

MONEY FOLLOWS THE PERSON
IDEAS/SUGGESTIONS/PRINCIPLES

ADAPT has been asked for some ideas/suggestions/principles that advocates could promote when their state develops their MFP proposal.

Below are some general points that may be helpful in your advocacy.

SYSTEM ISSUES:

1. State Agency Consolidation - Elimination of fragmentation - silo funding and administration of services make rebalancing difficult
2. Functional Services - Review for consolidation of waivers - inequities in per capita spending not necessarily based on need can make rebalancing difficult.
3. Nurse Delegation/Assignment - each state's Nurse Practices Act need to be reviewed and amended as necessary
4. Rule/program institutional bias review process - Agencies should be required to do a comprehensive review to identify barriers
5. Data collection - who, what, where - need to know the numbers of people on programs as well as waiting lists. Per capita spending per individual in each program also helpful.
6. Develop system for ongoing identification/service coordination process
7. Risk management - Dignity of risk - Negotiated risk - People with significant disabilities should not be prohibited from receiving services based on "safety" concerns.

IDENTIFICATION/SERVICE COORDINATION:

1. MDS Q1a numbers - Get Data Use Agreement from CMS to identify the numbers of folks who have answered yes on the question about wanting to move into the community from nursing homes.
<http://www3.cms.hhs.gov/apps/mds/q1a2.asp>
2. Contracts with ILC's and/or AAA's for identification/relocation - Community organizations can be contracted from the state to do the identification/relocation.

3. Targeted Case Management - This can pay for relocation function - Medicaid funded option that state can use for relocation.
4. Role of VR - IL skill training option - Necessary skills for transition - IL's can use MFP funds to provide individual transitioning out of the institution the skills necessary to live in the community.
5. Adding transition costs to waivers - States can add a "Transition service" to their Medicaid waiver to pay for deposit, furniture, dishes etc of individual transitioning.
6. Expansion of consumer directed principles/contractors statewide (agency, Fiscal intermediary, agency with choice)

HOUSING (Accessible, Affordable, Integrated):

1. Coordination among Medicaid office, Housing Finance Agency and Public Housing Authorities to facilitate the process of getting housing at the same time as support services are available.
2. State/local Architectural Barrier Removal Program - Community Development Block Grant funds can be used to eliminate barriers in existing housing stock.
3. Fair Share, Mainstream, 811, HOME or other voucher money dedicated to those transitioning out. States and local communities can dedicate tenant based rental assistance voucher funds to people transitioning out of institutions.
4. Section 8 funds that go to the state (versus local PHA) target to those transitioning out. Give a state preference to people coming out. In addition to local PHAs, states have access to Section 8 vouchers.
5. Housing locators/coordinators (could be part of relocation/navigation function) Since housing is such an integral part of moving folks out, it needs to be a priority in all MFP proposals.
6. PHA MFP Education/Outreach training program development. Housing community frequently is oblivious to the needs of people with disabilities. Ongoing training/communication will help bridge these differences.

MENTAL HEALTH:

1. Re-invigorate PASAR process. Folks with developmental and mental disabilities are not supposed to be admitted into nursing homes. MFP can assist in identifying folks wrongly placed.
2. Coordination between administering nursing home state agency and mental health system. These two system almost never communicate. Make those transitioning out of nursing homes and ICF-MR's a priority for mental health services.

CONSUMER INVOLVEMENT:

1. MFP statewide advisory group - Yearly report to legislature. This report will assist in updating policy makers on the progress or lack of in the MFP rebalancing. If your state won't do this, make your own independent group.
2. Regional MFP groups - Info sharing with state MFP group. The more statewide involvement the more ownership from the whole community. Yearly MFP Conference and/or MFP Report to the legislature.
3. Report should include data, number of transitions and system changes.

QUALITY/ACCOUNTABILITY:

1. Development/use Community Integration evaluators such as consumer direction, accessible, affordable, integration housing, community based services and consumer satisfaction.
2. Satisfaction survey - 3-6 month follow-up - Can't just move folks out and leave them without support.
3. Numbers out - What locations? The ultimate outcome is how many folks have transition out and where did they move.

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ADAPT Definition of Consumer Direction

As it relates to program design for attendant services, consumer direction means the right of the consumer to select, manage and dismiss an attendant.

The consumer has this right regardless of who serves as the employer of record, and whether or not that individual needs assistance directing his or her services.

This includes but not limited to delivery systems that use:

Vouchers

Direct cash

Fiscal intermediaries

Agencies that allow choice (Agencies with Choice)

(Concept included in MiCASSA S. 401 and HR. 910)

MEDICAID LONG TERM CARE DATA - 2005

(September 2004 through September 2005)

Total Medicaid -----	\$300.3 billion	
Total Long Term Care (LTC) -----	94.5 billion	
LTC - 31.78% of Medicaid		
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Nursing Homes -----	\$ 47.24 billion	50.0% of LTC
ICF-MR (public) -----	7.54 billion	8.0%
ICF-MR (private) -----	4.56 billion	4.8%
 Total Institutional -----	 59.34 billion	 62.8%
 Personal Care -----	 \$ 8.57 billion	
HCBS Waivers -----	22.70 billion	
Home Health -----	3.57 billion	
Home and Community Services ---	.32 billion	
 Total Community -----	 \$ 35.16 billion	 37.2%

HCBS WAIVER BREAKDOWN 2005 BY CATEGORY

Total HCBS Waivers -----	\$ 22.70 billion	
 MR/DD -----	 \$ 17.03 billion	 75.34%
Aged/Disabled -----	3.942 billion	17.44%
Physical Disability -----	.722 billion	3.20%
Aged -----	.470 billion	2.07%
Tech Dependent -----	.109 billion	.48%
Brain Injury -----	.230 billion	1.02%
HIV/AIDS -----	.062 billion	.27%
Mental Illness/SED -----	.040 billion	.18%

Numbers are taken from a report by MEDSTAT (www.medstat.com)
 The MEDSTAT Group Inc. - (617)492-9300
 MEDSTAT data taken from CMS 64 reports submitted by the states
 Compiled by ADAPT - July 2006 (All numbers are rounded off)
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Agency with Choice Model

by Bob Kafka, ADAPT

The disability community, historically, has not had good experiences with agencies that provide personal attendant services. The disability community's focus has been on consumer controlled models that usually make the individual the employer of record with assistance from a fiscal intermediary agent. Traditional home health agencies, funded mostly by Medicare and Medicaid, use a medical focus that tend to control what goes on in the home of the individual and the agency is the employers of record. These negative experiences have deterred us from looking at alternative contract agency models -- models that are different from traditional home health that could provide consumer choice and control although the agency remains the employer of record.

The "Agency with Choice" model instills the "Independent Living" principles of choice and control in the contracts of all agencies that provide personal attendant services. These principles would be made requirements or minimum standards for any contract that is made for the delivery of personal attendant services. The ability to have control over who provides your personal attendant services is fundamental to the principles of independent living. This does not mean you must have an employer/employee relationship.

The disabled person would have the ability to select, manage and dismiss personal attendants. Service recipients would be encouraged to find their own attendants and send them to the contract agency for employment. If an individual cannot find an attendant, the contract agency would be required to send several people from among whom the disabled person can choose an attendant. Service recipients would also be able to dismiss the attendant if they cannot work together; however, the attendant would remain an employee of the contract agency -- available for referral to other people, unless abuse or neglect was the cause of the dismissal.

Assessment of hours and services would be negotiated between the consumer and the contract agency, and an appeal process would be available if agreement cannot be made. Management of the hours and tasks, once assessed, would be the responsibility of the disabled person. Services would be available 24 hours a day, 7 days a week. Consumers would coordinate the schedule unless they requested that the contract agency act as scheduler.

The contract agency would be required to have back up and emergency systems in place as a fail-safe if the consumer's back up system fails.

Taxes, workers compensation, insurance and benefits would all be administered by the contract agency.

If multiple contract agencies provide the services in a given area, consumers would be allowed to choose any agency and to change agencies if they desire.

Concerns about the "Agency with Choice" model include:

- 1. Will the contract agency cost more because of profit motive and administrative costs?**
- 2. Will people with disabilities and families truly have choice and control?**
- 3. What about bureaucratic rules and regulations?**
- 4. Can contract agencies really provide all the choices the independent living principles require?**

There is no one or perfect model of delivering personal attendant service delivery. We must assess the trade-offs and understand the implications of choosing one model over another. Ideally the consumer would not only have the ability to select their own personal attendant but also select the service delivery option that best meets their needs.

These various models are not mutually exclusive and can be provided side by side or in combination. There are variations on the pure voucher, fiscal intermediary and "agency with choice" models that combine facets of each. This sometimes is called the Spectrum model. These variations and different options should be available to meet the diverse consumer direction/self determination needs of people with disabilities and family members regardless of the individual's age, disability or skill level.