

## Notes from Visions and Values Focus Group Work

### Group 1 - 3/28/07 In-Person Meeting

|                         |                  |
|-------------------------|------------------|
| Roger Fouts-Facilitator | Beverley Laubert |
| Sue Fredman-Scriber     | Priya Lal        |
| Suzanne Minnich         | Bob Butler       |
| Deborah Clayton         |                  |
| Bob Pawlak              |                  |
| John Alfano             |                  |

### Group 2 - 3/28/07 In-Person Meeting

|                         |                   |
|-------------------------|-------------------|
| Sara Abbott-Facilitator | Roland Hornbostel |
| Julie Evers-Scriber     | Gary Collins      |
| Chris Murray            |                   |
| Jana Tucker             |                   |
| Kathleen Anderson       |                   |
| Steve Mould             |                   |
|                         |                   |

### Group 3 - 3/28/07 In-Person Meeting

|                          |                        |
|--------------------------|------------------------|
| Kelley Scott-Facilitator | Lesli Anderson-Scriber |
| Dave Swyer               | Julie Tomlison         |
| Christine Kozobarich     | Christina Miller       |
| Paul Mosher              | Bibi Manev             |
| Scott Layson             |                        |
|                          |                        |

### Group 4 - 3/28/07 In-Person Meeting

|                            |                           |
|----------------------------|---------------------------|
| Susan McKinley-Facilitator | Debbie Moscardino-Scriber |
| Kimberley Austin           | Judy Patterson            |
| Julie Johnson              | Jane Taylor               |
| Pete Van Runkle            | Pat Luchkowsky            |
| Sue Hetrick                | Lois Flanagan             |
|                            |                           |

### Written Submissions

|                              |                                |
|------------------------------|--------------------------------|
| Suzanne Dulaney, OACBHA      | Christine Kozobarich, SEIU1199 |
| Jan Sennett, Fairfield MR/DD | Bob Pawlak-Goodwill Dayton     |
| Laura Mathew's               | Marianne Huff, Ability Center  |
| Judy Stang, Grace Works      | Mary Butler                    |
| Shelley Papenfuse            |                                |

**1. Describe what is meant by the term *long-term care (LTC)*. What is the array of services needed to assure balance?**

**Group 1**–

**Part 1A.**

- SNs, Home Care, Adult Day Care, Hospice, L.T. Acute Care.
- Services an eligible individual needs for more than 6 months.
- Institutional LTC Community LTC Supports/Services needed to help individuals avoid institutionalization and remain active, Healthy and happy in community.
- LTC should be available to everyone regardless of payer source.
- LTC support irreversible conditions in some capacity over time.
- Adults and Children have LT needs.
- Does LT institution include children in care of children's services system?
- Community LTC doesn't always lead to Inst. LTC.

**Part 1B.**

- LTC regardless of setting, CM-SWK, Benefits analysis, housing, employment services, crisis intervention svc., financial planning, personal care/homemaker, (See List), Rec. Soc. Support. ADC, Family/Friendship, Faith based, Pharm., MH, Med Support, Assistive Tech., Transport.
- Can't get services on your own
- Should include: General access to continuum of serves across com/inst. Settings.

**Group 2**

- LTC services and support regardless of age
- Providers who do LTC and ST services
- Define by service, not provider
- Chronic disabilities  
ADL Services
- Transportation
- Skilled therapies
- Array of services
- Don't start with "as is"
- NF—state plan
- HH—State plan
- Purpose of services
- Is MFP only chronic LTC needs?
- Need to find 2200 families for relocation
- Adult daycare
- Make sure consumers have what they need to maintain.
- Consumers don't ask for more than they need
- Adult family homes
- Medically fragile kids
- Different age groups require specialized services
- Meals
- Dietary services

- Respite
- Transportation
- How to access resources
- Consumer education
- After 6 months in NF
- Lost relationships
- Fear develops
- Transition/re-integration
- Teach families how to help consumer services like adult day care for kids
- Education needs
- Early 20's in adult day care
- Habilitation
- Families wait till last minute – limits choices

### **Group 3**

#### **Part A1**

- LTC?—
- Ongoing and rehabilitative, habilitative
- Institutional or home and community based
- Continuum-could be linear/sequential or 3 dimensional.

#### **Part B1**

- Array of services
- Depends on severity of condition, needs
- ADLs
- Medicaid case management services
- Managing direct support and professionals
- Depends on individual – left up to indiv/family... medical team including medical/non-medical services.
- What's needed throughout the day/supports e.g. day programs-array of services, programs, medical-therapies, nursing
- Transportation
- Guardianship-someone should pay for it.

### **Group 4**

#### **Part 1A**

- Array of services supports not acute and in makeup
- Sustain
- S&S needed when you have longer care for self over an extended period of time.
- Array of services at difference intensity periods. Some need over course of life time.
- Anything from small amount to large amount for difference lengths
- Define around ADL's, can be HAB as opposed to rehab.
- Comfort
- Assist with medical care
- Different time periods

- Difference degree of support
- Broad type of services
- Acuity levels different
- Length of time
- Long term care is different than acute care
- Long term care can be delivered in hospital in some cases
- Also LTCAC hospitals
- Minimum number of days?
- Defined by where or type of facility?
- Person may look the same
- Chronic?
- What is LTC in terms of Medicaid or define and then see what part Medicaid plays in it?
- Care needs that are not going away
- Stable/unstable
- Exclude rehab?

#### **Part 1B**

- Anything available in other settings.
- Point (tension) of get back to either where you were or where you want to go.
- Dynamic between move acute-long terms
- Different needs at different times in one's life
- Continuum of care
- Flexible on individual needs
- Easier to ID life areas
- ADL/IADL's
- Medical issues
- Changing needs
- Supervision
- Could be anything (constrained by money)
- Community based supports and services
- Access served regardless of setting
- Social mental health issues
- Two goals of MFP have different meanings for LTC
- Defined by services, LOS
- Should not exclude any services, current in LTC
- Defined beyond medical model
- Services to sustain life not depended on where care is given
- Person needs care
- Not just care but support and service also
- Don't consider LTC a medical?
- Needs medical and/or other
- Don't build medical only
- All things together that help one live their life.
- **Written Submissions**

For the behavioral health system, long-term care means independent Living and supportive housing as opposed to nursing homes or private Hospitals.

Individuals that are in a long term care facility receive many needed services. We will need to assess need to replace these services on a case by case basis. Services to consider: assistance with dressing, assistance with toileting, assistance with medications, assistance to eat, provide three meals a day, need for housekeeping and laundry assistance, social interaction, and access to the grocery store, bank, pharmacy. Does the person require any nursing services or personal care services? We need to make sure they have all of the adaptive equipment they may need: lift, shower chairs, toilet adaptations, and grab bars for the shower, wheelchairs etc. We need to make sure the place that they live can meet their special needs. If they are in a home or apartment are there systems in place to address maintenance and grounds keeping or is the person responsible for these services. If the cost to have them live in the community exceeds the cost of their institutional care should they remain in the institution? For example: do we provide 24 hour care in the home?

The Ability Center of Greater Toledo states as follows: The term “long-term care” will perhaps become an outmoded manner of describing community-based services and supports for persons with disabilities, the aged and other persons who are in need of assistance in order to live in the community because the term implies a medical model approach. The use of the language “long-term care” implies an institutional medical model that does not describe, in a meaningful way, living independently in the community with a person’s choice of supports. Therefore, the array of services that will be necessary for person’s with disabilities to use to be able to live successfully in the community will be as follows:

1. Personal Care Assistance-Including the skilled services of a trained CNA or a Home Health Aide.
2. Private Duty Nursing
3. Community Living Supports services/staff to aid in teaching individuals independent living skills.
4. Respite services including in-home and community-based services.
5. Chore service workers
6. Assistive technology that includes, but is not limited to: computers, environmental controls, automatic door openers, assistance animals, durable medical equipment, wheelchairs and lifts, home modifications, and those items that will enable a person with a disability to be able to live in an independent setting. Please note that this list is not all- inclusive.
7. Eviction prevention, housing preservation and affordable housing;
8. Targeted case management that is available to ALL individuals with disabilities at any age (from birth to the elderly).
9. Housing assistance including assistance with security deposits and other initial housing costs.
10. Transportation

Long-term care is any service or support that a person needs in order to sustain their life as an individual. It can be funded publicly, privately or one provided

informally by a family member, friend or other. Long-term care service arrays should include any services or supports that an individual needs in order to maximize their ability to function as independently as possible. The services and supports provided should be based upon standardized individualized **functional** needs assessments, and flexible budgets should be developed that are based upon reasonable costs within available funding constraints. Every effort should be made to ensure that: 1) streamlined processes exist for people to access services (a one stop shop approach), 2) multiple eligibility requirements must be streamlined, 3) individuals are not unnecessarily penalized for their ability to contribute to the cost of their care, and that 4) the prevention of unnecessary institutionalization is the primary objective.

In the community: Providing the supports and services needed to help individuals avoid institutional care and remain active, healthy, and happy in their community.

- Case Management/Social Work
- Housing
- Benefits Analysis
- Crisis Intervention Source
- Employment Services
- Financial planning and counseling
- Personal/Homemaker Services
- Recreational/Social Support - Community

Connections

- Family/Friendship Support
- Faith-Based Support
- Medical Support (includes visiting nurse)
- Pharmaceutical Services
- Mental Health Support
- Assistive Technology/Adaptive Equipment Services
- Adult Day Services
- Hot Line/Help Line

- The array of services needed should be defined by the consumer with help from their team of medical professionals and caregivers in order for the consumer to live the least restricted, most integrated lives possible. The array must include non-medical supports and services.

Anyone with a significant disability will probably need long term care (services and supports, but NOT necessarily “care” and what that implies). Most people with disabilities need services and support, and MUST go into a nursing home/ICFMR to acquire assistance for the necessary tasks.

I don't know how “balance” is used here. Each person will need different services and supports determined by the functionality of their disability. Centers for independent living have “assessments” that they use at a nursing home or at someone's visit to the CIL. Most of the time it is a person with a disability doing the assessment and the people normally need less support and service than they initially thought they needed.

What one person needs should not be compared to what someone else needs because every disability is different and people's functionality will be different.

**2. Describe your ideal long-term service and support structure – the “to be” state. What are the constraints?**

**Group 1**

**Part 2A.**

- See Last item to question 1B.
- Person centered - See 1
- Information/education/Services coordination.
- Should a waiver loc look difference than an institutional loc?
- Mix/Match menu system that is more flexible and not confined to a particular setting.
- Avoid institutionalization (as A Priority)
- Support Choices
- Provide Choices on sliding scale based on consumer income (buy-in) as opposed eligible/ineligible.
- 2B.—Constraints
- Lack of cash
- Lack of information re: what's out there?
- Current LOC definitions
- Services are provided in Silos and the providers are found in silos
- Reimbursement of staff/providers is low.

**Group 2**

- No waiting list for anything
- Providers not asking for anything
- Need assessed individually
- Need vs. want
- People can take advantage of any of array of services
- Make assessments available
- Accessible from where person is
- No wrong door
- More consumer direction
- Give people cash, let them spend it
- Like cafeteria Plan – Choices driven by assessment
- Direct to volume purchasing – help get value
- Designate portion of funds for specific services (e.g. med)
- Pilot in different settings (rural/urban)
- Florida-health savings account
- What don't spend builds from month to month
- Purchase LTC insurance for people
- At the end of 5 years:
- Finishing pilots, more slots, service array expanded-services grids

- More consumer direction, NH patients more acute, more supportive housing available, more acute cases at home, telemedicine/tele-health services (help with workforce shortage), AL Waiver, Nursing Shortage and support a problem, training and support for family members, paid family members, all consumers who wants to self-direct could, hire fire caregivers, skill level, not relationship drive payments, should you pay parents to care for kids.

### **Group 3**

- Minimize consumer liability monitoring, advocacy
- Adequate transportation supports (look at creative solutions)
- Specialized services (behavioral treatment, dentist that accepts Medicaid)
- Choice on the front end-knows options, can choose pot of many-person chooses services and supports and controls money
- Consumer direction and self determination
- Washington model
- Pockets of excellence –VT and NH
- Stable and adequate workforce to support consumers, direct services professionals, (wages, and benefits) Example: MN
- Stable support system
- Supply doesn't meet demand—wage elasticity, job supports in caregivers and families, more male as caregivers, immigration flexibility.
- Balancing accountability and flexibility
- Money and services are soloed

### **Group 4**

#### **Part 2A**

- Integration=best system is best, close to. The most integrated setting to meet needs of one chooses.
- Ideal system available, one can move within-flexibility.
- People only look at terms of setting
- Access
- Flexible
- Choice
- Think creatively
- Informed choice, one must be informed
- Robust communications
- Someone helping making choices
- Provide network capacity to meet choices.

#### **Part 2B**

- Current system is soloed
- Cash is not enough
- Money now is not flexible
- How do we educate consumers on what is available? (Everyone, providers, natural supports support coordinator.
- Direct support worker or lack of.
- Competing interest

- Natural supports are lacking
- Adequate housing
- Safe and flexible
- Transportation
- Employment

### **Written Submissions**

Ideally, behavioral health clients will be able to live in the least Restrictive setting possible.

Constraints: For the behavioral health clients served by this program, there is no automatic mechanism for the money following the person. What Is the vision for using the MFP grant to help Ohioans with behavioral? Health issues live in the least restrictive setting possible?

Is the question long term service at home? Ideally each person over the age of 75 would have a case manager who would conduct an annual assessment of needs. Some individuals may need require this at a younger age. They would visit the home and assess ability to complete IADL's, ADL's, family supports, medication administration, meals, housekeeping, home maintenance, cognitive ability, and transportation. The constraints are the person's safety living in the community and the overall cost of the supports that are put into place. Once the cost of supports exceeds the cost of the institution then a move should occur. The group should discuss the issue of safety. What is our tolerance for safety?

The Ability Center of Greater Toledo states as follows: The services that are described in the answer to the first question should be part of a comprehensive array of services and supports that should have no end-point and that should continue throughout the lifespan and/or as needed. These services and supports must be community-based and should be provided in response to a person-centered planning process that places the unique needs, wants and desires of the individual at the center of the services. Placement in a nursing home facility, ICF/MR facility, developmental center or any other institution must be the placement of "last resort". Public policy and best practices need to be re-developed that is no longer reflective of the medical model and these new best practices must be implemented and adopted by providers across all healthcare systems.

We have to find ways to better match capacity with customer demand. Realistic expectations must be clarified. Long term planning needs to be a priority. Better data needs to be collected and used to make policy and fiscal decisions. Housing and transportation needs must be addressed. I believe that consumers must have the option for 3<sup>rd</sup> party fiscal intermediary services if true self-direction is to happen. Often, we can address one aspect of a persons needs, but other problems prevent realizing a lower overall cost of care taken as a whole. Reasonable rates and additional training for providers are needed to procure and retain high quality care. We must avoid whenever possible soloing of funds and services into separate and distinct budgets, departments or disability categories. We must acknowledge and work to reduce inherent conflicts of interest where they exist. There also must be some discussion between balancing health

and safety and individual risk. Finally, real or perceived litigation often seems to be the standard method to either avoid or force systemic change.

The starting point to identify the ideal service structure is to learn from Past experiences. Each stakeholder brings a different perspective to the table and the synthesis of the information is a challenge. Policies that Attempt to accommodate all views to be all things to all people often results in an ineffective system.

The Level 1 ODMRDD Waiver was developed to refinance county board adult Service programs and to provide a limited amount of respite to caregivers who provided unpaid support in their family homes.

The basis for this waiver was the assumption was that families had the capacity to identify and select friends and neighbors who could become certified as an independent provider with minimal training. The family was Expected to provide individual specific training to the provider of respite services regarding the specific needs of the waiver recipient. For that reason the provider qualifications are minimal. In some situations, this premise has been effective.

In many situations it is not effective.

1. The family may not have a support network to access to deliver quality services and ensure health and safety.
2. The family may lack the capacity to provide the training.
3. The family as guardian of an adult child may become certified themselves to add to their income and provide no additional services or substandard service.

The ideal service system must have clearly defined goals and develop a structure to accomplish those goals within a cost effective framework. Monitoring services after the fact is not often cost effective. The structure must be in place to only allow for the selection of providers who are adequately prepared to perform a clearly defined service. Such a structure will potentially exclude some good people and will limit choice. We must be prepared to accept this to ensure health and safety.

The challenge of working with so many constituency groups is to develop a system with adequate safeguards based on data instead of philosophy and opinion. Self-directed services work well in limited situations and cannot be the model for all long-term care. If we are to ensure health and safety we need to have the tools and structure to obtain desired outcomes. The discussion of a need for system safeguards must occur early in the development of services and service models.

A structure that provides a quality, stable, well-trained workforce with minimal turnover, and adequate staffing levels according to each individual consumer's needs, by ensuring, but not limited to the following:

- A structure that professionalizes all levels of caregiving, and provides educational and training opportunities to achieve this
- a living wage, adequate insurance and other benefits for all formal caregivers
- a safe work environment
- respite services and supports for informal caregivers
- A structure that ensures continuity of caregiver to ensure continuity of care.
- A structure that provides caregivers with a voice in the direction of the programs in which they work
- A structure where the consumer's right to choose their caregiver supersedes any third party anti compete clause
- A structure where Ohioans, regardless of age, income or asset level, or disability have the right to high quality *long- term care supports and services of their choosing*, in the setting of their choosing, in order to enable all Ohioans to live lives of maximum freedom, independence, and dignity
- A structure that ensures individuals be allowed to stay in their homes for as long as they desire and is medically possible
- A structure that ensures that no individual will be prematurely, or unnecessarily institutionalized
- Washington State's model of a single agency, overseeing a single budget, with a single point of entry, not in terms of a geographic location, but a team of people who come to the consumer (whether at home, in a rehab facility, hospital, nursing facility) to determine both Medicaid, and level of care eligibility, and who have the authority to make that determination (as opposed to having a JFS employee have to sign off on the actual determination, which can take up to months), fair rate setting and contracting processes for providers
- A structure that ensures the consumer's right to have access to understandable information and any screenings necessary to make informed decisions about their options for long term supports and services
- A structure that is coordinated, not fragmented, that avoids duplication of services
- A structure that ensures every Ohioan receiving care in the structure the right to dignity, privacy, choice of provider, and quality of life in addition to being cared for safely and securely, with the understanding of the balance that needs to exist between quality of life and safety and security ("*managed risk*")
- A system that ensures an adequate pool of easy to access back up providers
- A structure where the consumer has the ultimate right to hire and fire home care workers
- A structure where the consumer and provider have legal protections to these rights

Constraints:

- The current "siloes" system of funding, caregiving, and information.
- Unequal playing field for providers, some get rate increases, others don't
- The nursing home reimbursement rate in statute instead of administrative code
- Waiver caps
- Turf issues between agencies, adding to silo effect
- Different budgets, agencies, caregivers, funding streams= one person. Doesn't make sense, increases risk of duplication of services

- Confusing reimbursement systems
- Lack of respite care for informal caregivers
- Geographical anomalies in care and funding options
- Health care costs in general

My “ideal” long-term service and support structure would be a single door entry with people being offered true choice of in the community or nursing facility. My “ideal” structure would have a “unified long term budget” so that the money could be moved to where it is needed. (The “ideal” would be operated similar to Washington State.)

Start-up could be on a smaller scale (like people with disabilities between the ages of 21 to 50 – that group because they have nothing being offered to them when MRDD has the Martin settlement and older adults have Home First).

Constraints:

- Institutional bias – “entitlement” to nursing home/ICFMR/other institution
- MUST close beds to be able to “rebalance” the long-term system and to eliminate “backfilling” (otherwise MFP will just be an additional expense!)
- Need to eliminate some nursing homes so that other states stop sending people across the border to fill Ohio’s vacant beds
- Minimum wage job with no benefit package for direct support workers – causing a shortage of direct support personal (competing with fast food stores) NOT a living wage.
- Nursing home/ICFMR reimbursement formula in statute in Ohio
- Lobbyists paid for by the nursing home/ICFMR organizations, who will say anything to keep the beds occupied.
- Money given to legislators’ campaigns by nursing home/ICFMR organizations
- Nursing homes owned and/or operated by legislators or legislators who own nursing facility stock.
- In Ohio more than 1,000 nursing facilities/ICFMR buildings with more than 91,000 beds and a vacancy rate of about 15% statewide. Additionally 3,000 licensed “banked beds” which can be sold at \$25,000 to \$30,000 EACH.
- Nursing facility/ICFMR organizations will fight to keep the beds filled because they will not be paid if people leave.
- Some nursing facilities are unwilling to change the structure of their finances (assets) to include assisted living, independent living or providing direct home services and support workers.

**3. Describe how MFP will meet consumers’ needs/expectations. What is an integrated and flexible system? What is community?**

### **Group 1**

#### **Part 3A.**

- Truly cross-disability
- Integrated, coordinated system
- Adequate information will be available
- Know what consumers’ needs and preferences really are

- Consumer choice
- Spend less cash
- More consultation with independent living centers
- Education and training of consumer to direct
- No gaps-geographic, regulatory
- Leverage existing systems to meet some of the needs
- Availability of safety nets so people don't fall through cracks.
- Consumers need to know what to expect, what things mean
- Who will mind and/be responsible for integrated system?
- Consumer Expectations: safety, quality, sufficient workforce
- Community-get away from structure (people)
- Means different things to different people (could be neighborhood/immediate family).
- Avoid community/institutional black and white. Develop community character in both.
- Community-work together-staff and consumer
- Ability to have impact on own environment (control/direction)

### **Group 2**

- Eden project/greenhouse project is community
- SNF can be community
- CMS – “domain and control”
- Community meets consumer direction
- Is quality of life better than before MFP?
- Quality of life for family members
- Control
- No waiting list
- Choice

### **Group 3**

#### **Part 3A**

- MFP is ability to choose, range of choices, informed choice
- People (including family members) need to know what options are available
- Account manager vs. case managers
- 3b. Community is
- Different for each individual
- Choice
- Not just geographical, as varied as your interests
- A mixture of independence and inter-dependence
- Communities (Plural)

### **Group 4**

#### **Part 3A**

- Consumer directed
- Meaningful choices

- Information has to be provided in a meaningful way: people need to go see and experience.
- Concern MFP will still keep us in silos.

### **Part 3B**

- Holistic: see person whole individual does not segregate person in to need “parts”
- Flexible over person’s life goes with person
- MFP; LTC follows person
- Consumer does not have to worry about what program they receive. Just go to one point and access service
- Consolidated budget, regulations, State Medicaid program.
- Waivers are exception to the rule. Person’s needs money to follow? What is the need?

### **Part 3C**

- Community is where you would live, be, work, and recreate if you did not have a disability.
- Where community is not a special event.
- You are integrated into it.
- Community character is a statutory term.

### **Written Submissions**

1st - Community, for some individuals, may in fact include an institutional setting hence consumer choice. However, for the purposes of grant guidelines then whatever environment the consumer is most comfortable in be it a small group setting, an apartment complex designed for people with disabilities, in random housing that meets their needs both physical and psychological, or a house.

Behavioral Health clients served by the MFP grant will have their needs met by being able to live in the least restrictive setting possible. Having this choice is the cornerstone of an integrated and flexible system. For behavioral health, "community" refers to non-institutional settings such as supportive housing and residential living.

In the ideal world MFP will be available to individuals prior to going to a nursing facility to prevent the admission. This is good case management and adequate funding for Passport and other home and community based systems. We need to consider technology that supports a integrated system-medical monitoring by the case manager from a distance (blood oxygen levels, blood pressure, glucose, chest xrays, medication supervision, face to face discussion over the internet) that are then communicated to a physician. Proactive monitoring to decrease hospitalization. It is not realistic to think that every person will not be in a nursing home. There is a role for a nursing home when somebody requires 24 hour care and has cognitive issues that make it difficult for them to live at home safely. What is community? I am not sure if you mean the community that supports them or how they engage in the community. I see a person’s sense of

community who they want to interact with on a regular basis and the ability to have the interaction (church, grocery, family, etc)

The Ability Center of Greater Toledo states as follows: MFP will meet consumers' needs and expectations by: 1. including a person-centered approach that incorporates all of the consumer's natural and community supports into the process of choosing services and that has, at its core, the basic needs, wants and desires of the consumer. In essence, it is consumer driven; 2. All choices and possibilities must be effectively communicated to consumers and their families in a person-centered manner; in other words, consumers must be able to make an informed choice; and 3. A flexible system allows consumers the opportunity to make choices regarding services and service providers and allows consumers to have "self-determination" budgets.

Community is defined as being the place where the consumer believes that he/she is achieving a desired quality of life that would not be achievable in an institutional setting. Community is based upon individual choice and includes all of the consumer's natural and professional supports.

Allowing individualized budgets and services that are based upon functional needs assessments. We must first ask what people want or need, not tell them what we have to offer. Individuals must have a sense of control over their lives. An integrated and flexible system allows and encourages that. Front line staff is knowledgeable; respect/embrace the principles of self-determination and self-direction. The definition of community is as varied as the individuals that are a part of it. It may change from day to day, or event to event. A flexible system allows and encourages to the maximum extent possible, consumer direction to occur.

MFP will begin by allowing for 2,200 Ohioans to who are currently in institutions and do not wish to be there, the freedom to receive supports in the setting of their choice

MFP will be truly revolutionary by bringing together all stakeholders in LTC in order to envision a new, balanced system that will maximize consumer choice, and will truly allow for no wrong door into the system, and no wrong/ or closed door to receiving services.

Providing funding for required services not covered by existing government or private resources

- \* Provide an integrated and coordinated service system structure
- \* Provide leadership and structure for governmental interagency coordination and leverage of services
- \* Break down barriers that prevent or inhibit a person's ability to maintain their independence in the community
- \* Personalize and individualize services to meet the unique needs of each consumer

B - What is an integrated and flexible system?

- \* A system that meets the unique needs of each consumer within the least amount of time, with efficient and effective outcomes

C - What is community?

- \* The group of individuals and institutions that support and meet the physical, mental, social, and spiritual needs of an individual

MFP will be a vehicle to accomplish getting out of an institution. Once placed in an institution, they lose all hope of ever getting out again, especially if they are aware of waiting lists, waivers limited funding, etc. ODJFS has written wonderful ways for people's needs to be met. "Expectations" must be realistically addressed by the peer support person so that the expectations are doable, rational, realistic, needed, and cost effective.

An integrated and flexible system is a system that can provide what is needed because of the person's limitations and functionality, and may include a medical need. Those services should be available in the community and with the same kind of flexibility any other person in the community has.

Community is the FREEDOM to be able to chose where you live, who you want to associate with, who your friends are, who you eat with, having the ability to have a telephone and being able to call people, having the ability to shop, having the ability to use public transportation, ability to attend a church of your choice, to be able to go to a movie, to be able to do other things that other people take for granted. Peer support will be a necessary part of "community" for a portion of the first year (different for each person).

**4. Do you think a balanced system will be less expensive, cost-neutral or more expensive than the current LTC system? Why?**

**Group 1**

- Assumes we don't have balanced system today. Balance means choice. If there's choice the costs will become more balanced.
- As percentage of people in NFs are there because they need to be. By expanding community care, it will cost more.....
- Research?
- Cash?
- May cost more, but service will be better
- How many beds do we need?
- Cost to system?
- Cost per individual?
- On the front end, it is likely to be above costly because Ohio is an aging state (baby boomers)
- Rebalance and cost, how do you transition?
- Where is the housing that will be needed when system is rebalanced?
- If we're changing the system to save cash, we're doing it for the wrong reason.

## **Group 2**

- More expensive-more services to more people
- Less expensive-Ohio above PMPM, least exp pmpm-oregon
- Cost more-training
- NF cost above, because sicker resident population
- Not reducing number beds/services/facilities
- Repurposing beds
- Still need beds – aging population
- Budget – Political process
- Less expensive – state looks at needs in 2030
- Reinvest savings in home care rates, adult day care
- Saving to new services, cost of living increases
- Increase quality
- Above NF rates – more quality - more consumers return to community
- Don't look at ST savings; less expensive to prevent future financial disaster for state
- Discounted rate – cash and counseling
- Accountability and quality
- Workforce/caregiver training
- People vote with feet
- Link to unified LTC Budget
- How do you differentiate pay?
- More oversight family members than agency
- Rates among providers
- E.g. training, services, drive time, licensing requirements, quality requirements.
- Balance cash on system oversight and providing care
- Is non-agency, non-regulated providers cost effective?

## **Group 3**

- Putting state money in enforcement and admin or supporting people's needs
- Less, but some people will still be very expensive
- People may need to bring their own resources for “wants”
- Balanced: meeting basic needs
- Based on individuals needs, supports
- More because we will have more consumers
- Surviving vs. thriving

## **Group 4**

### **Part 1A**

- Cost neutral; taking money from serving people here to service people somewhere else.
- To really balance, it will cost more.
- Shift so Medicaid money is at least 50-50 (now 75% spent on institutions)
- Cost neutral compared to what?

- Studies show if one has control of money they spend less, but there are controls.
- More expensive based on balanced system.
- Average cost per person would be less
- Everyone would be correct depending upon where we are coming from
- Timing key
- May have to invest above money but, long term savings below money
- Serve more people overall

### **Written Submissions**

Less expensive. Clients in the community are less costly than those residing in state hospitals or long-term institutional settings.

It should be less expensive because the current system pays for services and care levels that these individuals may not require. In the new system we are paying for only the needed services. If we utilize HUD funded housing it will cost the state less. If we move high care need individuals into expensive housing it can cost more

In answering question 4, The Ability Center of Greater Toledo states as follows: A balanced system will be less expensive than the current system, but it will require that money be re-directed from nursing home facilities, developmental centers, ICF/MR facilities and other facilities to community-based services. The state of Ohio needs to examine the cost effectiveness of reducing nursing home beds as opposed to continuing the back fill beds as individuals are discharged from nursing homes. In other words, the entire Medicaid system needs to be not only re-balanced, but there must be an ideological shift from a model of institutional bias to one that embraces the philosophy of independent living and person-centered choice.

In addition to redirecting funds from institutions to community-based services, the state of Ohio needs to critically examine its current list of state-planned services which fail to adequately meet the needs of individuals because there is so much money being utilized for institutions. Also, there is heavy emphasis upon the use of Medicaid waivers to provide community-based services. In reality, if more Medicaid dollars were directed to community-based services, Ohio could provide a more comprehensive array of state-planned services, thereby reducing the reliance upon waivers, and providing more choice to consumers.

Less expensive. I believe community based services and care are less expensive than institutional services.

If the system truly gives choice to the consumer, if the workforce and infrastructure are truly strengthened, I believe the system will be less expensive per person receiving services than the current system. Data from other states that have rebalanced have shown significant savings. Charley Reed said: If you give people choice, we have discovered they will on average choose the less expensive choice.

Most all of the data I have read indicate that individual costs are lower, however, overall, with increased demand, long waiting lists for services, etc., total funds spent over the

long run, often increase. Over the years, numerous data sources have offered comparison data that tracks LTC total costs by state and identify costs of care between HCBS and NF. The newest document that was distributed at the CMS Conference from Lisa Alecxi, VP of the Lewin Group, ([lisa.alecxih@lewin.com](mailto:lisa.alecxih@lewin.com)) that provided statistics for 1995-2005 Medicaid LTC Trends for Elderly and Individuals Under Age 65 with Physical Disabilities. From a fiscal perspective, Ohio has a long way to go, particularly compared to comparable states in our nation, to better utilize the existing resources we have. We cannot afford to stay with the status quo. As our population continues to age, we must address this.

A balanced system will be LESS expensive than the current system. How I know is that there are many states who have rebalanced their long-term systems and not even one has found it to be cost-neutral or more expensive. One person may cost the same or more if they have intense needs for supports and services, especially if they need 24 hour a day care 7 days a week. But all states have reported their cost results in the “aggregate” (across all the consumers) and they all have reported that the cost is less in the community.

Kansas has been doing this for the last 25 years, and has stated that there is no person in a nursing facility that could not be served in the community. Texas has been doing this several years and their statistics are phenomenal! I am attaching a one page summary of the Texas statistics. Those of us who attended the AARP Long-Term Care Forum a couple weeks ago heard a wonderful report on them rebalancing their system. They found that their costs are averaging three times as much in a nursing home as it costs them to keep a person in the community. Those of us who have been wanting this to happen in Ohio for many years have been told that the aggregate nationally to keep someone in the community is one third to one half the cost of them being in nursing homes. (PASSPORT costs even less, about 4 ½ to 1.)

In institutional settings, the federal government pays for the housing through the Medicare or Medicaid the person receives plus more Medicaid (“run-away expenses”). In the community setting, the federal government pays for the housing through Social Security or Social Security Disability checks sent to the person OR the person gets a job and then is able to pay for their housing themselves.

## **5. What is meaningful choice? What is self-direction?**

### **Group 1**

- Meaningful Choice:
- Serves have to be available to choose.
- Choices vs. preferences
- Informed choices
- Consequences to choices
- Information should be consumer-friendly and consumer driven
- Choices of services
- Choices within those choices

- meals, schedule, room mate, wake-up time, all the way through, range of options, know the price tag of your choices
- Self Direction:
  - Being in control of choices,
  - Controlling one's own life
  - Asserting control over choices
  - Personal responsibility
  - Long term care planning
  - Make self knowledgeable before care is actually needed.
  - May work for some, but for others that's not financially possible
  - Need to support people to self direct. Help them to understand so they can make the choices that are right for them.

### **Group 2**

- Informed consumer for who-family/consumer
- Limited list many not be meaningful
- Consumers as employer of record can consumer negotiate rates?
- Higher rate/fewer hours
- Low rate/more hours
- Self Direction varies with population.

### **Group 3**

- Control of assets
- I get to choose what affects my life
- With freedom comes responsibility, informed choice
- Dignity of risk-where do we draw the line for health and safety
- Creative options-I can choose things outside the box
- What are the boundaries or constraints?
- Generally accepted principles of self-direction:
  - freedom
  - authority
  - responsibility
  - support
  - confirmation

### **Group 4**

#### **Part 5A**

- See previous responses.
- What we all do in our life everyday- we meaning general public, not consumers in LTC today.
- Informed choice
- Involves more than 1 choice
- Things to people disabilities that we would never allow for yourself without disability
- Choice should not be delivered by disability

- Risk
- People did not dream the same way as people without disabilities
- Not just give inform but experience
- Have to be able to make a mistake because we are using public money, the scrutiny does limit or makes difference to choice.
- Will take time set changing
- Is okay to make a mistake
- Just getting to make a choice would be meaningful to some people.

#### **Part 5B**

- Some of the same
- Free to make choice yourself
- If you can dream self, you are able to choose
- “Self-direction is meaningful choice that is honored”
- Self direction would be able to control whole pot of money
- No one model fits everyone.

#### **Written Submissions**

Meaningful choice and self-direction allows the client to have the opportunity to determine what is the best, and least restrictive setting, for their long-term care.

The ability to make a decision about items that are needed for survival. This may not include all of the persons wants. What is self-direction? The ideal may be that the person makes the choice on their own. Reality may be that they make a choice from a list of options and depending on the abilities of the person (cognitive) it maybe the choices made by their POA or case manager that are consistent with the perceived wants of the individual. Many elderly do not get to make all of their own choices as even families begin to take over their lives and options.

In answering question 5, The Ability Center of Greater Toledo states as follows: Meaningful choice and self-direction are defined as providing consumers with the means to become empowered to make choices.

Empowerment means that the consumer is provided with all information about programs, supports and services that are available and this information is communicated to them in an effective manner that gives them the opportunity to participate, in the development of their person-centered plan. In short, self-direction and meaningful choice are determined by the consumer and not by public policy.

I have commented on this already but will add these words. Person-centered, control over the who, what, when, where and why. Options that are viable, comprehensive, choice in service arrays and providers. Self-direction or self-directed care seems to be the preferred terminology to use rather than free choice of provider or individual control.

The decision of who from, what, when and where you receive the supports and services that you need in order to have the highest quality of life possible

Informed choices that you control, add to your well-being, and pursue your sense of future.

B - What is self-direction?

\* Being in control of your choices.

Meaningful choice is the ability to choose knowing what that choice does both in positive ways and in negative ways (understanding the good and the bad of the choice) and accepting the responsibility of that choice. Simple meaningful choices would be like who to have as friends, what activity to do, when to eat, what to eat, when to go to bed at night, when to get up in the morning (early or late), what to watch on TV, what music to listen to, everyday choices that we all make on a daily basis and never think twice about it. Someone in a nursing home does not have those choices.

Self-direction is similar to meaningful choice and the opposite of institutional existence. In self-direction the person is in control of their lives. They can say what they are thinking or what they believe without fear of punishment.

**6. at the end of five years, how will success be defined? At the end of ten years? Longer?**

### **Group 1**

- What's changed?
- How do project goals compare to where we are in 5 years.
- Provider availability, services expansion, no disability populations are left out
- Pre-test/post-test/benchmark comparisons
- Number out of institutions
- Comparison of quality of life
- Consumer satisfaction
- 5years-benchmarks achievements - (buy in)
- 10 years-institutionalized changes, sustainable funding, commitment to continue/proceed
- Barriers are eliminated. Everyone is still around the table in 5 years.
- Flexibility/changing roles of advocates/partners. Single plan with funding attached.
- Less cumbersome financing of services
- Uniform quality of care regardless of geographical location (financing, etc)

### **Group 2**

- See Previous Discussion

### **Group 3**

- Money really does follow the person - when they make choice it follows them
- Don know
- Quality of life (better)
- Needs have been met wherever setting is

- Are they able to make choices like they wanted to?
- Percentage of people who felt they had options
- We reach our “to be state
- Removal of barriers and obstacles (doesn’t cycle back around)
- System is more financially sustainable

#### **Group 4**

- **This is actually our vision statement: If I need care, I can get care in, the setting I want from the people I want, and if needs change the care will change for me.**
- I will go to a single point of entry, one door, one assessment, in unified system of care. (Multiple access locations) and if I need help with this process, I will get appropriate help.
- Measurable
- Look over time shift of utilizations/cash or both
- Better data
- Sampling of people to compare before and after. E.g. use MFP numbers of folks.
- Capacity to meet needs
- Ongoing system to ID barriers, how we are fixing, keep moving.
- Do not just create another continuous improvement

#### **Written Submissions**

- 5 years: Adequate, well paid, professional, stable workforce with a collective voice; Infrastructure of new system in place
- 10 years: Ideal system (see above) in place;

We have achieved the goals and expectations of the MFP proposal

B - At the end of ten years?

All recommendations of the success project are fully achieved and incorporated in the "how we do business" structure of our local, regional, and state-wide communities

C - Longer?

We are continually refining and developing our "how we do business" structure.

Improvement never ends (continuous quality improvement)

Please see the article entitled Potential “Rebalancing” Outcome Indicators: Measures of the Degree of Rebalancing or Progress with Interventions that Lead to Increased Rebalancing by Robert Kane, Lisa Alecxih, Rosalie Kane and Brian Burwell. Distributed at 2007 New Freedom Initiative Conference. It is an excellent, comprehensive article that covers measuring Visibility/Awareness and Informed Choice, Enhanced Access to LTC services, Efficiency and Effectiveness measures, using administrative data as well as survey methods. The article includes discussion about outputs (legislation, policy changes, numbers of persons served, and costs) and outcomes or expected results (how well rebalancing efforts have been achieved, how well goals are met, etc). If you cannot locate this piece, I would be happy to fax a copy to you. This is a terrific topic for the rebalancing committee to discuss and make further recommendations. It is an essential component to establishing “buy-in” to the vision and systemic changes that are being

addressed in the MFP initiative and an important piece for the communications subcommittee to focus on.

In answering question 6, The Ability Center of Greater Toledo states as follows: Successful implementation of the MFP grant will be defined in many ways. First and foremost, within five years, the state of Ohio will have a comprehensive array of state-planned services that will be available to all persons of all ages and conditions that is not dependent upon being the recipient of a waiver. Second, the state of Ohio will have a policy that requires service providers to engage consumers in a person-centered planning process as they choose services and supports to be utilized in the community.

Thank you for giving The Ability Center of Greater Toledo the opportunity to respond to the questions of the MFP Planning and Advisory Group. We look forward to working in a collaborative manner with the state of Ohio Department of Jobs and Family Services and the Bureau of Home and Community Services as they seek to implement the “Money Follows the Person” grant.

Success: From a data standpoint one would think that the acuity of those in a nursing facility will increase because those with lower needs will be able to stay in the community and those with excessive needs will be in an institution. There will not be any negative outcomes that result in bad media coverage- like the person who passes away and nobody realizes it for a week.

At the end of ten years? Longer?

From a behavioral health perspective, the success of this program will be determined by the number of clients successfully living in the least restrictive environment possible and continued funding to enable that to happen.

2nd - Success of the MFP Demonstration Grant should be determined by "presumption of eligibility" for and availability of home care services EQUAL to the current eligibility and availability of institutional care. Given Gov. Strickland's commitment to a Unified Long Term Care Budget implemented by 2010 this should be the 5 year success meter. The 10 year success should be gauged by a lack of individuals still residing in institutions who could be more appropriately served in the community and who no longer wish to reside in those institutions.

At the end of five years success will be defined (in my mind) if we have begun a unified long-term services and supports budget, a state office of disability and aging exists and is attempting to have a one-door entry, and we have been successful in getting close to the 2,231 people back in the community and been able to close the beds behind them.

In ten years we will have solidified the unified long-term services and supports budget, the Office on Disability and Aging is well accepted and has a one door operating smoothly, offering people true choice in where they want to spend their remaining years, we have improved the shortage of direct support by having them now receiving a living wage and offering those who want it a chance to move up the “healthcare” ladder instead

of leaving for more permanent jobs in other fields. We will have a way to truly offer people a choice and have been successful in mandating that we only pay for filled beds in any institution instead of having a fee for certified beds not used. We will have a state which have completely eliminated the "entitlement" to an institutional bed and people can chose without pressure.

Longer: Most people will not even remember that people were forced into institutions to be able to stay alive by receiving services only in that situation. All states now will look to Ohio as a "model" state, able to change from an" archaic" system to a very "modern" system. The new system offers choice, free from fear of mandating people do what they do not want to do to get services.

### **ADDITIONAL THOUGHTS:**

Nursing facilities should really be only for people who are very ill, NOT to warehouse people with disabilities so that people living in the community do not see diversity and are not reminded of our own vulnerability in our humanness. This is the only minority that everyone is able to join in one split second, like Christopher Reeve when he fell from his horse.

The Unites States Supreme Court Justices said that it is discrimination based on disability to segregate people with disabilities into institutions. No one is anxious to be able to go to a nursing home! The United States had laws that allowed sterilization of people with disabilities (even against their will) as late as the 1970s. The Smithsonian Museum has documentation that proves that into the twentieth century nursing homes were used to "hide" people with disabilities and when they died (as a child or adult) were buried with their number to mark their grave (to dehumanize), not using a name.

Parents of children with a disability at birth are told, by their doctor, to put the baby in an institution because they will never be able to do anything for themselves. This still happens today. Two weeks ago, a phone call was made by a mother of 2-year-old triplets wanting to put one of the babies in an institution because her baby was born with cerebral palsy and still could not sit up. She had not had any counseling, support, assistance, contact with other mothers of children with CP, etc. I am hoping this type of situation will be a thing of the past once the long term system is changed.

Nursing Homes, GAO Report and Your State. Information Bulletin #101, 2/06

Recently, a well-known national disability advocate, philosopher, and political wizard noted, "We have not changed the cultural mind set that nursing homes are where we [younger disabled persons] and old folks [older disabled persons] belong. Where has been the outrage about the institutional bias for the last 50 years?" When the Disability Odyssey Continues reporter asked him why he thought this has not occurred, the wise person responded "because people aren't aware of the options in the

community." Obviously, this is correct to a large extent, but probably is not the full explanation.

Another reason is the fact that nursing homes are a \$75 billion dollar a year industry (\$65 billion is from our tax money via Medicaid and Medicare), and there's a LOT of profit. (See the Information Bulletin "Salaries, Profits and Nursing Homes, 7/13/05.) With financial profits comes political donations. Maybe someone needs to do a survey nationally and state by state regarding political contributions from the nursing home industry and lobby to our elected officials. Otherwise, what policy reason justifies your elected officials not welcoming a "Money Follows the Person" in your State to save money! (Mississippi and New Mexico are on the way of passing such legislation.)

After all, in the past twenty years, virtually every State has wisely reduced and/or eliminated its institutional State Centers for persons with developmental disabilities and provide community-based services. Most States have significantly reduced their institutions (euphemistically called "hospitals") for persons with mental disabilities and provide community-based services. So again, the question why have we not changed the cultural mind set regarding persons unnecessarily institutionalized in nursing homes?

Which leads to another reason. The DD state centers and MI "hospitals" were dangerous and caused significant physical harm and injury to persons in them. They could not be "fixed up." National press focused on this and helped change the cultural mind set.

Which leads to the January 17, 2006 Government Accountability Office Report regarding the failure of States to accurately report the injury and harm that nursing homes AFFIRMATIVELY CAUSE to persons with disabilities. Since 1998, the GAO has issued 14 reports on significant nursing home deficiencies, but there has been very little if any outrage from editorial pages, no national TV reporting, even very few news coverage of the GAO reports, and no press calls to give people a Real Choice where they want to live.

Now the most recent GAO report (GAO-06-117, "Nursing Home Quality and Safety Initiatives") reports State by State (see below for your State) how your State inspectors "allows homes to conceal problems...." Here are some of its findings:

1. "Nursing homes repeatedly caused ACTUAL HARM to residents, such as

worsening pressure sores or untreated weight loss, or placed residents at RISK OF DEATH or SERIOUS INJURY." If a relative did that, there would be criminal charges filed. Shouldn't nursing homes have criminal charges against them for the same conduct?

2. "The results of state inspections ... UNDERSTATED the extent of SERIOUS quality-of-care problems, reflecting ... inconsistent application of federal standards." Why hasn't the federal agency, CMS, withheld federal Medicaid funds in those States for violating the federal standards, over and over again? Why hasn't your State agencies withdrawn the MA funding from these nursing homes? Why hasn't your State Attorney General or local District Attorney investigated and filed criminal charges? Why hasn't the U.S. Department of Justice taken action?

3. "SERIOUS complaints by residents, family members, or staff alleging HARM to residents remained UNINVESTIGATED FOR WEEKS OR MONTHS...." Again, where are the criminal investigations of such derelictions? Where is your Medicaid office? Your State Attorney General? District Attorney? DOJ?

Let's review only the "understating BY STATE SURVEYS of SERIOUS DEFICIENCIES" in nursing homes that place residents at risk of "actual harm or immediate jeopardy." What is very important to keep in mind is that CMS ACKNOWLEDGES the following percentages of nursing homes in your State are UNDERSTATED BETWEEN 8 TO 33 PERCENT. That's correct, whatever your State survey found and reported is low by 8 to 33 percent. CMS also acknowledges that there is an "increase in such discrepancies [between what your State admits and what CMS found in the same nursing homes] from 22 to 28 percent." Also, it is also very important to remember that these are percentages of nursing homes b not people in them.

Percentage of nursing homes cited by State officials for CAUSING actual harm or immediate jeopardy, including "instances of severe weight loss, multiple falls resulting in broken bones and other injuries, and serious, avoidable pressure sores," as well as "numerous instances of serious, understated quality-of-care problems." Remember, the following are UNDERSTATED by 8 to 33%:

Percentage of nursing homes cited by your State agency for causing actual harm or placing residents in immediate jeopardy:

|          |       |
|----------|-------|
| Alabama  | 19.2% |
| Alaska   | 0.0%  |
| Arizona  | 8.2%  |
| Arkansas | 20.5% |

|                |       |
|----------------|-------|
| California     | 6.3%  |
| Colorado       | 24.3% |
| Connecticut    | 54.3% |
| Delaware       | 16.7% |
| D. C.          | 33.3% |
| Florida        | 5.5%  |
| Georgia        | 16.4% |
| Hawaii         | 17.8% |
| Idaho          | 36.3% |
| Illinois       | 16.2% |
| Indiana        | 21.4% |
| Iowa           | 14.0% |
| Kansas         | 30.5% |
| Kentucky       | 9.5%  |
| Louisiana      | 10.8% |
| Maine          | 9.4%  |
| Maryland       | 17.6% |
| Massachusetts  | 16.9% |
| Michigan       | 22.6% |
| Minnesota      | 12.2% |
| Mississippi    | 18.2% |
| Missouri       | 13.8% |
| Montana        | 17.8% |
| Nebraska       | 16.4% |
| Nevada         | 20.9% |
| New Hampshire  | 21.7% |
| New Jersey     | 9.6%  |
| New Mexico     | 24.7% |
| New York       | 9.2%  |
| North Carolina | 20.2% |
| North Dakota   | 13.3% |
| Ohio           | 11.6% |
| Oklahoma       | 18.6% |
| Oregon         | 14.2% |
| Pennsylvania   | 20.6% |
| Rhode Island   | 9.3%  |
| South Carolina | 32.0% |
| South Dakota   | 16.8% |
| Tennessee      | 19.1% |
| Texas          | 12.7% |
| Utah           | 10.6% |
| Vermont        | 16.7% |
| Virginia       | 9.8%  |
| Washington     | 26.5% |
| West Virginia  | 13.1% |
| Wisconsin      | 10.2% |
| Wyoming        | 12.8% |

The national average was 15.5%.

What advocates should do:

1. Hold a press conference with persons who have escaped the nursing home and who have either witnessed or been victims of the this harm. Bring copies of the GAO report. Change the cultural mind set. Nursing homes are

institutions that like DD Centers and MI hospitals cannot be "fixed."  
The  
only option is community-based services, exactly what most people want!

2. Ask your State Attorney General why s/he has not conducted criminal investigations into these homes?

3. Ask your Governors why they are using precious Medicaid funds to keep these facilities in existence and causing serious injury to persons with disabilities? Unless your State offers Money Follows the Person, it is condemning persons with disabilities to be at significant risk in nursing facilities.

4. Ask your Governor whether s/he will personally spend (incognito) the next four weekends as a resident in a nursing home? Would your Governor or State legislature place their relatives at such risk?

5. Ask your State Medicaid officials why they have not withheld MA funds from these nursing homes and decertified them?

Steve Gold, The Disability Odyssey continues

Back issues of other Information Bulletins are available online at <http://www.stevegoldada.com> with a searchable Archive at this site divided into different subjects. To contact Steve Gold directly, write to [stevegoldada@cs.com](mailto:stevegoldada@cs.com)

--

Steve Gold, The Disability Odyssey continues

Money Follows the Person - One State's Data, Info. Bulletin #109  
(5/06)

Texas' Money Follows the Person has operated since September, 2003. Here is the data for the past nearly two and a half years.

Since it began in Texas, 10,711 people have opted to leave the nursing facilities, have the institutional MA funds follow them, and move into the community. Who are these 10,771 people and where did they move?

1. Who are they?

Nearly 7.5% are over 90 years of age, and 10 were over 100 years old.

About 38% were under 65 years old, and 11% were under 44 years. Another 19% were between 65 and 74.

65% were female and 64% were white (not of Hispanic origin).

2. What were their living arrangements when they left the nursing

facilities?

Nearly all received Medicaid Waiver services.

22% live alone, 47% live with family, and 2% live with other persons who are in a waiver program.

Most of the remaining 29% live primarily in Residential Care or Adult Foster.

It seems quite reasonable to conclude for at least the 69% who live either alone or with their families that Texas and the federal government's Medicaid Programs save significant amounts of money. One estimate is that Texas saves between 20 and 35% of what it previously spent for these people in nursing facilities.

Texas's Money Follows the Person has never had an enhanced federal which will now be available with the new federal Money Follows the Person MA legislation.

Disability Advocates:

1. Your States can begin a Money Follows the Person program NOW - like Texas did, or

2. It is estimated that in late August the federal RFP will be available for the enhanced federal match.

3. Either way, there is NO EXCUSE for States NOT to start a Money Follows the Person program.

If your State's MA officials wish to learn more about the Texas success, they can email Mark Gold (not a relative), Manager, Promoting Independence Initiative, TX Dept of Aging and Disability Services, [www.dads.state.tx.us/business/pi/index.html](http://www.dads.state.tx.us/business/pi/index.html) or 512-438-2260.

Steve Gold, The Disability Odyssey continues

Back issues of other Information Bulletins are available online at <http://www.stevegoldada.com> with a searchable Archive at this site divided into different subjects. To contact Steve Gold directly, write to [stevegoldada@cs.com](mailto:stevegoldada@cs.com)

--

Steve Gold, The Disability Odyssey continues

