

State Strategies to Build and Sustain Consumer Advocacy

Topics in Rebalancing State Long-Term Care Systems, Topic Paper No. 1

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Table of Contents

| | |
|---|----|
| Preface | i |
| Executive Summary | ii |
| Introduction..... | 1 |
| Scope of Topic Paper | 2 |
| Definitions and Building Blocks..... | 3 |
| Consumer Advocacy | 3 |
| Goals and Targets | 5 |
| Building Blocks | 5 |
| Federal and State Statutory Requirements..... | 5 |
| Olmstead Planning Groups | 7 |
| Advisory Groups for Real Choice Systems Change Grants | 7 |
| Exemplars from States in the Rebalancing Study..... | 8 |
| Arkansas..... | 8 |
| Florida..... | 9 |
| New Mexico..... | 10 |
| Texas | 11 |
| Vermont | 12 |
| Washington | 13 |
| General Findings..... | 14 |
| 1. History and Context Shape Advocacy Possibilities..... | 14 |
| 2. Direct Consumers Are Especially Effective—but Need Training and Support | 15 |
| 3. Money Helps Fuel Advocacy Efforts | 16 |
| 4. Individuals and Personalities Matter..... | 17 |
| 5. Advocacy Efforts are Fragmented by Disability Type and Age..... | 18 |
| 6. Advocates for Persons with Mental Health Disabilities Have Unique Issues | 19 |
| 7. Development Disability Advocates Have Unique Issues Regarding Rebalancing..... | 20 |
| 8. Common Problems are Identified by Consumer Advocates..... | 20 |
| Conclusions..... | 21 |
| Appendix: Federally Mandated Consumer Advocacy Programs | 23 |

Preface

In 2003, Congress directed the Centers for Medicare & Medicaid Services (CMS) to commission a study in up to 8 States to explore the various management techniques and programmatic features that States have put in place to rebalance their Medicaid long-term care (LTC) systems and their investments in long-term support services towards community care. In October 2004, CMS accordingly commissioned this study to examine that topic. The States of Arkansas, Florida, Minnesota, New Mexico, Pennsylvania, Texas, Vermont, and Washington are participating in this 3-year Rebalancing Study. For the study, CMS defined rebalancing as reaching “a more equitable balance between the proportion of total Medicaid long-term support expenditures used for institutional services (i.e., Nursing Facilities [NF] and Intermediate Care Facilities for the Mentally Retarded [ICFs-MR]) and those used for community-based supports under its State Plan and waiver options.” CMS further clarified that a balanced LTC system “offers individuals a reasonable array of balanced options, particularly adequate choices of community and institutional options.”

The products for the study include State-specific case studies that look qualitatively and quantitatively at each State’s management approaches to rebalance their long-term care systems; the first set of those reports, reviewing each States experiences up to July 2005 and a Highlight Report summarizing all 8 States, have already been released.¹ Updates of the State-specific case studies summarizing changes up to July 2006 will appear in the fall of 2006 and more follow-up is planned for release in the Fall of 2007.

The other products for the study comprise a series of papers, called *Topics in Rebalancing*. Each Topic Paper highlights an issue of importance in State rebalancing efforts, and each draws on experiences in some or all of the 8 States in the Rebalancing Study to illustrate the issue.

For this particular Topic Paper, *State Strategies to Build and Sustain Consumer Advocacy*, we drew on our original State case studies and a wide range of interviews with State officials and representatives of advocacy groups. We also reviewed documents and web materials, including rosters and minutes of various advisory groups. We thank everyone who took the time to share their experiences and impressions. We also thank our CMS project officer from CMS, Dina Elani, for her continual assistance. The findings and conclusions in the paper are those of the authors and do not necessarily reflect those of CMS or its staff, any State officials, or the advocates whom we interviewed. We hope that this Topic Paper will stimulate discussion, and we welcome any comments or reactions.

Rosalie A. Kane, Project Director

¹ The Executive Summary and the 8 abbreviated case studies are available on the CMS website at http://www.cms.hhs.gov/NewFreedomInitiative/035_Rebalancing.asp#TopOfPage, as well as on <http://www.hcba.org> and the Study director’s website at <http://www.hsr.umn.edu/LTCResourceCenter/>. Longer State reports can be found at the last sites.

Executive Summary

All 8 States in the Rebalancing Study have consciously used mechanisms to involve consumers in long-term care policy-making. The Topic Paper profiles selected exemplars.

- The State of Arkansas established an especially active Governor's Integrated Services Taskforce, a broadly based stakeholder group, to oversee the state's response to the Olmstead decision. To foster more consumer leadership, Arkansas also used grant funding to create an Aging and Disability Leadership Academy.
- By statute, the State of Florida established a Family Care Council in each of its 15 service areas for developmental disability programs. Through the Agency for Persons with Disability, the State maintains 2 FTEs to provide support for these councils and funds each council with \$10,000 annually.. Membership is strictly limited to consumers and family members.
- New Mexico created a Policy Advisory Committee structure for the Aging and Long-Term Services Department and each of its 5 Divisions. These standing committees work in conjunction with large and open-membership stakeholder work groups of interested parties who provide input around specific policy initiatives.
- The Texas Health and Human Service Commission (HHSC) created the Texas Promoting Independence Advisory Committee, staffed by HHSC's Division of Aging and Disability Services (DADS); members include consumer and provider stakeholders as well as many high level officials from State agencies. The stakeholders are required by law to submit annual reports with their opinions and recommendations. Widely available and systematic, these Stakeholder Reports are a vehicle to track rebalancing progress.
- The State of Vermont uses an array of structural mechanisms and special information gathering approaches to incorporate consumers and other stakeholders into nearly every aspect of planning for community long-term care and support services.
- The State of Washington established a free-standing Home Care Quality Authority (HCQA), operated by a 9-person board dominated numerically by consumers, including actual users of services. The HCQA has rule-making authority to ensure the quality of in-home care and to encourage stability in the individual provider (i.e. non-agency) work force.

Drawing on all 8 States, we found concurrence that direct consumers are particularly effective advocates, especially for legislative advocacy, but may need training and support. Direct State funding to advocacy groups proved helpful, as did State staffing for advocacy efforts. Considerable fragmentation was found across disability groups and between advocacy efforts by aging versus other disability groups. Unique issues for advocacy relate to persons with developmental disabilities (where considerable rebalancing success has already been achieved in many States) and for advocacy for persons with mental health disabilities (who tend to rely more heavily on a medical care paradigm).

The Topic Paper concludes that States have engendered an effective consumer advocacy presence to guide rebalancing policies and expansion of community care programs. Steps in that direction include: 1) taking stock of existing advocacy capabilities; 2) ensuring that all disability constituencies, representing people of all ages, are included; 3) seeking the views of consumers early in the process of program or policy development; 4) involving advocates who are direct consumers of services; 5) institutionalizing in statute processes for consumer involvement; and 6) engaging in a multi-faceted strategy including representation on policy and advisory committees, education and self-education efforts, and public hearings.

State Strategies to Build and Sustain Consumer Advocacy

Introduction

Connection to Rebalancing

Many States see building and sustaining consumer² involvement in the policy process as a key component of their efforts to rebalance their long-term care systems. Various Federal and State laws and funding programs related to promoting community care actually require consumer participation. Furthermore, active involvement and participation of consumers in the planning of strategies and policies that affect their lives is supported by the principle of procedural fairness,³ reflected in the oft-quoted motto used by disability rights organizations, “*nothing about us without us.*” Beyond legal mandates and ethical arguments for consumer involvement, practical and political reasons support consumer engagement in the long-term care policy reforms directed at increasing community care. Consumer participation in states’ rebalancing activities can serve six inter-related functions:⁴

Consumer involvement in rebalancing policies can:

- ✓ *enhance State decision-making,*
- ✓ *increase public confidence,*
- ✓ *increase community knowledge and information sharing,*
- ✓ *foster accountability,*
- ✓ *boost acceptance of decisions, and*
- ✓ *reinforce rebalancing objectives.*

- *Enhance State decision making.* Consumers bring insights, experiences, and first-hand information that allow decisions to be made with a richer and more complete understanding of the issues. Working together, public officials and consumers can inventory the gaps and barriers in a LTC system far more comprehensively than State officials could do on their own.⁵ Consumer involvement in policy development can help assure that programs and services better meet the expressed needs of those who use them.
- *Increase public confidence.* Consumer participation in the policy process can increase public confidence in LTC policy decisions, program development and implementation, and in the overall long-term care system. It also counteracts the fear and distrust that arises when there is limited contact between consumers and government officials.
- *Increase knowledge and information sharing.* Consumer involvement allows public officials to solicit consumer input and to provide information to consumers. Dialogue between public officials and consumers can help articulate clear goals and establish a set of core, shared principles which can then serve as the foundation for designing programs

² The term “consumers” is used in this paper to refer to all persons who need to access public and private long-term care services, including Older Americans and younger persons with disabilities. It is a broader term than alternatives often used in reference to these persons, such as participants, clients, and beneficiaries.

³ Daniels, N. and Sabin, J. E. (1997). Limits to Health Care: Fair Procedures, Democratic Deliberation, and the Legitimacy Problem for Insurers” *Philosophy and Public Affairs* 26:4;303–350

⁴ Some items on this list are adapted from Olson, K. and Perkins, J. 1999. *Recommendations for Making the Consumers’ Voice Heard in Medicaid Managed Care: A Guide to Effective Consumer Involvement.* National Health Law Program.

⁵ See, for example, Pennsylvania Intra-Governmental Council on Long-Term Care (2002). *Home- and Community-Based Services Barriers Elimination Work Group: Report.*

<http://www.aging.state.pa.us/aging/lib/aging/BarriersEliminationReport.pdf>

Topics in Rebalancing: Consumer Advocacy

and implementing strategies for LTC systems change. Consumer involvement also provides opportunities for various stakeholders to communicate in a cooperative environment. Every consumer and advocate involved in the policy process is likely to be part of a larger system of peers and colleagues, enabling information to spread beyond those involved on particular task forces or particular hearings.

- *Foster accountability.* Consumer feedback about the impact of a policy or program can “play a large role in monitoring the system’s accountability to the public and the people it serves.”⁶
- *Boost acceptance of decisions.* Consumer involvement in policy development can lead to joint ownership of systems-change initiatives, providing additional support for decisions about policies or programs. With a sense of shared ownership and “buy-in,” consumers and advocates will be more likely to implement and abide by system changes.
- *Reinforce the state’s rebalancing objectives.* Consumers’ interests dovetail with States’ rebalancing initiatives. Persons of all ages with disabilities and long-term illnesses have long expressed strong preferences for care in home and community settings and delivered in a manner that preserves autonomy and respects their dignity. States’ efforts to rebalance their long-term care systems aim to provide individuals a choice among an array of options to assure that they receive services and support in the most appropriate and integrated setting relative to their needs. This alignment of consumer interests with states’ goals means consumer advocacy in long term care should help States advance their rebalancing goals. States will undoubtedly hear from and must listen to consumers and provider stakeholders who support the status quo, including institutional options. But States have ample reasons to believe that the intrinsic attractiveness of community-based services will result in informed consumers and consumer advocates being strong supporters of State initiatives that maximize their personal choices and their integration into the community. If such constituencies of consumers supporting community care do not exist it is arguably in a State’s interest to encourage their formation.⁷

Scope of Topic Paper

Advocacy is a broad term and advocacy efforts have long histories in the 8 States, generally and in relation to long-term care. In this Topic Paper, we limit our scope in three ways.

⁶ Olson and Perkins, 1999, See Reference # 4.

⁷ Early rebalancing experiences in Oregon support this contention. For example, nursing home providers launched a vociferous campaign against new community-based group residential settings for older people, such as adult foster homes, in the late 1980s. The industry seized the case of a probably unavoidable fire with resident fatalities in an adult foster home as reason to call for expensive sprinkling systems for each foster home, which would have driven many out of business. When seniors themselves served as the defenders and spokespersons for the new programs and held a press conference of senior advocates to oppose the new regulations, this was more creditable and effective than State agencies could have been. See Kane, R. A., Kane, R.L., and Ladd, R.C. (1988). The Heart of Long-Term Care. New York, Oxford University Press.

Topics in Rebalancing: Consumer Advocacy

1. We focus on *policy advocacy*, defined as the pursuit of influencing outcomes, including resource-allocation decisions, at the system level. Policy advocacy is distinguished from individual advocacy to gain services or benefits for a particular consumer, and from legal advocacy through litigation. Litigation has had a significant impact on long-term care policies and programs.⁸ Activated and capable consumer advocates may indeed use litigation as a tool for policy change, but the role and impact of long-term care litigation on States rebalancing efforts is beyond the scope of this topic paper.⁹
2. We focus on *strategies used by State governments*, including approaches to hearing consumer voices, ensuring strong consumer voices from all constituencies of people with disabilities, strengthening the self-advocacy of consumers, engaging consumers in the policy process, and getting organized and broad feedback from consumers. Self-advocacy and consumer interest groups have their own histories, structures, goals, and dynamics apart from any State policies to encourage their development, seek their input, or interact with them; however, our focus is on State practices. States' support for consumers and their agents ranges from creating formats to inform consumers and elicit their feedback, involving consumers in high-level policy-making decisions, and providing resources to support consumer groups so that they can provide an independent advocacy voice.
3. We concentrate on activities that occurred *since the Olmstead Supreme Court decision of 1999*, recognizing that previous advocacy activities and earlier State initiatives related to inform and involve consumers and strengthen their advocacy activities provides the context for any State's efforts in the post-Olmstead period.

Definitions and Building Blocks

Consumer Advocacy

Advocacy by consumers and people with disabilities is not the same as advocacy on their behalf. Some consumer advocates also represent care providers. Disentangling roles can be difficult.

Consumer advocacy in rebalancing long-term care involves a range of constituent groups whose

roles are not always easily distinguished. Consumer advocates include not only persons who directly use long-term care, that is, the consumers themselves, but also others who advocate on their behalf, such as family members and representatives of organizations that have dual provider and advocacy functions. In a few states, most notably Washington, unions representing home health or other workers in long-term care advocate for consumers when their agendas overlap (e.g., improved working conditions that improve the quality of care). Consumer advocates in

⁸ Hayden, M.F. 1997. Class-action, civil rights litigation for institutionalized persons with mental retardation and other developmental disabilities. *Mental and Physical Disability Law Reporter*, 21:411-423.

⁹ For a report, updated every 4 – 6 weeks, on relevant LTC litigation, see, Smith, G.A., 2006. *Status Report: Litigation Concerning Home and Community Services for People with Disabilities*. Human Services Research Institute at: <http://hsri.org/index.asp?id=news>. Also, the case studies performed for this project on the 8 participating States review relevant litigation: see, http://www.hcbs.org/moreInfo.php/nb/doc/1622/Management_Approaches_to_Rebalancing_Long-Term_Car

Topics in Rebalancing: Consumer Advocacy

long-term care, which include advocates for community care as well as advocates for institutional care, can be classified into:

- Persons with disabilities of all ages who use long-term care services (consumers)
- Family members and agents of consumers
- Representatives of consumer groups served who are not necessarily consumers of LTC themselves, including staff of consumer advocacy organizations
- Provider organizations that are heavily represented by consumers in their staff and/or governance structures so that they carry some credibility as consumer advocates while also having a provider stake in the decisions

The interests and perspectives of the constituencies listed above could differ. For instance, the perspective of consumers may differ from the perspectives of their family members, friends or other agents, however benevolent. For some target groups, however, such as people with profound levels of mental retardation or people with advanced Alzheimer's disease, the consumers' agents may provide the only consumer voice.

Some consumer groups for persons with disabilities advocate for retaining institutional care and improving its quality. Where such groups exist, including chapters of Voice of the Retarded, it may behoove States to include their voices and perspectives in rebalancing efforts. In Arkansas, for example, a strong statewide interest group exists, Arkansas Advocates for Human Development Center Residents, along with parent associations for the separate Human Development Centers. A representative of that perspective, which emphasizes preserving institutional options, has been included on the *Olmstead* work group in Arkansas. Bringing such consumers into broader LTC reform initiatives arguably promotes information sharing and education on rebalancing goals and accomplishments. In a few states, consumer groups, often in combination with State employee groups or unions and professional groups, have effectively pushed towards retaining high quality institutional capacity for persons with mental retardation, a phenomenon observed in Texas, Arkansas, and Washington. State informants have suggested to us that strategies are needed to clarify and address the concerns of consumer constituencies representing institutions, making it easier to design a transition phase to demonstrate effective moves out of State hospitals, to demonstrate new residential models on State hospital campuses, and to organize work opportunities for Regional Centers in local communities. This strategy, combined with finding roles for State employees of State regional centers in community care and small ICF-MRs was used successfully in Minnesota prior to the *Olmstead* decision, and is now being actively attempted in Washington and Arkansas.

Oddly, we have not seen a similar direct representation of elderly nursing home residents and their family members on consumer task forces. An asymmetry can be noted between advocacy related to support services for elderly people and for younger persons with disabilities. With elderly persons, the actual consumers and family members involved with them are much less visible; instead, professional advocates are more likely to speak on their behalf. Advocates from organizations such as AARP and Senior Centers tend to have much broader agendas than community supports, and tend not to be current users of help unless they have aged with a disability.

Some provider organizations (such as Centers for Independent Living and, in some States, the Arc) are staffed or led by people with disabilities or their family members and can claim a consumer perspective, but they also have provider interests. Additional complexity may arise when influential community care providers offer a full range of services. It is not unusual, for example, for developmental disability providers who are active in developing supportive housing and employment options to also own and run ICF-MRs.

Goals and Targets

Essentially the goals of consumer advocates, expressed broadly, fall into three categories: 1) advocacy for greater resources, which may include changed eligibility for services, or expanded coverage; 2) advocacy for quality of services (often related to resources); and 3) advocacy for policy directions, including greater consumer autonomy over services and full societal participation for people with disabilities. Consumer advocacy specific to rebalancing and community supports shares these goals. Although resources for services are always a priority, advocates for community services typically point out policy obstacles that prohibit access to the services consumers most need and want. The thrust for personal attendant models of service, consumer direction, and independent providers very much reflects the priorities of disability advocates.

Targets for consumer advocacy include State legislatures; executive agencies that plan, develop, operate, and regulate long-term care programs; or both. The advantage of focusing on legislation is that successful efforts create binding legal authority, though it is also time-consuming and cumbersome. Our informants suggest that focus on legislation is usually more appropriate when used to address general problems, set broad standards, or create regulatory structures. On the other hand, directing attention to executive agencies is important to address detailed issues in the design and implementation of policies and programs.

As an illustration, consumer organizations representing the elderly in Florida concentrate their long-term care advocacy efforts on the legislature, believing the executive branch to be currently preoccupied with Medicaid managed care reform. In contrast, other states, including Arkansas and Vermont, have well-established, positive relationships between the advocacy community and executive agencies and these groups work hand in hand to promote new public policy. In addition to being the object of advocacy efforts, agencies have at times joined forces with consumer advocates, when their agendas coincide, to propose or influence legislation. Executive agencies in several states have worked with consumers and advocacy organizations to promote the executive branch's programs or issues before the legislature by, for example, recruiting and preparing consumers to provide testimony at and providing transportation for consumers to attend legislative hearings.

Building Blocks

Federal and State Statutory Requirements

All States can draw on various federally mandated and publicly sponsored programs that have advocacy built into their missions. Five potentially important vehicles found in every State

Topics in Rebalancing: Consumer Advocacy

are Centers for Independent Living, State Units on Aging, State Protection & Advocacy (P & A) programs, State Developmental Disabilities Councils, and State Long-Term Care Ombudsman Programs. The role and authority for each of these programs are described in Appendix A. Also potentially relevant are the other programs grouped with the Ombudsman program under Title VII of the Older Americans Act for Vulnerable Elder Rights Protection Activities; these include: elder rights and legal assistance development programs; benefits outreach, counseling, and protection programs; and prevention of elder abuse.

These publicly funded advocacy activities appear to have had varied impact on post-Olmstead rebalancing efforts. Although P&A Services and Ombudsman Programs, for instance, advocate at the systems level, their core responsibility is to advocate for and serve individual clients; policy advocacy is a secondary activity. (An important exception is when the P&A pursues class-action litigation.) Committees and councils whose members are appointed by a state's Governor (such as DD Councils and SUA Advisory Councils) can reflect the status quo and may be hampered in their ability to advocate for "non-official" changes. The recommendations, policy positions, or legislative agendas developed by these groups are usually thoroughly vetted, but have been criticized by some advocates for lacking creativity or bold direction. Nonetheless, DD Councils have played significant roles in training consumers and family advocates about legislative and policy advocacy. Centers for Independent Living networks vary across and within States in their forcefulness, but their representatives typically serve on stakeholder groups formed to advance rebalancing. In the aging arena, the cluster of elder protection programs, including the Ombudsman programs often reflects the voice of professional advocates more than of the elders with disabilities and their families. With additional funding, the Ombudsman program could be re-gearred to play a role in encouraging transitions from nursing homes and in enforcing autonomy rights across the whole spectrum of home and community based services, but we have not identified any examples of that use within the 8 States.

In some States, advisory groups to existing agencies have statutory authority; appointments are typically made to achieve geographic and other stakeholder representation. Such standing advisory groups then become a vehicle to interact with any special groups created for Rebalancing. States have sometimes strategically briefed their standing groups on special rebalancing efforts and arranged for cross-representation on standing groups, Olmstead planning boards, and other special bodies working on community care.

Silver-Haired Legislatures, mandated by legislation in many States and designed to promote leadership and civic engagement by older people, could be a vehicle to advance rebalancing for seniors. The Texas Silver-Haired Legislature (TSHL), established by the Legislature in 1985, is particularly active, meeting in even-numbered years to propose resolutions and prepare policies to advance to the Texas Legislature, which meets in odd-numbered years.¹⁰ Advocacy training is

¹⁰ The Texas Silver-Haired Legislature's (TSHL) website, at <http://www.txshl.org/> provides enormous detail about the committee structure and current leadership, and the resolutions enacted in each session, and the effectiveness in terms of the take-up of its issues by the Texas Legislature. A review of resolutions at http://www.txshl.org/past_res.php shows that for the most part the topics do not highlight community long-term care, though fuller funding for waiver programs and Texas' state Medicaid plan services have been part of the recent agenda.

Topics in Rebalancing: Consumer Advocacy

a direct part of the TSHL mission. Thus, the TSHL has served to create a body of informed senior citizens from the entire large State of Texas and could eventually become a formidable voice on behalf of seniors who use community care. Citizen groups of older people often have a broad and varied agenda, with community long-term care receiving relatively low priority.

Olmstead Planning Groups

State responses to the Supreme Court’s 1999 *Olmstead* decision have been central to long-term care system reform. These response efforts have provided consumers and advocates significant opportunities to become engaged in LTC rebalancing. Beginning in 2000, most states created official task forces or commissions to achieve compliance with the *Olmstead* decision. The groups were to assess the state’s long-term care system and recommend changes; many also developed, as suggested by the Court in the *Olmstead* decision, “a comprehensive, effective working plan [for the state] for placing qualified people in less restrictive settings.” Nearly all of these Olmstead groups were broadly representative, including consumers, advocates, providers, and government officials; the exceptions: Washington’s Olmstead Workgroup, which was comprised of government officials only, and Minnesota, which did not establish a formal Olmstead process.

Table 1 summarizes the Olmstead groups established in 7 of the 8 States. Current incarnations of the Olmstead groups in 5 states (AR, FL PA, TX, and VT) continue to be significant venues for consumer input into LTC system reform. The Arkansas and Texas groups are discussed further below as exemplars of mechanisms for consumer input into policy.

Table 1: Groups Established in Response to Olmstead

| State | Olmstead Group | Year Begun | Size | Olmstead Plan Developed? | Current status |
|-------|--|------------|-------------------------------|--------------------------|--|
| AR | Governor’s Integrated Task Force (GIST) www.arkansas.gov/dhhs/aging/olmsteadar.html | 2001 | 23 | Yes | Remains key player in LTC reform and oversight |
| FL | ADA Working Group (ADAWG) www.abilityforum.com/ | 2001 | 15 | No | Remains key player in LTC reform and oversight |
| NM | Governor’s Committee on Concerns of the Handicapped (GCCH) | 2002 | Unknown | Yes | Disbanded. |
| PA | Stakeholder Planning Team (SPL) www.dpw.state.pa.us/Disable/HomeCommServices/HCBSTeam/ | 2002 | 25 | Yes | Remains key player in LTC reform and oversight |
| TX | www.dads.state.tx.us/business/pi/index.html | 2002 | 19 | Yes | Remains key player in LTC reform and oversight |
| VT | Olmstead Commission http://humanservices.vermont.gov/publications/olmstead-commission/vermont-olmstead-commission-comprehensive-plan/view | 2002 | 13 | Yes | Remains key player in LTC reform and oversight |
| WA | Olmstead Workgroup www1.dshs.wa.gov/olmstead/index.htm | 2000 | Unknown; Govt officials only. | Yes | Disbanded |

Advisory Groups for Real Choice Systems Change Grants

Through five funding cycles beginning in FY2001, CMS has awarded to states a total of almost \$250 million through nearly 300 Real Choice Systems Change grants, providing a major

impetus for states' long-term care system reform efforts.¹¹ In response to the CMS mandate that consumers be involved in System Change grant activities, States have included consumers and advocates in both grant implementation activities (typically through membership on advisory boards or committees) and evaluation activities. Reviews of Systems Change advocacy activities are mixed. Some consumer advocates value their participation on the advisory committees and believe it influences program design and implementation. Other advocates, however, acknowledge the committees provide an opportunity for input but question the impact of their participation on them. Some believe the committees at times may have only symbolic value or token influence.

Some States have made particular efforts to coordinate their mechanisms for Stakeholder input, for example, by effectively using Federal or State statutory bodies, and by ensuring that Policy Advisory Groups for the Executive agencies themselves are briefed on Rebalancing activities and that cross-representation occurs between such Advisory Groups and special groups for Olmstead Planning or to develop particular projects.

Exemplars from States in the Rebalancing Study

The 8 States in the Rebalancing project have recently employed a variety of strategies that they deem effective to involve consumers in rebalancing reforms, ranging from establishing special or standing task forces and advisory committees (and sometimes providing them with staff support) to conducting statewide hearings to training consumers in becoming effective advocates. A few of these States provide a small amount of unrestricted funding to existing consumer organizations to enable them to develop and strengthen their own advocacy efforts. Typically, States pursue multiple approaches.

The following examples illustrate, but clearly do not exhaust, the range of strategies employed by any of the States to engage consumers and advocates in long-term care reform initiatives. The examples were selected because they include features not typically found in similar initiatives in other States.

Arkansas

Arkansas makes substantial efforts to engage consumers and advocates in its rebalancing initiatives, assigning sufficient state

Arkansas' Governor's Integrated Services Taskforce is a broadly based Stakeholder group that is intensively engaged. Also, the Arkansas Aging and Disability Leadership Academy, a weekend school for advocates, operated under a Systems Change Grant to enhance advocacy capability.

personnel to staff the activities. A key mechanism is the Governor's Integrated Services Taskforce (GIST), the state's 23-member Olmstead working group, comprised of persons with disabilities, advocates, providers, and government representatives. The Division of Adult and Aging Services (DAAS) provides staffing support. The GIST issued its Olmstead plan in 2003 with a detailed, prioritized list of recommendations and now formally monitors accomplishments

¹¹ Each of the 8 states in the Rebalancing LTC Systems project has received multiple Systems Change grants.

against the plan's priorities.¹² Without exception, the GIST members interviewed for this report appreciated the leadership and focused attention provided them by the DAAS staff, felt the task force was well-supported, and believed the state's leadership understood their issues and concerns. Some GIST members note difficulties in developing a cross-disability focus that encompasses all groups and the full range of disabilities; the service systems and needs differ so greatly that subgroups have been necessary. The continued existence of GIST and its relatively high intensity helps address those problems. The body meets almost monthly, its minutes are published, and its website announces broader consumer hearings around topical issues such as the DAAS plan to apply for Money Follows the Person funding.

Because of the need for stronger and more informed consumer advocates, Arkansas used funds from a Real Choice System Change grant to develop an Aging and Disability Leadership Academy. The goal was to strengthen advocacy leadership by identifying, training and developing volunteer leaders and educators in issues related to aging and disabilities. In its promotional literature the Academy suggests "participants will be empowered to become effective advocate leaders to represent the interest of Arkansans." To date, three classes of stakeholder participants have graduated from the well-attended Academy's weekend training sessions in Little Rock. A vicarious benefit to state agencies is greater insight into stakeholders' concerns gleaned from information supplied by Academy participants on their applications.¹³

Florida

In 1993, Florida established by statute local Family Care Councils in each of the 15 service areas of the state's Agency for Persons with Disabilities (APD)¹⁴ to

For developmental disabilities, Florida supports a Family Care Council in each of state's 15 service areas. The State maintains 2 FTEs to provide support for the Councils, funds each council with \$10,000 and reimburses travel for bi-monthly meetings. Membership is strictly consumers and family members. Advocates believe this vehicle has fostered the growth of community care.

advise the APD on the needs of persons with developmental disabilities (DD) and their families (FS 393.502). Chairpersons of the local councils make up the statewide Family Care Council Florida (FCCF).¹⁵ Combined, these councils are the primary vehicle for consumer involvement for LTC policy for persons with DD in Florida.

Membership on local councils is restricted to consumers and families. At least 3 of the 10-15 members of each local council must be individuals with DD; the other members are parents, siblings, or guardians of individuals with DD. New members receive orientation training on relevant laws, regulations, and programs within 90 days of appointment.

¹² Governor's Integrated Services Task Force (2003). *The Olmstead Plan: A Catalyst for Collaboration and Change*. (Submitted by Arkansas Department of Human Services to Governor Mike Huckabee, March 31, 2003). Little Rock: State Department of Human Services. <http://www.arkansas.gov/dhhs/aging/OlmsteadReportVer6.doc>

¹³ One graduate of the Aging and Disability Leadership Academy joined Herb Sanderson, the DAAS director in presenting at the 2006 New Freedom Conference and described how the experience motivated him to run for the State legislature.

¹⁴ Despite its broad title, the Agency for Persons with Disabilities' mission is limited to providing support to persons with developmental disabilities.

¹⁵ The statewide FCCF is not legislatively mandated but was established by the local councils themselves.

In addition to advising the APD, the local councils are required “to develop a plan for the delivery of family support services within the local area, and to monitor the implementation and effectiveness of services and support provided under the plan” (FS 393.502[7]). They are also required by law to work cooperatively and share information with other local family care councils. The primary purpose of the statewide FCCF, according to its by-laws, is “to speak [with a “unified voice” on behalf of the local councils] to the Governor, Agency for Persons with Disabilities, Legislators, providers and others regarding the needs and concerns of individuals with developmental disabilities and their families.”

The APD provides each local council with \$10,000 per year and reimburses members’ travel and per-diem costs for the local councils’ bi-monthly meetings. A full-time APD staff person, the “Family Care Council Administrator,” serves as the Agency’s liaison to the FCCF and local councils. To balance the top-heavy family participation on the Family Care Councils, Florida created a new full-time position in 2006 (“statewide self-advocacy coordinator”) to increase involvement of self-advocates (i.e. direct consumers) with both the councils and other advocacy activities. Florida thus allocates \$150,000 per year and two FTEs to build and sustain advocacy for persons with DD in the state.

APD staff and Family Care Council representatives agree that the councils have been invaluable for bringing the consumer’s voice to the table and identify the legislative mandate as the critical feature that gives the councils their power and influence. Without the legislation, “no one would pay attention,” according to the FCCF’s current chair. Florida does not have similar legislatively mandated committee structure for obtaining consumer input from other populations who need or use long-term care services, nor have we seen similar vehicles in other States.

New Mexico

The 2002 statute establishing the Aging and Long-Term Services Department (ALTSD) also mandated

In New Mexico, a standing Policy Advisory Committee structure for the entire Aging and Long-Term Services Department and each of its 5 Divisions works in conjunction with large and open-membership stakeholder work groups of interested parties who provide input around specific policy initiatives.

formation of a 13-member Policy Advisory Committee (PAC), which includes provider and consumer stakeholders, to “advise the Secretary regarding programs, policies, and issues addressed by the Department.” For each of the ALTSD’s five divisions the PAC formed a subcommittee, with at least two members of the PAC as official members of each subcommittee. The current priorities for the long-term care subcommittee are the self-directed Mi Via waiver, the Coordinated Long Term Care (CLTC) initiative, and money follows the person.

In addition to this standing committee structure, the ALTSD (in conjunction with the departments of Health and Human Services) initiated in 2004 what has now become an ongoing series of regularly scheduled meetings on selected major policy initiatives. These large meetings are open to all interested parties and have had upwards of 50+ attendees, including consumers and families, advocates, providers, and other stakeholders. Meeting agendas and detailed summaries are widely distributed through an email list serve. Without formal membership,

meeting participants vary month to month, but with significant carry over. Meetings are facilitated by a former NM Human Services Department employee, now under contract to ALTSD.

The first series of informal meetings (called “stakeholder work groups” by the ALTSD) began in December 2004 to address the conceptual framework and design of the self-directed Mi Via waiver. This first work group helped prepare the Mi Via application, which the ALTSD submitted to CMS in March 2006. The ALTSD has found the open work group format extremely useful for involving consumers and other stakeholders and has adopted it for two other initiatives -- money follows the person and the CLTC.¹⁶ Thus New Mexico currently has 3 distinct, but somewhat overlapping stakeholder work groups, mirroring the policy priorities of the PAC’s long-term care subcommittee.

The ALTSD’s formal advisory committee structure (the PAC and its subcommittees) is integrated with the more informal work groups. Deliberations of the informal groups are carried back to the LTC subcommittee and the full PAC, whose responses are reported back to the work groups. ALTSD staff guide the flow of information in both directions. The work groups’ influence has been significant. Concerns raised by the CLTC work group, for instance, prompted the state to slow the program’s implementation and get more input from consumer advocates and stakeholders. The ALTSD is now considering institutionalizing the stakeholder work group process as a permanent practice to assure that it continues regardless of changes in agency personnel or in political priorities.

Texas

In response to the *Olmstead* decision, then-Governor Bush issued an executive order in

Stakeholders on the Texas Promoting Independence Advisory Committee, the state’s Olmstead group, are required by law to submit regular reports with their opinions and recommendations. These Stakeholder Reports are a vehicle for accountability.

September 1999 for a Promoting Independence (PI) Initiative, which required the state’s Health and Human Services Commission (HHSC) to conduct a comprehensive review of all services and support systems available to people with disabilities in Texas and develop recommendations for improve the state’s community-based programs. The PI Advisory Board (PIAB), which was also the State’s Olmstead planning committee, was created to ensure Stakeholder input. After several iterations, the group is now called the Promoting Independence Advisory Committee (PIAC). The PIAC meets at least quarterly to monitor implementation of the state’s bi-annually updated Olmstead plan. Responsibility for the conduct of the PIAC is vested in the Division of Aging and Disability Services (DADS) within the HHSC.

The PIAC’s membership continues to evolve: in 2004 the committee had 14 members, including 5 consumers and/or representatives of advocacy organizations and 9 representatives from state agencies and commissions, with no provider representatives at that time. Responding to provider pressure to be included on the PIAC, membership was expended in 2005, adding 3

¹⁶ The ALTSD established the CLTC work group in April 2006, or nearly 2 years after the Medicaid agency issued the RFP seeking contractors to design and implement the program, in part due to criticisms that the CLTC initiative had been developed without input from consumers and advocates.

Topics in Rebalancing: Consumer Advocacy

representatives from provider organizations, including the state's nursing facility trade association. Several additional consumer and provider members have been added since then. The effectiveness of the PIAC is enhanced by the existence of sophisticated consumer leaders in Texas, including policy-savvy national leaders of ADAPT, and by the involvement of the highest level of State officials in DADS and other Departments of the HHSC in the PIAC deliberations.

By law, the stakeholder members of the PIAC (i.e., exclusive of the State officials) must submit an annual report, commonly referred to as the "Stakeholder Report," to the Executive Commissioner of the HHSC. These reports are prepared with staff assistance from DADS. The 2005 Stakeholder Report includes a status report of existing programs and initiatives, the non-agency stakeholders' policy directives for the upcoming year, and a set of resolutions to advance "general policy stances the non-stakeholders want to promote." A footnote in the 2005 PIAC Stakeholder Report makes clear that it "reflects the views and opinions of a consensus of the *non-agency stakeholders*" of the PIAC and not necessarily "the policy of the HHSC, DADS, or any state agency represented on the Committee" (italics added).¹⁷ The PIAC's Stakeholder Reports, provide a public record of stakeholder members' assessments of the state's long-term care system and recommendations for future change, and have been instrumental, according to advocates and government officials, in shaping Texas' rebalancing efforts and imposing accountability.

Vermont

Vermont uses many structural mechanisms and special information gathering approaches to incorporate consumers and other stakeholders into every aspect of planning for community long-term care. The Attendant Services Program and the Equity Committee are two examples of how Vermont consumers engage, respectively, in operations of programs and prioritizing policies.

Vermont views consumer participation and advocacy as integral to its long-term care decision making and policy development. Perhaps assisted by the geographic compactness, at many levels and in numerous ways,

Vermont purposefully seeks and utilizes consumer input. The State has a number of standing advisory committees, some with a majority of consumer members, which are designed to inform and influence policy decisions at the state level. Furthermore, the State regularly interacts with and solicits additional information from many advocacy organizations (and any interested persons) before making decisions about new initiatives.

Vermont's recent rebalancing activities have concentrated on aging services and mental health in relationship to expanding HCBS services and reducing nursing home populations. (Vermont no longer has any people with developmental disabilities in institutions.) The recent focus has been on evolving Vermont's 1115 waiver, Choices for Care, which restructures the state's Medicaid long-term care services. The state sought input and advocacy for this initiative from consumers and other stakeholders through a series of community forums and meetings that began early in the planning stages and has involved these groups in all subsequent steps as well.

¹⁷ PIAC (2005). *Promoting Independence Advisory Committee 2005 Stakeholder Report*. http://www.dads.state.tx.us/business/pi/piac_reports/piac_2005.pdf.

Topics in Rebalancing: Consumer Advocacy

Early and sustained consumer participation has undercut any serious opposition to Choices for Care on behalf of institutional care providers.

Vermont's commitment to consumer involvement extends to the individual service level. Boards of Directors of provider organizations that serve persons with developmental disabilities or mental illness are required by statute to have a majority of members who are individuals with disabilities and family members (18 V.S.A. Section 8909). Vermont also has a number of creative ways in which consumers have direct control and decision making roles regarding services. To cite two examples: (1) in the Attendant Services Program, which provides attendant services for adults with physical disabilities, an eligibility committee comprised solely of people enrolled in the program determines how many hours are allocated to others who apply; (2) an Equity Committee has been established to review funding proposals and assist the state and providers making joint decisions for new applicants seeking various long-term care services. Committee membership includes 2 consumers or family members, 2 state agency staff, and 5 providers.

Washington

The Washington Home Care Quality Authority (HCQA) was created by Citizen Initiative 775 in 2001 (and codified into state law in 2002 [RCW 74.39A.220 to 290]) to “ensure that the quality of long-term in-home care services provided by individual providers is improved through better regulation, higher standards, increased accountability, and the enhanced ability to obtain services [and to] encourage stability in the individual provider work force.” (RCW 74.39A.220) In addition to establishing a small new regulatory agency, the initiative also provided a means for individual providers (i.e., non-agency direct-care workers) to form a union and bargain collectively with the state. The state of Washington serves as the employer of record (solely for the purpose of collective bargaining) for independent direct-care workers and the Service Employees International Union (SEIU), Local 775 represents the approximately 25,000 direct-care workers in Washington.

The HCQA has a 9-member board appointed by the governor, and

In Washington, the Home Care Quality Authority, a consumer- controlled entity, has rule-making authority to ensure the quality of in-home care and to encourage stability in the individual provider work force.

staff support from the State. By law, at least 5 board members must be current and/or former consumers of long-term in-home services provided for functionally disabled persons.¹⁸ Consumer advocates in Washington argue that the HCQA's rule-making authority and its consumer-dominated board give consumers unusually direct input into long-term care policy reform.

Originally, the HCQA negotiated the collective bargaining agreement with the union. Over time, however, the HCQA's ability to impact the collective bargaining process has been diminished. Since 2004, House Bill 2933 transferred that responsibility to the Office of Financial Management and the HCQA's role related to the contract shifted to “providing

¹⁸ See <http://www.hcqa.wa.gov/> for a range of information about the mandate, authority and membership of the HCQA and its current activities

consultation to the Governor's Office on issues that were important to consumers of In-Home Medicaid services.”¹⁹ Once the union and the state hammer out a contract, it goes to union members for a vote; if approved, the state Legislature can then ratify or reject the contract but not modify its terms.

The brief history of the HCQA is linked with the rise of political power for the Services Employees International Union (SEIU). Although present in Washington for decades, the full impact of SEIU began to be felt in the election of 2001. Frustrated by the state Legislature's inaction on addressing the concerns of home-care workers, the SEIU took its demands directly to the voters in the form of Initiative 775, spending about \$1.3 million to put the initiative on the ballot and leading the campaign to pass it. Building on its successes in helping to establish the HCQA and in improving the wages and benefits of the independent providers and their overall working conditions, the SEIU moved aggressively to cement its power and is now seen by many in Washington as the key driver of long-term care reform in the state. Nonetheless, the HCQA illustrates a mechanism whereby consumers have effective control over an operational agency that is central to the evolution of a flexible, consumer-directed form of community care in the State.

General Findings

The exemplars described in this Topic Paper and the comments of key informants from all 8 states suggest some overall generalizations about policy advocacy in the service of rebalancing programs.

1. History and Context Shape Advocacy Possibilities.

The environment for consumer advocacy in long-term care reform activities, including the level of involvement of consumers and advocates and their ability to impact policy decisions and program design, varies significantly across the 8 states participating in the Rebalancing Study.

Differences in political culture. Some of the 8 Rebalancing states, such as Minnesota and Vermont, have long traditions of public/private partnerships to address social problems and have built relatively strong safety nets for their citizens. Other states such as Texas adopt a more minimalist approach to government and have a sharper divide between the public and private sectors. States with a history of involving the private sector are more likely to adopt an “open door” approach to government. In a few states, bringing advocates and stakeholders into LTC policy discussions early on, before any substantive decisions are reached, has become routine; in most states, however, even though consumer involvement is valued, its role in policy and program development is not yet secure.

Level of state's commitment to rebalancing agenda. Although all 8 states are moving towards a more balanced LTC system, their level of commitment to rebalancing differs, as does the degree to which their LTC systems are “rebalanced.” The advocacy agenda for aging and

¹⁹ See HCQA website at: http://www.hcqa.wa.gov/Collective_Barg/coll_barg_input.htm as of last visit, September 26, 2006.

disability organizations is different in states where a rebalanced LTC system is a publicly endorsed goal (e.g., Pennsylvania) or has already been achieved (e.g., Washington), than in states with other political priorities (e.g., Florida). For advocates in the former states the challenge is to work with government officials on “how to rebalance” while advocates in the latter states must still advocate for “why.” Moreover, in states pursuing rebalancing goals primarily for economic reasons, arguments based on appeals to values or ethics are unlikely to sway legislators and government bureaucrats.

Level of involvement of and coordination and cooperation among advocacy organizations. The level of involvement in rebalancing efforts by aging and disability organizations in rebalancing efforts varies across the 8 states. In most of these states, relative to the aging community, the disability advocacy community is much more organized and/or active on long-term care system reform. In Minnesota, for example, reforming the long-term care system is a top priority for the Consortium of Citizens with Disabilities (CCD), a coalition of disability organizations, but rebalancing is not even on the agenda of the Minnesota Senior Federation, whose primary focus is on Medicare prescription drug reform. Just the opposite pattern applies in Vermont and Washington. In Washington state, advocates of and for seniors, working primarily through the Senior Citizens Lobby (a coalition of aging advocacy organizations in the state), have been more active and perceived as more influential in the evolution of community LTC system than the greater disability community. In Vermont, advocacy is judged to have been as strong and effective for and by elders as it has been for younger persons with disabilities.

2. Direct Consumers Are Especially Effective—but Need Training and Support

Representatives from the disability community are adamant that consumers, that is, people who need and use long-term services themselves, must be involved in advocacy activities. People with disabilities live with their problem around the clock, know the issues intimately and in ways that persons without a disability never will, and are experts on which services work well and which do not. Professional advocates such as staff members of consumer advocacy organizations who do not share the characteristics of the clients, do not have the same legitimacy of the clients themselves. Moreover, advocacy by others, including family, may not always reflect disabled persons’ interests and priorities.

According to consumer spokespersons, direct consumers are important for legislative advocacy. Who the messenger is matters to legislators. Advocates and government officials agree that consumers are much more effective before the legislature than bureaucrats or even professional advocates. Even if the message is the same, having a consumer rather than professional advocate present at a legislative hearing personalizes the issue, allowing legislators to connect a real person to a problem. According to one consumer advocate, a message has more power if it is delivered by “people who are facing the issues in their daily lives.”

Several executive agencies have capitalized on consumers’ credibility at legislative hearings. For example, when Washington State’s Aging and Adult Services Administration (now the Aging and Disability Services Administration) spearheaded the state’s initial long-term care system reform efforts in the mid 1990s, it worked with the Senior Citizens Lobby to recruit ordinary older Washingtonians to present the reform proposals before the legislature. Having

clients from a sophisticated lobbying group “carry the water” before the legislature was crucial, according to the Administration’s director at the time.

Some State agencies, including the Disability Services Division of the Minnesota Department of Human Services, are seeking to add more consumers to their existing advisory committees but it is not clear if these efforts are to obtain the unfiltered views of direct service recipients, or if they are designed to strengthen consumer advocacy. If the latter, efforts to recruit consumers may need to be coupled with proactive steps to enable them to participate actively and meaningfully. Simply inviting consumers to boards or committees is not enough. Agencies should have a demonstrated commitment to meaningful consumer participation. This means addressing transportation, child care, reasonable accommodation and other potential barriers to participation. It also means “adequate orientation, training, and support in order to provide all participants with a common framework for involvement.”²⁰

Several states have funded programs to train consumers to become (or become more effective) advocates. New Mexico’s Aging and Long-Term Services Department used grant funding to host two “Train the Trainers Workshop” (in June 2005 and February 2006) designed to “assist in the development of regional advocates to become systems change advocates for long-term services in New Mexico.” The workshops were developed and led by people with disabilities, and provided participants, most of whom were also people with disabilities, the skills and tools they need to more effectively participate in the policy process. The state’s willingness to “put money into supporting the disability community to develop their own leaders and advocates” was the key to the workshop’s success, according to one of its trainers. Similarly, the Minnesota Legislature authorized funding (through the Department of Employment and Economic Security) for Advocating Change Together (ACT), a grassroots disability rights organization that promotes self advocacy. ACT uses these unrestricted funds to “build a self-advocacy leadership base” by training a cadre of “self-advocates.” As noted above, Arkansas created its Aging and Disability Leadership Academy to increase the supply of informed and effective consumer advocates.

3. Money Helps Fuel Advocacy Efforts

Providing or increasing unrestricted funding to existing disability and aging advocacy organizations, which frequently operate on shoestring budgets, was cited by many advocates as a more effective strategy for states to build and sustain consumer advocacy than for the state to seek to build advocacy from the ground up. To support this admittedly self-serving suggestion, advocates identified advocacy organizations’ existing networks, their direct connection to constituents, and their intimate knowledge of their members’ needs – all of which take years to develop. Direct efforts by states to create an advocacy base may instead result in unforeseen directions. In the late 1990’s, for instance, the Aging and Adult Services Division of the Minnesota Department of Human Services sought to build stronger advocacy on behalf of older adults for LTC reform. The division organized meetings of older Minnesotans across the state to brainstorm and strategize long-term care systems reform. The outcome of this process, however, had little to do with such reform. Rather, the outcome was a call for changing the social

²⁰ Chaney R. 2002. The Value of Consumer Involvement in Medicaid Managed Care. Center for Health Care Strategies. CHCS Brief

perception of seniors – away from vulnerable, frail elderly in need of services to one of “vital” older persons in the prime of their lives – which ultimately led to formation of the Minnesota Vital Aging Network, which is not particularly focused on long-term care.

4. Individuals and Personalities Matter

Successful advocacy is sometimes the result of the right person in the right position at the right time, be that a consumer or a government official; likewise, a single government official (e.g., agency head) can stifle effective consumer advocacy. It is clichéd perhaps, but one dedicated and knowledgeable advocate *can* make a difference. Bob Kafka’s persistent, creative, and forceful advocacy is commonly acknowledged to have shaped disability policies and programs not only in Texas but in many states and nationwide.²¹ In the mid 1980s, Norm Schut formed the Washington State Senior Citizens Lobby to develop an advocacy agenda for the state’s aging community. As a former labor leader with many political connections, Mr. Schut was able to open doors to many influential legislators and to provide the Senior Lobby with an immediate power base.

Having the right person at the right time in the right agency position can also profoundly impact the success of advocacy efforts. For instance, the ability of the Consortium for Persons with Disabilities, a Minnesota coalition of disability organizations, to influence long-term care policy rose sharply after Kevin Goodno, a former legislator with a long and well-known personal interest in disability issues (not shared by his predecessor), was appointed Commissioner of the Department of Human Services. Commissioner Goodno actively solicited the Consortium’s advice and feedback on new programs and policy proposals.²² Many agency leaders in other States who are personally and professionally committed to involving consumers and advocates in the policy process have been similarly influential in building and sustaining consumer advocacy. A government employee with a disability who works in a department or agency with long-term care responsibilities can also be influential. Such an “insider” can be invaluable for bringing the perspectives of consumers to bear (functioning, in the words of one advocate, as the “conscience” within an agency).

Stability among personnel -- in government agencies, advocacy organizations, and the legislature -- also plays a role. Much advocacy rests on the trust and mutual respect in personal relationships developed over many years. The Senior Citizen’s Lobby has long been the most potent advocacy force for rebalancing efforts²³ in Washington State in part because of the personal connections with legislators, legislative staff, and government officials that its founder (Norm Shut) had and that its current president developed and nurtured over his own 10+ year leadership of the organization.²⁴

²¹ Bob Kafka is National Organizer and Co-Director of ADAPT (American Disabled for Attendant Programs Today). Mr. Kafka has been a leader in the disability rights movement for many years and has played a key role in many policy initiatives, including money follows the person; see, <http://www.npr.org/templates/story/story.php?storyId=6076125>

²² Commissioner Goodno resigned in July 2006.

²³ Most observers in Washington agree that in the last couple of years, advocacy power in long-term care has shifted to the SEIU.

²⁴ Bruce Reeves, the Washington Senior Citizens Lobby’s President, observed that “lots of money and raising hell” are two ways to get you noticed, but may not be as effective as strong personal relationships.

5. Advocacy Efforts are Fragmented by Disability Type and Age

The well-noted fragmentation of advocacy efforts and organizations, splintering people with disabilities into different organizations, is attributable in part to the division of long-term care support into a multiplicity of programs. Various constituencies have stakes in the perpetuation and quality of particular programs. This fragmentation across organizations affects advocacy by impeding cross-disability cooperation. Nonetheless, ad hoc and more formal coalitions of advocacy organizations are becoming more common in many states. Many of these coalitions focus on long-term care systems reform.

Advocacy organizations within many states have formed coalitions to join forces and build common agendas, some of these coalitions are informal (e.g., CCD in Minnesota and the VT Coalition for Disability Rights) others are formal umbrella organizations with their own funding and staff (e.g. the Washington Senior Citizens Lobby). Although there is some cross-over membership, the coalitions are typically comprised of either disability organizations or aging organizations. State involvement with these coalitions appears to be minimal. One exception is the Senior Organization Network in Minnesota -- the state's Board on Aging (BoA) provides staff support to the network, is itself a member, and the BoA chair currently chairs the network. One state used Systems Change grant funding to try to bring the aging and disability advocacy organizations together, but the effort (Florida's Real Choice Partnership Project) was largely unable to counteract the historical lack of cooperation between the two communities.

More significant than the fragmentation within the disability community is a sharp division between the aging and disability communities, which differ in political philosophy, tactics and strategies, and level of commitment to the rebalancing agenda..

Advocacy in aging and disability communities differ in political philosophy, tactics and strategies, and level of commitment to the rebalancing agenda. Advocacy by and on behalf of older people tends to be diffuse, rather than focusing on community care.

Political philosophy. Individual autonomy is an important value for both the aging and disability communities. But whereas autonomy may be the ultimate value for some disability communities, for the aging community it is sometimes tempered by other values. In an

illuminating example, the Board of the Minnesota Board on Aging cautiously endorsed consumer direction as a principle for long-term care reform not because it believed consumer direction would expand individual autonomy and independence, but rather because the Board thought consumer direction would “be a better way to spend public money” and allow for more tailored solutions to individuals’ service needs.

Younger persons with disabilities have primarily based their claims to entitlement on a civil rights argument derived from a social model of disability. They view disabled persons as a segregated minority who deserve equal protection under the law. They insist on inclusion in mainstream community activities – isolation in nursing facilities and other institutions is almost always seen as a defeat. Older adults, in contrast, have relied on a medical model whereby the illness that produces the disability is the basis for service eligibility. For them, disability results from underlying disease and is a natural consequence of aging. Community integration is

important but not essential and “improving nursing homes rather than starting over” is a legitimate policy goal.²⁵

Tactics and strategies. Aging advocacy organizations tend to avoid high-publicity, high-visibility tactics. At the extreme, angry seniors express their views at the capitol with loud voices, placards, and banners. Some disability advocates are more comfortable and have greater and longer term experience than their aging counterparts in using more assertive tactics, including sit-ins and blocking traffic and building entrances.²⁶

Level of involvement in rebalancing efforts. In the majority of the 8 Rebalancing states, the disability community is much more engaged in LTC reform efforts. The history of disability organizations’ advocacy for alternatives to institutional care goes back several decades. In addition to initiating many of the lawsuits in the 1960s and 1970s that fueled the deinstitutionalization movement, disability advocates were early proponents of money follows the person, consumer direction, and other approaches that have now become central elements of long-term care reforms. Although aging organizations in most states share the same agenda, their support has been more muted. Only in Washington and Vermont have the aging communities been as or more organized and aggressive than the disability communities in advocating for community care. It remains uncertain if the divergence between these two populations is a generational or cohort effect and whether the aging of the baby boomers, many of whom are aging with disabilities, will help bridge the gap between aging and disability communities.

6. Advocates for Persons with Mental Health Disabilities Have Unique Issues

The medical model has been soundly rejected by most in the disability community, who view disability not as a problem of the person, caused by disease, trauma or other health condition, but primarily as the negative aspects of the interaction of a person’s impairment with the social and physical environment.²⁷ Yet for persons with severe and persistent mental health disabilities, the medical care paradigm is often the key to additional resources and to the public policies affecting their lives. As a result, mental health is characterized by many, including advocates from mental health organizations, as the “wild card” or the “odd man out.” Although mental health organizations are typically members of statewide coalitions of disability advocacy organizations, they find themselves more frequently than other coalition members at odds with the agenda of the majority. Advocacy activities of mental health advocacy organizations also more frequently involve the funding and quality of treatment programs and, therefore, focus on government departments and agencies with responsibility for health care policy and programs rather than those with responsibility for long-term care.

²⁵ Kane, R.A (2006). Coalitions between Aging and Disability Interests: A Potential Vehicle to Promote Community Care for Older People. In Putnam, M (ed). *Aging and Disability: Crossing Network Lines*. New York: Springer.

²⁶ See “ADAPT Shuts Down S.F. City Hall and Wins Meeting with Mayor Brown”
<http://www.adapt.org/freeourpeople/aar/lh/lh-nr03a.htm>

²⁷ As previously noted, advocates for older people whose disability results from chronic diseases likewise argue for better health care as well as, increasingly, for more community support services.

7. Development Disability Advocates Have Unique Issues Regarding Rebalancing

The deinstitutionalization movement for persons with developmental disabilities (DD) in the United States began in the 1970's, spurred in large measure by class-action litigation initiated by persons with DD or their families. These legal actions and other advocacy targeting deinstitutionalization led to the creation and evolution of a community services infrastructure for persons with DD.²⁸ A handful of states, including New Mexico and Vermont have no persons with MR/DD living in state institutions; many others have fewer than 100 persons living in their institutions. Often, the remaining ICF-MRs are small facilities, housing 6 or fewer residents. In States where the service structure is already largely rebalanced, DD advocacy may be directed towards preserving the gains already made, arguing for more resources to create greater quality, and bringing greater consumer choice and control to existing services. When State institutions and large ICF-MRs remain in a State, DD advocacy is directed at increasing waiver slots. When a State is actively involved in rebalancing for seniors and others, DD advocates may rally to hang on to the resources and programs they already have. Given their successful earlier efforts, advocates for people with DD recognize that they might have the most to lose from coalitions with other groups and from strategies for cross-disability equity. The projected rapid increase in the number of persons with disabilities – particularly over 65 years old, but under 65 as well – may exacerbate for disability advocacy organizations the tension between cooperating with other organizations for general disability advocacy and advocating on behalf of their own constituent population.

8. Common Problems Identified by Consumer Advocates

Many consumer advocates in the 8 states feel they have an effective voice in the policy arena and a real impact on long-term care policy decisions and program design and implementation. When advocates reported less than successful efforts, they tended to point to the same kinds of problems. Among the specific criticism brought by consumers and advocates:

Hearings are sometimes held after policy decisions are made; consumer participation is sometimes overpowered by other stakeholders; consumer input is sometimes sought on peripheral rather than pivotal issues; and practical barriers, including lack of accommodation to disability, may limit participation by people with disabilities.

Hearings are held after key policy decisions are made. Florida, for example, enacted legislation in 2005 calling for the creation of a managed long-term care pilot project in two areas of the state. The proposal, called Florida Senior Care, is widely seen as positioning the state firmly on the path for a statewide managed LTC system. Public hearings were held in the two affected areas but, advocates contend, the hearings were foremost for providers and were held after the program's parameters had been set; moreover, consumer input solicited at hearings in

²⁸ In the 20-year period between 1977 and 1996, the total number of persons with DD in the U.S. living in state institutions dropped from 154,638 to 58,320. Also, 1996 was the first year more individuals with developmental disabilities were served in community service settings (190,230) than in ICF/MRs (129,449); an additional 30,591 lived in nursing homes. Today, 39,098 persons with DD live in state institutions, 101,821 receive ICF/MR services, 30,027 live in nursing homes and 443,608 receive HCBS. See Prouty, R., Smith, G., and Lakin, K.C. (2006). *Residential services for persons with developmental disabilities: Status and trends through 2005*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration

2006 has been limited to fine-tuning the proposal in response to CMS's request for revisions in the state's waiver application for the proposal.

Consumer participation is outweighed by other stakeholders or by agency representatives.

A single consumer advocate on an advisory committee, or a group of advocates if outnumbered, may be seen as providing only token representation. Even if committee membership is evenly balanced, the familiarity of agency officials and provider trade association representatives with committee processes and technical issues may give them disproportionate influence relative to consumer members. As noted above, States can and do take steps to minimize this result.

Consumer input is sought on peripheral rather than pivotal policy issues. New Mexico, for example, developed and issued in July 2004 an RFP for a managed long-term care program, the Coordinated Long Term Care (CLTC), without significant consumer input. In April 2006, partly in response to the backlash from the aging and disability communities, the ALTSD and the Medicaid Division of the Department of Human Services began hosting a series of public meetings across the state soliciting feedback on the CLTC. As we previously noted these Stakeholder Work Groups have been perceived as effective and have slowed down implementation of the program. But some critics contend that consumer input at these meetings will at best lead to changes on the margins, with core issues already set.

Practical barriers limit participation. A variety of practical issues need to be addressed to ensure consumers' meaningful participation, including transportation, stipends to compensate for time away from work, child care, and accessibility accommodations (e.g., physical accommodations, interpreters, and meeting information prepared in alternative formats and/or in advance). Efforts are also needed to make consumers feel at ease, to explain complicated topics, and prepare them for what is expected of them as committee members.

Conclusions

The 8 States have consciously developed a variety of strategies to strengthen consumer involvement in the policy process. Based on their collective experience, some suggestions can be made for States wishing to channel the energies of consumer advocates to support the rebalancing agenda and wishing to ensure that their policies and programs reflect consumer needs.

- States should take stock of and build on existing advocacy capabilities and groups within the State. States have also found it useful to ensure that standing Advisory Committees for the various lead agencies in the rebalancing effort are briefed on rebalancing activities and that members of these standing committees are appointed to task forces and other ad hoc groups established around community care development.
- In developing Task Forces and Advisory Groups, the State needs to ensure that all types of disabilities and age groups are represented. States have found it important to create cross-disability stakeholder groups that also include providers, to make sure that high level government officials are positioned to hear consumers, and, at times, to create working subgroups by disability or age to address specialized issues.

Topics in Rebalancing: Consumer Advocacy

- States are well-advised to seek the views of consumers early in the process of program or policy development before crucial decisions have been made.
- Involving advocates who are direct consumers of services is important, especially for legislative advocacy. To maximize the effectiveness of consumers on advisory and policy-making groups, staff support and even training may be needed.
- States should consider institutionalizing in statute processes for involving consumers in the policy process, to assure consumer advocacy plays a role in rebalancing efforts, regardless of changes in agency personnel or in political priorities.
- States should consider a multi-faceted strategy for consumer involvement, including use of policy and advisory committees, education and self-education efforts, and public hearings to get consumer feedback. A single strategy is unlikely to be sufficient.

Appendix A

Federally Mandated Consumer Advocacy Programs

Centers for Independent Living (CILs) are private, nonprofit corporations that provide services to maximize the independence of individuals with disabilities and the accessibility of the communities they live in. They are typically consumer-controlled, community-based, and cross-disability. CILs are funded in part by the Department of Education, Rehabilitation Services Administration, Independent Living Branch. In addition to their mandated core services (including advocacy, independent living skills training, information and referral, and peer counseling), CILs provide an array of independent living services.

Protection and Advocacy (P&A). In response to widely publicized abuses in state institutions for persons with mental retardation, legislation introduced in 1975 mandated establishment in all states of Protection and Advocacy (P&A) Systems for individuals with disabilities. Originally intended to protect people in mental retardation facilities from abuse and neglect, the P&A network is now the largest provider of legally based advocacy services to people with disabilities in the United States. In a number of states, this federally funded program has attracted additional state, local, and private support to extend its services to all people with disabilities regardless of the nature or severity of those disabilities.

State Councils on Developmental Disabilities., whose members are appointed by the state's Governor, are funded by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act). The concept of self-determination is central to the DD Act and Councils utilize a variety of strategies, including training, advocacy, educating policy makers, and coalition development "to promote independence, self-determination, productivity, integration and inclusion of people with developmental disabilities in all facets of community life." These strategies are incorporated into five-year State Plans that include, and are based on, a comprehensive review and analysis of services, supports, and other assistance in the state available to individuals with developmental disabilities.

State Units on Aging (SUAs). SUAs are designated by governors and state legislatures to administer, manage, design and advocate for benefits, programs and services for the elderly (and, in many states, for adults with physical disabilities).²⁹ Essentially SUAs administer the Older Americans Act (OAA) in their respective states and, through a state network of Area Agencies on Aging and state-level programs, provide a range of services, planning, and protection. Most SUAs also engage in policy advocacy: the mission of the Minnesota Board on Aging, for example, includes "promoting policies to the State Legislature, the Governor and State Agencies that fairly reflect the needs and interests of older Minnesotans." Typically, a State will have a Governor-appointed oversight or advisory body for the SUA that will include many older people in its membership.

²⁹ "State Unit on Aging" is a general term: the specific title and organization of the governmental unit varies across states and may be called a Department, Office, Bureau, Commission, Council or Board for the elderly, seniors, aging, older adults and/or adults with physical disabilities. See: <http://www.nasua.org/StateUnits.cfm>

Long-Term Care Ombudsman program & other Vulnerable Elder Rights Protection Activities. The Long-Term Care Ombudsman Program (LTCOP) was initiated as a demonstration project in several states in 1972 to meet the needs of residents over age 60 facing problems in nursing homes. Congress expanded the project in its 1978 amendments to the Older Americans Act and mandated that each state establish a LTCOP that provides information and mediation around consumer issues for older nursing home residents. In 1981, the mandate of the Ombudsman program expanded to “board and care,” and thus to the community based residential settings where long-term support is provided, such as assisted living, residential care facilities, and small group homes (i.e., adult foster homes), although the funding for such expansion was not always present and some ombudsman programs lacked experience and protocols to work effectively in residential care. The Nursing Home Reform Act of 1987 gave the ombudsman office formal access to nursing home facilities and residents’ records in a way not available in the residential care sector. Some States, including Minnesota, have expanded ombudsman activities to spheres such as home care, and hospital discharge planning. In 1992, the LTCOP and 3 other elder rights programs were consolidated into a new Title VII of the Older Americans Act. The other programs are: elder rights and legal assistance development programs; benefits outreach, counseling, and protection programs; and prevention of elder abuse. These advocacy efforts under the Older Americans Act largely entail the activities of professional advocates, (though the LTCOP has a large volunteer component) and tend to act protectively and paternalistically. Reshaping would be needed for them to have maximum impact in the rebalancing efforts.