

Dear Reader,

We are proud to launch The Indicator, the first newsletter for the National Core Indicators (NCI) Program. Time has flown, and the effort is no longer in its infancy. For eight and a half years, collaborators across the United States, in conjunction with the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI), have been developing and using standardized measurement tools to collect data on performance and outcomes for developmental disabilities services. The most recent wave of consumer surveys yielded data on more than eight thousand individuals with cognitive and other developmental disabilities. The list of participants now includes twenty-four states, Washington, D.C., and four California regional centers (Orange County, Golden Gate, East Bay, and San Andreas). The Indicator is designed to keep you abreast of developments and best practices in performance and outcome measurement as exemplified in initiatives among NCI participants.

As financial and political pressures on human services intensify across the country, the need for the NCI Program is clearer than ever. Quality improvement hinges on systematic measurement of performance and outcomes. By pooling resources and knowledge, participants can more economically develop valid data-collection strategies.

Eyes and Ears on the Prize: Self-Advocates Open a Window

Interviewing individuals with developmental disabilities can be daunting. NCI investigators are finding that the involvement of self-advocates in creating and editing interview questions and in the interviews themselves helps to overcome potential barriers to communication and enhances the validity of data. Currently, eight NCI participants (Arizona, Connecticut, Kentucky, North Carolina, Pennsylvania, Vermont, Washington State, and California's Orange County) use people with disabilities as interviewers for the NCI survey. This first issue of The Indicator will focus on self-advocacy and its role in the collection of meaningful data on consumer outcomes.

Vermont: Reaping the Benefits of Self-Advocacy

Vermont has a proud history of self-advocacy that predates the National Core Indicators Program. Green Mountain Self-Advocates (GMSA), a statewide network operated by people with developmental

disabilities, celebrated their tenth anniversary this year. According to June Bascom of Vermont's Division of Disability and Aging Services, self-advocates have enhanced the way in which data on consumer outcomes is gathered for NCI, and played a key role in the recent reorganization of Vermont's developmental

services systems, influencing the entire redesign, despite their difficulty in coming together in a rural state where public transportation is limited. The GMSA board and members meet monthly, using interactive TV two to three times a year; Bascom says this is extraordinarily effective.

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Questions from Self Advocates

- * Do people have access to transportation?
- * Do people know how much money is in their budget?
- * Do people get the services and supports they need?

Patty Derouchie (see picture) is a paid staff member and the president of GMSA. Transportation, she says, is not the only obstacle. “Lots of times, consumers are afraid to speak up to their case managers or their day supports providers. They are afraid that no one will listen to them. Many say, ‘Why bother asking? If I ask, I’m told that I don’t have any choices.’ This is not the way it should be.”

June Bascom has seen Derouchie’s life turn around through self-advocacy. “Five years ago, she was a quiet, retiring person. It was not at all obvious that she had leadership qualities.” Since becoming a self-advocate, Derouchie has emceed conferences of four hundred people or more. She is one of a group of consumers trained as trainers, following Steven Covey’s methodology for self-empowerment, in which members teach peers in schools and serve on boards of directors.

Derouchie’s disability does not interfere with expressing herself, but it does make her keenly sensitive to the needs of people who have difficulty making their wishes known. “Whether they are verbal or nonverbal, people can understand,” she says. “I feel it’s really important for consumers to be able to advocate for themselves and to be heard.”

Consumers were involved from the outset in designing Vermont’s survey, which was introduced in 1995 and contains more questions than the NCI survey. In 2001, GMSA worked on revisions, adding items related to self-

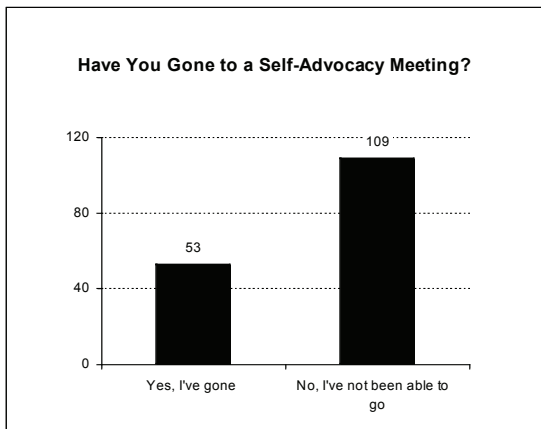
advocacy and contributing questions about health and well-being, lifestyle choices, self-direction of services, and overall quality of life. The original NCI survey incorporated many elements developed in Vermont, and subsequent revisions have been influenced by changes to the Vermont questionnaire. For example, items related to transportation, individual budgets, and access to services and supports, developed based on input from Vermont self-advocates, were later adopted by NCI. (See accompanying box.)

Vermont’s interviewing teams include one or two persons with developmental disabilities, assisted by two or more with typical abilities. All are paid for their work. Only the consumer, not family or staff, may answer questions. According to June Bascom, it is critical to conduct face-to-face interviews that take into account a person’s particular disabilities. Patty Derouchie attests to this: “A lot of people feel less afraid talking to another consumer than to someone in authority. I am gaining awareness of how helpless they can feel and how limited the choices are that they are allowed to make. This work is very important. You can look at the results and see that consumers don’t have choices each step of the way in the delivery of services.”

When it came to interviewing, Derouchie reports, “At the beginning, it was challenging: understanding some of the questions, how to check off the boxes. But by watching my fellow team member and by doing it myself, I improved, and now I am told that I am doing a great job!”

Spreading the Word

Derouchie is pleased with her new skills and source of income, and with the survey data. And the news is spreading: in 2004, 39 percent of consumers surveyed said they attended a self-advocacy event, 62 percent of those who did not said they wanted to, and 82 percent saw themselves as self-advocates.



In Vermont, self-advocates are on the front lines, not only as interviewers but as reporters. The state produces a special report of survey results aimed at consumers with developmental disabilities. Most of the data is chosen by self-advocates and presented in an easy-to-read format. Bar graphs are used instead of pie charts, which many find confusing.

Efforts to promote self-advocacy continue to

expand in Vermont. In fiscal year 2004, as part of a \$2 million Real Choices Systems Change grant, eleven teams of self-advocates and support workers led fifty-two workshops, providing training to more than seven hundred participants. A manual prepared by GMSA, entitled *Get on Board and Make a Difference* (<http://www.state.vt.us/dmh/docs/ds/pubs-dev.html>), was presented by self-advocates to thirteen provider agency boards and standing committees to assist them in involving persons with disabilities in policy-related activities.

Speaking to the growing recognition that people with disabilities can participate in controlling their own lives, Vermont's DDS 2005 Annual Report (<http://www.ddmhs.state.vt.us/docs/publications/annuals.html>) notes that "Increased knowledge, skill and practice standards have resulted in an immeasurable improvement in the life quality of the people who depend upon the community system." Self-advocates can take credit for much of this progress. Patty Derouchie concludes, "People need to be given every opportunity to get what they want. They need to be included in every step of the program."

For more information, contact June Bascom (jbascom@ddmhs.state.vt.us)

Teaming Up for Surveys in Orange County

The Regional Center of Orange County, California (RCOC) began collecting survey data for NCI in 2001, and LeeAnn Christian calls the current year "the most exciting time. We had a lot to learn during our first year of data collection. We spent the second year working out bugs. In the third year, we began to have more confidence in how we were managing the process. Now, we are taking a solid look at our data, detecting trends, and developing plans to improve our services based on the survey results from our consumers and their families."

RCOC's self-advocates enable many consumers to freely voice their views about quality of services. Orange County conducts approximately six hundred random face-to-face interviews each year, at least 20 percent involving pairs of interviewers who include a consumer or a consumer's family member.

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Wendel Starkey has been interviewed by such a team. Starkey has cerebral palsy and uses a wheelchair. He is also a member of the Board of Directors of RCOC. One of his interviewers had a developmental disability. “They made it seem comfortable and easy to open up,” says Starkey. “The willingness to explain the questions and make clear what they were looking for was good.”

Starkey sees the NCI interview as a self-advocacy tool. “Not everyone is able to stick up for themselves or advocate easily for themselves.” RCOC’s interviews, he feels, help consumers to understand their rights and choices. For those who are wary of interviews, he stresses, it is important to make clear that the survey is independent of the provider agency, and that honest answers will not adversely affect services.

By this fall, Orange County aims to publish its first consumer-friendly report on survey results, which will be presented to the RCOC Consumer Advisory Team. LeeAnn Christian feels it is critical to make data available to the broadest audience possible: “Brian Story, the Consumer Advocate for RCOC, assisted me in the development of the report, based on the model we had from another state. In general, the reports that HSRI develop are great, but they are not easy for consumers to understand. We developed a consumer-friendly report because we wanted to make sure that our consumers had a way to read about the results. In presenting the results in this fashion, we hope they can give us feedback about what action we might want to take to improve areas in which consumers show dissatisfaction. Additionally, we hope they will tell us if we should be asking them different questions. Perhaps we aren’t asking about things that are important to them and thus are not doing anything to improve things in those areas.”

For more information, contact LeeAnn Christian (christian@rcocdd.com)

Kentucky: Lights, Camera—Interview!

If you’d like to be a fly on the wall when peer interviewers conduct an NCI consumer survey, look no further. Team Up for Success, a video produced by the Interdisciplinary Human Development Institute of the University of Kentucky, spotlights these pioneers in action. Kentucky joined NCI in 1999. In 2002, the state received a three-year Real Choices Systems Change grant. One goal was to draw on skills of people with disabilities to develop interview teams, thus enhancing the collection of data. Because Kentucky NCI is coordinated at the University of Kentucky, several UK students with disabilities who were pursuing degrees in social work were among those receiving training as project interviewers.

According to Dr. Kathy Sheppard-Jones of IHDI, the Real Choices funding “allowed us to methodically set up the training and interviewing process and involve as many folks as possible in creating survey teams. In order to submit good data, it is critical to have qualified staff. We had high expectations for our students, and they rose to the challenge.”

Interview partners Shannon Caldwell and Arline Wilson are featured in Team Up for Success, first shown in 2002 at the Reinventing Quality conference in Chicago. Shannon is a consumer advocate with visual and

hearing impairments; Arline has typical abilities. Shannon uses a Braille survey instrument during interviews. His disabilities, he says, give him a distinct advantage. “I’ve learned to communicate with people in a variety of ways, not just verbal. I have some sign language skills, and I communicate through nonverbal assisted listening devices.” Interviewee Marie Allison, mother of a person with disabilities, says there are other advantages.

“I really did like having Shannon there because I think he would understand where I was coming from; he is a person with disabilities and I knew he’d be sympathetic to asking questions in a way that would be comfortable for me.”

While his presence may help an interviewee to relax, Shannon is aware that the opposite may happen. “I think some people get nervous when they first see a blind person come into the room, so having Arline there makes people feel a bit more comfortable. Most people have received me well and have been able to communicate with me very well.”

To make interviews user-friendly, the team offers flexibility. Marie Allison appreciated this. “Arline and Shannon gave me choices as to where they would interview me; they said they would come to whatever location was most comfortable for me.” According to Arline, this approach has resulted in some unlikely locations. “We’ve actually done interviews in a K-Mart parking lot, on top of the hood of a car...That’s as flexible as you can get!” Shannon remarks, “I like unusual, unfamiliar situations; I kind of feel my way through.”

In Kentucky, lack of transportation prevents many people with disabilities from getting jobs. The state’s Real Choices grant provided funds to pay interviewers for their work, and, if necessary, for wheels to get there. In Caldwell’s case, a driver was provided. According to Kathy Sheppard-Jones, “Training as interviewers and conducting surveys helps people like Shannon to develop résumés.” And as he works, others get the message. “One of the nicest things that’s happened is that people with disabilities witness the professional abilities of their peers.” Team interviewer Pat Berdine adds, “It gives families and consumers the opportunity to see someone with disabilities out working. It gives them encouragement.”

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Lessons Learned

By April, 2005, six consumers and one family member were trained and conducting interviews. Consumer self-advocates were participating as

- Ø interviewers;
- Ø trainers of new and continuing consumer and non-consumer interviewers;
- Ø work group members, assisting in evaluation of project activities, ensuring goals are being met, and if not, recommending changes; and
- Ø follow-up evaluators, contacting interviewees to assess satisfaction with interviewers.

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Because of the success of the team approach, it was decided in fiscal year 2005 to expand the pool of interviewees to include those who receive services through the Kentucky Division of Mental Health and Substance Abuse. A total of 402 Mental Health and 514 Mental Retardation–Developmental Disability interviews were completed and submitted to HSRI for analysis. Many of this year’s interviews were conducted by five persons with disabilities. The spring quarterly report for the Real Choices grant noted, “The Kentucky Division of Mental Retardation is committed to continued support of interviewers who happen to have disabilities as NCI consultants.”

Kentucky has now gone through five NCI data cycles. With a minimum of five hundred face-to-face interviews a year, nearly three thousand surveys have been completed. Kathy Sheppard-Jones calls the resulting data set “invaluable to the state”. Self-advocates, by helping to expand a state’s knowledge base, have advanced a key goal of the community-based service system. The Director of IHDI, Harold Kleiner, puts it this way: “Including an interviewer with a disability increases the message that the perspective of consumers is valued.”

Team Up for Success is available to all NCI states. To obtain a copy, send an e-mail request to Sarah Taub at HSRI: staub@hsri.org. For more information, contact Kathy Sheppard-Jones (kjone@uky.edu).

Pennsylvania— It’s in the Numbers

In the Commonwealth of Pennsylvania, collection of data takes place on a grand scale.

According to Celia Feinstein—a member of the original NCI technical advisory committee— Pennsylvania’s consumer survey contains about fifty more questions than the NCI survey, and the state conducts a whopping 5,500 face-to-face interviews with people with mental retardation each year.

The involvement of self-advocates in the surveys is impressive: roughly one-third of interviewers are people with disabilities; of these, about one-half have developmental disabilities. Their participation is an aspect of Pennsylvania’s Independent Monitoring for Quality (IM4Q)—a system that relies on information gathered from individuals receiving services and their families, and by people in the community who are independent of agencies delivering services.

IM4Q grew out of the Multi-Year Plan for

Pennsylvania’s mental retardation service system. In July 1997, the Plan called for the creation of independent teams at the local level to monitor quality of services. These teams were to comprise individuals with disabilities, family representatives, and advocates, and be charged with the responsibility of assessing quality of life, as measured in terms of outcomes as well as satisfaction.

Today, forty-seven county programs contract for IM4Q through Pennsylvania universities and colleges, local chapters of The ARC, and centers for independent living. There are roughly 150 teams of interviewers. Each is made up of at least two people, and must include a consumer or family member.

In fiscal year 2005, 603 persons with a developmental disability participated on survey teams, as did 38 individuals with another disability. In addition, 194 family members of individuals with developmental disabilities took part, as well as 34 family members of persons with other disabilities.

According to Feinstein, one of the real benefits of IM4Q is that it provides positive and productive employment for people with disabilities.

- Ø Questions should be asked simply, in plain English, avoiding professional jargon
- Ø There are creative ways to elicit responses from interviewees with developmental disabilities, including using visual icons, like the ones NCI uses. Pennsylvania ran a pilot project in which people were interviewed in multiple settings, enabling the team to develop a deeper understanding of individual communication styles. This enriched the data, but was extremely time-intensive.
- Ø Training, training, training—there cannot be enough! Considerable resources have been spent in Pennsylvania to show people how to ask questions, record results, and so on.

The IM4Q program has merged with the NCI Program. Pennsylvania sends a subset of about 30 completed questionnaires per county to NCI. HSRI analyzes about 1,200 surveys, breaking out the NCI questions from the rest.

Lessons learned from the Pennsylvania experience with IM4Q are listed in the accompanying box.

Because of the involvement of self-advocates and their families, Celia Feinstein believes the resulting data is far more credible than it would be otherwise. “Who better to interview people with disabilities than people with disabilities? They understand the life situations of people with disabilities better than anyone else.”

For a description of the IM4Q program, go to the state’s Web site at <http://www.dpw.state.pa.us/Disable/MentalRetardationServices/003670114.htm>
For more information, contact Celia Feinstein
shoes100@temple.edu

For more information, visit the NCI website at www.hsri.org/nci

