private business sector often ask "Why don't more people know about these programs when there are so many who need them?" But from the social services perspective, marketing something that will take years to deliver doesn't make sense.

Given that almost no one wants nursing facility placement, why is it that this option still gets the lion's share of the money?

While there are multiple factors, leadership is key. Several years ago, Mary Eleanor Wickersham, a professional in long term services conducted a training session with nursing facility managers. In that session, she asked them "How many of you look forward to spending your final years in the nursing facility that you run?" Not a single hand

[10] *Across the States*, 6th Edition, 2004 AARP Publication. Authors: Mary Jo Gibson, Steven R. Gregory, Ari N. Houer and Wendy Fox-Grage.

was raised. Yet these same people - particularly those at the top of the bureaucracy - vigorously defend the nursing facility as a "valuable part of the continuum". Until Georgia has leadership with a commitment to serving others as they would like to be served, the pace of change will continue to be agonizingly slow.

Thirty years ago, a visionary public leader in Oregon recognized that people with financial means had virtually no choice. There were no services available other than a bed in a nursing facility. This circumstance resulted in people rapidly exhausting their private funds, becoming impoverished (and consequently Medicaid eligible) sooner than they otherwise might have. This leader's epiphany was the impetus for establishing a community-based, service delivery infrastructure so that people with financial means could purchase home-based services, thereby avoiding the more expensive 24 hour, 7 day-a-week nursing facility option. In FY 2006, Oregon invested 54% of its Medicaid long term service dollars in the Home and Community - Based System whereas Georgia invested 11% on the community side.[11]

What are the gaps in services?

Georgia does not have "gaps" in services. It has gaping holes, canyons, abysses, chasms and bottomless pits.

What is needed?

Above all else, Georgia needs visionary leaders who will address the real barriers to home & community based services rather than the minimum it will take to stay out of federal court. Many of us in the advocacy world describe the Olmstead case as "Georgia's gift to the rest of the country" because many other states are using the decision as an opportunity to push real change. Again and again, advocates have made efforts to bring the following issues to the forefront:

1. Equalize Eligibility Standards

Most people who live on Social Security Disability Insurance or on Social Security Retirement are NOT eligible for Medicaid unless they move into a nursing facility or are lucky enough to get one of the few HCBS slots with the same eligibility standards as institutions. SOURCE does not serve people with incomes above the SSI level of $637 per month. The Community Care Services Program has a cost share for people with incomes above this level.

2. Deal with Nurse Practice Act Issues

Some people say that the Nurse Practice Act prohibits certain types of care that many disabled people see as routine: Bowel and bladder care, ostomy care, trach and vent care, tube feeding, etc. Others say that

[11] *A Balancing Act: State Long-Term Care Reform.* AARP Public Policy Institute. Authors: Enid Kassner, Susan Reinhard, Wendy Fox-Grage, Ari Houser and Jean Accius.

nurses may train people to deliver these services as long as they are non-paid people (family, volunteers). Still others say that the issue is not the Nurse Practice Act but rather liability insurance carriers who prohibit non-licensed people from performing these services. Georgia also has providers who train paid personal care assistants and feel confident in this approach. This is an issue that has existed since the beginning of HCBS (the late 70s?) that we seem to have made NO progress on.

3. Invest in Housing Vouchers

In a recent follow up study conducted by the Centers for Independent Living, 46% of the people transitioned out of nursing homes utilized Section 8 rent subsidies. Only 6% moved into market rate housing. Depending on where one lives, the waiting list for rent subsidies can be years. The Department of Community Affairs is working to make housing vouchers available but the process is cumbersome and not easily coordinated with support services. For example, a person gets a housing voucher but can't get a waiver slot or vice versa. There are states that invest state dollars in housing vouchers rather than relying solely on HUD.

4. Fund Home Modifications

Some people require accessibility modifications (ramped entrances, grab bars, etc.) either as a way to avoid nursing facility placement or to accomplish a transition back home. The Centers for Independent Living (CILs) that provide this service do so with a fragile patchwork of fund sources. The waiting list for home modifications from the CILs is over 300 people.

5. Fund Adaptive Equipment/Assistive Technology

Assistive Technology ranges from simple items such as a bath bench and hand held shower to very expensive computer operated technology such as an ECU (Environmental Control Unit). In some instances, technology can take the place of human assistance. ECUs allow people who have no use of their hands to operate the phone, lights, etc. through the use of a mouth controlled switch. Automatic door openers and remote door lock systems allow independence. Talking glucometers and CCTVs enable people with vision impairments to independently check their blood or read the mail. The CILs have a waiting list of about 60 people who need some type of disability-related equipment or technology.

6. Provide Adequate and timely community services for people being discharged from hospitals

It is a common occurrence for hospital discharge planners to assume that a nursing facility bed is the only available option for a person with a severe disability. There are too few community-based providers with the resources and agility to put home-based services in place quickly.

9. Fund Services for People who are Deaf and Mentally Ill or Developmentally Disabled.

People who use sign language as a means of communication have very few options for services. *My daughter is mentally ill and Deaf. She is in a program in Florida but we would like to move her up here near us (Atlanta). So far, I haven't found a program that is staffed by people who know sign language.*

10. Provide Peer Support. People with disabilities who are living satisfying, successful lives can be role models and mentors. The peer support program in the Mental Health system offers a valuable example of how peer support can be more cost-effective than traditional mental health services. Peer support could become an effective tool in nursing home transition if there were a funding source for it.

Call to Action

The first step is for opinion leaders and policy makers to comprehend the truth: Georgia is a rapidly growing state with an increasing proportion of citizens who need daily assistance. Without significant investment in a Long-Term Care infrastructure, people who need assistance will continue to rely solely on family and friends. Georgia needs a public policy that complements the efforts of family and friends to meet the needs of those they love and that enables people with disabilities to be as independent as possible. While financial investment is a major part of the equation, no amount of money will replace visionary leadership, the cornerstone of social change.