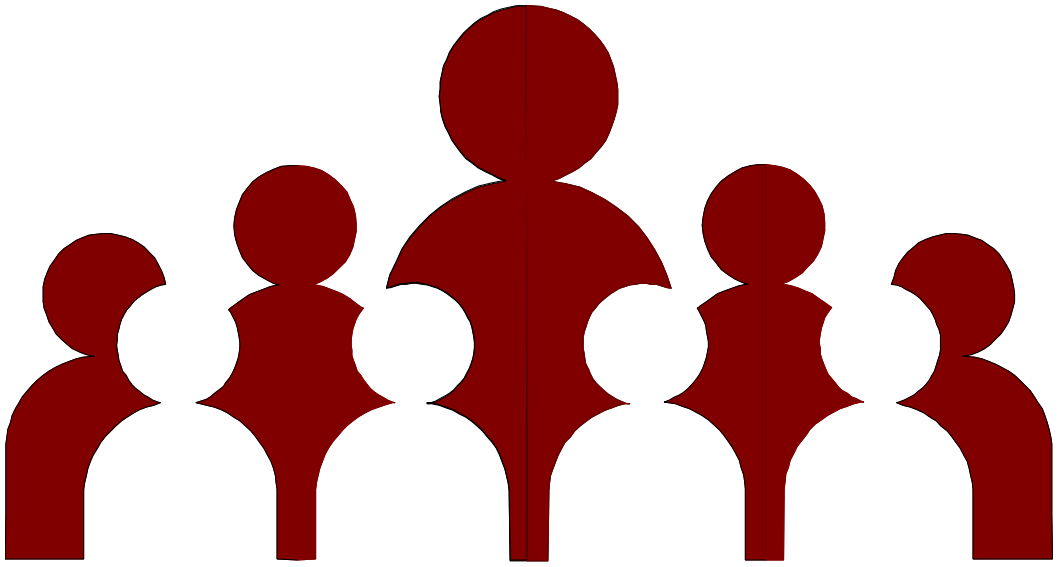
Person-Centered Supports — How Do States Make Them Work?



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Person-Centered Supports — How Do States Make Them Work?

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Overview

Purpose of State Case Studies

The fundamental aim of the Reinventing Quality project is to support the efforts of state and local stakeholders of all types to accelerate the more widespread adoption of person-centered principles and practices in the operation of public systems serving people with developmental disabilities. This project has been governed by the Principles of Person-Centered Supports developed during the grant's first year and disseminated widely in "Person-Centered Supports – They're for Everyone!" The principles, hammered out by a diverse, broad group of stakeholders in the developmental disabilities field, are a comprehensive statement of the essential values that state systems must embrace so that all people with developmental disabilities are supported in realizing their own goals and aspirations for community life. Accompanying markers or indicators also were identified to assist in gauging the extent to which the principles are present in the operation of public systems. The project also started with the proposition that effective practices are in fact present or "coming on line" in some form during the project period. Therefore, a main project goal was to investigate and validate particular practices or approaches to the broad adoption of person-centered principles and to determine whether they were seen as effective in the eyes of system stakeholders, including and especially people with developmental disabilities and their families.

To this end, the project staff selected 4 states where there was evidence think that person-centered practices had taken hold to a significant extent – Wyoming, Wisconsin, Kansas, and Connecticut. The specific site selection methods and site visit protocols are included in Appendices A and B. The full reports concerning each state are available on the project's Quality Mall website (www.qualitymall.org), and on the website of the Human Services Research Institute (www.hsri.org).

During the course of each site visit, the project staff interviewed scores of individuals in each state, including people with developmental disabilities, families, public officials, advocates, direct support professionals, service agency managers and others. They generously shared their experiences in advocating for and implementing person-centered supports.

Organization of the Monograph

The following brief analysis is a synopsis of what was learned on site, the lessons learned, and potential implications for other public systems in fostering person-centered supports for people with developmental disabilities. While each of the four states traveled a different path in embracing the principles of person-centered supports in the operation of their systems, their collective experiences and discoveries hopefully will provide valuable insights to reformers around the country.

Selected States – Different Paths and Disparate Strategies

Each of the four states took somewhat different paths toward embracing the principles of person-centered supports in the operation of their DD service systems, both because of the context and history of each system as well as the approaches used to pursue change.

With respect to the organization and configuration of their service systems, the four states varied widely:

- Wyoming's system historically has revolved around nine regional, non-profit developmental disabilities service providers, but in recent years the state's system has become more diverse.
- The Wisconsin system is highly decentralized and administered locally by 72 separate county human services agencies that are responsible for a broad portfolio of human service and social programs, including community supports for people with developmental disabilities.
- In Kansas, the state structured its system around local/regional authorities (Community Developmental Disabilities Organizations (CDDOs)) that serve as the single point of entry for publicly-funded developmental disabilities services and provide community direction for the provision of services.
- Finally, Connecticut is a state-administered system that is managed through the Department of Mental Retardation's regional offices.

These four states span the most common ways that states organize their developmental disabilities service systems.

Historically, the four states started their movement toward person-centered supports from very different places. In 1990, the substantial majority of Wyoming's resources paid for institutional services and funding for community services was very low. The same can be said of Kansas, where congregate services predominated. The Wisconsin system, on the other hand, was broadly regarded as a leader in promoting progressive community supports for people with developmental disabilities as well as to individuals with other disabilities. In 1990, Connecticut had a somewhat conventional but relatively robust and well-financed service system.

The antecedents of reform in each state varied:

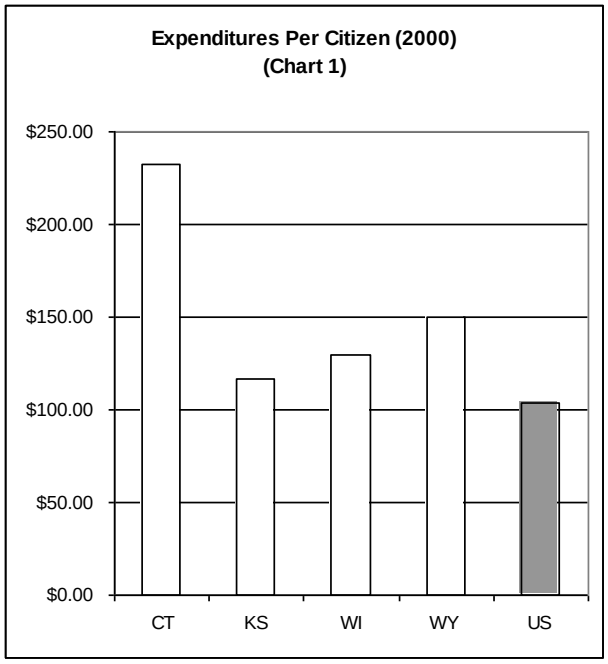
- In Wyoming, the Weston lawsuit triggered a major overhaul of the state's DD service system, including the rapid expansion of community services. The state was also blessed by strong legislative support to do the right thing along with solid leadership and stakeholder collaboration.
- As noted, Wisconsin has enjoyed a long history of promoting foreword-thinking community supports, particularly in the arenas of family supports and supported living. It also has boasted a strong advocacy community. A major milestone in the state that

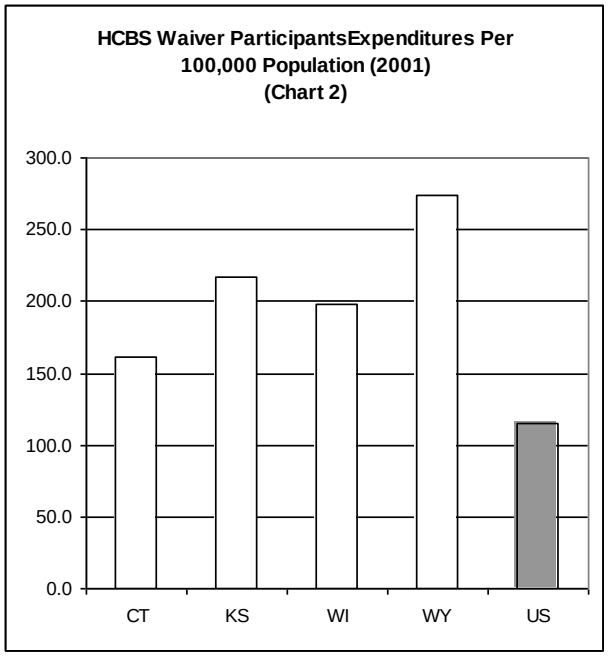
added momentum to continuing community expansion was Wisconsin's entry in the Community Supported Living Arrangements Program (CSLA) – a time-limited federal authority that helped states to demonstrate the feasibility of more individualized supports funded through Medicaid. As a result of participation in CSLA, Wisconsin stakeholders realized that there were untapped possibilities in the arena of person-centered supports. State informants also pointed to the importance of the state's participation in the RWJ Foundation Self-Determination initiative.

- In Kansas, reform was propelled by strong collaboration between the advocacy community and state officials who agreed that the state's DD service system was not offering the supports that individuals and families wanted. This collaboration led to the development of a strategic plan to reform the Kansas system and culminated in the 1995 passage of milestone legislation, the Developmental Disabilities Reform Act. Kansans also attribute important improvements in person-centered supports to ongoing strong leadership and a mission animated to support the expectations of families and people with disabilities. Kansas also participated of the RWF Self Determination project.
- Finally in Connecticut, part of the backdrop of change was the presence of two major class action suits – one aimed at institutional improvement and the other at community development. In addition to participating in the Robert Wood Johnson project, Connecticut also had a strong reputation for community employment services for people with developmental disabilities. Informants also noted that the pace of change, once there is agreement to proceed, was accelerated by the centralized character of the the state's service system and the ability of state officials to effect policy change across the system.

Shared Characteristics

These four states, while starting from very different contexts and taking different routes toward system reforms, share many similarities that contribute to their capacity to furnish person-centered supports. Specifically, each state financially supports people with developmental disabilities at an above average level of effort, as shown in Chart 1[1]. Throughout the 1990s, all four states significantly reduced the number of persons served in large public institutions and devoted an increasing proportion of their budgets to community supports, due in large part to their aggressive use of the Medicaid Home and Community-Based Services (HCBS) waiver program. Chart 2[2] shows the number of individuals participating in each state's HCBS waiver program in 2001, indexed to state population and compared to the nationwide average. Employing the HCBS waiver program enabled all four states to broaden access to community supports and offer individuals and families diverse services that could be tailored to their needs and preferences.





These states also had other characteristics in common including the following:

- ☑ Each has shared, well-articulated values and a sense of mission
- ☑ There is continuity of leadership – not just at the top but throughout the system and at the provider level

[1] Figures are based on: David Braddock et al. (2002). The State of the States in Developmental Disabilities: 2002 Study Summary. Boulder Colorado: University of Colorado, Coleman Institute for Cognitive Disabilities and Department of Psychiatry.

[2] Figures are from: Robert Prouty, Gary Smith, and K. Charlie Lakin (eds.). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2001. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

- ☑ There are vigorous family support programs that have grown and improved over time
- ☑ These states have built solid quality assurance and improvement efforts that:
  - Are systematic and comprehensive
  - Include ongoing monitoring from a variety of sources (e.g., case managers, advocates, quality committees, state quality staff, etc.)
  - Reflect a person-focus by concentrating on the experience of people receiving services, their quality of life, their involvement in their communities, and their ability to make choices
- ☑ The Developmental Disabilities Councils, Protection and Advocacy agencies, and the University Centers for Excellence in Developmental Disabilities are valued partners and collaborators in reform. In Kansas, for instance, the head of the Developmental Disabilities Council was a pivotal figure in the mobilization of support for the 1995 DD Act.
- ☑ Each state has a relatively low case management ratio (i.e., between 30 and 35 individuals per case manager).
- ☑ There is diversity and choice in case management (e.g., in Kansas, Wyoming and Wisconsin, individuals increasingly have a choice of traditional or independent case managers).
- ☑ There is a commitment to person-centered planning and continual training in person-centered approaches. In Wisconsin, for instance, this effort has been ongoing for many years and has been particularly important in a state where decision making and control are divided between the state and localities. Similarly, Kansas has invested heavily in continuous, systemwide training in person-centered planning.
- ☑ Each state has been supportive of self-advocacy efforts, including enlisting self-advocates in system-level advisory capacities.

Keys to Success

In reviewing the collective experience in the four states, we think there are several important considerations that help to explain why the person-centered practices took root and continue to grow.

☑ **Importance of person-centered system architecture that:**

- Links a specific allocation of funds to individual budgets that enables person-centered planning teams to make real decisions about services and supports. In Wyoming, the state has developed the DOORS mechanism which bases individual budget allocations on the functional characteristics and needs of the person. Decisions regarding the deployment of funds are left to the individual and his or her circle. In Kansas, fiscal intermediaries have been designated to provide back up financial management services to persons who opt to manage their own individual budgets.
- Ensures open and competitive markets. Connecticut has embarked on a gradual "deconstruction" of agency budgets to allow for the portability of funding.
- Affords individuals and families an unencumbered choice among qualified service/support providers. In Dane County, Wisconsin, the individual is free to pick their own service worker. That individual in turn is employed by the Salvation Army which ensures they are trained and receive fringe benefits. In Connecticut, supports are based on "individual service agreements" unique to each consumer.
- Retains flexibility. Kansas has initiated an innovative "limited license" that allows families serving 2 or fewer individuals to initiate resident services without the level of cumbersome bureaucratic requirements involved in obtaining a full license.
- Supports person-centered quality assurance. In Kansas, the state monitoring system – Kansas Lifestyle Outcomes – focuses on the individual and the extent to which critical outcomes are realized. Wisconsin has adopted a comprehensive quality assurance plan that is likewise keyed to individual outcomes as well as other important concerns.
- Locates decision-making with the individual's circle of support. In Wyoming, once the decision is made regarding the individual budget allocation, it is up to the person and the circle to determine what and how services and supports will be provided.
- Supports well-resourced service coordination. Connecticut has instituted service brokerage for individuals who chose self-determined supports. These brokers have smaller caseloads than conventional case managers.
- Draws data from a variety of sources and employs data to support continuous quality improvement. For instance, Connecticut has instituted a "system integrity" process at the regional level that involves periodic review of all relevant performance data and the use of the findings to improve specific areas of the system.

- Creates a solid base of information about system performance to provide "transparency" in order to enhance the information available to individuals and families. In Wyoming, all licensing reviews are available on the state website. Connecticut is planning on a similar step. Kansas publishes the results of the Kansas Lifestyle Outcome surveys.

- ☑ **Collaboration and shared vision among all stakeholders is critical**.

- ☑ **A person-centered culture is the product of continuous, ongoing attention and an emphasis on training**. The presence and resilience of this culture is critical to the ongoing viability of person-centered practices and is a shield against any dislocation generated by changes in leadership. The persistence of this culture is particularly strong in Wisconsin and is clearly present in the other three states.

- ☑ **Change does happen, but how fast reform is implemented is affected by system size, the state context, and the extent to which old ways have to be unlearned and contrary approaches undone**. It is also a product of the "opportunistic" use of external factors such as litigation, expanded waiver use or even the choices necessitated by a budget downturn.

- ☑ **In every state, there is a tipping point – i.e., a point in time when a sufficient number of individuals are receiving person-centered supports, thus creating momentum for change throughout the system (and a uniform demand for such supports)**. In Connecticut, for instance, as the number of individual service agreements grows beyond the current 500, the momentum for change will clearly accelerate.

Challenges

While the experiences in these four states underscore that there has been positive movement toward a truly person-centered system of services, there are several important challenges that must be addressed in these states as well as in other states around the country:

- ☑ In all four states, informants were quick to point out that the shift to person-centered supports was still unfolding. A common theme was "We're not there yet." Challenges remain in embedding the principles of person-centered supports systemwide.
- ☑ The exuberance that accompanied the expansion of person-centered supports during the 1990s must be tempered by the realities of budget shortfalls. This suggests that new ways must be found to keep the momentum going while putting into place the most cost-efficient approaches.
- ☑ Each of these states faces the pressure to expand services to meet continually increasing demand, both from younger families and from aging families.
- ☑ Workforce issues pose a major constraint to service expansion and quality. Each state is struggling to find ways and resources to address this crisis. However, this year, the Wyoming legislature approved a substantial increase in funding to boost worker wages to competitive levels.
- ☑ There is an increasing struggle in each state to maintain the flexibility and individuality of person-centered supports in the face of escalating pressures to standardize supports as a consequence of the need to expand the scope of quality assurance activities.
- ☑ Each state faces the final throes of institutional phase down and closure.

Implications for Other States

These states exemplify the spirit and energy that characterize the journey to person-centered supports. While none of stakeholders interviewed in Wyoming, Wisconsin, Kansas and Connecticut would claim that they have arrived at their destination, they are in the vanguard of the movement to embrace person-centered practice systemwide. The lessons that they have learned should be taken seriously by the developmental disabilities field at large, including:

- ☑ Hone person-centered planning skills through continuous training and indoctrination;
- ☑ Rethink and retool case management so that it is sufficiently funded and capable of guiding and assisting people toward person-centered supports;
- ☑ Sharpen the state's vision through strategic planning and/or the enactment of reform legislation;
- ☑ Strengthen and support self-advocacy;
- ☑ Retool traditional quality assurance systems by putting the experience of the individual at the center of the quality calculation;
- ☑ Take advantage of the flexibility of the HCBS waiver program to support the state's vision of individual supports and expand access to services;
- ☑ Reach out to and collaborate with key stakeholders; and
- ☑ Implement quality improvement processes that analyze performance data and use such data to move toward increasingly person-centered practices.

Appendix A
State Site Selection

State Selection

In order to determine how and whether these principles were present in the context of actual public DD service systems around the country, the Human Services Research Institute (HSRI) chose four states to exemplify how these principles have been woven into specific public systems. In order to narrow the field to the final four, HSRI canvassed available statistics that ranked states based on performance in a variety of areas. The following indicators, arguably, can serve as "proxies" for person-centered practice:

Community Inclusion and Integration

- ☑ Percentage of individuals living in community ICFs/MR as a proportion of all individuals residing in the community.
- ☑ Number of individuals with MR/DD receiving HCBS waiver services per 100,000 in the general population.

Deinstitutionalization

- ☑ The percent change in the number of individuals residning in institutions from 1990–99.
- ☑ The number of individuals with MR/DD living in small (under 6) residential settings per 100,000 in the general population.
- ☑ The number of individuals with MR/DD living in large,state-operated or privately operated (+16 beds) residential settings per 100,000 in the general population.

Early Intervention and Education

- ☑ The proportion of special education children in regular classrooms compared to all children receiving special education.
- ☑ The proportion of individuals in special education who receive a diploma compared to the total number of such students exiting secondary schools.
- ☑ The percent of the infant and toddler with disabilities and developmental delays receiving early intervention services.

Integrated Employment

- ☑ The percentage of individuals engaged in supported employment programs as a proportion of all individuals enrolled in day/vocational services.
- ☑

Fiscal Effort

- ☑ Annual per family expenditure for family support services.
- ☑ Annual per capita expenditure on HCBS waiver.
- ☑ State fiscal effort in community spending.

System Organization and Efficiency

- ☑ Number of individuals with MR/DD on a waiting list per 100,000 population.
- ☑ Total number of individuals with MR/DD receiving residential services (regardless of type).
- ☑ The number of individuals served per 100,000 population

Data on each of these indicators were arrayed for all states nationally and an aggregate score was developed. With the assistance of the Participant Advisory Committee, the project staff reviewed the top 10 ranked states and picked the final four states. The final selection took into account geographic distribution, rural/urban characteristics, population size and the configuration of the state system (e.g., county-based, state regions, etc.). The states selected were: Wyoming, Wisconsin, Kansas, and Connecticut.

Site Review Process

During Years 2 and 3 of the grant project, HSRI and NASDDDS staff conducted 3 day site visits to these four states to learn from stakeholders the key elements and strategies that were instrumental in bringing about broad scale system reconfiguration in the selected states. The aim was to gather and synthesize information concerning how the jurisdiction addresses each key element as well as probe concerning additional factors (e.g., leadership) that played a central role in the jurisdiction's broad-scale adoption of person-centered principles to guide the provision of supports for people with developmental disabilities and their families. It is hoped that the identification of exemplary public systems will give stakeholders confidence concerning the feasibility of broad system redesign initiatives as well as informing them, in practical rather than theoretic terms, about the actual strategies employed.To ensure that the state case studies yielded relevant insights, an inquiry guide was developed. During each site visit, the project staff posed the following general questions:

1. *Is the system reasonably person-centered? How well is it working?* Through interviews and focus group discussions with a variety of stakeholders, the project staff validated the selection of the particular state as a model person-centered system.
2. *What strategies did state leaders use to make this happen?* Focusing on interviews with state leaders, the project staff reviewed the history of the state's service delivery system and described the critical path leading to the development of a person-centered system.
3. *What can we distill from this state's experiences that may be useful to other states?* The project staff sought illustrations of exemplary practices, lessons learned, and experiences that may be transferable to other states.

Key questions were framed based on the markers described in the consensus statement "Person-Centered Supports - They're for Everyone!" The inquiry guide is included in Appendix B.

Appendix B
Site Visit Inquiry Guide

1. To what extent do people/families have authority over their lives?

- Give some examples of ways people/families in your state exercise authority. (e.g. involvement in planning, making choices, developing budgets)
- What does the state system do to ensure that people/families have authority over their lives? What practices are in place to support people/families to exercise authority? (e.g. support brokerage, person-centered planning, rights education)

2. To what extent to people/families determine their own supports?

- Do people/families make important choices about services that impact their lives, such as where to live, with whom they live, who provides their personal care and support?
- Are there enough options available for people/families?

3. To what extent do people/families control the money available for their supports?

- Are dollars flexible? Tied to people/families rather than programs?
- Do people/families have individual budgets? Describe how such budgets are created and monitored.
- Are fiscal intermediaries used? Vouchers? Other reimbursement methods?

4. Are there brokers or agents available to people/families to assist them to plan, secure, and arrange supports?

- Describe the role of the broker or agent, and how these services are utilized by people/families in your state.

5. To what extent are people supported to have relationships and community membership?

- Do people see their friends and families as often as they'd like to?
- Do people feel that their need for intimate relationships is respected and supported?
- Do people participate in the community activities of their choice, as often as they would like to?

6. Are people supported to contribute to their communities and to engage in meaningful work?

- What creative strategies has the state used to support people in community employment or other meaningful work?

- Are people making contributions to the community that they feel good about? Doing work that is rewarding?

7. To what extent are families valued and supported in their own right?

- Do families report that supports are tailored to their individual needs?
- Are families supported to keep children at home?
- Do families feel they are treated with respect and their opinions valued?

8. Are relevant information and training opportunities continuously available to people/families?

- What types of education and training are available to people/families on an ongoing basis? What topics? Who can access them?

9. To what extent does the system work in partnership with other networks of support?

- Give examples of unique or creative ways your system has found to support people using generic or other community supports.
- How are natural supports and generic supports addressed in a person's support plan?

10. To what extent are people/families invited, welcomed, supported as full participants in system planning and decision-making?

- To what extent do people/families hold meaningful leadership roles in the system? Does the system support them to do so?
- Is there an active network of self-advocates? Of families?

11. Do people/families feel safe and secure?

- Do people have individualized health & safety plans (that do not compromise personal rights and freedoms)?
- How are instances of abuse/neglect/exploitation handled? Does the public DD system work together with the legal/criminal justice system to address these incidents?

12. Are people's rights affirmed and protected?

- Does the state have a rights education and training program? For staff? For people and families?
- Are people/families aware of their rights? Do they understand procedures for reporting problems?
- Are problems/grievances addressed promptly and satisfactorily?

13. Do people get the health and related services they need?

- Are people/families satisfied with access to health care services? With quality of services? With the skills and knowledge of health professionals who provide their care?

- What does the state do to ensure access to competent, reliable, and timely community health care?
- Does the state emphasize wellness and prevention as well as routine care? Give examples.

14. Is the system accountable, understandable, and responsive to people with disabilities and their families?

- Describe how your system demonstrates accountability to people/families.
- How do your policies, rules, programs, and practices reflect person-centered principles? Give examples.

15. Is there universal access to community services and supports for all people/families who need them? Describe any gaps or barriers to access and what steps have been taken to address them.

- Do people/families get enough information, in accessible formats, at the appropriate time?
- Do supports begin promptly?
- Does the system annually report on the needs of people/families to legislative and funding bodies as well as to all stakeholders?

16. What does the state do to achieve cultural competency?

- Do people/families feel that their culture, traditions, and beliefs are respected?
- Do people/families report that interpretation and translation services are readily and freely available?

17. Does the state have a continuous quality improvement process? Describe.

- How are services evaluated? Do people/families/citizens participate in evaluation of services?
- Do QA/QI systems focus on person-centered results? How is this collected, analyzed, and disseminated?
- What is measured, how often, and by whom?

18. What does the state do to ensure a high quality workforce?

- Any initiatives to expand, train, empower, reward, retain, invest in, promote excellence among the direct service workforce?

Following the completion of each site visit, a state case study summary will be compiled and posted on the Quality Mall Web site. A preview of results will be presented at the NASDDDS meeting in May, and a formal presentation will be made at the Reinventing Quality Conference in September.