

Links

June 2003
Volume 33, No. 6
www.ancor.org

An **ANCOR** publication of private provider practice and federal policy issues.

Public Policy Update

New National Wage Survey

It is well known that pay and benefits present a major challenge for ANCOR members to recruit and retain a stable, well-trained direct support professional workforce to meet both the current and the growing demand for community services. The findings of a new national wage survey help to quantify and demonstrate the challenges facing private providers of supports to people with disabilities.

The Research and Training Center on Community Living, Institute on Community Integration (UCEDD), University of Minnesota has completed a wage survey and published a policy brief titled, *Wages of Direct Support Professionals Serving Persons with Intellectual and Developmental Disabilities: A Survey of State Agencies and Private Residential Provider Trade Associations*. Authored by Barbara Polister, K. Charlie Lakin, and Robert Prouty, the survey was encouraged and endorsed by ANCOR and the National Association of State Directors of Developmental Disabilities Services (NASDDS).

The purpose of the survey was to gather and summarize available state-level information on wages paid to direct support professionals (DSPs) within each of the states. In addition to wage statistics, the survey also gathered information on legisla-

tive and other DSW wage initiatives within the states.

The shift from institutional to community living for persons with ID/DD has substantially affected the role of the direct support professionals (DSPs) who provide the ongoing personal support needed by individuals with ID/DD. Increasing use of in-home services, supported living arrangements, and smaller residential settings have placed new demands on DSPs as they work with far less direct supervision and substantially greater responsibility than DSPs in institutional settings.

According to the UCEDD policy brief, the increased autonomy and responsibility placed on community DSPs and the relatively low compensation for people within non-state agencies have affected the ability to recruit and retain people. Staff turnover among non-state communi-

ty service agencies is consistently found to range from 50-75% per year or more, as compared with about 20-25% per year in state-operated services.

Of concern in responding to the challenge of recruiting and retaining direct support professionals are a number of issues, including the following:

1. actual wages provided to people in the DSP roles;

2. rate of change in DSP wages over time;
3. discrepancy between DSP wages and average worker wages; and
4. discrepancy between wages paid to state and non-state agency DSPs.

Highlights of Wage Survey

The policy brief includes a chart summarizing wage statistics gathered from each of the states, including a) average beginning and overall average wages for DSPs in state-operated institutions and community services; b) average beginning and overall average wages in non-state community services; c) state average hourly wages as reported by the Department of Labor for 2000; d) non-state average beginning and average for all DSPs as a proportion of the averages for DSPs in state-operated services; and e) the average wages for all state and non-state DSPs as a proportion of the average hourly wage for all employees in the state in 2000.

Average Beginning Wages

- **State-Operated Services:** Nationally the average of state averages for beginning DSP wages was \$9.49 per hour. The average beginning wages in state-operated community services was \$9.34 and \$9.51 in state institutions. There was a wide range among the states in 2000, with the average beginning wage of less than \$7.00 per hour in 8 states, and more than \$11.00 per hour in 10 states.

- **Non-State Services:** Nationally, the average beginning salary for DSPs working

continued on page 5

As the residential service system has shifted from state operation by state employees to contracted services provided by non-state employees, the relative pay and other compensation for DSPs has also been affected. A number of studies have shown that DSPs working for non-state agencies tend to be less well compensated than state employees working in the same general DSP role.

UCEDD, University of Minnesota Policy Brief

ANCOR

The American Network of Community Options and Resources (ANCOR) was founded in 1970 to provide national advocacy, resources, services and networking opportunities to providers of private supports and services. *Links* provides a nexus for the exchange of information, ideas and opinions among key stakeholders.

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From the Top Down to the Bottom Up, the Imperative Is to Embody the Brand

Renée Pietrangelo

Ann Turnbull, MD, president-elect of AAMR, keyed this year's YAI Conference, which I attended in early May. The title of her presentation was "Family Quality of Life as an Outcome



of Supports Services: The New Paradigm." Her main point among other excellent ones was that in the new paradigm the emphasis of supports and services

will be on supporting and accommodating individuals within a family quality of life model that includes all members of a broadly defined family. Quality in this context is measured by the degree to which the family members' needs are met; the extent to which they enjoy their time together; and the extent to which they are able to do the things that are important to them in the broad environments of culture and society, the community, the supports and services, and the consumer and family.

This led my thinking to the necessity for branding our organizations in the evolving world of consumer-directed supports and services and money following the individual, which will take on an even more crucial role than in the past.

It seems to me that there is great risk in separating the "what" from the "who," i.e., the spectrum of support and services offered from those engaged in the day-to-day efforts to serve the customers. Ultimately, no matter how good a marketing effort your organization initiates, the value of your brand depends *entirely* on how you satisfy customer expectations.

In the age of greater and greater transparency, any excuses for not moving effectively to close performance gaps are seen for what they are, failures of will and competence. Hoping we never left, the new paradigm brings us back to basics in a big way. You build trust by doing what you say you're going to do. You keep trust by staying in close touch with the needs of

those you serve. You must remove every obstacle that blocks the integration of your organization's purpose and process. And you must inspire in your people wholehearted belief in that integration at every level.

The inspiration must come from the people in your organization who embody the brand and who model the core values. Managers, even in good organizations, who can't or won't model the best values of the organization in their relationships with employees, threaten its most important resource—access to talent. Good people avoid bad managers. They'll leave an organization they like, even one they're proud of, if they don't respect their supervisors or don't feel respected by them. It's "what the research says" about the leading cause for staff turnover.

"It's pretty basic," said one executive quoted in an American Demographics study of the effect of employee-management relations on productivity, quality and profits. "Even if you work for a good company, if you have a lousy boss, you have a lousy job."

The authors of the best-seller "First, Break All the Rules: What the World's Greatest Managers Do Differently," said in the book's introduction, "Our research yielded many discoveries, but the most powerful was this: Talented employees need great managers. Talented employees may join an organization because of its charismatic leaders, its mission, its generous benefits and its world-class training programs, but how long those employees stay and how productive they are while there is

determined by their relationship with their immediate supervisor."

Ultimately, then, even if your organization has a worthy vision, mission and values to embrace, you can put everything at risk by not modeling your values consistently—not only for your customers *out there*, but also for your people inside.

An organization's reputation is built on its determination to achieve the highest possible levels of quality and effectiveness. That depends on your ability to align continually your purpose with your processes throughout the organization, which requires acting consistently with integrity in all relationships. If you can do that, you gain spectacular practical advantages, not only in representing yourself to customers and the public, but in managing the nuts and bolts of daily operations. It's about leadership—focusing on the promises we make to all our partners, both inside and outside the organization. ■



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Setting Goals in a Changing, Stimulating Environment

Fred Romkema, President

Each year, our agency sets annual goals, no doubt similar to those of most well run corporations. Usually, this is accomplished with a minimum of discomfort and life goes on.



I read with interest this year, however, the analysis by a case management supervisor as they dealt with limitation of the rights of people served.

Her analysis went as follows: *"The NHTC case management team continues to coordinate with the Division of Developmental Disabilities in attempts to develop a better understanding of what constitutes a restriction of rights versus a support for a person with a developmental disability. There is*

much confusion among agencies, between agencies and the Division, and even among the staff of the Division themselves.

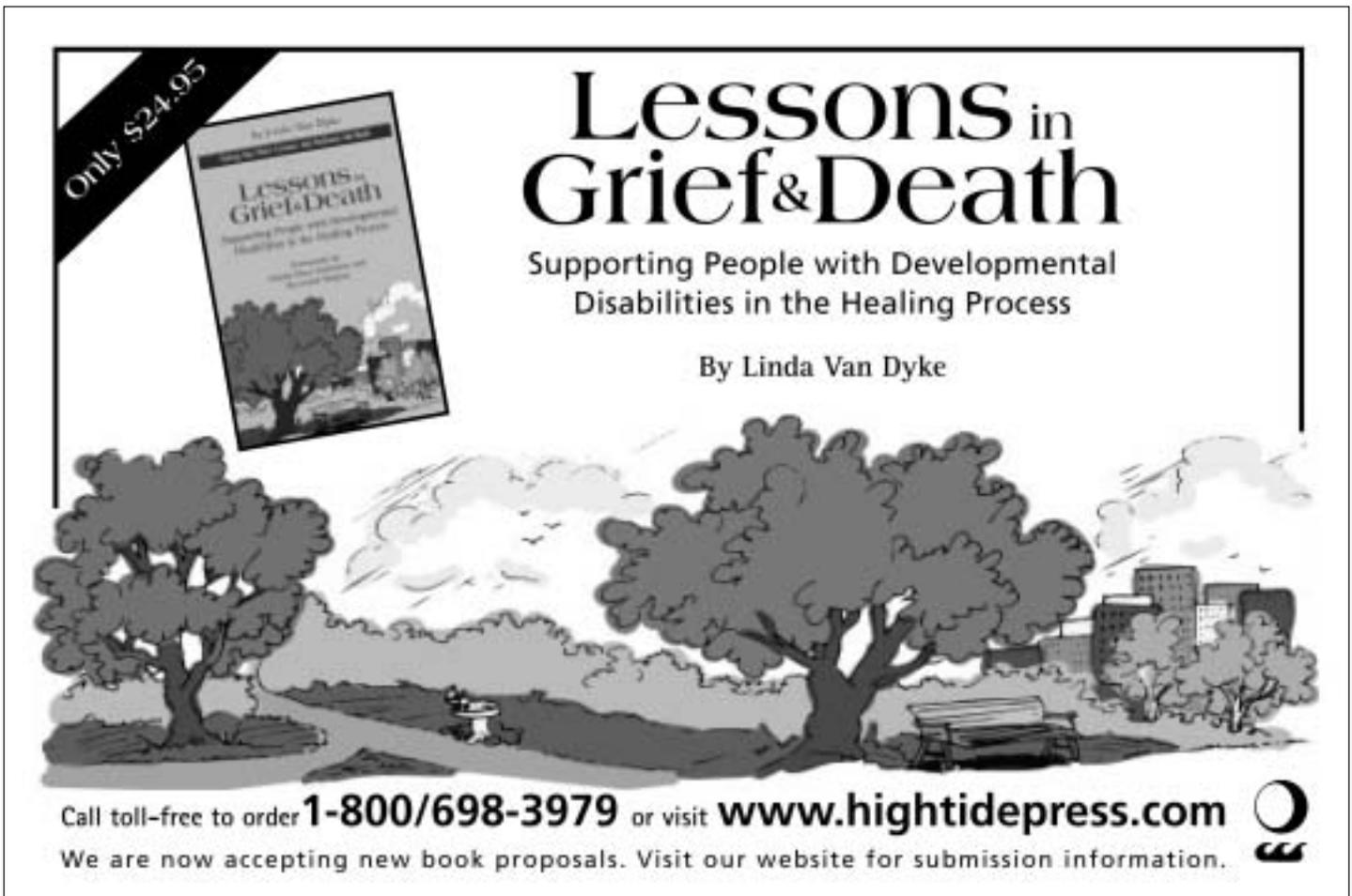
It is difficult to set goals if the essence of what we do is not clearly understood. As agencies go through goal-setting exercises, new and modern standards of service are usually applied involving more self-determination, independent living and competitive employment (logical and desirable goals for all people). The underlying philosophy is correct but requires adequate financial support and, ultimately, dedicated people who deserve to be paid a professional wage.

To address our need to set realistic goals and acquire the resources with which to accomplish them, our agency is actively lobbying at the North Dakota state capitol for increased funding and for support of increased taxes to fund the deficit.

ANCOR has been actively lobbying on the national level on a number of

issues, including an immediate, temporary infusion of federal assistance to the states including an increase in the federal medical assistance percentage (FMAP) for the states' Medicaid programs. ANCOR co-hosted a press conference in conjunction with Citizens for Long Term Care urging Congress to provide at least \$20 billion in additional Medicaid relief. ANCOR is also working to address provider concerns with the Administration's Medicaid reform proposal and is working with Congress on the re-authorizations of the Workforce Investment Act, the Rehabilitation Act, and Temporary Assistance for Needy Families (TANF).

ANCOR is doing its part. Among its goals is a clear effort to impact decision makers to increase funding so that our case managers and other staff may acquire the tools with which to accomplish their goals. We can expect no less. ■



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New National Wage Survey *continued from page 1*

in non-state agencies was \$7.33 per hour. There was less notable variation in the range across states, with 10 states reporting average starting wages of less than \$7.00 per hour, with no state reporting an average starting wage of \$9.00 per hour or higher.

Overall Average Wages

• State-Operated

Services: The average reported wage for all DSPs working in state-operated services was \$11.67 per hour; with the average in state-operated community services at \$11.76 per hour. The range was from less than \$8.00 per hour in 3 states to more than \$13.00 per hour in 14 states.

• **Non-State Services:** The average reported wage for non-state residential service agencies was \$8.68 per hour, with the range from less than \$7.00 in 3 states

Comparison of State and Non-State Wages

On average non-state community DSPs had starting hourly wages that were only 77.2% of those of state employees. The average discrepancy between average wages of all DSPs was even greater. Non-state DSPs averaged less than 74.4% of the hourly wage paid to state DSPs. The greatest proportional differences in which comparisons could be made were in California (non-state wages were 53.5% of state), Minnesota (56.8%), Pennsylvania (57.6%), and Connecticut (57.9%).

tion of average state wages were California (51.7%), Colorado (49.2%), Georgia (48.6%), Illinois (49.2%), Maryland (49.4%), Massachusetts (45.8%), Minnesota (51.7%), New Jersey (46.5%), Oklahoma (48.2%), Pennsylvania (49.7%), Texas (44.8%), and West Virginia (50.3%).

to \$10.00 or more in 7 states.

Average DSP Wages as Proportion of State Hourly Average

Comparisons of both state and non-state DSP average hourly wages and overall wages showed both to fall far below the state averages.

• State DSPs averaged only 74.4% of the average wages in their respective states.

• Non-state DSPs averaged only 55.4%.

• States with the lowest for non-state DSPs earning the lowest propor-

• The only DSPs to earn 90% or more of a state's average wage were in California (95.9%), Iowa (103.0%), Maine (102.8%), Minnesota (91.1%), Nevada (97.0%), and Wisconsin (97.0%).

Changes in DSP Wages, 1989 and 2000 State DSPs

• In states where statistics were available for comparisons, the average increase in starting wages for state employees in DSP roles was \$3.22, or a 51.3% average increase of beginning salaries of state DSPs over the period.

• The greatest dollar increase in average beginning wages was in California (an increase of \$6.46 to \$14.45 per hour).

• The largest percentage increase was in Kentucky (an increase of 98% to an average beginning wage of \$8.63)

• Average wages for all state-employed DSPs in this period increased by \$3.50 as compared to an average beginning salary increase of \$3.22.

Non-State DSPs

• Average starting wages for non-state

continued

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DSPs increased by \$2.21, or 43.2%.

- Average starting wage of non-state DSPs experienced less proportional growth than state DSP average starting wages (which increased by 51.3%).
- Actual amount of the difference in wage increase was on average \$1.01 less for non-state DSPs.
- Average starting wage of non-state DSPs in 2000 was \$2.16 per hour less than the starting wage of state DSPs.
- Average wage of all non-state DSPs also fell further behind those of state DSPs over the period, despite a slightly greater percentage increase than the state DSPs (44.9% and 42.8%, respectively).
- In this period, average non-state DSP wages increased by \$2.69 as compared with an average increase of \$3.50 for state DSPs.
- The largest proportional increases were in Illinois, South Dakota, and Utah.

• Increases of 20% or less were reported in Connecticut, Massachusetts, Montana, and Oklahoma.

Even with greater autonomy, the authors point out that DSPs working in non-state community services earn an average wage of 75.9% that of state DSPs. Over the past decade, as state DSPs were experiencing an average \$3.50 hourly increase in salary, increases for non-state community DSPs were only on average \$2.69.

This discrepancy between average state and non-state DSP wages, however, is not the result of particularly high wages for state employees. Average state DSP wages in 44 states in 2000 were only 74% of the average wage in these states—with non-state DSP average earnings of only 55% of the average state wage in 2000.

Clearly, overall DSP wages are well below the average state earnings for all employees. *Time to change this situation!*

Join with ANCOR's National Advocacy Campaign and urge your Senators and Representatives to support the Direct Support Recognition Resolution (S. Con. Res. 21/H.R. Con. Res. 94) See ANCOR Alert and sample letters on ANCOR homepage at www.ancor.org.

Thanks to the authors and UCEDD for conducting this important and timely national survey and for publishing the results in their Policy Research Brief series. This work will contribute enormously to efforts nationwide to address efforts to recruit and retain a stable, well-trained direct support professional workforce. ■

FOR MORE INFORMATION For the full text of the UCEDD Policy Research Brief Vol. 14, No. 2, go online at www.ancor.org/dev/issues/Workforce_Shortage.htm. To order printed copies of the UCEDD Policy for \$3.00, go online at <http://ici.umn.edu/products/prb/142/default.html>.

New Housing Report Finds Rental Rates Higher than SSI Payments

For the first time ever, the national average rent for a efficiency or one-bedroom apartment is more than the entire Supplement Security Income (SSI) assistance of a person with a disability, according to a study released in May by the Consortium for Citizens with Disabilities (CCD) Housing Task Force and the Technical Assistance Collaborative (TAC). This is the third such report by TAC and is again funded by the Melville Charitable Trust.

Priced Out in 2002 was written by leading housing experts Ann O'Hara and Emily Cooper of TAC in Boston, Massachusetts. The report reveals that people with disabilities who rely on SSI to meet all their basic needs must pay on average 105 percent of their monthly income to be able to rent a modest apartment at the published fair market rent. The study compares the monthly SSI income of more than 3.5 million Americans with disabilities to the fair market rental rates for efficiencies and modest one-bedroom apartments in all of the nation's 2,702 housing market areas.

The fair market rental rate is determined by the U.S. Department of Housing and Urban Development.

The federal SSI program provides a monthly income to people with long-term disabilities who have no other source of income. The maximum SSI monthly income for an individual in 2002 was \$545—amount equal to only 18% of the one-person median household income. This is the lowest median household income ever for people on SSI. Twenty-four states add a small supplement to SSI.

According to the TAC/CCD housing study, people with disabilities in New York City needed 143% of monthly SSI to cover the cost of a one-bedroom apartment. In Chicago they needed 142%, in Miami 119%, and in San Francisco—the highest cost housing market area in the country—people with disabilities needed over twice their monthly

income, or 204%, to pay for a one bedroom unit.

While the need is increasing, the number of affordable housing units available to people with disabilities is declining. That means thousands of people with mental retardation and other disabilities are being forced to live in sub-standard housing or simply being pushed out of their homes altogether.

The five major findings in *Priced Out in 2002* are:

- In 2002, for the first time ever, the national average rent was greater than the amount of income received by 3.7 million Americans

with disabilities who must rely on monthly Supplemental Security Income (SSI) of \$545 to pay for all their basic needs. Specifically, the average national rent for a modest one bedroom rental unit in the United States rose to 105 percent of SSI—up from 98 percent reported in *Priced Out* in 2000. Now it is literally impossible for

If SSI is the safety net, then a lot of Americans are falling through. As housing values surge ahead, the poorest Americans with disabilities are being left behind.

Ann O'Hara, Technical Assistance Collaborative

these individuals with severe disabilities to obtain housing in the community without government housing assistance.

- In 2002, people with disabilities were “priced out” of every housing market in the United States. Of the nation’s 2,702 housing market areas, there was not one single area where modestly priced rental units were affordable¹ to people with disabilities receiving SSI.

- People with disabilities continue to be the poorest people in the nation. As a national average, SSI benefits in 2002 were equal to only 18.8 percent of the one-person median household income.

- Rental housing costs continued to increase much more rapidly in 2002 than the income of people with disabilities.

From 2000 to 2002, rental housing costs rose at twice the rate of SSI cost-of-living adjustments. In high cost housing market areas, increases in rental housing were six times higher than SSI benefit increases.

- Even if people with disabilities receiving SSI benefits (equivalent to an hourly wage of \$3.43) move on to full time employment at the minimum wage, they could not afford rental housing costs in

Priced Out proves that the combination of extreme poverty and record-setting rent levels has fueled an escalating housing crisis resulting in millions of people with disabilities falling through the Supplemental Security Income safety net. It shouldn’t be a surprise to anyone that there are over 1.9 million people with disabilities who remain in public institutions, nursing homes, or unsafe and overcrowded board and care homes or still live at home with aging parents. In addition to these housing needs—which are often hidden from view—hundreds of thousands of Americans with disabilities are homeless each night in the United States—a problem all too visible on the streets of our cities.

Ann O’Hara, TAC

2002. The National Low Income Housing Coalition’s Housing Wage for 2002 was \$12.08 per hour—about twice the minimum wage and more than 3 times higher than SSI monthly income.

Conclusion

The report recommends that federal, state and local housing officials:

- Set-aside more affordable and accessible housing units specifically for people with disabilities;
- Restore cuts to federal housing programs that benefit people with disabilities; and
- Increase the production of new affordable housing units for the lowest income Americans, including people with disabilities.

Priced Out concludes that only federally subsidized housing programs—not increases in SSI payments—can close the housing affordability gap for people with disabilities. Unfortunately, key federal housing programs for people with disabilities have been cut by 50 percent or more since the mid 1990s or were zeroed out altogether in the FY 2003 budget. *Priced Out* calls for funding for these programs to be restored, along with full funding for Section 8 rental vouchers and a new low-income housing production program targeted to the lowest income Americans. ■

FOR MORE INFORMATION To download a copy of *Priced Out in 2002*, go online to housing issues on ANCOR’s website at www.ancor.org.

New Report Presents Findings from Preliminary Evaluation of Ticket to Work Program

Initial Findings Based on Implementation in First 13 States

A newly-released report from the Social Security Administration (SSA) offers early information about the implementation of the Ticket to Work Program in the first thirteen roll-out states and the early experiences of stakeholders—including Employment Networks (ENs)—participating in the program. The report, *Evaluation Design for the Ticket to Work Program: Preliminary Process Evaluation*, presents a snapshot of how the Ticket Program is working in the 13 Phase I states, discusses challenges facing SSA ENs, and other stakeholders to implement the program effectively, and offers suggestions to improve the program in the short- and long-term.

The Ticket to Work Program (Ticket Program), established by the Ticket to Work and Work Incentives Improvement Act of 1999, increases access to rehabilitation and employment supports and services available to eligible Social Security beneficiaries who want work or return to work.

Private providers may participate in the Ticket Program as ENs, offering employment and other support services to Ticket-eligible individuals. The Act requires SSA to conduct an overall evaluation of the Ticket Program; SSA also elected to conduct a preliminary process evaluation, in part, to learn from the experiences of the first 13 states implementing the program. The Phase I states are Arizona, Colorado, Delaware, Florida, Illinois, Iowa, Massachusetts, New York, Oklahoma, Oregon, South Carolina, Vermont, and Wisconsin. The Lewin Group and Cornell University prepared the report for SSA. Information for the preliminary evaluation report was gathered between July and November 2002.

Report Offers Snapshot of Program from Phase I States

This preliminary evaluation is designed to provide early information to SSA and other program stakeholders about the status and early experiences of the program’s implementation.

Because the Ticket Program is brand new, the early experiences of stakeholder with the program cannot determine the program’s ultimate success. Instead, the report offers a snapshot of the program and provide important information about how the program is operating.

In addition to initial program data, the report offers other important findings based on the experiences of SSA, ENs, and other stakeholders. The findings have numerous implications for the Ticket Program, as implementation continues in the remaining thirty-eight states, the District of Columbia, and the U.S. Territories. Important initial findings include the following:

- Younger beneficiaries and individuals on the disability rolls for longer periods have the highest rates of Ticket assignment;
- With limited resources, SSA has struggled to do proper outreach to potential ENs and beneficiaries and provide staff training to do outreach.

continued



Snapshot of Ticket Program in First 13 States

(As of November 2002)

- SSA mailed 2.3 million Tickets to beneficiaries in the 13 states as of November 2002;
- 390 ENs were operating in Phase I states.
- 80% of ENs selected the Outcome-Milestone Payment System for payment from SSA.
- 9,894 of released Tickets

had been assigned to a state VR agency or an EN. Most assignments were made to VR, except in Arizona and Florida.

- MAXIMUS received 135 claims for payment from ENs.
- Within 1 year of assigning their Tickets, 91 individuals gained employment.

• EN recruitment has been challenging for many reasons, including lack of start-up funding available to providers,

concerns with the payment systems, administrative requirements, and variation in state political landscapes have all contributed to the difficulty of enrolling providers as ENs.

• Many ENs have experienced tremendous call volume from Ticket-holders in response to the program. While this may indicate demand for services, in general, ENs are providing information about the program to individuals with little further yield.

• Many ENs see the Ticket Program as a means of diversifying their funding.

However, only a few ENs believe they can make the Ticket Program work financially.

From the findings, the report offers several areas that have implications for the short- and long-term implementation, and ultimately the overall success, of the Ticket Program. Specifically, the report suggests SSA take steps to improve outreach to beneficiaries, outreach and technical assistance to providers. The report also encourages SSA to consider other provider concerns, including making changes to the current payment systems, building provider trust in SSA, and simplifying administration requirements for ENs. ■

FOR MORE INFORMATION A link to this report is available from ANCOR's web site at www.ancor.org. For additional information on the Ticket Program, go to www.ssa.gov/work.

AARP Issues New Report

AARP released a new report in late April, *Beyond 50: 2003: A Report to the Nation on Independent Living and Disability*. The report makes clear that more than anything Americans, with disabilities age 50 and over want independence and control in their daily lives, but they are too often thwarted by the lack of affordable options to help meet their needs.

Beyond 50 includes results of the first ever national survey of Americans age 50+ with disabilities and documents the gap between what they say they need and what is available. The report also raises concerns that the U.S. is ill-prepared to meet the demand for independence among people over the age of 50 who will experience disabilities in the coming decades.

The report includes sections on health services, family and social supports, long-

term supportive services, housing and physical environment, as well as demographic trends and disability rates, innovative programs and services, and key findings.

The report was released at a briefing with comments from Thomas Scully, Administrator of the Centers for Medicare and Medicaid Services, and Tony Young of NISH who is the Chairman of the Washington-based Consortium for Citizens with Disabilities.

Based on the "Beyond 50" findings, AARP outlines a number of proposals for critical long-term improvements:

• Individuals must be insured against the high costs of long-term supportive services. Ways must be found to share the risk of these unpredictable costs more widely among public and private sources.

• Public funding for long-term supportive services needs to be reoriented toward more options for home and community-based care. The nation also must

provide more options for "consumer-direction" in publicly funded programs.

• Communities need to be made more physically accessible for more people with disabilities.

• Information and services need to be more navigable for those who are trying to learn more about available long-term services and whether or not they are eligible.

• America's health care system must adjust its focus to enhance functioning and health-related quality of life, not just provide acute and curative care.

CCD Chairman Tony Young congratulated AARP on this report, citing the findings as supportive of the direction in which the disability community has been working. He reminded the audience at the briefing of the words in the AARP report: *The desire for independence and being in charge of our own lives spans all generations and all boundaries, whether demographic, geographic, or bureaucratic. This story is not just about persons with disabilities. It is about all of us—our communities, our families, ourselves.* ■

FOR MORE INFORMATION To download a copy of the 213-page report, go online at www.aarp.org/press/presskits/beyond50/keyfacts.html.

Excerpted Remarks of Margaret Giannini, M.D., FAAP to American Network of Community Options and Resources (ANCOR)

March 17, 2003, San Antonio, Texas



I am very pleased to be here today. And thank you for your continued leadership in bringing the needs of providers who serve persons with mental retardation and persons with developmental disabilities to the forefront of the Bush Administration. I bring with me greetings from President Bush, Secretary Thompson, and Deputy Secretary Allen and their sincere thanks for your dedication to improving the lives of persons with disabilities and persons with mental retardation.

I hope today will be the start of a long, productive, and innovative working relationship in which TOGETHER we develop REAL solutions to the REAL problems you face each and every day in getting the best care to those who need it.

As you know, a little over two years ago, President Bush launched "The New Freedom Initiative" aimed at eliminating the many barriers that unnecessarily hinder Americans with disabilities as they seek to participate fully in the life of their communities.

I think the *key words* here are "*unnecessarily hinder*," because with the technologies we have today and those being developed for the future—and with the federal government, the states, the private sector—all of our stakeholders working together, it is simply UNNECESSARY for persons with disabilities not to be able to lead fully independent lives. The Administration's goal, and—indeed, our SHARED goal—is to "*increase opportunity and to embrace the*

abilities and talents of these persons in every way we can."

Keeping the Promise—Where Are We?

As the "eyes and ears" to help improve the lives of disabled persons in the nation for President Bush, and for HHS Secretary Tommy Thompson, I must tell you—I *cannot do it alone*. I need and encourage your input.

HHS is committed to working with states to improve the quality of home and community-based services through a multi-pronged effort focusing on three areas, including: 1) the development of tools to assist states in assuring and improving quality; 2) the development and transfer of knowledge about quality; and 3) providing technical assistance to state agencies on waivers.

CMS has developed a Consumer Experience Survey that was released last week to solicit consumer feedback. Additionally, they have developed a workbook on how to design and implement quality improvements within home and community-based services and supports, as well as "Careplanner.org," a web-based decision support tool to assist consumers in decisions about supports and services. They have also developed a Home and Community-based Quality Review Protocol to conduct comprehensive, quality reviews for Medicaid home and community-based waivers.

CMS is also working with several national contractors dedicated to providing technical assistance to state agencies and CMS regional offices to enhance their capacities to assure and improve quality of services in a number of important areas.

Recruiting and Maintaining a Topnotch Workforce

Let me start off by saying we are all in agreement that something **MUST** be done to entice and maintain a topnotch workforce. ...Perhaps we should be more aggressive to motivate and entice young people to enter into the workforce. We need to be more creative about our ideas.

Going into the high schools could be a start, because not all young people want to go to college, yet, they want to perform meaningful human services. I would personally encourage the federal government to support these students to be trained for six months to a year at a prestigious school, so they get certificated. And, we've GOT to increase benefits and salaries, provide health insurance, child care, vacation, sick leave, transportation in some cases, and a pension. It is also important to consider that we include the workers in the decisionmaking process so they are contributing to the system in which they work.

We might also concentrate on personal "care attendants" "workforce—and we should do something about improving their qualifications.

We should be thinking about not only what would attract these people to the workforce, but also what can we do to make their jobs easier. In short, I have heard the phrase: *better jobs—better care*; and I like it! We also have to think about building a strong, long-term care workforce. We need to take a long look at the "culture" of the workplace and how to improve it. How do we do this? By persuading employers to be better oriented and aware of what initiatives must be part of the workplace.

...I think we also need to look at what is the key to being a caregiver? Who wants to be a caregiver? Why? And what keeps them from being motivated? What are the barriers to retention? I think we know.

They need better pay, better benefits, and better working conditions. So that's a message to us. Perhaps we could work with Department of Labor to set up better apprenticeships in colleges and other relationships with Labor to enrich the workforce.

There should be a way that we could propose training and career ladders so that it would be federal policy that individuals essentially graduate from worker, caregiver, etc., and other careers as a career ladder incentive. In short, the "image" of the job has to be elevated. And I do feel the federal government HAS to be involved.

I know a concern to you is that you

would like to see HHS provide more guidance to states—including benchmarks for quality—when they develop their Home and Community-based waiver plans. Perhaps HHS should go further and take steps to hold the states accountable for their waiver plans to ensure quality of care and that states should include private providers in the planning process.

CMS is moving in the direction of establishing clearer expectations with regard to quality in the waiver application and waiver process. Advocacy organizations such as yours should continue to work with states and other stakeholders to encourage a focus on quality, including establishing benchmarks.

We also understand that providers, especially smaller ones are going bankrupt due to inadequate Medicaid reimbursement rates. States do have considerable flexibility in designing and implementing their home and community-based waiver program. This, like the rest of Medicaid, must adhere to the Social Security Act (section 1902(a)(30) in establishing provider reimbursement rates. The citation requires states to establish payment rates that are “sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area.”

What Is HHS Doing in Terms of Reimbursement?

In terms of subsidizing or reimbursement of caregivers, there are a few programs in place. You may be familiar with the National Family Caregiver Support Program, which is administered by the Administration on Aging (AoA).

The program provides money to the states; the states, in turn establish a multifaceted system of support such as information counseling, respite care and adult day care for family caregivers of chronically ill older persons or those with disabilities. Additionally, innovative and demonstration grants are awarded to states. The State of Georgia, for example, was awarded an innovation grant (fall 2001) to develop five self-directed care programs. Known as the Georgia Self-Directed Care Voucher Program, the project is increasing service options for Georgia's elderly population by developing and implementing five self-directed care voucher programs in non-Medicaid home and community-based service settings that can be replicated in other states. Caregivers and care recipients—to the fullest extent possible—

are involved in the decisionmaking of the program together. Consumers have the option of choosing to receive services through the traditional service delivery system, or may elect to participate in the self-directed voucher program.

Each self-directed voucher program develops a component through which caregivers and care recipients have the option to hire relatives or friends to provide care. However, payments to relatives and friends who reside in the home of the care recipient are prohibited. Consumers provide a voucher to the person providing care, which is submitted to an appropriate third party. “The Caregiver Support and Satisfaction Survey” is being used to evaluate the effectiveness of this program.

Cash and Counseling. You may also be familiar with the “Cash and Counseling Program.” Since 1996, HHS and the Robert Wood Johnson Foundation have provided grants to states to support demonstrations of a “Cash and Counseling” alternative for providing long-term care support to Medicaid recipients with disabilities. Under voluntary projects in Arkansas, New Jersey and Florida, some people with disabilities receive cash allowances to purchase the care services they feel will best meet their needs and supportive services to help them manage their cash allowances. Boston College has been awarded a contract, scheduled for completion in September to examine, improve upon and expand this program.

So, we're doing a lot. *But we still have so much more to do.*

What are the gaps on which we must concentrate, and what are possible solutions?

- To focus on the catastrophic situation of the workforce infrastructure, perhaps partnering of the various Federal departments, i.e., Dept. of Labor, HHS, Dept. of Transportation, Department of Education, Housing and Urban Development, in their cross cutting could smoothly address and implement the existing barriers facing the workforce;

- To build a workforce, the essentials are vouchers for benefits, health and child care and transportation could be implemented;

- Creative initiatives must be put into place by the various Federal Departments, i.e., DOL, HHS, DOT, Education, HUD, must be accessible and available for training of the workforce on all levels;

We're doing a lot, but we need to do more. And we need to do it better. So

let's start now. In order for me to be “the eyes and ears” for disabled persons in the nation, for the President and for the Secretary of HHS on issues concerning disabled persons, I need to hear from you. I hope today will be the beginning of a two-way dialogue that will continue long into the future. ■

ANCOR Honor Roll

The following agencies have submitted the names of homes that have succeeded in having deficiency-free surveys, which qualifies them for appearance on the ANCOR Honor Roll.

ANCOR congratulates all of the staff who make these honors possible. Send your submission for the Honor Roll to: Attn: Barry Noel, ANCOR, 1101 King St., Suite 380, Alexandria, VA 22314.

Please send supporting documentation of the surveys.

Arizona

A.I.R.E.S.
Emily Place
Padres
Rosewood
Silverbeech
Solano
Taylor
Wilshire

Rochelle
Sheridan
Shoshone
Tall Trees
Vonachen
Wilco Apartment
Rue Vu De Lac

Florida

Miami Cerebral Palsy Residential Services, Inc.
N.W. 2nd Street

Delaware

Martin Luther Homes
Hockessin
Program

Indiana

In Pact
Berens Street (3rd year)
Sherwood Court (5th year)

Illinois

PARC
Baskin Ridge
Black Soil
Briarcliff
Castile
Fondulac
Forrest Hill
Kickapoo
Tiffany Court
High Oak
Laramie
Lehman
Lexington
Marlene

Iowa

CARF
Village Northwest
Unlimited

New York

AIM Services, Inc.
Gate House
Main House

Avoid Complacency in Medical Management

Michael S. Komoll

Those who operate community-based services for people with disabilities often do a great job of identifying and addressing common hazards. Most residential providers know effective ways to prevent scalds, eliminate choking hazards or support consumers as they take new steps towards independence. However, many residential providers are shocked to learn that one of the leading causes of death is improper assessment or management of a consumer's everyday medical needs. This article uses a case study to reveal some unknown hazards of medical management and suggests easy ways to improve quality and reduce risk.

The Case of Phil

The following is a hypothetical case study derived from experience with claims activity in the human services industry. It does not communicate the story of an actual agency or client.

Phil is a 23-year-old man from Milwaukee, Wisconsin, who happens to have a developmental disability. Despite his challenges, Phil and his three housemates live successfully in the community with the help of 24-hour awake staff. Although Phil often feels frustrated by his disability, he goes to work, has friends and generally enjoys his life.

One of Phil's most nagging problems involves an intestinal disorder. Like many people with developmental disabilities, Phil's bowel was delayed in its development, resulting in weekly bouts with moderate abdominal pain and indigestion. His regular staff is familiar with Phil's medical issues. They know he commonly has stomach aches. They also know to get help if his pain persists over 12 hours, if his abdomen becomes distended, or if he concurrently experiences diarrhea and vomiting, etc. Phil's staff also knows that he has PICA. As a result, they have not become complacent in addressing Phil's common abdominal complaints.

Last December, Phil's three housemates all went home to their families for the holidays. Phil's family was involved in his life, but this year spent most of the holiday season out of town visiting college campuses with Phil's younger brother. As a result, Phil's residential provider decided to close down Phil's home and move Phil into another home for a few weeks. Phil's family approved, and Phil was excited at the prospect of spending some time with a few fresh faces. Staff at his permanent home discussed Phil's needs and wants with the new staff.

After a few days in the new home, disaster struck. Phil awoke one morning with moderate abdominal pain. He could not well express to unfamiliar staff that the pain was different than the stomach aches he commonly experienced. Staff gave Phil doses of Kaopectate and Tylenol over the course of the day. His pain seemed to lessen, but persisted into the evening. Phil refused dinner that night, and later had bouts of vomiting and diarrhea.

Suddenly, he became lethargic and broke out into a cold sweat. Staff noticed for the first time that Phil's abdomen felt as tight as a drum. Phil had been pointing to his stomach for over an

hour, but no one thought to touch it. By the time staff drove Phil to the emergency room, it was too late. Phil passed away due to internal bleeding that came from an obstructed and eventually ruptured bowel. The obstruction occurred after Phil consumed a small foam ball one of the other residents used to work on his dexterity.

What Went Wrong?

Phil's service provider conducted an internal investigation into whether they could have done anything to prevent Phil's untimely death. Considering the situation with 20/20 hindsight, it became apparent that many common, everyday events combined in an unfortunate sequence, to cause Phil's death.

- **Consumer-specific training.** The most obvious problem related to this tragedy is staff training. When Phil moved into the new residence for the Holidays, new staff was advised he often had stomach aches and diarrhea. However, no one advised new staff of Phil's PICA behaviors, as those behaviors were well managed. Thus, when Phil became ill in the new residence, staff was complacent and did not know to be concerned about possible ingestion of foreign objects. This attitude contributed to a delay in treatment.

- **The plan travels with the consumer.** The provider's guidelines called for a consumer's service plan to accompany the consumer when any residential changes occurred. This rule was rarely followed. Had Phil's new staff reviewed his service plan, they would have identified the PICA behaviors, and possibly might have been more prompt in seeking medical treatment. It is unreasonable to expect that the contents of an entire plan can be related to the new staff in a brief conversation about the consumer's needs.

Phil was sick all day prior to his death. Furthermore, he had concurrent episodes of vomiting and diarrhea. Staff relied on Phil's history of frequent complaints to conclude that these symptoms were not dangerous. However, had staff consulted Phil's plan, they would have learned that these complaints were serious. They further would have known to check if Phil's abdomen was distended, which it likely was for hours before his death.

- **Train staff in company guidelines and policies.** Phil's new staff treated him with over-the-counter medications like Tylenol and Kaopectate. In this case, they only served to mask what was a life-threatening situation. The provider's guidelines required staff to call a nurse whenever OTCs were distributed. This guideline was often ignored. Had this staff called the nurse, they would have spoken to someone who knew Phil's physical issues quite well. The nurse would have likely identified the situation as serious, overruled the administration of OTCs, and called for emergency medical treatment.

- **Re-examine policies and procedures.** The provider's policies and procedures had not been examined in years. They required that staff speak first to their supervisor and then to the nurse on-call, prior to dialing 911 or seeking out medical care. Staff repeatedly paged the on-call nurse, with no response for a critical half an

hour. It was only after this consultation that emergency treatment was authorized. Experts who later reviewed this case indicated the current standard of care requires staff to call 911 immediately upon the suspicion of a medical emergency. Had that been done in this case, the outcome may have been different.

Another outdated policy required staff to transport clients to the emergency room in an agency vehicle, rather than call for an ambulance. As a result, staff had to wait another half an hour for additional staffing before the on-duty workers could safely leave the other clients and get Phil to the hospital. Staff wrongly believed this policy was adopted due to the expense of ambulance service. This testimony did not favorably impress the jury at the civil trial prosecuted by Phil's family.

- **Survey staff attitudes.** Staff at the new home was reluctant to call 911. They had done so frequently in the past, and were met by skepticism, and ill will by dispatchers, EMTs, police and emergency room workers who believed the agency's staff often "cried wolf" and wasted their time. This created reluctance among staff to seek emergency attention, even when they believed it might be warranted. Management knew of this attitude, but did not make a point of training staff to disregard their reluctance.

- **Be mindful of all transfers.** The culture of the agency did not lead management of staff to be especially mindful when clients transferred from one home or program to another. However, these transfers raised several obvious risk factors. First, new staff obviously could not know the needs of a particular client as well as regular staff. More significantly, such transfers alter a client's routine, and may lead to stress and increased behaviors. In Phil's case, his PICA behaviors had been well-controlled for two years. However, the stress of the transfer induced a recurrence of behaviors with tragic consequence.

- **Do not circle the wagons.** Phil's family had a good impression of the agency prior to the death. Following Phil's death, they wanted answers. Instead of meeting with the family, the agency advised all staff and management to decline contacts with the family. The family then became resentful and suspicious. They felt they had no alternative but to hire a lawyer to get to the bottom of what occurred. Friends do not normally sue friends. Because of the agency's post incident behavior, the family

began to see agency as an enemy.

Sometimes tragedies occur and accidents happen for a single, simple reason. More often than not, however, accidents happen when a number of simple, seemingly insignificant factors combine to cause an unexpected event. In Phil's case, any single factor would not have independently led to the unfortunate result. For example, despite the fact that Phil's plan did not accompany him to the new home, his death would have been avoided had staff called the on-call nurse before administering OTCs; it would have been avoided had staff called 911 when they first thought an emergency existed, rather than waiting for management and nursing approval, etc.

In the past, the management and staff had followed outdated guidelines, ignored

others, and allowed a culture of complacency to evolve. Staff and management alike developed a false sense of security that minor oversights would not lead to tragic results because nothing bad ever happened in the past. It was this sense of complacency, combined with the demands of a client's medical needs that ultimately led to this result. ■

AUTHOR LINK Mike Komoll serves as the National Counsel for the Human Services Program of CNA Insurance. His practice focuses on the defense of Agencies that serve People with Disabilities, as well as Mental Health Care Providers, and various Community Service Agencies. He also defends Human Service Providers locally in the Chicago area. Mr. Komoll can be reached at (630) 719-3217 or by e-mail at michael.komoll@cna.com

ANCOR Welcomes New Members

Great Lakes/East Region

Carol Mitchell, Regional Director

Eihab Human Services, Inc.
Fatma Abboud
Queens Village, NY

Heritage Christian Home, Inc.
Robert Pieters
East Rochester, NY
Daniel Berkowicz, Representative

Mid-Atlantic Region

Bill Loyd, Regional Director

Community-Based Services, Inc.
Jennifer Boyden
Richmond, VA
Jennifer Fidura, Representative

Chransye, Inc.
Chris Collins
Richmond, KY
Clyde Lang, Representative

North Central Region

Rod Braun, Regional Director

PAKS Developmental Services
Mary Lawson
Ogallala, NE
Tony Green, Representative

Northeast Region

Rich Carman, Regional Director

MERT Enterprises, Inc.
Mary Rush

Bangor, ME

Richard Farnsworth, Representative

South Central Region

Lisa Toth-LaTray, Regional Director

Heartstrings Community Foundation
Bunny Higgins
Overland Park, KS
Tom Kohmetscher, Representative

Riverside Resources, Inc.

Karen Baker
Leavenworth, KS
Tom Kohmetscher, Representative

South Texas Community Living Corp.
Debbie Adams
Spring, TX
Philip Haas, Representative

Southeast Region

Bernard Wagner, Regional Director

South Carolina Human Service
Providers Association
Rick Magner
Summerville, SC
Terry Rogers, Representative

Southwest Region

Wendy Sokol, Regional Director

Su Vida Services, Inc.
Michael Binkley
Albuquerque, NM
Mark Johnson, Representative

Sole Practitioners Offer Value Across the Board

Heathere Evans-Keenan

As public relations professionals venture out on their own, leaving corporations or large firms for the entrepreneurial path, more clients are asking an important question: Are there benefits to working with independent practitioners?

Robert Flood, former CTO of Cable and Wireless and currently CEO for Northern Virginia-based PingTone Communications, answers with an emphatic “Yes.”

“I chose a virtual PR agency to help me position my new telecommunications company. I’m impressed with how quickly my “team leader” PR counselor assembled a tight group of PR professionals with various types of expertise to support my business goals. I get reliable guidance and effective counsel from a team of senior-level professionals. This model is perfectly suited for my needs.”

Sole practitioners work in as many specialties as there are clients or product categories. And, they offer just as wide of a range of PR services, from planning and strategy development to pro-

gram execution, along with a myriad of specialty services such as crisis management, corporate identity, media training, Web services, and collateral development, to name a few.

There are also several ways sole practitioners conduct business, each offering a different kind of benefit to clients. Corporate clients in need of public relations services or PR agencies looking to augment their service offerings can find a wealth of seasoned talent in the independent practitioner community, including:

Freelancers

A freelancer is a specialist called upon for a short-term project, such as training a client in media relations, writing brochure copy or a press release, ghostwriting articles, conducting media relations for a product launch, conference or special event, supervising print production or news distribution concept through completion, managing a special program and more.

The freelancer may work directly for corporate clients and

INDEPENDENT SKILLS ASSESSMENTS

Independent Skills Assessment Scale 2003

Designed for persons receiving or being considered for fewer than 24 hours of staffing time. Key indicator areas are:

- Meal Planning and Preparation
- Personal Appearance and Hygiene
- Apartment/Home Maintenance and Upkeep
- Personal Safety/Use of Emergency Resources
- Civil Rights and Responsibilities
- Social/Recreation/Transportation
- Shopping,
- Personal Medications
- Money Management
- First Aid and Health,
- Telephone and Other Utilities
- Coping Skills and Behavior

Independent Skills Assessment Scale	10 for \$20.00
	25 for \$40.00
	50 for \$75.00

Clinical Nursing Care Needs

The scale assists in determining the level of Clinical Nursing Services and suggests a number of Clinical Nursing hours (RN or LPN) necessary for individual consumers as well as entire group facilities.

Personal Strengths and Needs

A quick, 100 item, two-page assessment designed to show skills and abilities, as well as programming and health needs, for persons of all ability levels and ages.

Nutritional Needs

Aids in determining nutritional needs for the individual, developing individualized skill training goals for food shopping and preparation, supplying health related information to the physician, planning pertinent staff training, arranging staffing patterns during meal times, and in screening referrals to the agency or program

Clinical Nursing Care Needs	20 for \$10.00
Personal Strengths and Needs	50 for \$20.00
Nutritional Needs	

Sexuality Assessment

Helps determine an individual’s social/sexual vulnerabilities and supervision needs. Identifies individual program objectives in the area of sexuality, prioritizes sexuality goals and objectives, and establishes homogeneous social skills groups.

Sexuality Assessment/Curriculum Guide:

The guide is to be used in conjunction with the Sexuality Assessment Worksheet. Describes how each assessment item should be answered and provides information that can serve as a basis for training and program development. Included with the guide are 18 line drawings in a three ring binder, helpful in both assessment and training.

Sexuality Assessment Worksheet:

100 questions designed to address knowledge and performance in such areas as privacy and ownership, basic anatomy, relationships, positive touch, sexual expression, birth control, victimization and sexually transmitted diseases. It can be used with individuals of varying levels of knowledge and abilities.

Sexuality Kit:

Includes 20 Sexuality Assessment Worksheets, a Sexuality Assessment / Curriculum Guide, 18 line drawings, anatomically correct male and female dolls, sanitary pads, condoms, an artificial penis and a soft carry bag.

Sexuality Kit – includes guide and 20 worksheets:	\$200.00
Sexuality Guide – Includes 20 worksheets:	\$20.00
Sexuality Assessment Worksheet:	20 for \$10.00
	50 for \$20.00



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small businesses as well as PR firms and ad agencies. They may specialize in several of the areas listed above. Full service agencies and corporate communication departments often call on freelancers to augment their staff when a project's deadline or unique needs might otherwise overwhelm the schedules of the regular staff.

"We've found working with independent PR professionals to be extremely valuable for our agency, says Mary Baum, principle of Baum Arensmeier & Talent, a 30-person marketing firm founded in San Francisco in 1962. "These experienced professionals allow us to offer a greater level of service to our clients without having to find and hire qualified, talented PR staff."

Consultants

Public relations consultants are typically seasoned PR practitioners who often have worked in senior management positions with large corporations or agencies. They provide the core services clients expect of a PR firm—including planning, development, crisis communications, branding and positioning, community relations, media relations, issues management, writing services and more.

Sometimes an ad agency or small PR firm will team up with an independent public relations consultant to round out their services. This way, an agency can offer its clients additional services without taking on increased overhead (hiring staff or renting additional office space). These creative alliances allow the agency to offer a wider range of service when servicing current clients.

The Virtual Agency

The virtual agency may be the evolutionary next step in the life of the consultant. As he or she develops a network of specialists, freelancers and colleagues to call upon, capabilities increase to the point that the consultant is able to provide the services of a full service agency.

By putting together a team of specialists that can be broken apart or reassembled to adapt to clients' changing business needs, the virtual agency offers maximum flexibility and service, without the overhead of full time staff, office space, receptionists, etc.

Rebecca Wood, vice president of marketing for Northern California-based Examen, Inc., a 200-employee company with offices in Sacramento and New York, explains, "I've worked with independent PR practitioners for the past three years. I get the wise strategic counsel I need to help grow my organization and my calls are answered directly—and often immediately—by a PR pro with years of experience. With this level of service and the fact that I'm getting effective strategic counsel, imaginative special event planning and media relations, reliable crisis management, and so much more, I plan to continue tapping into this group of experienced professionals."

There are new shapes and sizes for PR firms and more opportunities than ever to find the model that works best for clients' needs. Whether a freelancer or consultant can help augment an organization's communications team or a "virtual firm" can assemble a PR team with the specific skill sets required, independent practitioners are a great resource for agencies and corporations alike. ■

Developing Outcomes: “The Bottom Line”

Terry Wisecarver

In recent years there has been a shift from the old way of planning from lists of goals and objectives to the new way of outcomes. While many are on the bandwagon of this new process, a significant number appear confused about how to define and develop clear and measurable outcomes. My husband holds that to be able to do so “is a right brain function”. Although this may be true, there is no real mystery to being able to develop an outcome based plan.

As with all planning processes, those for organizations or for people, the process should begin with identification of strengths and needs. Many times plans are developed solely around needs and ignore strengths, even though they may have been duly listed. It is most often best to build upon existing foundations (strengths), since to do so utilizes skills or resources that already appear to be healthy. Strengths and needs, particularly in the case of people plan development, may need to be confirmed through specialized evaluations or assessments that identify specific areas where intervention should be considered.

Once strengths and needs are agreed on, the process may move forward to prioritization: identification of which areas are most important to address. Once priorities are set, move ahead to identify the expectations (outcomes) around each priority. And this is where confusion begins! The process is simple, however. All that is necessary is that:

- 1) focus on “the bottom line”
- 2) outcomes be written in clear and measurable language
- 3) activities not be confused with outcomes

First, let’s examine an organization plan:

Individuals who provide early intervention services must meet certain ongoing training requirements. The system should adhere to seven key principles. Outcomes for training are identified as:

- Participants will understand all seven principles,
- Participants will gain the skills to effectively implement the seven principles,
- Participants will change priorities and values from how the system “used to be,”
- Participants will enhance and expand their understanding of effective practices.

Following the three necessary steps, how would you evaluate these outcomes? What is the bottom line desired effect?

It is that participants understand, effectively implement, change priorities and values and enhance enhance and expand their understanding;

OR

that they *practice* these principles throughout the delivery of the services they provide?

How can the outcomes, as originally stated, be measured? Can we always tell if someone understands? What if my standards for “effectively” are lower or higher than yours; is the measurement here clear? How can we know if you’ve “chang[ed your] values”; what if you were with the program already...will you still have to

change? Suppose you already know all about “effective” practice? What if what I consider “effective practice” is different than what you consider it to be?

Outcomes for individualized service plans tend to confuse people, even more, because those from whom we are getting the information about what is desired may not be able to clearly articulate what it is that they want. Further, we, as professionals, often work from subconscious “to do” lists, and, therefore are even more inclined to mix up “outcomes” with “activities”.

While we strive for the development of functional outcomes, it may not always be necessary to follow a statement of what’s desired with the follow-up “so that...”.

An example used in recent training describes an early intervention family’s priorities as “We want our daughter to crawl.” Clearly stated and measurable. Yet when it was translated by the trainer into a family-centered functional outcome it translated into “Melissa will move independently on the floor in order to get her toys.” The desired result is much less clear. What’s the family’s desire for Melissa? That she crawl (as they stated, and a perfectly acceptable outcome), or that she “...get her toys”? The latter would seem to be somewhat less functional, since it is so restrictive. Wouldn’t a family want their baby to crawl so that it can move from place to place independently as a precursor to standing and walking?

Another example used in the same session describes Emily. We are told that she is an only child in a two-parent family and she has a stay-at-home mom. Her parents “love to socialize”. They are “anxious for Emily to be able to sit in a high chair at mealtimes instead of on mother’s lap, and to begin to eat solid food. Her grandparents are also concerned about her development.”

Concerns and needs were identified as:

- doesn’t sit without support
- won’t eat solid food (*with some oral sensitivity presumed)
- mom must hold her during feeding
- low muscle tone
- *oral-motor dysfunction

Strengths and resources were listed as:

- good health
- extended family (concerned)
- stay-at-home mom
- two parent family
- sociable parents
- parents aware of delays
- good cognitive skills

Outcomes derived from the above and the parents’ statement of the desire for Emily to “eat solid food and sit in a highchair” became: “Emily will sit independently in order to play with toys on her own” and “Emily will eat cereal and solid food so that she is exposed to a variety of nutritional resources”. What did Emily’s parents really want? Does sitting independently really contribute to her being able to play with toys on her own? Can she only play with toys in a sitting position? Are her parents/doctor concerned

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about Emily’s nutrition? One of the listed strengths is that she is healthy; there is no mention of a restriction of food variety, only that she refuses solid food.

There seems to be quite a difference between what the family simply and clearly stated that they wanted and what was developed as a final outcome. Sitting in a highchair and playing with toys are two distinctly different functions, as are eating solid versus a variety of foods. So what Emily’s mom and dad said they wanted has been in effect, ignored and totally reworked by professionals, thus flying in the face of several of the seven principles previously discussed, which demand a family-centered approach!

Let’s use another, very simplistic, individualized service plan example:

A family with a 23-month-old baby, David, has been referred to and found eligible for early intervention due to a delay in speech/language development. The baby uses only a few words, “Da” and “Ma,” but grunts or gestures to obtain attention and have wants and needs met. Evaluations have revealed that the baby’s development in all other areas is within acceptable range, and an audiological assessment indicates that hearing is within normal limits, as well. Strengths have been identified by an IFSP team as

- involved parents
- healthy baby
- all other areas of development within normal limits
- only child
- good receptive language skills
- follows simple directions (meets accepted guidelines for age)

Needs are determined to be:

- verbalize wants/needs by use of simple sentences (within guidelines for age)
- increase parents’ reinforcement of language over gestures
- increase parents’ modeling of words and simple sentences before response to David’s nonverbal indicators of want/need
- involvement with same-age peers (day care/play group)

Evaluations and subsequent assessments indicate that David has the capability of communicating with language as expected for a child of his age. When David’s parents are asked about priorities, they reveal that they are very active in their church and say that they want for David to attend Sunday School and to be able to play with his cousins during family get togethers.

While these are sincere priorities for this family, have they identified an outcome related to their referral to the early intervention system?

Not directly. In this instance the question “so that...?” can be useful. In order for David to fully participate in Sunday School and play with his cousins, what will he need to be able to do is related to his referral to the system. (Family priority: “We want David to attend Sunday School and play with his cousins so that he is able to interact with his peers”). In order to interact, he will need to be able to communicate [by speaking]. The outcome can be “David will talk (that is bottom line what his parents want). The family’s priorities will then relate to this outcome: *David will talk.*

Activities: David *will ask* for supplies during Sunday School. David *will say*, “I’ll play” when with a group of children.

• How David will begin to do this/learn how to do this will be addressed through individualized strategies identified by the team.

continued on page 20

State Representative Profile

“So, how did you get into this field?”



Steve Lesko
Alaska State
Representative

After 30 plus years in this field I often sarcastically think of that question as an agrarian conversation between two aging farmers in the midwest. My first temptation is to ask, “Which field is it that you reference?” But, being somewhat lucid and privy to interpretation of idiosyncratic meanderings, I have come to believe that people are, indeed, asking the wrong question. All of us, in our shared “field” that we label human/social services probably have a myriad of reasons why we chose to be where we are; but maybe the question should be, “*Why do you stay in this field?*” Now that’s worth considering! But, first things first, so on to our original question.

Born and raised in Newburgh, New York, I popped into the middle of an expansive nuclear family so many moons ago I often forget my age, or choose to deny it. One particularly vibrant memory was my cousin. We grew together, traveling many roads of adventure in this unfolding journey

called life. I considered her a friend as well as family. She was bright, somewhat shy, and had a smile that could redefine your day in the best of ways. Life was idyllic until we reached the arms of that beast called high school. It was then I discovered something I had never known before; I learned that this special friend of mine was special in another sense of the word.

She had been labeled an “educable,” a part of a special education class in a public school system. This typical teenager who could read and write and hold a very good conversation, who sought social opportunities and thrived in small groups, began to withdraw. Maybe it was the cruelties that can come with such a label, maybe it was the terminal effects of puberty in kids, but within a remarkably short period of time she just disappeared. Too much teasing and taunting, too much name calling and ridicule: She left school and began a new and devastating journey into darkness and isolation.

My last memory of her was a person who



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never left her house; who hid in the bedroom, cutting out paper dolls that adorned her environment and routinely sifted fingers through stolen grounds of coffee in the pockets of her dress. She barely spoke, and that smile was never seen again. I believe that she was the reason that I entered this field.

Through New York, New Jersey and eventually to Alaska, I have stayed in the field. My foundation is my incredible wife, Karen, and our kids. For over 20 years I have been executive director of Hope Community Resources. We have seven regional offices, with the largest in Anchorage. Centers are located in Kodiak, Seward, Mat-Su Valley, Juneau, Dillingham and Barrow. This brings a new meaning to the concept of rural service delivery!

Hope is founded on values translated into service delivery. We have no ICFs/MR in Alaska, either private or public, and are righteously proud that our institutions are now ancient history. We do not have a menu of services, but attempt to listen to families and wrap around sup-

ports that they request, formulate, control and direct. This can evolve into supported living, home ownership, in-home services, foster care, shared care, apartment living, crisis response, employment or whatever it takes to assist individuals in achieving dreams. Over 750 choose our community supports. Hope launched into programs for children with complex medical conditions, severe emotional disturbance, adults with physical disabilities, dual diagnoses and developmental disabilities. Our staff is the brightest and the best and shares a vision of full inclusion for all human beings.

We were members of ANCOR long before it became ANCOR. We have relied on the technical expertise of ANCOR staff in challenges of wage and hour interpretation, respite/voucher concerns and for recruitment and retention practices. We have enjoyed the benefits of representation at the federal table of policy and program decisions, particularly in the area of Medicaid funding and community development. There are lists of reasons why we believe in ANCOR and

the leadership role our national organization has so aptly assumed, but there is another!

And that leads to the real question behind the question: "Why do we stay in this field?" For me, the greatest benefit of membership is the opportunity to meet others who have committed their lives to this cause of human and civil rights; to share problems, concerns and solutions; to support each other through the hard and difficult times; to celebrate success and tell our stories of the human spirit. The character of so many ANCOR members reinforces the nobility of our cause and helps us heal in the middle of a very hurtful profession. There is no price affixed to people supporting each other, knowing that there is true understanding, compassion and concern. I have valued personal interactions with ANCOR members and staff. If we cannot heal each other, who will?

And then again, there's that incredible smile that I can still remember from some distant magical time when, for just a moment, there seemed to be no labels. ■

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Developing Outcomes

continued from page 16

Identifying an outcome need not be complicated; it is truly a bottom line process. One must evaluate the available information, determine what more may be needed and continuously ask, "what is really desired and/or needed, here?"

It is important, too, not to confuse "activities" with outcomes. It is very easy to establish a list of "things to do" (interventions) and to view these deliverables as outcomes. Activities are only the small steps that lead to the ultimate outcome.

Outcomes and the steps leading to them must be measurable and clear. Phrases, which denote value, must be avoided, because a diverse society may interpret events and actions in different ways. What one person or culture sees as "age appropriate", another may not. "Regularly" can have a variety of meanings, depending on the schedule of the person responsible for the deliverable. We can know if Lisa talks, we cannot truly know if someone understands.

Anyone should be able to identify outcomes, activities, strategies, deliverables, goals, objectives, interventions, responsible persons and timeframes in a

plan, regardless of which terms are used. That is to say that *anyone should be able to tell what is going to happen, what steps will be taken to ensure that it does happen, who will take those steps, how often they'll take them, and for how long.* Everyone should be able to reach exactly the same conclusions from a plan regardless of culture, experience or language. Anyone should be able to tell if an outcome has been achieved by looking at the end result of the proposed activities. Yet another indicator of the bottom line is the simplicity of the process.

To summarize, all plans should be built around identified strengths and needs that are confirmed through assessments. Strengths and needs should be prioritized so as to address the most important first. Outcomes should be identified; the outcome is the bottom line expectation of the result of the recommended interventions (activities). Activities must be related to the outcome and designed to bring about the expected end result. Those responsible for carrying out the activities must be identified, as must the frequency of the activity and length of time expected to reach the outcome.

If planning seems to be a confusing

process, it's too complex. In short, keeping it simple is the best approach to planning; and that's the bottom line! ■

ANCOR Calendar

2003

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| June 10-11 | CEO Summit—BWI
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Baltimore, MD
<i>(invitation only)</i> |
| June 17 | Audio Conference
Guidelines for Supporting
Sexual Activity: Legal,
Ethical and Practical |
| July 16 | Audio Conference
Fiscal Employment
Agents: Key Elements
and Issues |
| Sept. 7-9 | ANCOR's 2003
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