

Quality Councils: A Crucible for Change

How does the collection of NCI data lead to improved quality of life for people with developmental disabilities? To get the ball rolling, states form teams of people of different backgrounds, all with a vested interest in high quality developmental disabilities services, who convene at a common table. In this issue of The Indicator, we take a look at quality teams at work in four NCI

states. They are charged with various tasks: sharing views on data; identifying trends; suggesting additional outcomes and indicators; recommending targets for service improvements; and monitoring progress on targets over time. For a glimpse into their workings, achievements, and plans for the future, please read on.

RHODE ISLAND: WALKING IN THE SHOES

“In Rhode Island, historically, we have involved self-advocates and providers in advisory groups. On the Consortium, getting the perspective of family members has been significant.” *Sue Babin, Administrator for the Office of Quality Assurance and Special Projects, Division of Developmental Disabilities Services.*

In tiny Rhode Island, you can drive to any destination in one hour or less; the total number of adults receiving developmental disabilities services is approximately four thousand. The lay of the land lends itself to collaboration. A forty-five-member Quality Consortium was formed in 2002 to represent all of Rhode Island's constituents. Sue Babin says, “What's new here is that our membership is having input into a process that was never so open. It's a great opportunity to get the word out to a variety of people and listen to their individual perspectives.”

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Doreen McConaghy, family member on Rhode Island Quality Consortium.

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Rhode Island: Walking in the Shoes (continued from page 1)

Consortium member and parent Doreen McConaghy points out that “Health and safety means one thing to a consumer, another thing to the parent, and yet another to the provider. Our leadership in Rhode Island was smart enough, and cared enough, that they clearly understood all stakeholders must be at the table, that the Consortium had to be with people, not just to and for them.”

At the Quality Consortium’s first meetings, Val Bradley of HSRI coached members on the origins of NCI data and on what they should expect to do with the information. The Office of Quality Assurance walked members through “*The More You Know*,” a summary of seventeen data-collection activities in the state, including the NCI consumer survey, licensing surveys, reports of incidents, mortality data, and agency reviews.

Consortium member Pam Goes has an eighteen-year-old son who does not communicate verbally. “When teens are on the verge of adulthood,” she says, “parents can be very unclear about how to make the transition to adult services. It’s typical for them to feel overwhelmed as they approach a milestone which is not the one they expected. Often they are not well informed and feel emotional, even frightened.” On a Consortium committee, Goes helped create a booklet, *Ideas for Questions to Ask When Looking for a Service Provider*. Parents who receive it, she says, become better at making choices. **“If they are well informed and know what they want, they’ll be looking for quality, and this helps agencies to perform better.”**

Following a review of employment data, the Quality Consortium produced these results:

- Design and deployment of Rhode Island’s first statewide employment survey: investigation into rates of pay, length of time spent in jobs, and income taxes paid by consumers;
- Determination that the data show numbers of jobs have stayed level for two years; this is underscored by consumer survey data demonstrating that people want better employment opportunities;
- Use of two years of data to help drive consumer and staff education programs. The statewide Supported Employment Council uses data to identify staff training needs;
- Production of informational materials on community resources for people with disabilities and on how to conduct a job search; and,
- An Employment Information Network that has introduced classes at six one-stop centers on resume writing and interviewing for people with disabilities.

Consortium activities in the field of health and safety include:

- Production of a fact sheet, “Ideas for Preventing Incidents,” distributed to all providers;
- Designing and field testing a risk assessment protocol, to identify individuals’ vulnerability in areas of health, safety, and abuse and help Rhode Island comply with CMS’s Quality Framework Consumer Safeguards requirements;
- (Under discussion :) Publication of

- informational bulletins to address issues of financial exploitation, other abuses, and lessons learned from investigations; and,
- Inclusion of data on doctor, dental, and gynecological visits for people with developmental disabilities in Rhode Island's state budget document. The Legislature is following up with examination of a shortage of practitioners who accept patients with disabilities.

Rhode Island's Quality Consortium is also participating in the state's strategic planning process. This is a big step forward, according to Sue Babin. "The global goals of strategic

planning have been shared in the past with providers and people with disabilities," she says, "but now we are creating a much more specific plan to meet the quality management requirements of CMS. **People with disabilities and their families should be the force that drives systems development. Friendships, jobs, health and safety ... these are the basic components for a good quality of life. We all need to work together to make this happen!**"

WEST VIRGINIA: A MODEL FOR QUALITY REVIEW

"The NCI data show that consumers need more knowledge about dental resources available to them. After doing some outreach, we are already seeing notable improvements in this area." Frank Kirkland, Director, Division of Developmental Disabilities Services, Bureau for Behavioral Health and Health Facilities

Consumers and families are no strangers to participation in West Virginia's developmental disabilities services system. Now, they've joined with professionals to review NCI data on Quality Councils. With a grant from CMS to build an infrastructure for quality in two waiver programs, three quality groups have been formed:

- The Quality Assurance and Improvement Advisory Council for the MR-DD Waiver;
- The Quality Assurance and Improvement Advisory Council for the Aged and Disabled Waiver; and,
- The Quality Improvement Team, consisting of members of both waiver groups.

Members of the groups recently completed training about NCI, self-determination, best practices, and methods of reviewing and analyzing data. Their next step is to begin digging into NCI data.

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West Virginia: a Model for Quality Review (continued from page 3)

According to Frank Kirkland, Director of the Division of Developmental Disabilities, “West Virginia has a significant track record in reviewing data for the purpose of introducing quality enhancements.” This grew out of the 1979 class-action lawsuit *Medley et al. v. Ginsberg et al.*, which resulted in a 1981 consent decree. As part of the agreement, West Virginia pledged to implement a comprehensive plan for the development of community-based developmental disabilities services. Kirkland says, “The Medley management team’s use of the Core Indicators data served as an example for the work of our two new councils.”

Members of the Medley management team represent the Division of Developmental Disabilities Services, Special Education, Rehabilitation Services, the Developmental Disabilities Council, the Provider Association, and two advocacy groups. Using NCI data, the team has recently identified needs in the areas of:

1. Outreach and

education on dental care: With no dental coverage available through Medicaid, access to assistance comes only through a small grant program and two donated dental programs coordinated by nonprofit agencies. Starting one year ago, information about these resources was distributed to providers and case managers. Since then, there has been a documented increase in requests for dental assistance, and new dental providers have offered their services.



2. Awareness of grievance policies: Based on the Medley team’s recommendation, consumers will receive written information on grievance procedures when they begin receiving services, and once a year after that. The target date for initiating this practice is the end of the 2005 calendar year. However, Frank Kirkland says the picture began to improve even before the policy was changed. He attributes this to the system wide “buzz” generated by the team’s discussion. To the question “Are you familiar with the process for filing a complaint or

grievance regarding the services you receive or staff who provide them?” those interviewed responded:

- 2004 Always/usually - 38.9% Seldom/never - 51.7%
- 2005 Always/usually - 42.5% Seldom/never - 47%

Kirkland anticipates expanding quality enhancements with the input of the Quality Advisory Council; their work will include recommending improvements in data collection. Kirkland tips his hat to the NCI interview. “Currently, we contract with individuals to conduct the NCI interview for both Waiver recipients and non recipients. Our Waiver Quality Review has a satisfaction section consisting of an interview conducted by our Program Reviewers. The Quality Advisory Council is considering replacing this with the NCI interview and having our Program Reviewers conduct these interviews with Waiver recipients.”

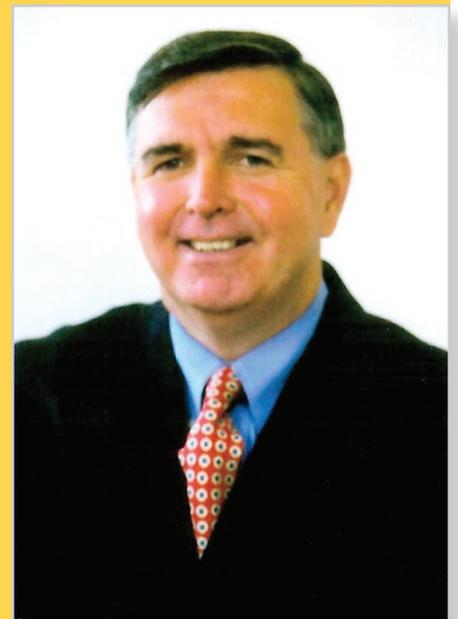
MASSACHUSETTS: HITTING THE GROUND RUNNING

“It’s a milestone to collect important information on indicators that can be used for quality improvement, and the NCI Program has brought us here.”

Gerry Morrissey, *Commissioner of DMR and Assistant Secretary for Disabilities and Community Services, Executive Office of Health and Human Services.*

In March, supported by a CMS Systems Change grant, one statewide and four regional Quality Councils began meeting in the Commonwealth of Massachusetts. Initially, professional staff worried that they wouldn’t have enough time for the meetings, according to Gail Grossman, Assistant Commissioner for Quality Management of the Massachusetts DMR. But when they began meeting, says Grossman, “they found it wonderful—energizing! They have met at least twice, and now they’re asking to meet more than quarterly.”

The councils include families, self-advocates, providers, and DMR staff, including Commissioner Gerry Morrissey, who is on the statewide Council. He finds the group a revelation. “DMR is accustomed to including family members and providers in an advisory capacity, but what’s unique here is that my staff is sitting and having a dialogue with them too. It’s fascinating, and encouraging ... like the E.F. Hutton ad ...everyone’s



Massachusetts: Hitting the Ground Running (continued from page 5)

listening, everyone's paying attention."

Michael Moloney of the Horace Mann Educational Associates (HMEA), and a provider member of the statewide Council, says, "It's been eye-opening to look at data that compares our agency's performance to others in the state and across the country. For the first time, I really understand the domains we are looking at. This makes me feel invested in better outcomes, more than I was before."

WANTED: Intelligence—Caution—Questioning Minds

The DMR trained members of the Quality Councils in the disciplines of reviewing and analyzing data. They were furnished with the User's Guide for Quality Councils, developed by Dr. Steven Staugaitis of the Center for Developmental Disabilities Evaluation and Research at the University of Massachusetts Medical School.

From *A User's Guide for the Massachusetts DMR Quality Councils*:

General Rules for Reviewing Data
While the consistent use of objective data can be a valuable tool in understanding and managing the quality of services it is important to remember that it is not "perfect" and must be used in an intelligent and cautious fashion

- I. **ALWAYS** make sure you:
 - a. Analyze the analysis.
 - b. Identify BIG issues that may compromise the data.
 - c. Do **NOT** generalize the findings beyond their limits.

- d. **BALANCE** your review. The data is one point of reference – take into consideration other sources of information.
2. **NEVER**:
 - a. Make assumptions about the data – ask questions.
 - b. Expand findings to the whole DMR population – unless appropriate.
 - c. Treat the data as "significant" unless it says it is.
 - d. Jump to conclusions without checking other sources.

The User's Guide takes into account the wide variety of experience that Council members bring to the table, according to DMR's Gail Grossman. She points out, "We didn't want to say to the Quality Councils, 'Simply go forth and analyze the data.'"

The Report's the Thing

“Massachusetts has produced an honest report card that sheds light on both strengths and weaknesses in its service system. Kudos to Massachusetts!” Nancy Thaler, Director, Office of Quality Assurance, Centers for Medicare and Medicaid Services.

Just as crucial as good training is the coherent presentation of data. To benefit the Quality Councils, the DMR has produced a report on available data intended for all potential readers.

The Massachusetts DMR Quality Assurance Report, which is available to the general public on the state's website: www.mass.gov/dmr, incorporates data from half a dozen different sources, including the NCI Program. It has drawn the attention of Nancy Thaler, at CMS in Baltimore, who says, “Not many government entities publish reports about their own performance that reveal opportunities for improvement. This allows for public discussion and debate and inspires confidence, in a wide array of constituents, in the government that serves them.”

Based on the top indicators and outcomes chosen by stakeholders in a strategic management forum, the current 2003 report is user-friendly, with a minimum of narrative and lots of visuals. “To publish this report is risky,” cautions Gail Grossman, “because the data are not all positive.”

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But Grossman is pleased to announce that the risk has been worth it: “Reactions to the report have been terrific! We were concerned that the information could be taken out of context or that conclusions would be drawn prematurely. This has not happened to date.” The 2004 QA Report is expected to be published later this year.

Where Do We Go from Here?

The Massachusetts Quality Councils have targeted two areas of emphasis for improvement: employment outcomes; and community involvement and friendships.

Developmental Disabilities Services here, as elsewhere, has had trouble keeping pace with changes in the job world. “Segregated workshops, for example, support people to reach their potential as workers,” says provider Michael Moloney of Horace Mann Educational Associates, “but we’ve closed many sheltered job sites, and it’s daunting for workers with disabilities to find and retain

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Where Do We Go from Here (continued from page 7)

jobs in a market-based system that's stressed by growing economic pressures." Moloney predicts that incremental efforts over time will be necessary to make substantive improvements.

Consumers and family members on the statewide Council have stressed that friendship and involvement in one's community are critical to quality of life. Commissioner Gerry Morrissey says their testimony is compelling. "This focuses our organization on where we are putting our resources. We are now examining the use of informal relationships in leading to meaningful membership in one's local community."

In praising Massachusetts's work with Quality Councils, Nancy Thaler of CMS recalls the words of former Supreme Court Justice Louis Brandeis: "Sunshine is the best disinfectant." Thaler emphasizes that "The only way that the sun will shine on governments is for them to voluntarily expose themselves. This involves risks, but the rewards are considerable: discovery, remediation, improvement. And an important key to quality is participation."

ALABAMA: A COUNCIL FOR CONSENT

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The quality of life for people with developmental disabilities in Alabama cannot be separated from the history of the landmark class-action lawsuit *Wyatt v. Stickney*. Filed in 1970 against the Alabama Department of Mental Health and Mental Retardation, the suit alleged that a staff layoff at Bryce Hospital in Tuscaloosa violated the rights of court-committed patients. The case resulted in a ground breaking set of standards of care for consumers of mental health and

developmental disabilities services. Compliance plans include census reduction at institutions, expansion of community-based services, quality improvement, internal advocacy, community education, and outplacement of special populations.

In 1986, a consent decree in *Wyatt* resulted in establishment of a Quality Assurance Bureau and a statewide Quality Enhancement Council that continues to meet today. Its twenty members include staff from the state's Division of MR, representatives of The Arc, case managers, family members, consumers, self-advocates, providers, the Alabama Disabilities Advocacy Program, and a member of the state's Office of Consumer Empowerment. At present, the council is studying NCI data from 2004, along with a variety of other information.

The Office of Quality Enhancement produces a summary from NCI data that notes opportunities for improvement in Alabama and compared to other states. Executive staff of the Division of MR reviews the summary and drafts recommendations for indicators and activities for the Quality Enhancement Plan. At this stage, the Quality Enhancement Council reviews the draft and makes additions. "We use the information to judge where we stand in the context of the CMS Quality Framework," says Jeff Williams. "The Council also has the power to take concrete actions, such as issuing alerts about health and safety issues and making formal recommendations for improvement in services to the Associate Commissioner."

Alabama has closed four of its five state-run Developmental Centers. Closing state facilities is hard work, but Williams sees the tough-

est work ahead. "We do a good job of getting people into the community. What's hard is getting people truly involved in their communities. We haven't gone far enough in this area. Yes, folks are going out shopping, but how many are going to church; how many are involved in meaningful, socially connected activities? How many of them have friends?"

Approaching these issues, the Division of MR Services is building an infrastructure for person-centered planning, assisted by consultants who employ a planning tool known as PATH (Planning Alternative Tomorrows of Hope). In the past year, these University of South Florida facilitators have also worked with case managers and providers in Alabama communities.

Jeff Williams looks forward to the day when Alabama's citizens with developmental disabilities make strides toward increased involvement in their communities. **"We are beginning to identify the important issues; we haven't seen a lot of changes yet. Our next step is to meet again with the team from South Florida to map out our itinerary for the next year."**

