

*This Special Edition of NCHSD's monthly eNews summarizes promising practices, information sharing, and strategic thinking from the 2005 National MIG Technical Assistance Conference in Chicago on November 1 and 2. Presentation materials were provided on a Conference Resource CD that is available at no charge by emailing Melissa Turner at [mwturner@hdadvocates.org](mailto:mwturner@hdadvocates.org). More information about the conference can be found on our website at [www.nchsd.org/Conference](http://www.nchsd.org/Conference).*

## 2005 ANNUAL FALL MIG CONFERENCE OPENS WITH KEYNOTE ON WORK AND RECOVERY

*Presenter: George Nostrand (VT)*

George Nostrand spoke at the opening session of the conference, delivering an informative and engaging presentation on the role of work in mental health recovery. George described the mental health cycle of crisis (such as hospitalization), then stabilization, followed by reduced services and supports, leading to destabilization and another crisis episode. This cycle is so often responsible for poor employment outcomes among people with disabilities, particularly mental health disabilities.

The expectations of an individual, as well as his or her loved ones, play a huge part in breaking the cycle. A key point in recovery is often when the individual is able to envision something better than "stabilization," or the absence of crisis. Individuals need to expect the things that contribute to true quality of life – a home, a car, a good job, relationships, hobbies, hopes, dreams and opportunities. Having these "normal" expectations represents healing from the loss of identity that goes with the loss of one's dreams and expectations about life, which many people experience when they are diagnosed with a disability.

George's personal definition of recovery is the individual, day-to-day journey of living with a mental illness (or any disability)—a constant awareness and alertness to the role the illness plays in your life. Recovery requires an accep-

tance that this is part of you that you have to live with on a daily basis. Eventually, you reach a point where recovery itself is no longer a full time job, when you have established a new identity. Although recovery often never completely ends, it takes a different role in your life—you stop looking over your shoulder for the next hospitalization and you start taking risks.

Employment is more aligned with recovery than with "treatment." Employment is about regaining a sense of identity, rebuilding self-esteem, taking calculated risks. How can MIG projects support work as a recovery tool?

- Address cultural and attitudinal barriers, the result of a disability system based on benefits.
- Help raise expectations about quality of life for people with disabilities.
- Create incentives for higher level goals – getting a better job, working more hours.
- Support job skills training.
- Provide security for risk-taking.

George is an employment counselor with Vocational Opportunity Works! (VOW), a supported employment program of Rutland Mental Health Services in Vermont. He is a frequent public speaker, community resource developer, and a person with a mental illness. You can visit his website at [www.chatauquaproject.com](http://www.chatauquaproject.com).

## STATES SHARE STRATEGIES TO REACH FULL ELIGIBILITY

*Presenter: Steve Knapp (CMS); Facilitator: Sara Salley (NCHSD)*

MIG states with conditional PAS eligibility attended this session to discuss the challenge of achieving full eligibility for future funding, with Steve Knapp of CMS on hand to answer states' questions.

Conditionally eligible states have only 1 or 2 years, depending on the grant cycle they're in, to achieve full eligibility or else lose the opportunity for future MIG funding. Fully eligible states must have PAS programs that can support full-time employment. Many states fall short by not offering services outside the home, or providing less than 40 hours of services per week.

States face challenges that include:

- Adjusting provider incentives that encourage agencies to deliver home health services limited to inside the home, rather than personal assistance services that could be available at the workplace;
- Engaging reluctant Medicaid agencies and gaining legislative support for expanded personal assistance programs in a difficult fiscal climate; and

- Overcoming administrative complexities and bureaucratic barriers to amend state plans and waivers, or get approval for new waivers.

Steve Knapp emphasized that CMS does not want to turn down grant applications because of PAS eligibility, and encouraged states to work closely with the Ticket team at CMS to develop and implement program changes. Although the Ticket team does not approve or disapprove waiver and state plan amendments, the team can try to help.

Steve also clarified that when considering waiver sufficiency, CMS counts the number of eligible waiver clients, rather than just the number of clients who use personal assistance services. CMS will also look at whether the services being delivered are personal care services, or home health or home-maker services.

**Conditionally eligible states should contact Carey Appold early in 2006 and prepare for an eligibility determination.**

## MIGS ADDRESS OUTCOMES TRACKING REQUIREMENTS

*Facilitator: Peter Baird (NCHSD)*

This session helped states identify the outcomes that are most important to MIGs and how states are measuring and tracking them.

- *Measuring Employment:* Several states are focusing on linking Medicaid Buy-In and earned income data, to track earnings before and after enrollment into the program. Some of the key earnings measures are average monthly wage, the number of people working half-time or more, the number earning above Substantial Gainful Activity (SGA), connection to VR and other employment services, and the average number of quarters a person is continuously employed. Most states indicated they are just starting to understand the impact of the Medicaid Buy-In on employment.
- *Differentiating Employment Outcomes By Population:* Several attendees stated that employment outcomes for Medicaid Buy-In enrollees differ greatly across populations. Some groups of people greatly increase earnings, while others see steady or even dropping earnings. States indicated that they were trying to understand what differentiated these groups.
- *Economic Progress:* Some states felt the key issue was to measure assets, and others were looking at such issues as housing or education. States expressed interest in learning about self-sufficiency standards that were created by the National Economic Development Law Center.
- *Health Status:* One state was using the Johns Hopkins Adjusted Clinical Group Case Mix System survey, the SF-12/36 Health Status surveys, World Health Organization Quality of Life 100 survey and the WHO Health and Work Performance Questionnaire. All four surveys are intended to give the state information on people's health status as they enter employment and become more integrated into their communities.

## STATES GAIN VALUABLE STRATEGIC PLANNING EXPERIENCE

*Presenters: Larry Glantz (ME) & Molly Michels (WI); Facilitator: Melissa Turner (NCHSD)*

This session covered the lessons learned about designing a strategic planning process, gathering information, developing leadership, and moving the plan to action. Ten states have developed comprehensive strategic plans through the MIG grants in 2005.

Larry Glantz explained that Maine decided it was important to use existing groups and to build on existing strategic planning activities. The state's Workforce Investment Board and a Strategic Plan Leadership Group led the planning efforts. The grant hired strategic planning consultants to explain various planning approaches and staff selected the *Action Research Cycle*, a network or

social learning model. The grant also relied on existing data, including findings and recommendations that emerged from other planning efforts. Maine used consultants, technical assistance from NCHSD, and a professional strategic planning facilitator.

Maine's planning process had four steps: 1) systems inventory to catalog current systems and how they support employment; 2) systems analysis/resource map to help understand gaps in services and supports, and their strengths and weaknesses; 3) strategic assessment to determine which areas of the system can be changed, how to change them, and what resources will be

needed; and 4) strategic plan development to identify achievable, measurable actions, and a timeframe and leadership.

Maine captured a great deal of rich information, which challenged them to make it useful, meaningful and accessible. Maine also struggled to deal with state agency boundaries—a strong commitment from the top had to be carried through lower administrative levels, and some resisted their efforts due to strategic planning fatigue. Maine sees the need for continued strategic planning, and intends to be constantly involved in on-going analysis and planning to gauge the im-

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## MIGS TACKLE ATTITUDINAL BARRIERS TO EMPLOYMENT

*Presenters: Jean Hall (KS), Millie Ryan (AK) & Tim Tremblay (VT)*

*Facilitators: Peter Baird & Marci McCoy Roth (NCHSD)*

Three states provided information on their efforts to understand and reduce attitudinal barriers to employment.

In Kansas, attitudes toward employment of people with disabilities was continually mentioned in focus groups and planning meetings. A survey of Medicaid eligibility specialists in the state revealed that only half of specialists believed people with disabilities wanted to work, and a smaller number (24%) felt people with disabilities could work. In response, the Kansas MIG is planning additional research, conducting outreach to providers and employers, and providing new staff development training.

Survey results in Alaska showed that people with disabilities had low expectations around employment, so the MIG decided to promote higher expectations for people with disabilities. Alaska will conduct research, provide consumers and providers with information on the importance of returning to work as soon as possible, develop policies

to expose more people to successful role models of people with disabilities who work full time, and develop comprehensive marketing plans.

The Vermont MIG identified consumer, provider and employer attitudes as a significant barrier to work through planning meetings under their Comprehensive grant. Despite efforts to remove systemic and policy barriers, people were not taking advantage of the new programs in part due to these attitudes. Vermont is planning research using theoretical models from psychology and communications research, as well as a pilot program to test how different professional and financial incentives affect provider behavior and employment outcomes.

NCHSD presented information on theoretical models used in psychology and communications to measure and change behavior, including a summary of the "Theory of Reasoned Action" developed by Lawrence Fishbein.

## STRATEGIC PLANNING EXPERIENCE, CONT.

pact of activities and policy changes.

Molly Michels discussed how Wisconsin used the University of Wisconsin-Madison Office of Quality Improvement to help with their strategic planning. The Council on Workforce Investment (CWI) was the leadership group. It established a special planning "design team" chaired by a State representative and members used a web "blog" to stay in touch.

Wisconsin conducted consumer and employer surveys and community listening sessions, and hired an external consulting firm to conduct an environmental scan of current systems and conditions. The design team identified common themes among the various sources of information.

At monthly meetings, the team developed six priority areas; smaller teams examined each and developed action steps. They solicited project proposals for the priority areas, each of which defined an employer focus and benefit. The design team reviewed proposals and developed outcome measures, timelines, milestones and point people. They also wrote the final strategic plan.

The planning process yielded these key insights and lessons:

- Stakeholders tend to think really big—which planners have to translate realistic activities and deliverables.
- Design team members need to stay involved to monitor plan progress.
- Linking with existing projects can create economies of

scale.

- Expect attrition on the planning team.
- There was remarkable consistency throughout the state on several issues.
- Reach out to all partners multiple times.
- The planning process must be transparent and broad enough to reach all partners.
- A local focus is crucial, because all employment is local.
- With employers, avoid using jargon and always consider how your priorities will be good for business.
- Planners can find useful resources in their own agency.
- A hands-on consultant is invaluable, as is adequate administrative support.

## ADVOCATES IDENTIFIED AS KEY STAKEHOLDERS

*Presenters: Tom Alexander, Jim Moench (ND), Beverly Johnson (OH) & Elaine Richard (LA)*  
*Facilitators: Barbara Otto (HDA/NCHSD) & Joe Entwisle (NCHSD)*

This session helped to increase participants understanding of the many roles advocates play in a MIG initiative and detail some strategies for MIG projects to collaborate successfully, balance agendas, keep the peace, and make lasting systems change.

Barbara Otto described Health & Disabilities Advocates' (HDA) efforts to help Illinois advocates move away from an attitude of "us versus them" when communicating with policy makers. Instead, they focused on proposing solutions, such as how to pay for changes and improvements. Advocates worked hard to become key resources on critical issues and used this knowledge to form partnerships with agencies and other stakeholders. Using evidenced based research, advocates could offer a roadmap for decision makers on how to achieve true systems change.

Tom Alexander explained the North Dakota MIG's important role in creating a neutral table for advocates and the state's Medicaid agency to work collaboratively on improving the Medicaid Buy-In program. The MIG supported the development of a joint working committee through sharing data and research to explain program nuances and impact. The result was strong support for continued programming in the Governor's budget and a removal of the sunset clause on the MBI legislation.

Jim Moench discussed his position as coordinator of an education, information and advocacy group comprising 23 disability organizations. These organizations tired of playing against each other for attention and resources from the legislature. One goal of the coalition was to become "the" group asked to the policy table on every disability issue in the state, and they achieved this through strength in

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## ADVOCATES ARE KEY STAKEHOLDERS, CONT.

numbers and the ability to speak with one voice.

Beverly Johnson focused on how she helped develop advocacy and relationships with Ohio state agencies through the Olmstead Task Force, which rallied together to nudge the state to apply for the many grants available to support employment and community living. The Task Force now serves as the consumer advisory group for all the CMS grants. The group teaches people to be effective advocates and serves as a major information conduit. A key lesson has been to pay close attention to accessibility so everyone is able to participate to their fullest capacity.

Elaine Richard described her MIG advisory council, created by a state resolution and comprising 60 members from 26 agencies. The MIG contracted with the Mental Health Association to handle council logistics—they facilitate meetings and make sure (with MIG support) to address ADA compliance issues and specific accommodations. The MIG also ensures the council has solid information for making good recommendations. This group is different from other groups in Louisiana because participants have a real say in the policymaking process and are true partners in planning decisions. State agency staff have found that effective advocates actually make their jobs easier.

## COMPREHENSIVE GRANTEES DISCUSS NEXT STEPS WITH CMS

*Presenter: Steve Knapp (CMS); Facilitator: Melissa Turner (NCHSD)*

In this session, Comprehensive Employment (CE) MIG staff provided feedback to Steve Knapp of CMS about their strategic planning experiences and their thoughts on the future of CE projects.

CE grantees discussed the impact of their strategic planning activities. Several states reported that through the planning process they have built important new relationships with employers, agencies and other projects. The process sometimes helps to break through some of the divisions between agencies. For some states, planning activities have strengthened these partners' understanding of the importance of employment for people with disabilities; for others, planning has brought a new focus on local infrastructure.

CE grantees recommended that CMS provide more feedback and guidance to help them understand CMS' expectations about the strategic planning process and the final plan. It was unclear how MIG strategic

planning activities should fit into states' other planning activities, and how they should fit in with earlier and ongoing MIG activities. Steve Knapp explained CMS chose not to provide too much guidance, so states would have the flexibility to develop processes and plans to fit their individual state situation. But based on the plans states produce this year, CMS may be able to offer "blueprints" for other states to

use.

Looking towards the future, states expressed their hopes that CMS would work to break down fragmentation that exists in the federal system, help make the infrastructure changes MIGs are working on sustainable in the long term, and support the development of best practices and outcomes metrics research.

### **POSTERS HIGHLIGHT OUTREACH INITIATIVES**

*This session featured more than 20 poster presentations on MIG outreach initiatives. The table-top displays provided a summary of the project, strategies employed, and results achieved. Each poster also included lessons learned from the project and many states displayed print and audio-visual materials. The outreach initiatives ranged from disability awareness media campaigns and staff training manuals, to Medicare Part D flyers and Medicaid Buy-In videos.*

*The session represented an experiment in finding ways to make it easier for states to share information with each other about their activities. Using an online form, MIGs provided information about their project, which NCHSD used to create the posters. The posters and materials were on display throughout the first day of the conference, and were included in the Conference Resource CD provided to everyone who attended the conference.*

## MEDICARE PART D CHALLENGES MIG PROJECTS

*Presenters Jean Hall (KS) & John Coburn (HDA); Facilitator: Barbara Otto (NCHSD)*

This session provided an opportunity to discuss how the implementation of Medicare Part D may affect Medicaid Buy-In enrollees and the outreach challenges Part D presents to MIG projects.

Implementation of Part D in states seems to be proceeding in three phases. First is the "Paul Revere" phase with everyone crying, "Part D is coming!" The second phase is upon us now, where we all work to educate people so they can make informed choices. The third phase will involve working with people after the program has started.

Jean Hall presented a study from KS that compared the

pharmaceutical coverage needs of working age people with disabilities to seniors. The Medicaid Buy-In population has significantly different needs, and will be dealing with different issues. The Buy-In population is less likely to use generic drugs, will have higher drug costs, may require more prior-authorization and exemptions, and may have trouble getting access to certain drugs for weight gain, anti-inflammatories, and others.

John Coburn from HDA discussed the "Making Medicare Work" coalition and the important role it plays in addressing policy and service delivery challenges related to Medicare Part D. Overall, many older

persons have a relatively simple process of moving from no coverage to Medicare drug coverage. But the transition for people coming from Medicaid is much more complicated, and most people are not ready for it. Many people believe that Medicaid recipients will not need to enroll in Part D if they are dual beneficiaries.

Other myths include the belief that all plans accept the state subsidy, that employer plans will allow you to split out coverage with Part D, and that physicians and pharmacists understand all the implications for Medicaid Buy-In enrollees who enroll in Part D. MIGs need to address these myths in their outreach efforts.

## MIGS BUILD BENEFITS PLANNING CAPACITY

*Presenters: Anne Rea (MD) & Jonathan Kraeszig (IN); Facilitator: Barbara Otto (NCHSD)*

This session discussed how MIG projects are sending a message about employment as an option and ensuring consumers access information about the benefits of work by providing resources for state public benefits training, assisting with funds to increase limited travel budgets, developing conference opportunities for consumers to meet one-on-one with a benefits specialist, supporting print materials, and including benefits planners in the strategic planning process.

Jonathan Kraeszig, in Indiana, described the state's innovative model called a Benefits Information Network (BIN), through which Vocational Rehabilitation pays for the cost of 'pre-benefits counseling.' A local BIN counselor meets with and gathers key information from the consumer and then refers them to a benefits planner for actual benefits analysis. This process saves time and allows the benefits planners to meet with more consumers. The MIG project provides training well as monthly meetings, skill updating, sharing information, and a connection to the SSA Area Work Incentives Coordinator. BINs are housed at the local vocational rehabilitation agencies, within the disability navigators, at the centers for Independent Living, and in many other locations.

Anne Rea described efforts to build capacity in Maryland. One initiative involves three local projects that support a position to work with consumers at the point of referral to VR (funded by RSA). Any client on public benefits (not just SSA beneficiaries) can receive support to encourage an employment outcome. Fifty percent of clients in the first year of the project have gone to work. Efforts are locally managed, and the staff positions are attached to all of the partners at the One-Stop. Another effort is focused on providing funding to house a benefits planner in the One-Stop. Maryland has found working with the One-Stop to be invaluable, as they always welcome a paying partner. Having a benefits planner at the One-Stop has increased their capacity to serve people with disabilities, and encouraged more effective use of the benefits planning service. This arrangement can provide quality services before placement in a job to reduce subsequent job loss.

## STATES SHARE RESEARCH EFFORTS AND CHALLENGES

*Facilitator: Sara Salley (NCHSD)*

In this facilitated discussion, states discussed a variety of research initiatives, as well as the use of research in policymaking and how MIGs influence the national research agenda.

- Several MIGs reported putting a significant amount of their resources into research and analysis activities. Some states have research embedded into all their grant activities. States often use contractors to carry out research projects.
- States are conducting consumer, employer and service provider surveys, working with administrative data, and developing comprehensive databases to answer a variety of key questions about the effectiveness of programs and ways to improve employment outcomes.
- Since overall increases in earnings are hard to detect in some states, MIGs are breaking their Medicaid Buy-In population into subgroups to study differences in earnings behavior between groups. Motivations and opportunities to earn more may differ based on when someone enrolled, their disability status, age and other factors.
- Several states are seeking to learn more about employers through research methods such as surveys and focus groups. Understanding employers' knowledge of disability issues, and their concerns and attitudes towards hiring people with disabilities, can help MIGs craft education efforts and enable them to work with employers more effectively.
- Some states have used research to anticipate the impact of Medicare Part D and are basing some of their education and outreach policies on this work. States would like to conduct research to document the impact of the new prescription drug coverage on the Buy-In population.
- Several MIG projects are developing cost-benefit analyses of their Medicaid Buy-In programs to better understand the impact of the program on Medicaid budgets and other benefit programs.
- States are interested in cross-state comparisons and analytical efforts, such as the SSDI Pilot project and New England's cross-state work on consumer surveys.

## GRANTEES TAKE ADVANTAGE OF Q&A WITH CMS

*Presenter: Steve Knapp (CMS); Facilitator: Peter Baird (NCHSD)*

This session provided an opportunity for MIG grantees to discuss grant administration, reporting requirements, and grant activities.

*Reporting:* Using state "finder files," CMS has linked Medicaid, Medicare, Social Security Administration and earnings data for Medicaid Buy-In enrollees in 22 states. These linked files open up new opportunities for research and analysis and will significantly reduce MIG reporting requirements.

CMS wants to explore having states include person-level Medicaid claims data with the finder file. The Medicaid data CMS gets is more than a year old; states could provide more current data. States expressed concerns about file size, data reliability and comparability across states. They would like to explore ways to get access to the

linked data set. Perhaps the records could be de-identified, to address confidentiality concerns.

*Medicare Part D Outreach:* The supplemental funding from CMS for MIGs to do Part D outreach is for outreach targeted to Buy-In enrollees only. CMS will probably ask for some kind of accounting of how the funds were spent. CMS is not planning a formal study of the impact of Part D on Buy-In enrollees, but would encourage states to do so.

*State plan amendments:* CMS clarified that state plan amendments go through the regional offices to the central office, though different regional offices handle things differently. Roy Trudel in the central office has ultimate responsibility; the Ticket team does not approve state plan amendments.

## NATIONAL EXPERTS DISCUSS THE FUTURE OF MEDICAID

*Presenters: Larry Brown (Columbia University) & Alan Weil (NASHP)*

*Facilitator: Barbara Otto (HDA/NCHSD)*

This plenary session offered historical context for the role of Medicaid and Medicare in our healthcare system, discussed how the states efforts to develop coverage for workers with disabilities plays into future planning and opportunities, and considered the impact of Medicaid reform on the Medicaid Buy-In and other health care programs for people with disabilities.

Dr. Brown noted that Medicaid is constantly criticized, but also surprisingly robust. Medicaid has never been more important to more people than it is now. Although health coverage is portrayed as an employer-based, private market system, the government provides 50% of overall health care funding.

Originally designed as a program for "deserving poor," Medicaid has transformed into a crucial system covering health care needs for a huge number of people, many of whom are not below the poverty level. It is the primary insurance program for working age people with disabilities. While Medicare costs are largely driven by demography, disease patterns and providers, Medicaid costs are driven by all these factors plus the growing number of people with no insurance coverage.

Because of Medicaid's size and the way costs are shared be-

tween state and federal government, the program has become a fiscal headache. The more it grows, the more anti-government forces resist its growth. It is hard to predict what will happen to Medicaid in the coming years, but it has shown great resilience to those who oppose it, and continues to grow.

Alan Weil explained how Welfare to Work reform efforts of the 1980s and 1990s brought political opponents together, blurring the lines between health care and social policy. Many welfare recipients did not get private insurance when they went to work, and continue to rely on Medicaid. In a similar way, policy makers are now encouraging people with disabilities to work, and are finding that workers with disabilities are rarely able to access employer-based insurance.

When the economy weakens, enthusiasm for welfare and programs for people with disabilities weakens. Those who see Medicaid as a cost problem push to scale back Medicaid. But states have found that scaling back Medicaid causes a host of other problems, and these efforts have largely ceased in the last year or two.

Others see Medicaid as way to

respond to a health care problem. Medicaid is still expanding in many states. Some are exploring Medicaid-based premium assistance plans to bridge the gap between private and public insurance. Others see Medicaid as a key piece of a universal health coverage plan.

Increased state flexibility, consumer control of resources and block granting of Medicaid budgets are all strategies that states are using to reform Medicaid. All three strategies

***It's hard to predict what will happen to Medicaid in the coming years, but it's shown great resilience so far.***

have opportunities but significant pitfalls, as they may not meet the needs of individuals with the most significant disabilities. Medicaid will not be fundamentally unraveled, but it will be reformed in ways that can be harmful to people with disabilities and their significant health care needs.

Dr. Brown is Professor of Public Health at Columbia University's Mailman School of Public Health, Division of Health Management.

Mr. Weil is Executive Director of the National Academy for State Health Policy in Portland, Maine.

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