Technical Assistance Guide To Assessing a State Long-Term Care System

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Forward

In response to the advocacy of people with disabilities of all ages and their families, many states are rebalancing their long-term support systems to reduce institutionalization and increase opportunities for people to live in the community. Between 1995 and 2005, for example, the share of Medicaid long-term care spending for home and community-based services (HCBS) increased from 19 to 37 percent.[1] In addition to the considerable efforts at the state and local levels, the Centers for Medicare & Medicaid Services (CMS) has supported state rebalancing efforts in several ways, including policy changes that allow states more Medicaid flexibility to design their long-term care systems and seed money for new initiatives through the Real Choice Systems Change Grants.

As states continue to rebalance their systems, it is important to assess their progress. Developing a profile of a state's long-term support system can assist with this assessment, as shown below.

A State Long-Term Care Profile Can:

- Provide policymakers and stakeholders with a high-level view of the long-term support system, to ensure that all are working from the same knowledge base;
- Identify opportunities for improved coordination – among long-term support programs and with other health and social services;
- Acknowledge the success that has occurred;
- Identify service gaps; and
- Provide a framework for comparing rebalancing efforts across states.

Recognizing the importance of measuring a state's progress toward rebalancing, CMS contracted with Thomson Medstat to develop a model profile of one state's long-term care system and a companion technical assistance guide that other states can readily use to replicate and adapt the profile. This document is the technical assistance guide.

Overview of the Profile

The guide assumes readers have access to the model profile, which presents an analysis of the Commonwealth of Pennsylvania's long-term support system.[2] The bulk of this profile describes the

[1] Burwell, Brian; Sredl, Kate; and Eiken, Steve "Medicaid Long Term Care Expenditures in FY 2005" Thomson Medstat: July 5, 2006.

[2] Eiken, Steve; Nadash, Pamela; and Burwell, Brian *Profile of Pennsylvania's Long-Term Support System: A Model for Assessing a State Long-Term Care System* Thomson Medstat: October 2006. This profile is available at www.cms.hhs.gov and www.hcbs.org.

long-term support delivery systems for five population groups that account for the majority of people who need home and community-based services.

For each population group, the profile describes available home and community supports and discusses gaps in services. It then presents demographic and utilization data to show the demand for and use of long-term supports. These data include comparisons of Pennsylvania to other states. Finally, it describes the state's progress with respect to eight system components (shown below) previously identified by researchers as important for a rebalanced long-term support system.[3]

Key System Components:

1. **Consolidated state agencies** – a single agency for both institutional and community services that coordinates policies and budgets to promote community options;
2. **Single access points** – a clearly identifiable organization managing access to a wide variety of community supports, ensuring people understand the full range of available options before receiving more restrictive services;
3. **Institution supply controls** – mechanisms such as Certificate of Need requirements that enable states to limit or reduce institutional beds;
4. **Transition from institutions** – outreach to identify residents who want to move and assistance with their transition to the community;
5. **A continuum of residential options** – availability of support services in a range of options from mainstream single-family homes and apartments to integrated group settings for people who need 24-hour supervision or support;
6. **HCBS infrastructure development** – recruitment and training to develop a sufficient supply of providers with the necessary skills and knowledge to encourage consumer independence;
7. **Participant direction** – people who receive HCBS having primary decision-making authority over their direct support workers and/or their budget for supports; and
8. **Quality management** – an effective system that: a) measures whether the system achieves desired outcomes and meets program requirements and b) identifies strategies for improvement.

[3] See, for example: Crisp, Suzanne et al. *Money Follows the Person and Balancing Long-Term Care Systems: State Examples* Medstat: September 29, 2003; Eiken, Steve and Heestand, Alexandra *Promising Practices in Long Term Care System Reform: Colorado's Single Entry Point System* Medstat: December 18, 2003; Horvath, Jane and Thompson, Rachel *Promising Practices in Long Term Care System Reform: New Hampshire's Community-Based Service System for Persons with Developmental Disabilities* Medstat: December 5, 2003; Justice, Diane *Promising Practices in Long Term Care System Reform: Vermont's Home and Community Based Service System* Medstat: September 8, 2003; Justice, Diane and Heestand, Alexandra *Promising Practices in Long Term Care System Reform: Oregon's Home and Community Based Services System* Medstat: June 18, 2003; Mullen, Dorothy; Eiken, Steve; and Steigman, Daria *Promising Practices in Long Term Care System Reform: Pennsylvania's Transformation of Supports for People with Mental Retardation* Medstat: March 3, 2003; Reinhard, Susan C. and Fahey, Charles J. *Rebalancing Long-Term Care in New Jersey: From Institutional toward Home and Community Care* Milbank Memorial Fund: March 2003.

The model profile also contains two sections with introductory information. A background section summarizes major factors that have shaped long-term support policy across population groups. An administration section introduces the government agencies responsible for publicly funded services and describes the roles typically played in systems change by the legislature and by consumers and families.

Organization of the Guide

The technical assistance guide first describes necessary resources for completing a state profile. The following section describes the type of information collected for the profile, including sample questions to ask regarding the system components on page iii. The profile concludes with strategies for obtaining this information.

Section I. Available Resources

Completion of a state profile requires two primary resources: expertise (described below) and time. Time refers to: 1) elapsed time between initiation and completion of a profile; and 2) cumulative time spent collecting information and writing the profile.

Necessary Expertise

- An understanding of long-term supports,
- Data interpretation skills, and
- Interview skills to elicit information from people with a variety of perspectives.

States may possess the necessary expertise internally, either in the state Medicaid agency and/or the agencies that manage long-term supports. Most states have independent agencies to evaluate government programs that could provide competent staff to prepare an effective profile. However, these agencies may not have sufficient long-term support expertise because they evaluate all aspects of state government. Alternatively, states could contract with consulting organizations with expertise in long-term supports, if funding is available. An additional benefit of this arrangement is that, ideally, the stakeholders involved will view the profile as unbiased. In some states, the state Medicaid agency or an agency managing long-term supports may have earned the stakeholders' trust. Other states may choose to involve an outside organization to bring an independent perspective to the process.

Whatever organization develops the profile should have enough available staff time to complete it within the state's timeframe. The timing of a state profile may be particularly important for a state's systems change efforts. For example, the profile could inform a state's executive branch budgeting process or its legislative process. It is also critical that planners consider whether the timing is realistic for participants who are essential to the research process – e.g., the state employees who generate relevant data and who need to be interviewed. A short amount of time before an important event, such as the Governor's State of the State address or release of the proposed budget, may require the state to limit its profile.

A state may choose to pursue a more limited profile. States could profile only certain population groups, or present only certain information covered in the model profile. For example, a state may focus on certain parts of the profile that require less time to complete than others. In most states, basic information – such as a list of available programs, their administrative agencies, and the services they commonly provide – will be easy to find. In addition, compiling and analyzing the demographic and utilization data is relatively easy, using the nationwide data sources identified in this guide. Other aspects of the profile, such as describing efforts to build community service infrastructure and explaining the process for accessing services, will take more time. The actual time required for each component will vary, based on the availability of information about the state's system and the specific skills and expertise of the people developing the profile.

Section II. Information Collected

This section describes the type of information included in the model profile of Pennsylvania's long-term support system. Following the model profile's organization, it first discusses the state's background and system administration information. This section then focuses on obtaining information about the long-term support delivery system for one or more specific population groups regarding: available programs and services; demographic and utilization data; and the eight key infrastructure components associated with rebalanced systems.

Background

The background section provides a context for the sections that follow, which focus on certain populations. It highlights relevant information (shown below) that can affect systems change across age and disability groups.

Relevant Background Information:

- Demographic indicators of demand for long-term supports;
- Utilization data to indicate the level of services currently available; and
- Historical and political factors that influence systems change.

There is no need to collect data specifically for the background section. Rather, information for the target population sections should be collected first. Then the authors of the profile can select data for the background section that best tells the state's story.

System Administration

This section outlines the basic structure of state and local administration of HCBS programs with the information shown below. Most of this section focuses on the executive branch of government, which has day-to-day management responsibilities. The profile also summarizes the roles of the legislature, consumers, and advocates.

System Administration and Management Information:

- A list of state agencies with responsibility for long-term support programs, and the population groups they serve;[4]
- A list of local agencies that administer these programs at the local level (e.g., enroll consumers and develop plans of care);
- Recent organizational changes and their rationale;
- A list of systems change initiatives in progress;
- An overview of the state legislature's role in systems change; and
- An overview of the role of consumers and advocates in systems change.

Long-Term Support System Descriptions

After the background and system administration and management information, the profile describes services for major population groups. The model profile addresses five groups that reflect the organization of Pennsylvania's long-term support system: older adults, people with physical disabilities, people with mental retardation,[5] people with mental illness, and children. States can identify major population groups based on their system.

Each population group is covered in a separate section. The sections include: available programs and services for that population; relevant demographic and utilization data; and an assessment of the state's progress regarding the eight infrastructure components associated with rebalanced systems.

Programs and Services

The profile includes a brief description of each HCBS program for the population group. Any notable gaps in coverage are documented – whether a lack of needed services or people ineligible for services. For each population group, the profile should include the information shown below. The profile may also contain historical information about the program, such as when it was established and the particular need it was designed to address.

[4] The model profile for Pennsylvania did not list each program due to their large number, but knowing what programs are available is essential to identifying the agencies involved.

[5] Pennsylvania operates a separate system specifically to serve people with mental retardation. Other long-term supports programs for people with developmental disabilities are part of the system that serves people with physical disabilities. As discussed in the profile, people who do not fit into either system do not have access to services.

Information for Each Program:

1. The program's name;
2. A brief description of eligibility criteria;
3. Funding sources (including participant cost sharing);
4. Maximum benefit amount, if any;
5. Whether there is a waiting list and how many individuals are currently waiting; and
6. Commonly used services.[6]

After describing all programs serving the target population, a table presents the relative size of the programs and recent growth. In the model profile of Pennsylvania's system, the table shows participants served in the most recent state fiscal year with completed data (State Fiscal Year 2004-05). For trend data, it presented the average annual participant growth rate for the three preceding years. These data were readily available for most programs. States may choose another time span based on data availability and the need to illustrate the results of recent initiatives. For example, if a major initiative started in State Fiscal Year 2000-01, that year may be a better benchmark.

The profile also contains a brief summary of other public programs that commonly fund services for this population group. The summary of non-HCBS programs illustrates the patchwork of supports people typically combine when living in the community. Appendix A of the model profile presents additional information about programs that provide income support, health care, transportation, housing, nutrition, and vocational training that can be essential for participants' quality of life. It also includes information about the size of these programs and recent trends.

Most of the information on non-HCBS programs relates to federal programs, or programs common to many states. Few changes would be necessary for a state to incorporate this information into its own profile. A state would insert its own data on the number of people served by the non-HCBS programs and recent trends. The state may need to add other state programs, however, or include federal programs that have little effect on Pennsylvania. For example, the Indian Health Service is a significant health and long-term support provider in several states, but not in Pennsylvania.

Demographic and Utilization Data

For each population group, the profile presents data that indicates the demand for long-term support services and the relative use of institutional and community long-term supports (shown below).

[6] How common services are defined varies. Some programs have one service, such as personal attendant services, which is a core service that most participants use. Other programs have more varied service use, and one may need to mention several services – e.g., those used by 25 percent or more of participants – to describe the services people receive. In instances where service-specific utilization data were not available, the model profile listed all available services.

Demographic and Utilization Data:

- Current, historical, and projected trends for the proportion of people in a state that are in the population group (e.g., people age 65 or older, people under age 65 with disabilities);[7]
- Relative spending for institutional and community long-term support services;
- Current and historical institutional care utilization; and
- Current and historical HCBS utilization.

When obtaining historical data, states may choose to look only at recent years or include data from the past two or three decades to show the impact of previous systems change efforts. The model profile emphasized recent data, but also included some information about the long-term trends toward closing state institutions for people with mental illness and people with mental retardation.

Whenever possible, the model profile compared Pennsylvania data to either the national average or other states, presenting data on a per capita basis to facilitate comparisons. Other types of comparisons may also be appropriate. States may want to compare themselves to other states in their region, for example. Also, a state that is a leader in providing HCBS may want to compare itself specifically to other leaders. The data sources on pages 8 through 11 present information for all states. State comparison data about community long-term care services for some populations, such as people with mental illness and children, are not available.

Components Associated with Rebalancing

The profile describes the state's experience with eight system components associated with rebalanced long-term support systems. Answers to a series of questions (listed below in Table 1) will provide basic information about the state's status with respect to infrastructure necessary for rebalancing.

[7] Projected trends are particularly important for the population of people age 85 and older, which will grow rapidly in most of the country and is more likely to need long-term care.

Table 1. Questions to Assess System Components Associated with Rebalancing	
System Component	**Questions**
Consolidated state agency	1. Which agency or agencies manage programs for this population? 2. Is one agency responsible for both institutional and community care? 3. How do long-term supports fit within the agency's overall duties? 4. Does the state have a mechanism to move funding to the community when institutional usage declines?
Single access points	5. What organization(s) determine functional eligibility for HCBS and institutional services? 6. How do the assessments fit within the organization's overall duties? 7. What mechanisms or processes are in place to ensure people can receive services quickly no matter where they start ("no wrong door")? 8. If there is a waiting list for community supports, how are individuals on the list prioritized? Approximately how long do people typically wait for services, and what options are available in the interim?
Institutional supply controls	9. What is the state's recent history, if any, with regard to closing state institutions? 10. What process is required for adding new institutional beds (e.g., Certificate of Need)? 11. What incentives are in place to reduce institutional capacity and help providers move their business toward community services?
Transition from institutions	12. How are institution residents interested in transition identified? 13. What organizations are responsible for coordinating transitions? 14. What is the standard or typical process for transition? 15. What publicly funded support is available for one-time expenses that are often necessary in transition, such as housing and utility deposits, furniture, and household items? 16. How many individuals have moved to the community under recent initiatives?
Continuum of residential options	17. What residential settings are available, including mainstream homes or apartments, small group residences, and -- if appropriate -- assisted living environments? What supports are offered in each setting? 18. How many individuals in the state live in the different types of residential settings? 19. Is information on affordable, accessible housing readily available? 20. Is there a partnership between the long-term support and housing agencies to develop more community housing options?
HCBS infrastructure development	21. What is the history of provider and service development? How were services initially established? 22. What mechanisms are in place to anticipate future demand for services? 23. What current service development and provider recruitment efforts are in place? 24. How does the system identify and implement new service models?

Table 1. Questions to Assess System Components Associated with Rebalancing	
System Component	**Questions**
Participant direction	25. Is participant direction commonly used? 26. Are participants allowed to employ their own worker to provide HCBS? 27. Are participants allowed to manage their service budget and purchase goods and services outside the standard service package? 28. May individuals choose a representative to assist with participant direction responsibilities? 29. What support is available for participant direction (e.g., supports brokerage and financial management services)? 30. What organizations provide these supports and how do they fit within the organizations' overall work?
Quality management	31. What information is collected to measure quality? 32. What outcome measures have been developed, if any? 33. Who collects and analyzes information related to quality measures? 34. What is the role of participants in quality measurement? 35. How is quality measurement information used to inform program changes and quality improvement initiatives?

Section III. Data Collection Strategies

As indicated in the previous section, the model profile includes a variety of information to develop a high-level, yet comprehensive description of Pennsylvania's long-term support system. Four basic types of data sources informed this profile (shown below).

Data Sources Used in the Model Profile:

1. Sources of national data on state long-term supports;
2. Previously written state materials, including agency Web sites, budget documents, and planning documents;
3. Interviews with system experts, including state and local program staff, provider leadership, and leading advocates; and
4. Focus groups of 8-10 program participants and/or their family members.

National Data Sources

An important use of a profile is the comparison of a state's long-term care demand and utilization to other states. This section recommends national data sources that provide demographic and utilization information for most or all states.

Demographics

The U.S. Census Bureau provides most of the demographic data that can be used to prepare a profile of a state's long-term support system. Each year, the Census Bureau updates population estimates for each state's population, broken down by age, gender, race, and ethnicity. Projections are also available, but are not necessarily updated annually. The most recent versions of the data used in the model profile are available at the links below.

Demographic Data Sources:

- Overall 2005 population estimates, and estimates for commonly used age groups such as age 85 and older, are available at http://www.census.gov/popest/states/asrh/tables/SC-EST2005-01Res.xls.[8]
- More detailed information on population estimates is available at http://www.census.gov/popest/datasets.html. The most specific age-related table is "State Single Year of Age and Sex Population Estimates: April 1, 2000 to July 1, 2005 – RESIDENT", with estimates for single year age cohorts for each year since 2000.[9]
- The most recent projection data, by state and by age group (released in 2005) are available at http://www.census.gov/population/projections/SummaryTabB1.xls.[10]

In addition, the annual American Community Survey provides estimates of disability prevalence, available by age group. These data are presented for all states at http://factfinder.census.gov/. Click "get data" under "American Community Survey." Click "Ranking Tables" to access disability prevalence information across all states.[11]

Another indicator of long-term care demand is the percentage of people who receive Supplemental Security Income, which is an indirect expression of the number people with disabilities living in poverty. State-level 2004 data on SSI participants for three age groups – less than 18, 18 to 64, and 65 and older – are available at http://www.ssa.gov/policy/docs/statcomps/supplement/2005/7b.html.[12]

Utilization

Several different sources provide national data comparing institutional and HCBS utilization. Per capita rates for each state can be derived by combining the Census Bureau population estimates with these utilization data. Table 2 on the following pages provides links for the data sources used in the model profile and a description of the source data. HCBS comparison data for a majority of states were not available for people with mental illness and children.

[8] U.S. Census Bureau, 2005 Current Population Estimates, "Table 1: Estimates of the Population by Selected Age Groups for the United States and States and for Puerto Rico: July 1, 2005 (SC-EST2005-01)" August 4, 2006.
[9] U.S. Census Bureau "SC-EST2005-AGESEX_RES: Estimates of the Resident Population by Single-Year of Age and Sex for the United States and States: July 1, 2005" August 4, 2006.
[10] U.S. Census Bureau "Interim Projections of the Population by Selected Age Groups for the United States and States: April 1, 2000 to July 1, 2030" April 21, 2005.
[11] U.S. Census Bureau, American Community Survey, *2004 Ranking Tables* August 30, 2005.
[12] U.S. Social Security Administration *Annual Statistical Supplement, 2005* February 2006.

Table 2. National Sources for Long-Term Services Utilization Data	
Source	**Available Data**
Burwell, Brian; Sredl, Kate; and Eiken, Steve "Medicaid Long Term Care Expenditures in FY 2005" Thomson Medstat: July 5, 2006. Most Recent Data: 2005 Link: http://www.hcbs.org/moreInfo.php/nb/doc/1636	✓ Expenditures for total Medicaid, Medicaid long-term care (LTC), and particular programs like nursing facility, intermediate care facility for people with mental retardation (ICF/MR), personal care, and HCBS Waiver. ✓ Relative percentages of long-term care spending for institutional and community services ✓ Expenditure growth over time for total LTC and for individual programs
Centers for Medicare & Medicaid Services' Medicaid Statistical Information System (MSIS) State Summary Datamart. Data extracted from the Datamart in January 2006. Most Recent Data: 2003 Link: States may extract data at http://msis.cms.hhs.gov .	✓ Nursing facility and ICF/MR participants, days of service, and expenditures ✓ Nursing facility and ICF/MR data by age group (e.g., 0-20, 65 and older)
Eiken, Steve; Burwell, Brian; and Selig, Becky "Medicaid HCBS Waiver Expenditures, FY 2000 through FY 2005" Thomson Medstat: July 6, 2006. Most Recent Data: 2005 Link: http://www.hcbs.org/moreInfo.php/nb/doc/1637	✓ Expenditures for HCBS Waivers by target population
Grabowski, D.C.; Feng, Z.; Intrator, O.; and Mor, V. "Recent Trends in State Nursing Home Payment Policies" *Health Affairs* Web Exclusive: June 16, 2004. Most Recent Data: 2002 Link: http://content.healthaffairs.org/cgi/content/full/hlthaff.w4.363/DC1	✓ Medicaid nursing facility payment rates
Minimum Data Set (MDS) National Repository *Active Resident Count Report* Most Recent Data: June 30, 2006 Link: http://www.cms.hhs.gov/apps/mds/, select report type "MDS Active Resident Information Report", select a calendar year quarter (report is based on a quarter's end date), then select "Resident Counts by State"	✓ Total nursing facility residents in facilities certified by Medicare and/or Medicaid
Minimum Data Set (MDS) National Repository *Active Resident Information Report* "Q1a: Discharge Potential and Overall Status" Most Recent Data: June 30, 2006 Link: http://www.cms.hhs.gov/apps/mds/, select report type "MDS Active Resident Information Report", select a calendar year quarter, then select "Q1a: Discharge Potential and Overall Status"	✓ Percentage of total nursing facility residents, in facilities certified by Medicare and/or Medicaid, that indicated a preference for returning to the community

Table 2. National Sources for Long-Term Services Utilization Data	
Source	**Available Data**
Kitchener, Martin; Willmott, Micky; and Harrington, Charlene *Home & Community-Based Services: State-Only Funded Programs* May 2006. Most Recent Data: 1998-2005 (varies by state and program) Link: http://www.pascenter.org/state_funded/	✓ Participant and expenditure data for state-funded HCBS programs
National Association of State Medicaid Directors *1915(c) Home and Community Based Services Waivers – By State* November 2004. Most Recent Data: 2002-2004 (varies by state and program) Link: http://www.nasmd.org/waivers/1915cdb.htm and Kitchener, Martin; Ng, Terence; and Harrington, Charlene. *Medicaid 1915(c) Home and Community-Based Service Programs: Data Update* Kaiser Family Foundation: July 2005 Most Recent Data: 2002 Link: http://www.kff.org/medicaid/upload/7345.pdf	✓ Participants for HCBS Waivers by target population. ✓ Expenditures and per-participant expenditures for HCBS Waivers by target population ✓ The NASMD source contains approximately 80% of waivers and has the most recent data. The model profile used the Kitchener, et al., data for the remaining waivers.
National Association of State Mental Health Program Directors (NASMHPD) Research Institute "State Profile Data and Reports: 2004" Undated. Most Recent Data: 2004 Link: http://www.nri-inc.org/defprofiles.cfm	✓ Residents of state institutions for people with mental illness in 38 states. ✓ Residential treatment facility data are available for less than half the states. ✓ Community service participant data, which includes Medicaid mental health participants for some states but not others.
Prouty, Robert; Smith, Gary; Lakin, K. Charlie; Bruiniks, Robert; and Coucouvanis, Kathryn *Residential Services for Persons with Developmental Disabilities: Status and Trends through 2005* University of Minnesota: July 2006 Most Recent Data: 2005 Link: http://www.rtc.umn.edu/docs/risp2005.pdf	✓ Participant data for state institutions, ICF/MR, and HCBS Waivers for people with developmental disabilities ✓ Change in state institution, ICF/MR, and HCBS participants over time
Summer, Laura L. and Ihara, Emily S. *State-Funded Home and Community-Based Service Programs for Older People* AARP: October 2004 Most Recent Data: 2002 Link: http://assets.aarp.org/rgcenter/post-import/2004_11_hcbs.pdf	✓ Participants and expenditures for state-funded HCBS programs serving older adults

State Written Materials

Much of the information required for a state profile may be available in existing documents produced by the state and/or its stakeholders. State documents range from brief program descriptions to policy manuals and in-depth studies of their long-term support system. Many of these documents are available on state Web sites. The profile's authors may need to request other documents. The types of state documents used in the model profile are shown below.

State Documents Used to Prepare the Model Profile:

1. **State agency Web sites** usually describe available programs and/or services. Information oriented toward participants and their families often describes the programs well. Agencies' annual reports may have information on expenditures and people served.
2. **The Governor's budget proposal** contains high-level expenditures data for many government programs, with information provided by funding source. It usually describes each program and gives a rationale for the program. Many state budgets also include program performance measures such as utilization data. Program descriptions and data are more likely to be available for large long-term care programs, such as nursing facilities, state institutions, and the larger Medicaid waivers. Smaller long-term support programs are less likely to have a specific line item or description.
3. **State laws and regulations** are usually available through the general state Web site (e.g., www.state.pa.us).
4. **Policy manuals and bulletins** have been developed for most large programs, and are available online in some states.
5. **Technical reports** on the long-term support system (or aspects thereof) are available in many states. These reports can identify challenges facing the system and initiatives to address them. Certain stakeholder groups may also provide similar reports.
6. **Ad hoc data requests** can provide information that is not readily available. For example, a state may not know how many people live in each type of licensed residential setting, but may be able to obtain this information from a database with a few hours of work. Most of the data in the profile is relatively simple, e.g., how many people use homemaker services or how many people have left nursing homes in a nursing facility transition program. These data may not be readily available, however, because a state may not use a specific type of data on a regular basis. As a result, a state may want to extract certain data specifically for the state profile.

Individual Interviews

Interviews with state staff and stakeholders – including provider associations, consumer advocacy groups, and local administrative agencies – are essential to achieve a full understanding of how a community service system functions in consumer's lives. Broad stakeholder involvement is important to implement systems change,[13] and contributing to the state profile could be one of many ways stakeholders can participate. To further this purpose, one of the first interviews could be a group meeting with a relevant task force or advisory committee to inform a broad stakeholder group about the profile at the same time and afford them an opportunity to ask questions about it.

The particular stakeholders that should be involved in the profile will vary by state. States may want to include most stakeholder groups that are involved in the system. The state also may want to include other government agencies with a specific advocacy role, such as the Protection and Advocacy Agency, the Developmental Disabilities Council, and the Long Term Care Ombudsman. State associations of consumers, families, providers, and local case management agencies often are key partners. In addition, the authors should interview individuals involved at the local level, such as managers and support coordination staff from local administrative agencies and local provider and advocacy groups. These locally based stakeholders are valuable resources, especially if a state is concerned about regional variations in service delivery.

The profile's authors may want to interview a variety of state staff, including senior and mid-level managers, data experts, and individuals leading particular systems change initiatives. Also, many state agencies have employees with decades of experience and a wealth of institutional memory who would be valuable resources for the profile. The interviews with state staff are also an opportunity to request utilization data or program information that is not available online, such as policy manuals and periodic unpublished utilization reports (These State Written Materials are discussed above).

Interviews can be conducted in-person, by phone, or both. The location of interviews may depend on the resources available for travel and the profile's deadline. A quicker timeframe or smaller travel budget would lead to more phone interviews.

There is no set interview protocol, because the focus of each interview can vary based on the informant's role and experience in the system. Senior officials and advocates are likely to know about all eight system-rebalancing components and be able to provide at least high-level information about them. Mid-level state staff and local staff are more likely to provide in-depth information about one or more components. These people and the more experienced advocates are likely sources of information about the program's history, since many senior officials are political appointees with only a few years' experience in their position. The 35 questions identified on pages 6 and 7 may be useful for the interviews. Most of these questions are open-ended and designed to allow the informant to speak freely about the system. For each informant, interviewers should make note of a few questions that they *must* ask and make sure those issues are discussed.

[13] Eiken, Steve "Promising Practices in Long Term Care Systems Reform: Common Factors of Systems Change" Thomson Medstat: November 9, 2004

Focus Groups

Focus groups can identify strategies that consumers and families use to establish or maintain a life in the community, including the use of HCBS and other supports (e.g., educational services, vocational rehabilitation, and transportation). Focus groups allow consumers and families to describe the services available, the consequences of service gaps, and their personal experience working around these gaps. Focus groups can provide invaluable information about consumer perspectives and the realities of service use, even though the number of consumers in the group, typically 8 to 10, is too small to draw statistical conclusions about the whole population. A sample list of focus group questions used in the model profile is below. These questions used simple wording to facilitate interviews with consumers with developmental disabilities. A state wishing to use group interviews may consider hiring consultants that specialize in focus groups to further structure the interviews and evaluate the findings.

Sample Focus Group Interview Questions

1. Did you help pick your home?
2. Do you like where you live?
3. Has anyone moved recently? What happens when someone tries to move?
4. Do you decide what help you receive?
5. Who has a job? What was your experience getting a job?
6. Does anyone want a job, but was not able get one? What happened?
7. Are you able to see a doctor when you need to?
8. Are you able to get a ride when you need it?
9. Is there any help you need that you currently do not get?
10. What happens when you try to get more help?
11. Were you ever on a waiting list for services? What did you do while you waited for supports you needed?

States may want to conduct focus groups for people with different types of disabilities to determine how the system responds to their particular needs. The focus groups could be taken from common population groups (e.g., older adults, people with developmental disabilities) or highlight groups that face particularly difficult challenges in the state's system. In Pennsylvania, for example, two focus groups were chosen from populations widely believed to be underserved – people with autism and people with brain injuries. Alternatively, a state may want to conduct focus groups using the same population group from different parts of the state to capture regional differences in service delivery. Advocacy groups and state or local program administrative staff can assist with identifying people for the focus groups and help find a local, suitable place to conduct the interviews.