

EDITORS' NOTE: *The Forum section of the Journal of Positive Behavior Interventions provides for an exchange of opinions, perspectives, ideas, and informative personal accounts. We welcome brief articles from family members, professionals, friends, advocates, administrators, researchers, and other individuals who are concerned with behavioral support issues. The purpose of the Forum is to facilitate a constructive dialog among our many stakeholders regarding important issues in practice, research, training, program development, and policy*

In the following pages, we continue a special section of the Forum focused on issues of behavioral interventions and families. We asked a number of individuals who are deeply involved with families and behavior support to respond to the following question:

"In your view, what are some important activities that should be encouraged in the next decade to improve the status of assistance and support for families that include a child with severe problem behaviors?" In the previous issue of JPBI, we printed six commentaries from researchers, practitioners, and family members that addressed this question. In the present issue, we offer two additional responses. Like the previous contributions, these brief articles provide thoughtful perspectives on families, community, and directions that the field should pursue to become more effective in addressing severe behaviors. It's a grateful to all of the authors who produced comments for this special Forum section, and we welcome additional input from JPBI's readership. We also welcome ideas for future Forum sections.

PARtnerships

Ursula Arceneaux Markey

For families who have a member with a disability, there is much to be hopeful about as we move into the next century. At the same time, the necessity to be assertive and clear about our needs will continue to be a priority for families in traditionally underserved communities.

I am an African American parent who codirects Pyramid Parent Training, a community parent resource center for families of children with disabilities in New Orleans. (Pyramid is funded by the U.S. Department of Education, Office of Special Education Programs.) We are committed to providing the information, training, and support necessary to implement research-based best practices in health and education in the traditionally underserved community of which we are members. To accomplish this, our staff engages in a process that includes educating ourselves about these theories and practices, consulting with experts in the various disciplines, and designing programs and services that factor in the conditions we know to exist in our homes, schools, and neighborhoods. In this way, we have been able to introduce the theories of positive behavioral support to our families through our project, Operation Positive Change. Operation Positive Change is funded by the Institute of Mental Hygiene of New Orleans.

This often difficult and time-consuming process has taught us that researchers and families have much to learn from each other and must engage in a collaborative process to discover strategies that are truly useful to families. Why should rigorous research lead to another rigorous process in order to yield practical applications for families? Why aren't certain variables

taken into consideration when research questions are formed?

We know that thousands and thousands of families live in traditionally underserved communities across America—communities that are home to families described by Congress as people of "diverse racial, cultural, and linguistic backgrounds who are isolated by geographic, social, language, cultural or racial factors" (Senate Bill 717: Report of the Committee on Labor and Human Resources, 1977). We also know that schools in these communities are largely racially segregated, isolated institutions that reflect the conditions in the communities around them. Why, then, do researchers so often discount the ways these factors affect learning and behavior?

In New Orleans, racism and poverty persist in traditionally underserved communities. Sixty-two percent of the population is African American. According to a September 1999 Times-Picayune article, "In the 1990 Census, poverty struck much harder at the black population (38% were poor) than the white population (7% were poor). Only 42% of poor whites lived in poverty impacted neighborhoods where 87% of all poor blacks lived. More striking, only 6% of poor whites lived in high poverty neighborhoods (where poverty rates exceed 40%), while almost half of all poor blacks (49%) lived in such deadly communities."

In our daily lives and work with families of children and young adults who have disabilities and/or challenging behaviors, we see the added stress created by long-term poverty. Families must also contend with crime and delinquency, alcoholism and drug addiction, substandard housing, and

deteriorating schools. Another September 1999 *Times-Picayune* article stated: "In the first statewide school performance rating, New Orleans public schools ranked among the worst in Louisiana, with nearly half (50 of the 103 New Orleans schools rated) labeled 'academically unacceptable'... Another 41 schools here were labeled 'below average.'"

These are the conditions that prevail in the homes and schools where we introduce families to the theory and practice of positive behavioral support (PBS) and inclusive special education. We see our task as having to adapt a comprehensive PBS science for practical application in our traditionally underserved community.

Everything in our history and experience as parents of a child with challenging behaviors tells us that PBS is important and reliable. However, everything in our history and experience in our community also tells us that we lack the resources to implement PBS as designed. For example, we would be foolish to expect that we would find teams of professionals willing to work with families in our community to develop and implement individualized and comprehensive PBS plans. Thus, we designed Operation Positive Change, our program for families of children and young adults with challenging behaviors, with these realities in mind. The following are some accommodations we have made:

1. We begin by using activities that draw on cultural mores to encourage families to examine their attitudes about behavior and discipline. These activities produce surprising insights for many participants who have never considered how they formed certain assumptions about behavior and discipline or questioned the validity of those assumptions.
2. We do not think of or use the word *intervention* in our training, as it suggests that PBS is something that is crisis oriented. We believe PBS can become an internalized practice, a way of being, for families whose lives are already challenged by crises in their daily lives.
3. We rely more heavily on families' powers of observation, intuition, and spiritual grounding to develop informal functional assessments and hypotheses about why challenging behaviors occur.
4. We emphasize practice over theory and afford families opportunities through interactive training to gain experience with some strategies they can try.
5. We begin with the home and an extended family team to give maximum opportunity to families to experience successes they can refer to when they interact with teachers and other professionals.
6. We maintain partnerships with reliable allies in research as we modify and improve the program.
7. We consider every participant in Operation Positive Change a potential trainer of other families.

The value of the research and the researcher is undeniable. Our families benefit greatly from the technology of PBS, and time devoted to adapting the science to facilitate its use is well spent. However, we feel that there are important partnerships among theoreticians, practitioners, and families that are now forming and will, in the near future, enhance everyone's ability to make positive changes for families. I am speaking specifically of participatory action research.

Over the past several years we have, through our affiliation with the Grassroots Consortium on Disabilities (a national multicultural alliance of community parent resource centers), engaged in a developing partnership with the Beach Center on Families and Disability (a rehabilitation, research, and training center funded by the National Institute on Disability and Rehabilitation Research) at the university of Kansas. Ann and Rud Turnbull, directors of the Beach Center, introduced the Consortium to participatory action research (PAR). It is a courageous new approach to rigorous research that includes families throughout the research process from formulating the research questions, to designing the research strategies, to participating in the analysis and dissemination of results to their communities.

Pyramid parent training is participating as a full partner with the Beach Center in an ambitious PAR effort to discover the relationship between disability policies, partnerships between families and providers, partnerships among providers, and quality of life for families who have a member with a disability. We have partnered with Beach researchers in the facilitation of two focus groups with Pyramid and Operation Positive Change families covering two topics-partnerships between families and providers and family quality of life. We are pleased to report that the process has yielded immediate and direct benefits for all who are involved. Families receive information about existing research-based best practices in health and education. They also get the support they need to participate in the dialogue about these issues, including transportation and childcare. Researchers learn about the ways social and economic conditions influence the integrity of research results, and providers are able to modify services according to the information shared in the sessions.

As a result of their participation in this PAR initiative, parents have gained a sense that their opinions and experiences are valued. Their concerns are being heard by researchers for the first time, and their comments are being incorporated into research that will benefit our society. Focus groups have also given our parents opportunities to share with each other. Their sense of isolation is lessened as they have the chance to meet and converse with other parents who have similar needs or circumstances. In discussing health and educational resources, parents evaluate services and providers and thereby share some of the more effective local resources and successful strategies with each other. Parents also express

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Parents also express appreciation because the process has necessitated their having to think about things they never considered before, such as the determinants of quality of life for them personally and for their families.

Through these exchanges, I have learned three very important things: First, the quality of life of the whole family is enhanced when the individual parent has the opportunity to pursue his or her personal dreams. Second, parent-teacher conflict is the greatest obstacle to implementation of positive behavioral support plans and Individualized Education Programs; hence there is a great need to facilitate parent-teacher partnerships. Third, a roundtable gives everyone a sense of true sharing, respect, and equal importance in a discussion. We believe PAR holds true promise for finally producing quality outcomes for all children and adults who have disabilities and/or challenging behavior.

ABOUT THE AUTHOR

Ursula Arceneaux Markey and husband **D. J.** are the parents of two young adult sons, **Duane** and **Teiko**. **Duane**, their firstborn, had autism and severely challenging behaviors. He passed away in December 1998 at the age of 26. Inspired by their sons, the **Markeys** established **Pyramid Parent Training**, a community parent resource center, in 1991. The program provides information, training, and one-to-one support to parents of children with disabilities in traditionally underserved communities in New Orleans. They are also charter members of the **Grassroots Consortium on Disabilities**, a national multicultural alliance of community parent resource centers. Address: **Ursula Arceneaux Markey**, 4101 Fontainebleau Drive, New Orleans, LA 70125.

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