

TEXAS: NEW KID ON THE BLOCK—WASHINGTON STATE: SEASONED AND GOING STRONG

“These states really get it! They’re analyzing data in a systematic, intelligent way – and they’re turning into performance measurement mavens.” – *Val Bradley, President, Human Services Research Institute*

As the National Core Indicators Program approaches its tenth anniversary, additional states continue to climb aboard. The energy of new blood and the steady work of veteran states stoke the engines of a coast-to-coast performance measurement system. In this issue of The Indicator, Texas takes off like a rocket, while Washington builds on years of experience.

WASHINGTON

“When I first worked for the Division of Developmental Disabilities, we had no ongoing quality assurance or consumer satisfaction initiatives. For a small fee, you get the whole NCI package of data collection tools and analysis from HSRI...it’s a great bargain. HSRI is very accommodating about requests for additional analysis and interested in the work our state has done in developing other questions for the surveys.” *Lisa Weber, Senior Research and Data Manager, Division of Developmental Disabilities (DDD), Washington State*

The Art of the Survey – What seven years have shown

In the magnificent state of Washington – graced with glacier-capped mountains, lush forests, national parks and coastal waters – 35,900 people of

all ages are enrolled in the developmental disabilities services system. About 1,000 adults reside in large DDD-operated institutions, another 7,000 dwell in other state-supported residential settings, and 12,000 persons receive services in their family home.

When the state joined NCI in 1999, DDD contracted with the University of Washington to complete the Consumer Survey. On a bi-annual basis, university researchers conducted face-to-face interviews with a sample of 400 individuals receiving developmental disabilities services and mailed surveys to 1500 - 3000 families. Having qualified researchers observe the system from outside was ideal – but expensive. When state budgets tightened up in 2003, DDD had to end the university contract.

WASHINGTON (continued from page 1)

Since 2005, face-to-face surveys with 325 Medicaid waiver recipients per year have been conducted by DDD quality assurance managers in each region.

“Using in-house interviewers is not our first choice,” says Janet Adams, Chief of Quality Programs and Services.

To increase the objectivity of the process, DDD has been working to “bring an outside eye,” as Adams puts it. When possible, regional QA managers are accompanied on interviews by volunteers recruited by the state’s Developmental Disabilities Council and paid a stipend. “Work on this is still evolving,” says Adams. “Consumers may or may not feel comfortable speaking to a volunteer, and in this rural state, some waiver participants reside in areas where volunteers have yet to be recruited.”

Annual data collected by Washington State DDD include information gathered through the face-to-face interviews and surveys mailed to families of all enrolled persons, as well as residential and employment services providers. Waiver participants have the opportunity to submit a survey at the beginning of each yearly planning cycle to express opinions about their involvement in and satisfaction with the process. The state also performs detailed mortality reviews for all people receiving residential services funded or authorized by DDD at the time of death. Initially, the division planned to mail out its surveys

once a year, but in order to economize and reduce the potential for consumer ‘survey fatigue’, DDD now sends them every other year, alternating surveys of families of adults and families of children. In exploring ways to increase response rates to questionnaires, the DDD has begun to promote NCI data collection as something akin to the U.S. census, according to DDD’s Lisa Weber. “That way,” explains Weber, “when families get contacted for an NCI interview or receive a survey, they’ll simply think that this was ‘their year’ to get randomly selected and they’ll respond, just as they would to a U.S. Census form.” Steps toward this goal include development of a brochure about NCI to be mailed in an introductory letter to consumer interview participants, and translated versions of surveys to non-English speaking families. (For more on DDD’s initiatives to inform a variety of stakeholder and advocacy groups about its surveys, see “Getting the Word out,” on the following page).

Flexible surveys: Vehicle for change

Washington has discovered that the NCI survey is an efficient, effective platform from which to launch its own pressing questions. This practice can produce swift results. For instance, when DDD faced a possible loss of outpatient services for community members in one institution, the division added survey questions to explore consumers’ needs for access to professional services and therapies. With the resulting data, the division was able to preserve an outreach program at the institution. This year, additional questions about future planning and stressors on caregivers were added to family surveys. A separate survey was developed to compile comparable data for families enrolled with the division, but not receiving paid services.

The information gathered will provide data to support requests to the state legislature to expand services.

Getting the word out

“Washington has done a great job sharing the information it’s collected,” says Sarah Taub of the Human Services Research Institute. “Using NCI data for internal management is extremely important, but just as critical is communicating with the outside world.” Washington shares NCI data twice a year with the State Quality Assurance Advisory Committee, a group of stakeholders that evaluates DDD’s progress. In response to figures that showed a growing need for public information on health care, the division and its nurses have formed a partnership with the University of Washington’s Center on Human Development and Disability and People First of Washington. The partners are collaborating to prepare materials on preventive care, in language accessible to persons with disabilities, and they are planning health care trainings throughout People First’s thirty chapters. Washington’s Developmental Disabilities Council

(DDC) has been deeply involved with NCI for the past three years, and is committed to continued involvement for at least another five. The DDC convenes independent stakeholders in carefully structured groups to study NCI data and issue recommendations based on the data, available on their website (www.ddc.wa.gov). In turn, the Office of Quality Programs and Services tracks DDD’s response to the recommendations. A glaring need identified in this process is effective communication from the division to the public about available services. “We’ve discovered that when families get a letter from DDD,” says Ed Holen, Executive Director of the DD Council, “they assume it’s going to be bad news! This has got to change.” Improvements are well underway, some “high tech, low tech, and in-between,” according to Holen. These include informational brochures and DVDs for people who would rather be informed about the service system by watching instead of reading. DDD funded the Arc to produce DVDs on the complaint process, fair hearings, and a new “Working Age Adult Policy.” The DDC has produced a guide to DDD services in DVD format and is constructing an independent website, “Informing Families, Building Trust” (www.informingfamilies.org), that aims to dissolve perceived barriers between the system and consumers. says Ed Holen, “to create a grassroots information distribution process to alert families to upcoming changes in non

Washington Caseloads: Impacts on Quality?

A critical issue in Washington is unwieldy caseloads: each case manager juggles from seventy-five to 350 participants. The following is a sample of survey questions that were added to explore the quality of case management.

- About how many times during the past year have you seen or talked with your case manager? _____
- When you leave a telephone message for your case manager, is your call returned by the end of the next work day?
- Does your case manager respect your choices and opinions?
- Did your case manager talk to you about other services that are available to you (e.g., food stamps, EPSDT, Supplemental Security Income, etc.)?

WASHINGTON (continued from page 3)

traditional ways.” The plan is to distribute informational capsules three times a year for insertion in newsletters published by groups like the Arc and Parent-to-Parent.

On the cusp of the future

Since resources for human services are perennially slim, Washington’s wish list includes production of an annual quality assurance report for the public, up-to-date website reports, and a team to monitor data on a monthly basis. This would more effectively utilize the ever-mounting quanti-

ties of NCI data, according to Janet Adams. “It is a challenge,” says Adams, “to find the staff time to respond to all of the available information in a critical and thorough way. We want to spend the in-depth time that’s necessary to do a better job.” Still, as Adams points out, the state is at an exciting crossroads. “We’re just on the cusp of drawing meaningful comparisons of our data with other states, as well as identifying trends and patterns. I wish more states would join NCI so that we could get our hands on an even better cross-section of information!”

TEXAS

“The new NCI program in Texas has been a huge undertaking, and they’re doing a wonderful job! They’ve used a complicated sampling methodology to collect an enormous amount of data, and very quickly produced some great reports.” – Sarah Taub, HSRI

“One of the things I am most pleased about is that people tell us that our reports are user-friendly. When we were designing them, a doctor warned me that they were going to be ‘fluff’.” But that’s not true --the bottom line is that people can use the data!” –Terri Richard, Manager of Quality Assurance and Improvement,

Center for Policy and Innovation, Department of Aging and Disability Services (DADS)

Taking off - Texas Size

It might be expected that the Lone Star State -- a land of legendary numbers and sprawl -- would take some time to launch its NCI program. After all, the Department of Aging and Disability Services (DADS) serves four hundred thousand persons and administers eight separate Medicaid waiver programs. But Texans don’t do things half-way. Since the state joined the NCI Program in 2005, DADS has pumped out two years’ worth of survey data, and is on the verge of publishing its second annual report.

“We’re very excited, we have a lot of momentum,” says Terri Richard, Manager of Quality Assurance and Improvement.

“Our first year of data gave us some valuable information. This year, we’ll be deciding how often to conduct each survey and how to focus our resources. Richard credits DADS’ Commissioner and executive staff with crucial support for the program, which was initiated and creatively driven by Don Henderson, now Director of the Center for Policy and Innovation.

Laying the Groundwork

Preparations began in 2003, when the Department assembled a Quality Assurance/Quality Improvement (QA/QI) Task force of stakeholders, funded by a CMS Real Choice Systems Change grant. [visual: group photo, preferably i.d.’ing G. Haas & T. Richard] In monthly meetings, the team of professionals and consumers collaborated to ensure that NCI surveys would gather critical data, and added questions about self-determination. Gary Haas of Austin, a self-advocate on the Task Force, sums up his contribution: “I know the life better than a provider does. I’ve been homeless, out on the street. I know what people need better than people higher up do.”

In 2005, Texas contracted with the NACES Plus Foundation to conduct surveys, and engaged them again in 2006, following a competitive bidding process. Three self-advocates, including Gary Haas, assisted in the training of interviewers. Haas, who participated in a mock interview, recalls, “The questions were easy for me to understand, but you have to watch out; another consumer might need more help with them.”

A total of 1,980 face-to-face surveys was completed in 2005. In 2006, the number expanded to 2,500. The Medstat PES (Participant Experience Survey) was used to survey populations without developmental disabilities. Summary reports including results of both surveys may be found on the DADS website, www.dads.state.tx.us



Methods: In Search of Quality

In an effort to ensure reliability, and with the encouragement of the QA/QI Task Force, DADS employed an inter-rater reliability test with its first few surveys. Two observers separately scored the survey while one interviewer asked the questions. Following the interview, the interviewers compared answers and submitted a third version based on 90 percent agreement.

TEXAS (continued from page 5)

Proportional sampling was calculated based on the number of people in each program by county. Terri Richard used a sample size calculator: “In looking at programs with different population sizes, you can determine the sample size you need. You can enter the amount you can afford to pay for, and it will calculate how confident you can be in the results of smaller sample sizes.” Links to online calculators and other sampling resources are available in a publication called “A Practical Guide for Quality Management in Home and Community-Based Waivers,” located at: http://www.hsri.org/docs/QF_sampleguide.pdf

The Road Ahead

To Gary Haas’ regret, the QA/QI Task Force has disbanded now, its grant completed. He misses the collaboration and the stipend he received for it, and hopes to contribute to similar projects in the future. DADS is charging ahead with its next steps, including development of a Data Mart to supply information to internal and

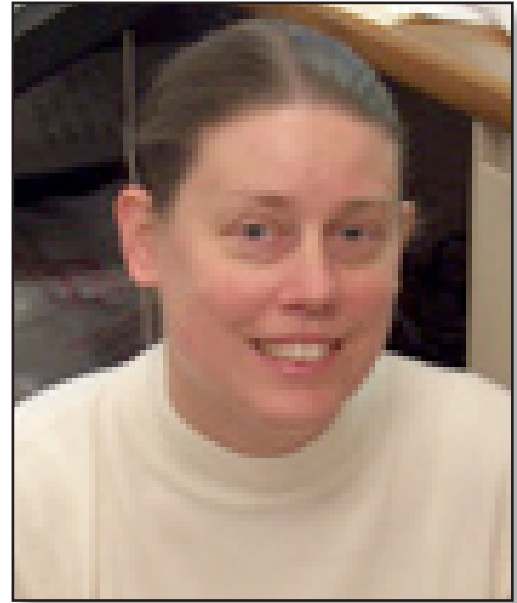
external stakeholders who wish to identify trends by gender, program, region and other factors. DADS is also using its first two years of data to develop strategies for improvements. Under discussion are a range of education, training and outreach programs to promote choice, health care, transportation, job and residential opportunities. Goals include person-directed planning at all state mental retardation facilities and an independent “virtual quality consortium”, accessible on line, providing updates from DADS and a mailbox for public input.

As she heads into her third NCI year, Terri Richard extends an invitation to all Stakeholders in Texas: “It really takes a team...state agencies can’t be the only ones that effect change. You have to be patient and able to work with other people. Partnerships are key—with your local community, advocacy, and provider organizations, as well as other state and federal agencies. We’ll only be able to make the improvements we want if we pool our resources.”

In the Information Age, A New Breed of Human

“Public managers in the field of developmental disabilities today need a different set of skills than their predecessors. A human services background used to be considered sufficient – now it’s important to have an understanding of how to use data.” – Val Bradley, *Human Services Research Institute* “As states head in the direction of increased data collection and analysis, there’s going to be a need for more researchers on staff. There is no way for existing state staff to do scientifically rigorous research and program evaluation, to analyze information and write the reports.” -- Lisa Weber, *Senior Research and Data Manager, Division of Developmental Disabilities, Washington.*

The spectacular west coast and a benign climate— these are just some of the reasons why Washingtonians stick with their state despite repeated economic downturns. The DDD’s Lisa Weber is a transplant from the east coast, and she says she’s ‘hooked’. “It’s friendlier and more casual here and there are more opportunities,” Weber enthuses. “Originally, I aimed to be a college professor...but I took a detour, and became an applied researcher in a government agency. What I do has an immediate impact – I love what I’m doing -- I wouldn’t trade it for an ivory tower!”



Lisa started out with an Associates Degree in Mathematics from Dutchess Community College in Poughkeepsie, NY. She followed up with a B.A., Cum Laude, in Psychology and Math, from Boston University. After earning a M.S. in Statistics at the University of Connecticut, she made her move west in 1987. Here she received a doctorate in Psychology from the University of Washington.

Lisa is a member of Mensa and received two Outstanding Team awards in 2004 and 2005 from the Aging and Disability Services Administration for her work on developing assessment tools for the DDD. She received a 2001 Governor’s Award for the DDD Incident Review Database Team. She is the mother of three young children and enjoys sailing on the Puget Sound.

Terri Richard of Texas

Terri Richard, who coordinates the NCI program in Texas, downplays her technical abilities. “I don’t think of myself as a researcher, although I’ve learned a great deal,” she says. Her first degree was a B.S. in Psychology and Sociology from Kansas State University, and she wryly recalls her initial research experience: “I assisted a psychology professor in collecting data on Type A behavior.

We observed third grade children attempting to accomplish various tasks.”

While launching the NCI program, Terri was also busy completing a Master’s Degree in Public Administration at Texas State University. She examined NCI in her applied research project: “Measuring Quality Using Experience Surveys: An Assessment of Texas Medicaid



TERRI RICHARD OF TEXAS (continued from page 7)

Waiver Programs for People with Disabilities”, available at ecommons.txstate.edu/arp/140. “My professors were blown away by some of the information,” says Richard, “particularly by how much the programs cost, and the challenge of trying to balance quality with fiscal constraints.”

In her thesis, Richard highlighted data that show:

- consumers in all programs participate to some degree in community activities;
- most consumers do not feel lonely;
- the majority of consumers receive annual physical exams;
- improvements are needed in all programs related to Self-Advocacy, Choice and Control.

In designing NCI methodology for Texas, Terri relied on researchers Dr. Leslie Cortes and Jane Eubank, Ph.D. “I had just taken a statistics course

that exposed me to notions of random samples and confidence levels,” she recalls, “and it really helped when we started having our conversations about sampling.”

While technical expertise is increasingly important, so is keeping in touch with one’s roots. Terri recalls her start in human services eighteen years ago, when she was an eligibility worker. “I observed a staff person who was cold, impersonal and downright rude to an elderly couple in a predicament. I went home and told my husband, ‘The day I can’t be available and responsive to the people we serve, I’m out of here!’ The bottom line is improving individual outcomes!”

Terri has two grown children and enjoys exploring the Texas hill country with her husband on their Harley Davidson motorcycles.

