



ASSOCIATION FOR POSITIVE BEHAVIOR SUPPORT

Newsletter

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Association for Positive Behavior Support

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APBS President's Update

A lot of progress is being made on a number of activities within the Association for Positive Behavior Support (APBS), thanks to the growing number of APBS members who are volunteering their time and becoming actively involved in committee work.

We have a new co-chair of the APBS Network Committee, **Lori Newcomer**. Lori has just started this year as co-chair with **Jennifer Zarcone**, and she is already bringing new ideas and energy to our network efforts. There are two places where you can learn more about APBS Networks. On the APBS home page (<http://www.apbs.org>), the left-side menu bar includes a link titled "APBS Network Finder." This link will help you to find out whether there are any APBS Networks in your state. Inside the Members Section of the website, you can learn more about each of the networks in more detail. If you are not a member, you can visit the Members Section for free up to three times by following the instructions after clicking on the button that says "Members Resource—Log In Here!"

In addition, Lori Newcomer and **Rachel Freeman** have been facilitating an **Inter-agency Statewide Conference Call** as part of a new effort to provide opportunities for APBS members to learn more about training and technical assistance efforts occurring in different states. The webinar/conference call events are being recorded so that anyone interested in becoming involved can do so in an asynchronous manner. Two of these meetings have already been recorded and should be available on the website soon! You can find more information about these

meetings by going to the Members Section and clicking on the APBS Networks link. If you see Lori before the next conference, please thank her for taking on a leadership role on one of our APBS committees!

Just formed is a new committee that we believe will be essential to the long-term success of APBS. The **Evaluation/Logic Model Committee** is working hard to improve the data collection within APBS as part of an annual self-assessment process. The APBS Board started working on a logic model that will provide the foundation for long-term planning and is in the process of linking the older action plans to this new logic model draft. This year, we will be sharing the logic model at the conference in March during a working lunch session so that we won't be competing with the excellent presentations that none of us want to miss. Please consider coming to this session to help us create a long-term vision for the Association

PBS in "Other" Community Settings: Quality of Life Issues in Memory Care

Kelley M. Gordham
Director of Oregon Intervention Systems

The late Edward Carr, while giving the presidential address at the 2006 APBS conference, defined the dimensions of *quality of life* (QOL) as follows:

(continued on next page)

(*PBS in Community Settings*, continued from page 1)

- material well-being
- health and safety
- social well-being
- emotional well-being
- leisure and recreation
- autonomy

Nowhere are these concepts more important than in providing supports to people who are experiencing Alzheimer's and other forms of dementia.

PBS has been a major force in addressing quality of life and challenging behaviors in community settings for well over a decade. The literature is rife with references to school-wide systems, programs for developmental and other intellectual disabilities, and so forth.

Along with other states, Oregon has made inroads into other venues—such as foster care, juvenile justice systems, and community mental health programs, to name a few. Oregon Department of Human Services—Seniors and People with Disabilities funded the development of the Oregon Intervention System in 1994, which became a major vehicle for training positive behavior supports in the state. Over the past three years, efforts have begun in earnest to bring elements of PBS to long-term care (LTC), that is, assisted living (ALF), enhanced care (ECF), skilled nursing (SNF), adult foster care, and in-home supports for our aging citizens.

Easily the most rewarding (and at times frustrating) experience, however, has been our work with “memory care,” primarily with individuals experiencing Alzheimer's and dementia. There are certainly special considerations in providing elements of PBS in facilities supporting individuals with dementia and memory issues. Each and every facet of QOL described by Carr (2007)—from material well-being to autonomy—is critically important to all persons, regardless of disability or impairment.

Special concerns, such as diet, exercise (Larson et al., 2006), strategies for maintaining skills (Squire, 1992), and building memories, were of importance when building person-centered plans or *Quality of Life Care Plans* (Gordham et al., 2007). Developing and maintaining rituals and routines are also critical in memory care.

Perhaps the most important component of QOL for persons with Alzheimer's, dementia, or other memory deficits is emotional well-being. Knowing the person's story, including joys and traumas, can give us clues to engineering an environment that is personalized to the individual (Pitonyak, 2004).

It is important to note that facility administrators requested our efforts in consulting on, training for, and monitoring of the development of PBS in each facility.

This commitment encouraged program staff to participate in earnest. Most of the facilities we encountered were open to the idea of a philosophical shift; however, we did happen upon a few obstacles that are noteworthy:

- First, the traditional and persistent treatment for persons needing memory care is based upon a “care model”; that is, health, dietary, and so forth occasionally “trumped” QOL goals. Negotiating these obstacles was frustrating at first but was resolved in due time.
- Another impediment that had to be addressed was licensing/certification. Sometimes interpretation of local or state regulations dictated that decisions be made by licensed, certified, or registered medical personnel. In most facilities, we found that any behavioral efforts currently in place (and there were few) had been initiated by an RN (most common), a social worker, or a psychiatrist (least common). We found the traditional behavior-consequence concept to be the most prevalent. Typically, explanation of and exposure to functional behavioral assessment and assessment-based support plans were instrumental in developing acceptance of PBS by these professionals.
- Another issue that we encountered was a certain “language barrier.” Terms such as *assessment* and *support plan*, for example, had to be dealt with, as they were often used to describe other functions. Creative use of language and terminology addressed this issue nicely.
- We also found that LTC operates under regulations (in most of the states where we consulted) that are substantially different from those in education and/or programs for persons with developmental disabilities. This was even more of an issue where LTC regulations were closer to mental health regulations than to developmental disabilities or school settings regulations. In several states, the regulations only addressed medical treatment. Many states we visited do not address behavioral practices in regulation.
- Long-term care has been given a bad rap over the past few years. Numerous articles and exposés in both local and national media have depicted less than stellar conditions, including questionable medical care, understaffing, and extensive reliance on the use of restraints, to name just a few. Facilities such as these certainly represent a small number of the total, but the effect of such press has caused a degree of defensiveness on the part of some program administrators, department managers, and

professionals working in LTC. Working through this often required a great deal of listening and patience with the process of change.

- The most significant issues we encountered in our efforts were not all that different from what we have seen elsewhere. Convincing staff of (or selling them on) the benefits of PBS was an issue we addressed early on. The time commitment required at the beginning was difficult for some programs, and scheduling consultations was problematic in some cases.

In spite of these minor challenges, we enjoyed working with the staff and residents of LTC programs. Hearing about how people with significant behavioral challenges are experiencing enhanced QOL or watching the “light switch on” for a direct support staff member continues to be the driving forces in this effort. We have noticed a “change in the force” in memory care, as evidenced in family satisfaction surveys, which is in every way similar to those changes in community programs for intellectual disabilities, school-wide programs, and other types of programs that have embraced PBS.

References

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Information at Your Fingertips

Randall L. De Pry

Did you know that the Member’s Section of our APBS webpage has a wide variety of useful resources that can support your work as a PBS practitioner? If not, take a few minutes to explore this incredible benefit offered only to APBS members. To access the APBS Member’s Section you will need your User Name and Password. Once you enter the site you will find sections with links to “APBS News” and “Members’ Pages.” One new feature

that is currently highlighted in the APBS News section is our online voting system. This system will eventually replace the paper-and-pencil ballot that we have used in the past. The board hopes that this new method of voting will provide you with an efficient way to vote on issues of importance. Conference resources are also available in both the APBS News and Members’ Pages sections. For example, information about our upcoming conference is highlighted, and archived information from previous conferences is available for viewing or to download. One resource that is a “must see” is the online video presentation by Dr. Rob Horner, who served as our keynote presenter at the 2009 Jacksonville conference. Other video presentations will be added in the future.

The Member’s Section also has links for online PBS articles and newsletters, information, and PBS topics such as autism, early childhood, functional assessment, mental health, school-wide PBS, and APBS Networks. A number of other resources and links are also available to members, but the amount of space allocated for this column limits mentioning them here. So, take a few minutes to see for yourself. The website committee has contributed countless hours to making the Member’s Section a great resource for all APBS members. Be sure to contact Kristin (link is on the webpage) if you have a recommendation for a PBS resource that you would like to see included. Membership in APBS has many benefits, including a website section that provides updated and useful information for APBS members. If you would like additional information on other membership benefits or would like to learn more about how you can become involved in APBS, please contact me directly (rdepry@uccs.edu).

Contribute to Our Newsletter

Please consider contributing to the APBS Newsletter. The newsletter is a mechanism for sharing perspectives on PBS. Please consider submitting:



- Innovative Applications
- Member Perspectives
- Training Events & Workshops
- Resources and Materials
- Success Stories

If you would like to submit to the newsletter, please contact:

Carie English, via phone: (813) 817-4586
or via email (carieenglish@yahoo.com)

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7TH INTERNATIONAL CONFERENCE ON POSITIVE BEHAVIOR SUPPORT

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