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Developing and Implementing Positive Behavior Support Strategies
TASH MISSION

TASH supports the inclusion and full participation of children and adults with disabilities in all aspects of their communities as determined by personalized visions of quality of life.

TASH's focus is on those people with disabilities who:

- Are most at risk for being excluded from the mainstream of society
- Are perceived by traditional service systems as being most challenging
- Are most likely to have their rights abridged
- Are most likely to be at risk for living, working, playing, and/or learning in segregated environments
- Are least likely to have the tools and opportunities necessary to advocate on their own behalf
- Historically have been labeled as having severe disabilities and
- Are most likely to need ongoing, individualized supports in order to participate in inclusive communities and enjoy a quality of life similar to that available to all citizens.

TASH accomplishes this through:

- Creating opportunities for collaboration among families, self-advocates, professionals, policymakers and other advocates
- Advocating for equity, opportunities, social justice, and rights
- Disseminating knowledge and information
- Supporting excellence in research that translates to excellence in practice
- Promoting individualized, quality supports
- Working toward the elimination of institutions, other congregate living settings, segregated schools/classrooms, sheltered work environments, and other segregated services and toward replacing these with quality, individualized, inclusive supports
- Supporting legislation, litigation and public policy consistent with TASH's mission; and
- Promoting communities in which no one is segregated and everyone belongs.

TASH (formerly The Association for Persons with Severe Handicaps) is an international advocacy association of people with disabilities, their family members, other advocates and people who work in the disability field. TASH actively promotes the full inclusion and participation of persons with disabilities in all aspects of life. To receive an information packet, contact: TASH, 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 or phone (410) 828-8274, ext. 8 or e-mail: info@tash.org.

WHOM DO I CONTACT?

- For issues of policy, chapter or committee support, or general concerns and suggestions, call: Nancy Weiss, Executive Director, at (410) 828-TASH, Ext. 101, e-mail:nweiss@tash.org
- For information on conferences, regional workshops, or technical assistance, call: Denise Marshall, Director of Meetings and Technical Assistance, at (410) 828-TASH, Ext. 103, e-mail:dmarshall@tash.org
- For questions about the 2002 Annual TASH Conference, call: Kelly Nelson, Conference Coordinator, at (410) 828-TASH, Ext. 105, e-mail:knelson@tash.org
- For questions about membership, conference registration or exhibiting, call: Rose Holsey, Director of Operations and Member Services, (410) 828-TASH, Ext. 100 or rholsey@tash.org
- For information on governmental affairs, call: Jamie Ruppman, Director of Governmental Relations, at (410) 828-TASH, Ext. 104, e-mail: jnruppman@tash.org
- For information on newsletter submissions and advertising, marketing and promotions, or permission to reprint, call: Priscilla Newton, Director of Marketing, at (410) 828-TASH, Ext. 102, e-mail:pnewton@tash.org
- For information on Research and Practice for Persons with Severe Disabilities (a publication of TASH), call: Frieda Brown, Editor-in-Chief, at (718) 997-5243, e-mail:fbrown@naacp-aol.com
- Don't forget to visit TASH's web site at http://www.tash.org
Welcome...

...to this special edition of TASH Connections that features positive approaches to supporting people with challenging behavior. This special edition of the newsletter represents one of the many activities of TASH's Positive Approaches Committee. As Co-chairs of this committee, we wish to thank each of the authors for their contribution to the field and, in particular, for their generosity of time in preparing the following selections in this newsletter. Likewise, we wish to pass along a hearty word of thanks to Priscilla Newton and the many TASH staff for their continuous advocacy endeavors and their support in the development of this special edition.

One question that we are often asked is "what do you mean by positive approaches...does this mean the same thing as non-aversive and/or non-coercive?" The short answer to this question (or these questions) is an emphatic "yes", however to try to simplify positive approaches by describing what they are not does little to help people understand what, in fact, are these approaches. Here is where the compilation of the articles and testaments on positive approaches that are highlighted in this newsletter come in.

Positive approaches (as you will read) are applicable across the lifespan and cut across socio-economic boundaries as they pertain to people with and without disabilities who engage in problem behavior. As such, we have been fortunate to recruit the contents of this newsletter from a number of distinguished authors/leaders in the field that describes the applicability of positive approaches with young children and their families in home and community settings, school-aged children in educational programs, and within integrated community settings with adults. In addition, we are pleased to highlight in this special edition a couple of examples of statewide outreach endeavors concerning adoption and utilization of positive approaches by school and service provider agencies. On a final note, we are thrilled to draw your attention to the list of worthy recipients (page 9) of TASH's Positive Approaches Awards from 2002. Each of the recipients listed, along with countless others who are out in the field promoting the use of positive approaches, are to be commended for their endeavors!

On behalf of the Positive Approaches Committee of TASH, and on behalf of TASH - Equity, Opportunity, and Inclusion for People with Disabilities, we hope that you find the following information timely, enlightening, and useful in your local endeavors. Please feel free to direct questions pertaining to how you can obtain further information on positive approaches to Nancy Weiss, TASH's Executive Director by e-mail, <nweiss@tash.org> or telephone, 410-828-8274, ext. 101.

Tim Knoster

Rob O'Neill
Families protest New Jersey State Assembly hearings on restraint, call substitute bill a mockery of Matthew Goodman’s death

BY PAT AMOS

On January 16, 2003 the New Jersey State Assembly was expected to hold hearings on Matthew’s Law (A2855), a measure requiring facilities for people with disabilities to cease the routine use of restraint in favor of positive teaching methods. Instead, hopeful parents found themselves the victims of bait-and-switch legislative tactics. From noon until 7:00 p.m. they were forced to sit in silence while their legislators presented them with a travesty of their proposed bill, assuring that restraints and other aversives would continue to be used in New Jersey’s facilities for children and adults with disabilities.

Matthew’s Law was introduced in the wake of the tragic death of 14-year old Matthew Goodman in February of 2002, following 16 months of mechanical and chemical restraint in a New Jersey residential facility. In the hearing room, Matthew’s mother, Janice Roach, and fellow supporters of Matthew’s Law were dismayed to find that a substitute bill, written behind the scenes and completed two days previously, had been put in place of the legislation they were prepared to address. Although few attendees in the crowded room had seen the new bill, Chairwoman Loretta Weinberg (D, 37) repeatedly urged those giving testimony to comment on the substitute, describing it as a compromise that improved Matthew’s Law. The substitute bill was summarily voted out of committee at the end of the day.

As Matthew’s mother discovered, the only key element in common between the substitute legislation, A2849, and Matthew’s Law was the committee’s determination to give it her son’s name.

Matthew’s Law was carefully written to reflect the successful nationwide trend toward employing restraints only in safety emergencies rather than as means of “habilitation” (i.e. teaching or treatment), and to comply with a growing body of Federal regulations and statutes that recognize the danger of restraint by limiting it to “emergency use only.”

Yet in a move virtually unheard of in legislative practice, A2849 would take the regulatory language currently used by New Jersey’s Division of Developmental Disabilities — the same outdated and deficient language which failed to prevent Matthew Goodman’s death — and enshrine it in state law. Matthew’s family, and the families of many other children injured, traumatized, and killed in restraint-related tragedies, came before the committee to give Matthew a legacy but were handed a mockery.

New Jersey regulations currently allow restraints as well as other “aversives” (such as slaps, hair-pulls, water and lemon squirts in the face, and the forced inhaling of noxious substances) to be included in the required “Individualized Habilitation Plan” (IHP) of a child or adult with a disability. Once included in this plan, facility staff may administer these techniques repeatedly at their discretion. Staff are held to significantly lower levels of documentation, parental notification, and medical oversight for “habilitative” restraint use than are required in cases of emergency restraint, creating a strong incentive for such use. Current state regulations also require that parents or guardians give permission to include restraints and other aversives in an IHP, and that a “human rights committee” approve their use. Matthew’s mother, as well as other parents who report abuse, counter that permissions are routinely coerced under the threat of losing the child’s placement and that human rights committees inevitably act as rubber-stamps to the requests of facility administrators. Substitute bill A2849 would merely continue the fatally flawed practice of including non-emergency restraints and other aversives in the IHP with parental permission and the approval of a “county human rights review board.”

Proponents of Matthew’s Law spent the month prior to the hearings researching and documenting best practices and outcomes in the field. Representatives of prominent New Jersey disabilities organizations such as The Boggs Center on Developmental Disabilities of the Robert Woods Johnson Medical School, New Jersey Protection and Advocacy, Cerebral Palsy of New Jersey, The Statewide Parent Advocacy Network of New Jersey (SPAN), New Jersey TASH, and The Family Alliance to Stop Abuse and Neglect were among those attending to present in favor of Matthew’s Law, while disabilities experts from neighboring states arrived to volunteer their testimony. For many, presentation times were cut from ten to as little as two minutes. National experts who were unable to attend the hearings, and who had sent written testimony to the Assembly committee, found that their documents were neither read nor considered.

If the substitute bill is passed, New Jersey would become the only state in the nation to move backward on this important issue of civil rights and protection from abuse, the only state legislature to endorse the use of restraint as a therapeutic treatment for disability.

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Families protest New Jersey State Assembly hearings on restraint
Continued from page 4

before the substitute bill was approved. “The die was already cast, the decision predetermined, the hearing just for show,” said Diana Autin, Executive Co-Director of The Statewide Parent Advocacy Network of New Jersey (SPAN), “We stand with thousands of parents, advocates, and children, youth, and adults with disabilities today in expressing our disappointment in the Committee substitute bill allowing the continued use of restraints and aversives in New Jersey’s public and private institutions. But we will not morn, we will organize! And Matthew’s Law will become law.”

Among those attending in opposition to Matthew’s Law and/or for the substitute bill were various New Jersey facility administrators, a statewide organization of facility providers, consultants to the facilities, and families who feared that their child’s placement would be lost.

Chairwoman Weinberg, Chairman William Payne (D, 29), Vice-Chairman Herb Conway (D, 7) and Vice-Chairman Joseph Cryan (D, 20) led the majority vote in favor of substitute bill A2949. Sponsors of Matthew’s Law Eric Munoz (R, 21) and Guy Gregg (R, 24) have demanded that their names be removed from A2949, and Matthew’s mother has refused to lend her son’s name to a bill that she believes would perpetuate the suffering he endured. “While other children played and went to school my little boy was lonely and afraid, with his arms immobilized in straps and his head in a helmet,” said Janice Roach, “And they called it treatment. I am determined that this will never happen to another child; then Matthew’s death will not be in vain. We parents will never give up until Matthew’s Law is passed.”

Postscript/Aftermath:
There is nothing like the continued glare of nationwide publicity to change hearts and minds. Matthew’s Law can and will be passed if the disabilities community continues to make itself heard. Concerned citizens across the country should urge the New Jersey Assembly to vote NO on Committee Substitute A2849 should it come to the floor, and to bring forth Matthew’s Law (A2855) for a vote.

One main talking point captures the issue: If the substitute bill is passed New Jersey would become the only state in the nation to move backward on this important issue of civil rights and protection from abuse, the only state legislature to endorse the use of restraint as a therapeutic treatment for disability. New Jersey would be taking this backward step at the very time when the Children’s Health Act of 2000, the regulations of the federal Centers for Medicare and Medicaid Services (CMS), and the legislation and regulations of most other states have moved decisively to declare that there is no legitimate therapeutic use for restraint, and to mandate medical oversight and prompt reporting in cases of emergency use.

Advocates are welcome to share their thoughts and experiences with Assemblywoman Loretta D. Weinberg, Chair of the Health and Human Services Committee (e-mail: AswWeinberg@njleg.org) and Assemblyman William D. Payne, Chair of the Assembly Regulatory Oversight Committee (e-mail: AsmPayne@njleg.org), who engineered the behind-the-scenes substitution of A2849 for Matthew’s Law.

Words of support for Assemblyman Eric Munoz, M.D., who introduced and continues to fight for the real Matthew’s Law, may be sent to AsmMunoz@njleg.org. Those wishing to send information in hard copy may address it to the above legislators at the New Jersey General Assembly, The Statehouse, Trenton, NJ 08625.

For further information please visit the Matthew’s Law web site:
www.matthewslaw.bravepages

Supporting Students with Disabilities in Inclusive Schools: A Curriculum for Job-Embedded Paraprofessional Development
by Gall Ghena, Jennifer York-Barr, & Jennifer Sommerness, University of Minnesota

Today’s special educators are not only teaching students, they are also training and supervising paraprofessionals who are delivering instruction in inclusive classrooms. This practical curriculum has been designed to assist elementary and secondary special educators in that growing training role.

The curriculum presents essential skills and knowledge that paraprofessionals can immediately apply in supporting students. It has seven instructional units, deliverable in 60-90 minutes each:
• What is Inclusive Education?
• Learning Opportunities for Students
• Prompt, Wait, Fade
• Natural Cues, Consequences, and Supports
• Individualized Adaptations
• Behavior as Communication
• Student Relationships

The package includes master copies of handouts, and guidance for special educators on facilitating the training.

Cost: $35. To order, contact the Institute on Community Integration, University of Minnesota, 612/624-4512, http://icli.umn.edu/products.
FROM THE EXECUTIVE DIRECTOR

From the Executive Director
BY NANCY WEISS

Excerpts from the Testimony of Nancy Weiss, Executive Director, TASH, at the New Jersey Restraint Bill Hearing, January 16, 2003.

Matthew Goodman’s death at the Bancroft School in this, my home state of New Jersey, is a tragedy. Of even greater tragic proportion is that people have died under similar circumstances before Matthew — here in New Jersey and in every state across the county — and that people will continue to be traumatized, hurt, and to die at the hands of those we call caregivers. This is torture, thinly disguised as treatment, and it will continue unless and until legislators like yourselves say, “enough.”

These are dangerous times for people with disabilities who have challenging behaviors. In 1998 the Hartford Courant’s groundbreaking series, Deadly Restraint, documented 143 instances over the preceding twelve years in which people with disabilities in this country died while in seclusion or while being restrained. Just as the names on the Vietnam Memorial in Washington only hint at the suffering that was endured, so read the names, dates, and one-line explanations that make up the data base of deaths assembled by the Hartford Courant reporters.

Within the few lines of text about each death there are hints at the true story, the true tragedy — a young woman killed because she refused to hand over a photograph of her family; a teen-aged boy because he was running across a playground; another because she wouldn’t go to her day program; or in Matthew’s case — because he was in a program that lacked the skills, knowledge or will to provide treatment that met even the most basic accepted standards of practice — and because no laws existed to protect this child from spending over 16 months in restraints that any of us would find unbearable for even an hour. With Matthew’s Law, the State of New Jersey has the opportunity to assure that no one else will die senselessly as Matthew did. With the passage of Matthew’s Law, the State of New Jersey has the opportunity to assure that Matthew did not die in vain.

People with disabilities behave in ways that challenge people and systems in an effort to assert some measure of control over their lives in environments in which their ability to have impact on their world has been severely curtailed. It is human nature to try to stake out some small claim to life when everyday opportunities to make your life your own have been stolen from you. People protest control by behaving in ways that are difficult or dangerous. It is not only ethically suspect but downright illogical to respond to desperate attempts to assert control by imposing greater levels of external control.

It is a sad paradox that the individuals who have the most severe disabilities are the most likely to be placed in the types of highly structured treatment environments that unintentionally produce the very types of behaviors for which restraints and other aversive procedures are used. In other words, the sad reality is, the more people dislike living in hospitals, institutions and other highly controlled settings, the more likely they are to attempt to protest against such treatment. The more demonstrative their protest, the more likely it is that their behavior will be viewed as an expression of their continued need for institutionalization and the less likely it is that their protest will be heard.

Seclusion and prolonged restraint are not only inhumane, they are unnecessary. There is simply no truth to the notion that because a behavior is severe that it needs or deserves restrictive procedures or restraints in order to modify it. Effective alternative approaches attempt to identify the individual’s purposes in behaving as he or she does and offer support and new skills to replace dangerous or disruptive behaviors with alternative behaviors that will achieve the individual’s needs. These positive approaches are not only more humane, they are as effective and more durable in their effect.

Restraints and seclusion are not treatment. Rather, they represent the failure of effective treatment. It is true that it is sometimes necessary to physically intervene briefly when someone is at imminent risk of hurting him/herself or others — but these are emergency interventions — not treatment. Any use of seclusion or restraint for prolonged periods is not an emergency intervention, it is not treatment, and it should be illegal.

TASH is not alone in its position on the use of restraints. The Federation of Families for Children’s Mental Health is strongly opposed to the use of restraint and views restraint as inhumane, cruel, and ineffective. The National Alliance for the Mentally Ill states that “the use of restraints is never appropriate as a therapeutic intervention but is only justified as an emergency safety measure.” The Joint Commission on the Accreditation of Hospitals states that any use of restraint poses significant risk to the physical and psychological health of an individual and that restraint should be used only as an emergency intervention. And finally, the National Association of State Mental Health Program Directors states that restraint is to be used as an emergency safety intervention of last resort and should never be used for the purposes of discipline, coercion or staff convenience.

TASH affirms the right of all persons with disabilities to freedom from restrictive and coercive procedures of any kind. TASH is unequivocally opposed to the inappropriate and prolonged use of restraint. We applaud the efforts of any state which takes the steps necessary to pass legislation that will result in the cessation of the dehumanizing and unnecessary use of restraint.


TASH: Public Policy in Action

MEDICAID PROPOSALS SPOTLIGHT LARGER POLICY ISSUES

Secretary of Health and Human Services Tommy Thompson recently announced a proposal to significantly change the national Medicaid program. The changes reflect a set of fundamental differences between and among advocates and policy makers in terms of how they view the federal government's role in the lives of citizens.

The discussion becomes particularly urgent in reviewing policies and programs that serve the needs of citizens who are in poverty, who are seriously ill and unable to pay for care, and for children and adults with disabilities and their families. Who is better suited to oversee and administer services and supports, the federal government or the state and local governments? When do services become "unfunded" mandates that restrict flexibility and innovation and why do states seem so uncaring of their citizens in need?

The current Medicaid "modernization" proposal seeks to encourage states to choose a new scheme that would collapse the Medicaid and Children's Health Insurance Programs into one capped block grant. The advantage to states that choose the new program would be an increase in funding (a "federal loan" of $3.25 billion in FY2004 and $12.7 billion over seven years), and vastly increased flexibility and discretion to essentially build their own programs for those individuals who are not currently members of mandated recipient groups.

Funding would flow in two allotments. One would cover acute-care health insurance and the other would be for long-term care and community services. States would be allowed to shift a certain amount of funds between the two allotments, depending on current needs. Secretary Thompson maintains that this would allow states to focus on "home and community-based care, and preventing or delaying inappropriate institutional care."

Disability rights advocate Bob Williams of the Advancing Independence: Modernizing Medicare and Medicaid Project isn't supportive of ending Medicaid as an entitlement, nor is he convinced that the proposal would bring about true reform. In his recent analysis of the Bush Administration's Medicaid proposal, Mr. Williams stated that "there is substantial reason to believe that it would force states to further reduce already limited services available to over 5 million children, adults and older persons on Medicaid who need daily help to live in their own homes and communities." He further points out that the increased flexibility might support those handful of states committed to building a high quality system of community supports. For the majority of states the proposed changes "would not be sufficient to reverse Medicaid's institutional bias. Nor would it guarantee people with disabilities, including those who are seniors, a real choice between getting the services they need to live at home and being forced to be in nursing homes or other institutions."

It is fair to point out that past administrations have done little to reform the institutional bias in Medicaid programs. Some would add that it is a positive step to have top adminis-

tration officials publicly state that bringing about increased quality and quantity of community living supports through Medicaid reform as a major policy goal. Still, the short term benefit to states facing budget shortfalls and cutbacks will be offset by the long term uncertainty for Medicaid recipients, and a probable loss of services for many without much to show either in the states' adopting progressive policies or in their increased capacity to provide quality community and home based supports and services.

The disability community and the current administration could both be more honest in their portrayal of the choices and issues ahead. Both the federal and state governments have demonstrated instances of utter indifference and ineptitude. It was state lawmakers who passed terrible laws excluding children with disabilities from public schools and, only recently have communities begun to tear down the notorious federal housing "projects" that became a blight and burden to generations of low income families. Neither the federal or state government can succeed without the meaningful participation of the "public" most affected by the actions of their government. TASH members are encouraged to learn more about the Administration's Medicaid program proposals and the response of the disability community by visiting the following web sites:

Advancing Independence: Modernizing Medicare and Medicaid Program
www.AIMMM.org

The National Health Law Program
http://nhelp.org

Bob Kafka at ADAPT:
bkafka@juno.com

Secretary's Press Release

For more information about this or other policy issues email Jamie Ruppman at jruppmann@tash.org
"It's Easy to Make the Wrong Choice When Presented With the Wrong Options"

BY DAN DOTSON

When trying to persuade legislators and policymakers on issues such as Matthew's Law, it is impossible to try and win the emotional argument when parents on both sides get up and deliver heartbreaking anecdotal testimony about their children. The parents who support the use of restraints for their children are just as emotionally invested in their children's lives as those of us who know that restraints are inappropriate. The tragedy is that the human services system is failing to meet the needs of children and families. Families are not always offered the options and practices by service delivery systems, i.e. education, medical, and social services, that are consistent with best practice and can result in positive outcomes.

We are hit over the head with our own mantra of "choice" as parents beg the legislators to support their right to choose to have their child in restraints or have aversive, "behavior changing" techniques applied. The parent’s right to choose is not always in the best interest of the child. Our society is willing to overlook the abuse and neglect of children with disabilities, yet there is a moral outcry when we hear stories of non-disabled children who are victimized by a parent who "chooses" to mistreat them. We have to get rid of the notion that we are choosing between good and bad. We have to convince the elected policymakers that removing the option of abuse is the best policy. We will not be able to change the minds of policymakers based solely on emotional arguments.

I attended the New Jersey Legislature's hearings on Matthew's Law. During the testimony, one of the supporters of Matthew’s Law directed a question to the parents who were there supporting the use of restraints, "would you still choose restraints and aversive if you were guaranteed a real functional assessment and effective positive behavior supports?" I didn't hear the question answered. It is a far-fetched hypothetical situation for a parent to contemplate when positive behavior supports are not even part of the system most families have an opportunity to see put into practice.

I can't judge the other parents for what they have chosen for their children. It is nearly impossible to make educated, rational decisions about the care of your child when faced with education and human service bureaucracies that are stuck in outdated models. The system is stacked against the weary parent looking for some respite and hope for their child's future. When presented with the wrong options, they will always make the wrong choices.

I recently had a confrontation in the halls of the Maryland General Assembly with a father of someone who has lived in one of Maryland's institutions for 30 years. It started out as a heated discussion on different sides of a proposed Developmental Disabilities Administration budget bill. But I quickly realized that he and I were really on the same side. We both want the system to do what we feel is best for our children. The major difference in our philosophies stemmed from our generational differences.

When his child, who is the same age as I am and from the same area in which I grew up, should have been starting school, he wasn't presented with the option of sending his child to school or offered in-home family supports. He was told by the social services system, the education system, and the medical system that the best thing for his child, and for his family would be to choose institutionalization. Thirty years later, there are services and supports in place that eliminate the choice of institutionalization for my child. I can't tell this loving father that he was wrong for deciding among the options he had at the time.

Thirty years from now, I will be at peace knowing that the decisions I made for my son today are not only based on my love for him as a parent, but rooted in the wealth of research and knowledge regarding best practices. But I wonder what choices I would have made if I didn’t work for TASH and hadn't read about inclusion and positive behavior supports. What if I did not have the opportunity to meet so many people who are teaching that there are better ways of treating people? What if I lived in an area where the school systems did not provide the supports that my son needs? What if my son's behaviors were more severe or become harder to manage as he gets older?

What's my point? I guess we need to face the fact that the parents who choose restraints and aversive for their children are not our enemy. In fact, we need them to help us convince policymakers that the real villain is a failed service system. We also need to solicit the support of the direct care workers who are not provided the training and tools to be able to deliver appropriate supports and interventions. It has to be shown that all stakeholders — individuals, families, providers, government agencies, and the whole community — would benefit from improving the systems that are in place to better serve people with disabilities.

We need to frame our arguments in a different way to demonstrate that our way really is the better way. The twenty-eight years worth of TASH Journals and Newsletters lined up on the shelf outside of my office contain the studies and data that support our positions. The hundreds of TASH members who are doing this work and successfully putting the theories into practice everyday have the expertise to show how things can and should be done. It should be the other side that is made to defend its position with real data and research. We can put forward any number of parents who will testify that their kids were mistreated because of restraints and aversive. The opposition can put forward even more parents to say how restraints saved their kids’ lives. So let’s get away from the emotional debate, and bring the discussion back to an intellectual, reasoned discussion that results in the best, most humane, and most effective supports for all of our sons and daughters.

Dan Dotson is the Information Services Coordinator for TASH, and the father of two sons, Matt and Tim.
**2002 TASH Positive Approaches Award Winners**

“TASH has a long history of recognizing people in the field for their leadership and advocacy concerning positive approaches to supporting people with disabilities who have histories of challenging behavior. In particular, TASH typically presents its Positive Approaches Award on an annual basis. Nominations for the Positive Approaches Award are specifically solicited through TASH’s Positive Approaches Committee with final recommendations by the committee made to TASH. Historically, and this year was no exception, nominees and recipients have come from many different walks of life and geographic areas. What recipients of this award share in common is their respective focus in their endeavors in the promotion, adoption and utilization of positive approaches. In particular, all recipients of this award have made a constructive difference in the field and in the lives of the people they have touched.”

It is with great pleasure that we announce the recipients of the 2002 TASH Positive Approaches Award:

Elaine Bailey, Cindy Fertsch, Kathy Mills, and Susan Thompson  
(Parent Team in New Jersey)

Bill Ashe  
(Executive Director of Upper Valley Services in Vermont)

Dr. Frances Clark  
(Coordinator for West Virginia Department of Education, Office of Special Education)

Scott Shepard  
(Director of Support Living Program and State Training Team Coordinator for the RRTC in California)

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**Thank You!**

TASH’s work is dependent on the financial assistance of our donors and members. We wish to acknowledge the generous donations of the following individuals:

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Moses Atayoha Odharo  
Chris Oliva  
Marianne Roche

A SPECIAL THANKS TO LIFETIME MEMBER

Ming-Gon John Lian

TASH’s lifetime membership option entitles you to full international and chapter member benefits for your lifetime, and the cost can be remitted over several monthly payments.

If you are interested in becoming a TASH lifetime member, please contact Rose Holsey at 410-828-8274, ext. 100.
Seven years ago, while training group home staff on basic behavior management and Positive Approaches, a "reachable moment" situation occurred. The group was composed entirely of women who worked supporting people who lived together in several apartments. I had just begun the training when one of the staff came in late. She looked frazzled and one of her co-workers asked her if she was okay.

"Lorenzo's at it again! I had to stay for a while in case they had to restrain him more."

"He doesn't belong in an apartment, that's for sure," one of the other women said. The rest of the group nodded in agreement.

I didn't know anything about Lorenzo, but it seemed as if all of the staff had had run-ins with him.

"Why don't we use Lorenzo's situation as a case in point for the training?" I suggested. "Let's see if we can figure out what's going on with him."

I began by asking what Lorenzo's problem was. Everyone felt that he was disrespectful, deceitful, "too big for his britches," and generally didn't listen to staff when they told him what to do. His behavior plan, which had been in place for years, hadn't changed how he acted, but it did give them some control over him, since it contained a restraint section.

"What happened today, Robyn?" I asked the staff person who had arrived late.

"He came in, didn't say hello, took a can of soda out of the fridge and went out on the balcony to sit down. He had those darn earphones on, listening to that music, and he didn't even hear me tell him it was his night to make dinner. I followed him out there and pulled the earphones off so I could redirect him back inside. As soon as I did that he jumped up and pushed the chair right into my leg. "Robyn pushed the chair in front of her, making it clang into another chair.

"That's Lorenzo," another lady said. "He doesn't care about you getting hurt. Just wants to do what he wants to do."

"Anyways," Robyn continued, "I grabbed him by the arm to do an extended arm assist and he dropped straight to the floor. When I tried to grab him again he sat there and kicked me four or five times. He was totally out of control."

"What happened then?" I inquired.

"I followed the behavior plan. It says that when Lorenzo gets aggressive we're supposed to put him in a restraint until he calms down, then have him stay in his room until he apologizes."

"He doesn't care if he stays in his room," one of the other staff remarked. "That's no real punishment for him. He's got his earphones and Gameboy, and I think he has candy hidden somewhere in there."

Robyn grinned mischievously. "Well I don't know about the candy but he doesn't have the other entertainment. I locked it in the staff office."

"You know that's a restrictive procedure," I pointed out. "Is that written into his plan?"

"No, but that's what works with my kids. Hit him where it hurts or his behavior is never going to change."

Again, more nods and supportive grins.

"So," I asked, "what's the current status?"

"It took two of us to get him in there. We had to drug him off the balcony, through the kitchen, down the hallway and into his room. He was kicking and screaming profanity the whole way. Once we got him to his room he calmed down. I think he does a lot of this just for the attention. Far as I know he's still in his room. It's not likely he's going to apologize."

"If he doesn't apologize, then what happens?" I asked.

"Sooner or later we let him come out. Sometimes even when we tell him it's okay, he won't come out, just so he can aggravate us."

"I usually take some food to his room if he doesn't come out," one of the others mentioned.

"And you see how he thanks you for being nice? He just keeps it up," Robyn added.

I jumped in to refocus the group. "Okay, folks. Here's what you're telling me. When Lorenzo becomes aggressive, you give him a verbal redirection. If that doesn't work, you try to physically assist him to his room. If he doesn't respond to that, you physically restrain him and take him to his room. Then, to get out of his room he has to apologize. If he doesn't apologize, he usually will be allowed to leave his room at some point later in the day. Does that about cover it?"

The group looked around at each other and murmured their assent.

I wrote all of this on a large sheet of paper and taped it to the wall. "Now," I announced dramatically, "I want you to think about a different scenario. Imagine yourself at home tonight after this long day of training. Pretend that as you walk into your house, all you can think about is sitting down, relaxing, and watching your favorite TV show. Can everyone picture that?"

"Sure can," one of them blurted out, "because that's exactly what I'm going to do!" We all laughed.

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"Like... so controlling! He knows what would happen if he acted like that towards me."

"You mean that you have some power in the relationship too?" I asked.

"Absolutely!" she responded with a chuckle.

"Right, ladies?" The group hooted in agreement.

I taped a blank piece of paper to the wall, next to Lorenzo's behavior plan, and labeled it, "Staff Behavior Plan."

"I want you to go back to the beginning of your scenario," I suggested, "and imagine a different course of events. See yourself sitting in a comfortable chair and watching your favorite sitcom. Your significant other comes in from the other room, gives you a hug and asks, 'What's for dinner? What would your reaction be?"

"Well, first of all," Robyn said, "I'd be getting up off the floor if he ever gave me a hug when I came in from work. After that, I'd probably tell him to leave me alone for a while, that I'm tired and I want to relax."

I wrote her suggestion on the wall.

"What else might you say?" I wondered, looking around at the group.

"Why don't you make dinner for a change?" a woman in the back called out.

"What else?" I asked, still writing.

"Let's make dinner together?" one of the others ventured tentatively.

"Why don't you take me out to dinner?" another challenged.

"I don't think we're talking about all of the time here," I reassured them, pointing to the list on the wall. "We're talking about choice, control, preference and opportunity. It isn't likely that any of you would go out for dinner every night or have dinner cooked for you all of the time either, but if those choices were part of the mix, wouldn't it be more interesting? Maybe once every week one of the people you serve could pick a dinner option from the list. My guess is that the other six nights might be a lot more pleasant. Just an idea."

I pointed back to Lorenzo's original behavior plan. "What do you think we can do about some of this? Can you see where we may be creating some of our own distress?"
Oh, That's What You Mean By Positive Approaches!
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"We could back off a little when he gets home," the woman in the back observed, "and let him chill out a while before we ask him to do his chores."

"Maybe he would rather cook on different nights?" someone else suggested.

"How about if he helps to choose the menu? I know he doesn't like some of the meals we have now," Robyn added.

"How are we going to find out which of these ideas will work?" I asked, trying to keep the momentum going.

"We'll have to talk to him," one of them noted, "and see what he likes."

"And maybe we can talk to Lorenzo's family about him and find out how they keep his behavior under control. They don't seem to have the problems we go through," reflected Robyn.

"Both of those ideas will take you in the right direction. Nice work!" I remarked. "I think Lorenzo and you are in for some better times."

There were smiles and nods all around.

Robyn looked at her enthused co-workers, then back to me, and exclaimed in a voice bursting with insight, "Oh, that's what you mean by Positive Approaches!"

POST SCRIPT
It was more than a year later that I received any feedback about how Lorenzo and his staff had made out. The new assistant director of the agency called me to arrange for another positive behavioral supports training. During the conversation, I asked how Lorenzo was doing.

"He's moved to his own place and he's doing well as far as I know," she said. "How do you know Lorenzo?"

I explained what had happened at the training the year before.

"I've been here for almost six months and don't remember hearing anything negative about Lorenzo. In fact, his team really pushed for him to get into the minimal supervision program, so they must have felt he was pretty capable."

Only two of the staff from that original training were still at the agency and attended the training. Before I began, I asked them what had transpired with Lorenzo.

"Oh, we did a lot of things," Robyn said. "I remember that we got him into a cooking course and we put him on the activity planning group."

He became so independent that he's in his own apartment now."

"We've got this other resident, though, and she's a real pistol," the other staff person said.

"Hey," I said. "Why don't we use her as a case study for today's training..."

NOTE: This article is reprinted with permission of The Pennsylvania Journal of Positive Approaches and appears in their current issue, Volume 5, Number 1.

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The Department of Special Education, School of Education, California State University, Fullerton is accepting applications for an Assistant Professor position. Responsibilities include teaching, student advisement and supervision, supervision of graduate level research projects, program development, creative and scholarly activities, university service activities, and development and continuation of collaborations with various community schools and agencies.

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Fullerton, CA 92834-6868
Editor's Note: While the adoption and utilization of positive approaches continues to grow across schools and communities, it is unfortunate that in too many places the use of positive approaches is viewed as the exception to the rule in terms of state-of-the-art practice (e.g., see articles pertinent to positive approaches versus the use of restraint in New Jersey in this issue of TASH Connections). In light of this reality, we must collectively remain vigilant in our advocacy for endeavors that build capacity and that result in systemic changes that are conducive to the use of positive approaches.

Tim Knose

In addition to other training and technical assistance efforts, the New Jersey PBS team has established the In-home Training Initiative. This Initiative is unique in that parents drive all activities. They are the lead trainers, mentor other parents, and have developed the curriculum and the new, "family-friendly" functional behavioral assessment form. The project is composed of four parent mentors, Cindy Fersch, Kathy Mills, Susan Thompson and Elaine Bailey and one professional, Chris Devaney.

PARENT MENTORS
The four mentors are parents who originally sought assistance for their children that have significant disabilities and behavior challenges. These parents have been through extensive training and are all state team members of the "Building Futures Project," New Jersey's RRTC project on Positive Behavior Support.

This article is co-written by Elaine Bailey, parent trainer/mentor and the mother of Tucker, who is described in the case study below. The article will provide a brief description of PBS as viewed by the participants, an overview of the training structure, and a description of Tucker's case to illustrate positive behavioral supports.

The parents and professionals involved in this Initiative feel strongly that the positive outcomes for those who have participated to date are due to the knowledge and experience the parent mentors bring to the effort. Some of the advantages of this parent driven PBS Initiative include:

- We all have children with disabilities and significant behavior challenges both at home and at school.
- We have a unique understanding — a view from the inside — of the PBS process.
- We understand how these challenges impact the whole family, especially siblings.
- We understand the need for support over time, i.e. continued support after the training.
- We have learned the value of teaming and collaboration with schools and community agencies.

CHARACTERISTICS OF POSITIVE BEHAVIOR SUPPORT
We view Positive Behavior Support as a means to better understand our children with problem behavior in order to help them become active participants in their schools and communities, enjoying the quality of life afforded to their siblings, classmates and other members of their communities.

PBS is a proactive and educational model of support that centers around determining the function of problem behavior from the individual's perspective and teaching socially acceptable replacement behavior to serve the same function. Positive Behavior Support is not about controlling behavior using rewards and punishment. Often, our first instinct when a problem behavior occurs is to react and reprimand or punish the individual. Yet, when we take the time to find the meaning of the behavior, it leads us to understanding and support.

The primary goal or objective of Positive Behavior Support is to improve the "quality of life" for the individual. It is about each individual being appreciated for his or her gifts and capacities and being able to contribute to family and communities in positive ways. It is about choice, self-determination and skill building. Most importantly, it is
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about love, meaningful relationships and friendships. When supports work and we truly understand each other, mutual change occurs. When this happens, there is learning and growth for the individual as well as his or her family, teachers, friends and all who are part of his or her life.

PBS IN-HOME TRAINING STRUCTURE

The training and mentoring structure began as a comprehensive 6-day training modeled after the Team Training Model used in the New Jersey Building Futures Project. Based upon the experiences of family participants, it has evolved into the process described below which includes two full days of "formal" training as a group with all other work done as in-home technical assistance and support.

A team composed of a parent mentor and a professional in collaboration with the family and their child. This work occurs in the home, school or community, basically wherever the child is demonstrating problems. Training materials from the Team Training and Building Futures projects serve as the basis, with modifications to make them more family-friendly. In addition, parent mentors have developed video tapes and sample interventions based on their personal experience to serve as concrete examples for trainees to adapt and use with their own child. An evening training is offered for families whose schedule prohibits them from attending the day training. Childcare is also provided when needed.

Three to five children with extreme problem behavior are targeted as focus individuals for the training. Their parents and other stakeholders in their lives participate as teams throughout the process, with all training activities designed to address the needs of the target children and their teams. Members from additional families are able to participate in the training process by becoming members of the focus individual's teams.

Prior to the first day of group training, each family receives a home visit for a pre-training assessment. The parent mentor & professional provide an outline of the training process, briefly describe PBS and Functional Behavioral Assessment (FBA) and begin gathering FBA information. This is done via interview using a modified version of the Functional Behavioral Interview format (O'Neil, Horner, Albin, Sprague, Storey, & Newton, 1996). The interview covers the range of information typically gathered for FBA. Additional information is gathered by observing the child in a variety of settings. The assessment information is analyzed and by the time of the first formal day of training, the team has enough information to begin forming initial hypotheses as to the function(s) of target behavior.

Following this the 2-day training is scheduled. Each family attending the training is assigned one of the parent trainers as a mentor. The two days of training are scheduled a month apart in order to complete a MAPS (McGill Action Planning System) i.e., person-centered planning session for each child and to conduct behavioral observations in the home/community. One of the major goals of this revised training sequence is to have enough assessment information to develop initial hypotheses and for families to have specific antecedent intervention strategies to implement at the end of the first day of training.

Training Day 1 Topics:

- Training Overview
- Person Centered Planning
- Functional Behavioral Assessment/Hypothesis Development
- Introduction to Antecedent Intervention Strategies

The training process includes a combination of lecture and hands-on activities. Each team conducts all activities in relation to their focus individual. The goal of this day is to develop hypothesis statements, plans for conducting further assessment and specific intervention strategies for each focus individual.

One major activity between the first and second training days is for each team to conduct a person-centered planning session using the MAPS process (Forest & Lushhaus, 1990). The session is facilitated by the parent mentor. This process gives the team a better understanding of the focus individual as a person, and facilitates action plans for improving quality of life in accordance with the individual's preferences and the values of their family.

In addition to the MAPS session, there are typically two visits with the family to assist in both conducting assessment activities and implementing antecedent interventions before the second day of training. The mentors guide the family through this process.

Training Day 2 Topics:

- Antecedent Intervention Strategies (continued)
- Components of Comprehensive PBS
- Skill Building
- Consequence Planning/Direct Intervention
- Crisis Management Strategies

As in Day 1, lecture is enriched with practical examples of interventions (for example, sample social stories, pictures, schedules and other visual supports), video dips of the impact of interventions on the problem behavior of parent-mentor's children and variety of hands-on activities that center around the focus individuals. A support plan is developed for each focus individual with action plans for implementation.

Following the second day of training, support is provided for each family on an ongoing basis as needed. Support is provided in implementing, evaluating, and making modifications in the support plan, as well as in other areas where support and/or information is needed.

Such support includes being in the home (or community) and modeling intervention, coaching the family and assisting them to evaluate the impact of intervention, making needed adjustments and when necessary, cycling back through the Functional Behavioral Assessment and hypothesis-generating process. Some families may need weekly visits for a period of time and then can reduce the frequency of visits to monthly, bimonthly, etc. Others may need more support for a longer

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period of time. At this point mentors have been available to the families, at least via phone, as long as the support has been needed. In addition, some families remain connected by joining the project and becoming parent-mentors themselves.

TUCKER’S STORY
“In April 1999 my son, Tucker, began to have significant behavior challenges related to his autism. I sought assistance from a statewide autism support center and attended a 6-week behavior program. Shortly after the third week of training we agreed, as a family, that the approach they were teaching was not respectful to Tucker and we discontinued the training. A short time later I was referred by a friend to a behavior support specialist trained in PBS.

Soon after we started working together, we realized that the process of PBS, with the focus on understanding the individual, respectful treatment, teaching functional skills, community inclusion and acceptance was a perfect fit for our family. The PBS process also allowed us to support Tucker in his struggles while honoring him for who he is, with his own unique gifts and strengths.”

BACKGROUND
Tucker is an 8-year-old boy with autism. He lives with his mom, dad, 2 brothers and grandmother. He was diagnosed with autism at the age of 4. He attends his community school and has been included in class with his typical peers since kindergarten.

Tucker has presented us with a variety of unique behavior challenges. A small selection of some memorable ones follows:

Transitioning to school bus from home: Meltdown, dropping to the ground, hitting, pinching, kicking, screaming and crying.

Refusal to speak to adults in school: Tucker wouldn’t respond to questions from adults or have any verbal interaction with them from September until mid-January.

Extreme hyperactivity and aggression: Tucker became physically aggressive toward his brother after school. Aggression included hitting, kicking, biting and throwing objects at his brother.

BEHAVIOR CHALLENGES, HYPOTHESIS, and SUPPORT STRATEGIES
1. Transitioning to school bus from home

We determined that Tucker had developed a fear of the bus, possibly from a loud noise or backfire.

Our list of strategies included:
**Visual bus schedule with days of the week listed using PECS (Picture Exchange Communication System).**
**Choice procedures were incorporated in all morning activities.**
**Visual morning schedule using PECS.**
**Social Story explaining morning expectations.**

2. Refusal to speak to adults in school

This was a behavior we had not experienced from him before. To this day we have no idea what prompted it other than his social differences due to autism. Over the years Tucker had developed a natural circle of friends. We decided to use this strength in the following way:

Temporarily allowing peers to support Tucker in the following way:
**Teacher presented question to peer.**
**Peer presented the question to Tucker.**
**Tucker answered the peer.**
**The peer relayed the answer to the teacher.**

Eventually his classroom teacher found that he would speak to her through a puppet (Curious George). The team also decided that the pressure to speak (answer) caused behavior escalation. He was simply given the time he needed to become comfortable with the new people and his environment.

Note: This was the regular education teacher’s first experience teaching a child with a significant disability. Her flexibility and creativity were critical in the positive outcome Tucker experienced in first grade.

3. Extreme hyperactivity and aggression

We decided that Tucker was probably falling apart after holding himself together all day at school. We had seen sensory difficulties causing this type of problem (aggression and hyperactivity) with him in the past.

Here are some of the strategies we used:

**School added a sensory break at the end of Tucker’s day.**
**Visual (PECS) schedule for after school.**
**Choice of chores on visual schedule that require physical activity and provide sensory input: watering flowers, taking out trash, moving wet laundry from the washer to the dryer, vacuuming.**
**Television and computer time as rewards for chores finished.**

SUPPORTS TO ENHANCE QUALITY OF LIFE

Sitting Support: A wonderful natural support for Tucker has been his older brothers, Jack and Manuel. Since they were young children, Jack has instinctively understood Tucker’s needs and was an interpreter for him before Tucker was able to communicate effectively. His other brother, Manuel, recognized his sensory differences (auditory sensitivity) even before his diagnosis and suggested support strategies (large hat to cover ears).

Supports to Encourage Friendships: Tucker is an engaging little boy with a dynamic personality. We have always made it a point to encourage Tucker’s desire to be included in the other children’s activities. We have found that as long as we educate people (adults and children) about Tucker’s differences then, without exception, everyone has been supportive. I began a more formal way of introducing Tucker to his classmates after his year in kindergarten.

Kindergarten had gone well, but Tucker’s different behaviors made some of the children nervous. He made one close friend, Matt, who initiated play dates and continues to be a very important person in his life. We were fortunate to have Matt and Tucker assigned to the same class again in first grade.

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I asked Matt to help me introduce Tucker to the class. I first asked the kids ways in which Tucker was different from the rest of the class. They gave answers like; “he has an aide with him,” “he doesn’t talk to grownups,” and “loud sounds hurt his ears.” I then asked ways in which he is the same as them. They answered; “He has a brother,” “he likes dinosaurs,” and “he likes to play.”

I gave them a brief overview of autism and passed out a sheet describing “How to be a friend to Tucker,” while Matt told them about playing at our house and the interests he and Tucker share. I also sent a toy dinosaur egg home with the kids in an attempt to start conversations about Tucker between the kids and their parents. The children were incredibly receptive to what I had to tell them and brainstormed among themselves ways to make Tucker feel comfortable in the class.

How to be a friend to Tucker:

- Talk to Tucker just as you would any other kid.
- If you want to play with Tucker and he is doing something silly, like pretending he’s an animal, say “come on Tucker, I want to play, be a boy.”
- If Tucker tries to hug you too much, remind him to do “high-fives.”
- If Tucker looks lonely and is playing by himself, go up to him and say “hi.”
- It is really nice to help Tucker but make sure he tries to do stuff himself first.
- Be kind. It’s okay to be different!

First grade turned out to be a wonderful success for Tucker. Matt and he are still close friends and he has added another best buddy, Anton. Matt, Tucker and Anton like to be known as the “Three Musketeers” and play very well together. They were assigned to the same second grade class and continue to see each other outside of school. Anton and Matt both have wonderful, open-minded parents who are happy to have their children playing with someone of different abilities. Anton and Tucker have joined our community basketball league. Tucker is a little apprehensive, but Anton is with him all the way reassuring him and cheering him on!

OTHER SUPPORTS:

Transition Supports: Tucker has always struggled with transitioning from one school year to the next. In pre-school a transition plan was developed where Tucker began visiting next year’s class 2 or 3 afternoons a week beginning three months before the end of the school year. He also meets the teacher and helps her set up the classroom during the final week of summer break. We also realized relationships are critical for a smooth transition. Therefore, we arranged to have several of Tucker’s close friends assigned to the same class for the next year.

Psychiatric Supports: In addition to autism Tucker has been diagnosed with bi-polar disorder. A critical part of Tucker’s continued success has been evaluation, medication and monitoring of this disorder by a pediatric psychiatrist specializing in the treatment of individuals with developmental disabilities.

Sleep: A major contributing factor to Tucker’s past behavior challenges has been sleep difficulties. Prescriptions and over-the-counter medications had failed to remedy the problem. On the advice of a fellow parent, melatonin was tried and Tucker responded favorably. He is now able to fall asleep easily and continues to sleep through the night.

Continued Challenges: We found that despite the successes there will always be new challenges. For example, as Tucker and his peers get older some of his delays become more apparent and additional supports are needed. He had little difficulty with first grade. However, in second grade we found that he needed more significant adaptations to his curriculum and more attention paid to his sensory difficulties. Another area that needs to be addressed is teacher/staff training in current inclusion technology and Positive Behavior Supports. However, following a positive behavioral support model, we have the tools to tackle each challenge as it emerges by cycling back through the Functional Behavioral Assessment process to develop hypothesis-based interventions that will work for Tucker, his family and friends.

In summary, the in-home PBS Support Training Initiative has had a positive impact on the individuals with problem behavior, improving the quality of their lives, as well as those of their parents and siblings. The project in supported in part by the New Jersey Department of Developmental Disabilities and by countless volunteer hours on the part of the mentor-parents and professionals. They are currently seeking external funding to support and expand this innovative and very effective PBS training initiative.

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References


Educating students with problem behavior can be, to say the least, a significant challenge. This challenge is often compounded by the negative reputations that can accrue over time for particular students with histories of problem behavior. Increasingly, more and more schools are implementing positive behavior support (PBS) in their efforts to provide appropriate educational services and programs for students in schools. As encouraging as this evolution in practice is, there continues to be a significant portion of schools that have struggled with adopting and utilizing the approach referred to as PBS.

While there are different reasons for this difficulty in spread of effect, it appears that one of the more prominent reasons is that many school-based teams struggle with the practice of linking assessment with designing interventions and supports. In particular, having a firm understanding of basic questions to ask when conducting a functional behavior assessment (FBA) and how to link the educational team's responses to those questions when designing behavior support plans is important.

**FBA and Basic Questions For Student-centered Teams To Ask**

It is understandable how some educational teams can become disoriented or confused when conducting an functional behavior assessment with a student who displays perplexing behavior. This confusion, in some ways, is not dissimilar to the state of confusion that can arise for a team that is conducting a functional academic assessment with a student who, despite good faith efforts on everyone's part, is not making sufficient progress in the school's curriculum. While there are a variety of information gathering approaches and tools that can be used when conducting an FBA, the core set of questions that need to be asked by the educational team in their search for what works with a given student can be framed in much the same way as the questions that we suggest children use when they are learning to read for comprehension. Asking the questions, Who? What? Where? When? and Why? can greatly facilitate an educational team's pursuit of effective interventions and supports in school.

**Who?** Who is engaging in the problem behavior and whom is that student with when he/she engages in the problem behavior?

**What?** What exactly - operationally — is the behavior of concern?

**Where?** Where does the student engage in problem behavior (in which settings)?

**When?** When (in which routines) does the student engage in the problem behavior and when is the student most successful (not engaging in problem behavior)?

**Why?** What function does the problem behavior serve for the student? What is he/she able to access or avoid as a result of engaging in the problem behavior?

Obviously there are numerous tools and approaches that a team may use to ask these five "W" questions during the information gathering process known as functional behavior assessment. As such, teams will likely use different data collection procedures that are most appropriate to the given student, team, and context at school (e.g., direct observational protocols, behavior scales and checklists, interview procedures). However, regardless of the information gathering procedures used, the five W questions remain as the core questions in the functional behavior assessment.

**Linking Team Responses to Questions to Designing A Student-Centered Plan of Intervention And Support**

While there are a variety of reasons why assessment occurs in school settings, one of the principal reasons is to increase the likelihood of successful instruction with students who are struggling. A functional behavioral assessment (as described above) can serve this purpose. The results of an FBA (a team's responses to the five W questions) are summarized into hypothesis statements. The following two types of hypothesis statements are recommended, as they capture both the specific details of student behavior across settings and routines and the larger picture (context) of the student's life circumstances.

**Specific Hypothesis:**

When this happens: (summary of fast and slow triggers that lead to problem behavior)
The Student does: (statement of the problem behavior)
In Order To: (team perspective on the potential function of the problem behavior)

**Example:** When Jon is presented with directions that are not paired with pictures depicting the task to be completed, or when he is presented with any task that requires him to sit still for longer than five minutes on days when he is not feeling well, Jon will make loud screeching noises and physically leave his work area in order to avoid the situation and/or task.

**Global Hypothesis (Other Relevant Information):**

A global hypothesis is a brief summary statement of other relevant information pertaining to the student's history including his/her likes and dislikes, opportunities for age
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appropriate choice/decision making, hopes and fears, and other factors that influence the student’s quality of life.

Example: Jon is a 17-year-old young man who has language impairment and has also been identified as having moderate to severe levels of cognitive impairment. He enjoys being with most of his local high school classmates and particularly enjoys job work-site activities that are part of his transition program (he works at the local newspaper with the support of a job coach).

Jon lives with his Aunt and Uncle (Mary and Paul), whose other children are all grown and are independently living in various communities. Their one son, David, lives nearby and includes Jon in some activities with him and some of his friends. Jon uses a picture wallet to communicate his needs and interests with others at school and in the community. While he appears to enjoy being around young people his own age, Jon does not appear (as reported by school staff and his family) to have developed any close friendships with peers at school or in the neighborhood.

Taken together, hypothesis statements serve as the primary navigational device for the educational team as they brainstorm, prioritize, and select intervention and support strategies. To illustrate, Jon’s team will not only need to attend to the details indicated in their specific hypothesis as noted above (e.g., the conditions under which Jon engages in problem behavior and the function that his problem behavior serves), but also broader quality of life factors as noted in the global hypothesis related to friendships and the implicit need to help Jon increase his opportunities for choice and degrees of self-determination that are age appropriate for a 17-year-old.

Addressing the Issue of Contextual Fit

In addition to logically linking interventions and supports with hypotheses, the design of student-centered support plans is also influenced by practical matters that include the feasibility of implementing relevant interventions and supports. This issue, referred to as contextual fit, is important in that it is highly unlikely that any given set of interventions and supports will be consistently implemented in school settings if team members do not:

1) have the support that they need to implement the plan coupled with

2) the team sharing the perspective that the agreed upon plan is realistic to the situation, and that the team’s plan has a higher likelihood of success than past practice.

Specifically, support team members should be encouraged to identify potential problems with implementation as they are prioritizing interventions and supports based on their hypotheses.

For example, while there may be a variety of ways to use picture systems paired with verbal directions at school the array of feasible ways in which to address communication concerns at Jon’s job site may create practical constraints. In light of such potential issues, student-centered support teams should carefully consider all relevant settings and typical daily routines within which the student of concern must function, and the skill level and needs of the support team members who will provide direct support to the student throughout the design process.

Summary

Practical application of PBS in schools starts with an understanding of the basic questions to ask when confronted with a student with problem behavior and how then to use the team’s responses to those questions (the five W questions) when designing interventions and supports.

The PBS process, while being grounded in person-centered values, is also an investigative search for what will work better than the current approach to practice. The educational team not only must link the results of the FBA (in the form of hypotheses) to the logical identification of interventions and support strategies, but also must address matters of contextual fit as previously described. Such an approach can serve well to address not only the specific needs of the individual student, but also other relevant parties involved with school-based programs.

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ARE YOU A UNIVERSITY PROFESSOR?

TASH has a Student Membership Program!

The program was developed through discussions with professors who wanted to encourage professional identity through student membership in a strong advocacy organization while assuring that their students had access to enough issues of Research and Practice for People with Severe Disabilities (RPSD) or formerly JASH) for them to be able to complete a variety of journal article review and comparison exercises they assign.

The package works like this: Professors can either assign TASH membership as one would a text book or package of readings, or can offer it as an option. Either way, if ten or more students join, they receive a discount off the already low associate member rate. The discount amount increases as the number of students signing up increases.

An introduction to TASH is likely to be one of the most valued resources you can offer students as they enter the disability community in their professional capacities. To learn more about TASH’s Student Membership Program, contact Rose Holsey, 410-828-8274, ext. 100 or e-mail: rholsey@tash.org

PAGE 19  TASH CONNECTIONS, JANUARY/FEBRUARY 2003
2003 Call for Presentations

Co-sponsored by: International TASH Conference
December 10-13th
Chicago Hilton and Towers

All people, regardless of their label or perceived level of disability, should have the supports they need to direct the course of their own lives, and to live and participate successfully in the community. All means All!

Proposals should be submitted on topics that demonstrate innovation, collaboration, energy, daring, and all that is possible for people with disabilities and their families. Presentations should be made by a team that includes individuals with disabilities, family members, advocates, and professionals.

1) If accepted to present, All presenters are required to pay conference registration fees.
TASH relies on membership and conference registration fees to be an independent and powerful advocacy organization. We strongly encourage presenters to be TASH members. International TASH members, self-advocates, parents, and family members are eligible to register at a reduced rate. Visit www.tash.org to determine what registration and audio visual rental fees may be if you are selected as a presenter.

2) A description or abstract of the proposed session must be sent along with the completed application, postmarked by March 27, 2003.
Abstracts need to contain the following information: (1) describe the topic or issue addressed, (2) describe the importance and contributions of the session, (3) describe how the proposal meets current or emerging standards for "best practice," (4) describe session format - i.e. skill-building, program discussion, panel, etc.

3) Proposal content must reflect the values and resolutions of TASH.
TASH is dedicated to disseminating information that reflects the realities of pursuing equity, social justice, diversity, and full school, community, and work inclusion for people labeled with disabilities, particularly those who are at most risk of being excluded from community life. The proposal title, description, and all content of presentations must use "people first" language, and must support the value of inclusion. Presenters need to ensure that materials used in their session are accessible to a broad range of ability levels, and are made available in alternative formats, such as making handouts in computer text files or large print, and ensuring that any videos used are captioned.

4) Please limit the abstract to 300-600 words (1 - 1 1/2 pages).
Do not send any other materials. You may submit the information on the application form or in alternate format, as long as all of the information requested is included. The form is available to download from TASH’s web page: www.tash.org. You must, however, print and mail the form as per the guidelines. Please DO NOT email your proposal, as we cannot assure receipt of electronic transmissions.

5) Proposals are cross-rated by three reviewers on the following criteria:

1) relevance to TASH mission
2) interest to TASH members
3) extent to which information is state-of-the-art or cutting-edge
4) practicality of content
5) clarity of the proposal

Each session chairperson will receive notification in July regarding the status of his/her submission. If you do not receive notification by August 1st, please contact Kelly Nelson. TASH uses email as the primary mode of notification. If your email address changes at any time during the process, please notify Kelly Nelson at knelson@tash.org to ensure that you continue to receive ongoing correspondence.

The 2003 TASH Call for Presentations is available in alternate format upon request.
29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204 ♦ www.tash.org ♦ 410-828-8274
2003 TASH Annual Conference

Call for Presentations  2003 TASH Conference Dec 10-13th  Chicago

2003 TASH Conference Presentation Application

Please complete all sections of this form. Submit 4 copies of the form and 4 copies of the required attachments listed below. Mail by March 27, 2003 to:

Kelly Nelson, TASH, 29 West Susquehanna Avenue, Suite 210, Baltimore, MD 21204
Questions? Phone: 410-828-8274 x 105
Sorry, faxed or e-mailed copies cannot be accepted.

Coordinator (You may only submit as a session coordinator on one proposal):

ORGANIZATION:

ADDRESS:  CITY:

STATE/PROVINCE:  COUNTRY:  ZIP/POSTAL CODE:

DAYTIME PHONE:  HOME PHONE:

FAX:  E-MAIL:

The above address is:  ☐ HOME  ☐ WORK  ☐ OTHER

Session Information  Please attach an abstract which includes the following information:

- Session Title
- A short (40 word) description of your session that will be used in the conference program. Participants will select which session to attend based on this description, so write the description with care!
- An abstract (not to exceed 600 words (1 1/2 pages) that describes: the topic, how the presentation meets current or emerging standards for "best practice," and the session format.
- A listing of all co-presenters, with contact information including: name, address, phone, fax, and e-mail for each person.

Requested Session Type:
(Please check only one)

☐ Preconference Full Day Tech Workshop
☐ Roundtable Luncheon Discussion
☐ Poster Session
☐ 1 Hour Breakout Session
☐ 2 Hour & 15 minute Breakout Session
☐ 1/2 Day Saturday Institute

Applicable Interest Area  (This category determines which committee reviews your proposal. Please pick only one)

☐ ADVOCACY  ☐ GUARDIANSHIP  ☐ SPIRITUALITY
☐ AGING  ☐ ALTERNATIVES  ☐ SEXUALITY/SEXUAL EXPRESSION
☐ ASSISTIVE TECHNOLOGY  ☐ GOVERNMENTAL AFFAIRS  ☐ STUDENTS WHO "SEVERELY"
☐ CREATIVE/PERFORMING ARTS  ☐ LEISURE AND RECREATION  CHALLENGE SCHOOLS BUT WHO
☐ COMMUNICATION  ☐ LITERACY  DO NOT HAVE LABELS OF
☐ COMMUNITY LIVING/HOUSING  ☐ MANAGEMENT ISSUES "SEVERE" DISABILITIES
☐ CRIMINAL JUSTICE  ☐ MULTICULTURAL ☐ TRANSITION
☐ INCLUSIVE EDUCATION  ☐ PARADEUCATOR
☐ URBAN EDUCATION  ☐ PERSONNEL PREPARATION
☐ HIGH SCHOOL INCLUSION  ☐ POSITIVE BEHAVIORAL
☐ INTERNATIONAL INCLUSION  ☐ APPROACHES
☐ STATEWIDE ALTERNATE ASSESSMENT  ☐ POST SECONDARY ED
☐ EARLY CHILDHOOD  ☐ RELATED SERVICES
☐ EMPLOYMENT  ☐ RESEARCH
☐ ETHICS/RIGHTS  ☐ SELF-DETERMINATION
☐ FAMILY  ☐ SPECIAL HEALTH CARE

☐ I understand that it is my responsibility to contact co-presenters regarding their participation in this session and to inform them of the requirements listed on the guidelines for submission (including payment of conference registration fees, which range between $84-$374) if accepted.

Signature (required):

☐ Please list one other related interest area to which this session would apply:

Indicate which content level is most descriptive of your session:

☐ Introductory  ☐ Advanced
BY CHRISTOPHER L. SMITH, DONNA WICKHAM, AND RACHEL L. FREEMAN

Introduction

Although the Individuals with Disabilities Education Act promoted the use of positive behavioral supports (PBS) for schools in its 1997 reauthorization, similar laws have not been promoted in other service systems such as child welfare, mental health, developmental disabilities, and juvenile justice.

Unfortunately, children with problem behavior who are supported by multiple state and local agencies often experience fragmented services, inconsistent treatment, and multiple home and school placements. The following statistics indicate the challenges we face in supporting America’s children:

- Children with severe problem behaviors often develop these difficulties in early childhood (Schroeder, Mulick, & Rojahn, 1980). This is particularly true for children with developmental disabilities, with research reporting a 13–31% rate of severe behavior problems (Eaton & Menolascino, 1982).

- As many as 560,000 children are in out-of-home placement in foster care each year (U.S. Department of Health and Human Services, 2000). Of the children in foster care, 85% are estimated to have an emotional problems or substance use issues (American Academy of Child and Adolescent Psychiatry, 2002);

- In the U.S., as many as 10% of all children suffer from a mental illness severe enough to cause some level of impairment (Burns et al., 1995; Shaffer et al., 1996). Of these children, only approximately 20% receive specialized mental health services (Burns et al, 1995).

The purpose of the Kansas Institute for Positive Behavior Support (KIPBS) is to establish a common language, and a common set of values and skills in positive behavior support and person-centered planning for professionals in developmental disabilities, child welfare, and mental health services. Important fiscal incentives in the form of a new Medicaid billing option for professionals are available to those who successfully complete the training. The Institute teaches professionals how to facilitate both person-centered planning and positive behavior support.

Person-centered planning (PCP) is a process for learning about an individual’s preferred lifestyle and is considered an important element of PBS. The PCP process helps an individual in creating goals that will assist him or her in achieving this preferred lifestyle in a collaborative team context. Children who have opportunities to express their preferences and communicate their needs are less likely to engage in problem behavior. This means that implementing a PCP can result in a reduction in problem behavior and decrease the need for more time intensive strategies. A combination of PBS and PCP provides a comprehensive approach for improving the quality of an individual’s life and reducing problem behavior.

Positive behavior support (PBS) refers to a set of research-based strategies that are intended to increase quality of life and decrease problem behaviors by designing effective environments and teaching individuals appropriate social and communication skills. PBS is defined as the integration of valued outcomes, behavioral and biomedical science, validated procedures, and systems change to enhance an individual’s quality of life. Both PBS and PCP identify the contextual and environmental variables that can improve a person’s quality of life. A professional learning about PBS and PCP at the Institute engages in online instruction, participates in field-based activities, and develops a personal portfolio documenting his or her work.

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Coordinating Positive Behavior Supports Training

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Online Instruction

The use of online instruction makes it easier for professionals to gain access to information about PBS and PCP regardless of their geographic location in the state. Professionals who live across the state of Kansas will now have an opportunity to collaborate, problem solve, and network using email, and other online communication strategies. Travel time is reduced for professionals living in rural areas who have to travel a significant distance to participate in training as long as they are able to access the Internet. In addition, students and instructors can keep track of their progress and work on homework assignments easily and at any time of day.

The content of the online instructional modules has been designed with the guidance of a National Advisory Board of experts in both PBS and PCP. National Advisory Board members have assisted in specifying standards for designing the curriculum; evaluating the professional development procedures; recommending “best practices” grounded in the research literature; and reviewing the online instructional format to ensure best practice.

Twelve online modules will be available to professionals. The online format has been designed to ensure that the modules will be accessible to individuals who may not have state of the art equipment available. Each module contains a specific content area related to PBS and PCP including:

1. Introduction to PBS
2. Person-Centered Planning
3. Introduction to Applied Behavior Analysis
4. Interpreting Data and Measuring Behavior
5. Functional Behavioral Assessment
6. Environmental and Antecedent Interventions
7. Teaching New Skills
8. Consequence Interventions
9. Emotional and Behavioral Health
10. Designing Positive Behavior Support Plans
11. Systems Change
12. Professional Development

The modules provide intensive instruction to professionals who will take a lead role in facilitating PBS and PCP in their organizations. A small number of professionals will be participating in the KIPBS course training that allows them to bill Medicaid for their work. However, all Kansas service systems will have access to these modules and will be able to use them for training purposes. Once the first set of modules is finished, the Institute will be creating a partner set of twelve modules designed specifically to be embedded into in-service training systems. These easy-to-understand introductory modules will outline the basic concepts and processes of PBS and PCP and will be available to anyone in the state of Kansas.

Field-Based Activities

A critical part of the training is to make sure professionals have opportunities to apply the information they are learning and to try new strategies for supporting the children with whom they work. Each module provides opportunities to apply new information in one or more field-based activities with the assistance of instructors located across four geographic regions of the state. These instructors have expertise in the areas of both PBS and PCP and will be able to offer instructional support to professionals as they apply the new skills they are learning. Field-based activities allow instructors to:

- model appropriate Positive Behavior Support and Person-Centered Planning skills, facilitate problem solving and collaboration with other professionals,
- provide feedback and assistance as professionals begin using PBS and PCP in real settings, and
- monitor professionals' progress toward the mastery of identified skills.

Portfolio Development

Each professional who enters the KIPBS training system will prepare a portfolio that shows their implementation of PBS and PCP. The initial application and continuing portfolio process is outlined in Figure 1.

![Figure 1: Initial Application and Continuing Portfolio Process](image)

<table>
<thead>
<tr>
<th>Comprehensive Professional Portfolio Development</th>
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<tbody>
<tr>
<td><strong>Initial Application Materials</strong></td>
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<tr>
<td>Resume or vita</td>
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<tr>
<td>2 signed letters of reference</td>
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<td>2 letters or documents of satisfaction from</td>
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<td>previous consumers</td>
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<td>A statement of professional philosophy</td>
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<td>One case study that demonstrates the professional's current work with an individual with disabilities (e.g., individual support plan, PBS plan, person centered plan, or other individualized planning documents);</td>
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<td>Certification of crisis management training</td>
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<td>Availability of necessary technology resources</td>
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<td>to view the online instruction</td>
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<td>Support letter from professional’s immediate</td>
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<td>supervisor to allow release time to complete</td>
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<td>training</td>
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<tr>
<td><strong>Ongoing Portfolio Materials</strong></td>
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<tr>
<td>Person-centered planning case study</td>
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<td>PCP Consumer satisfaction rating</td>
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<td>Functional assessment</td>
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<td>PBS plan (initial report, evaluation and</td>
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<td>maintenance)</td>
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<td>PBS Consumer satisfaction rating</td>
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<td>Systems change demonstration</td>
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Professionals who have completed the training are considered mentors and are expected to contribute twelve hours a year to maintain their active membership. These twelve hours are used to encourage ongoing professional development and to provide support to individuals who are just beginning to learn about PBS and PCP. Each professional in training is matched with a mentor who can provide onsite advice and assistance in the portfolio development. This also ensures that state of Kansas will have a network of professionals who support each other and value ongoing learning in a collaborative atmosphere.

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Although training in the first year is only being provided to professionals in developmental disability services, child welfare and mental health colleagues will be joining the KIPBS training in future years. The mentoring concept is intended to break down the barriers across agencies and facilitate the communication and networking of professionals across multiple services.

In addition to providing training to professionals, the Institute is responsible for a prior-authorization process to manage the quality and quantity of services and evaluate progress by engaging in a continuous system-level assessment of the Institute’s training and overall organization.

Prior Authorization

Professionals who successfully complete KIPBS training can be reimbursed for their facilitation of positive behavior support and person-centered planning. A professional who identifies a child in need of support will send in an application to a prior-authorization committee for review. Professionals who want to be reimbursed for services apply to the project’s prior authorization system which oversees 1) quality of professionals delivering services, 2) cost containment, and 3) delivery of services based on priority of each child’s needs. Currently, only children are able to receive support through KIPBS, however, the system is expected to be expanded to adults in the following year.

The prior authorization system is designed to provide reimbursement for PBS and PCP support in community-based services to children who experience problem behaviors at such a frequency or intensity that they are at risk of out of home placement, either in foster care or in an institutional setting. Children who may be referred can include:

- Any child who is a resident of Kansas with developmental disabilities and/or have a verifiable diagnosis of autism;
- Individuals between 16 and 21 years of age who have sustained a traumatically inflicted head injury and are Medicaid eligible; and
- Typically developing children who engage in serious problem behavior.

The prior authorization system will also be used to monitor the success of a sample of PBS and PCP plans as part of the Institute’s evaluation plan.

Continuous System-Level Assessment

The Institute is committed to the continuous evaluation of its training and services. Evaluation processes include:

- gathering information about the characteristics of those who apply for and participate in training as well as the consumers who receive services;
- describing changes in professional practice as a result of the project’s training;
- determining the effects of the project on children, family, and staff members; and
- evaluation of consumer satisfaction and perceptions regarding the quality of support received.

Summary

In summary, the mission of the Kansas Institute for Positive Behavior Support (KIPBS) is to create a community of professionals in the state of Kansas who: (a) are committed to improving the quality of life for all Kansans by designing effective environments for social growth; (b) have demonstrated expertise in the application of PBS and PCP; (c) provide training and support for individualized PBS while simultaneously attending to the systems level issues that contribute to the occurrence of problem behavior; (d) are committed to ongoing learning; and (e) form a network of individuals who will maintain a collaborative connection with KIPBS. The Kansas Institute for Positive Behavior Support was established to provide a statewide training network for professionals across multiple service systems in the fields of developmental disabilities, mental health, and child welfare. For more information, visit the Kansas Institute for Positive Behavior Support website: www.kibs.lsi.ku.edu.

References


Using Empowerment Evaluation to Establish and Sustain Schoolwide Positive Behavior Support

BY AMY McCART AND WAYNE SAILOR

Positive Behavior Support in Urban Schools

Inner-city urban schools face numerous challenges for many of its students. In Kansas City, Kansas, Unified School District 500 and Kansas University (KU) have been operating a university/school district partnership for over five years. This partnership was created to provide training and technical assistance on establishing schoolwide positive behavior support (PBS) in selected schools in the district, and to conduct research on the process.

Kansas City, Kansas is located in Wyandotte County, the third poorest county in the United States according to the National Census. The schools are largely non-white, attended mainly by African American and Latino children.

The long range goal of the partnership is to establish a social development or “citizenship” curriculum at participating schools that is fully integrated with the academic curriculum. Some of the partnership’s participating schools face severe punitive consequences, such as transfer vouchers, if students’ performance on standardized tests do not greatly improve in the near term. KU’s research is directed to the question, “can inner-city schools perform at the level of the State average through combining a social development curriculum (schoolwide PBS) with ongoing comprehensive school reform?”

The logic goes like this: Inner-city schools, affected by poverty, suffer deteriorating performance on standardized tests of academic achievement by students due to decreased time in instruction. Decreased time in instruction is attributed to steady increase in office referrals for discipline reasons, in-school suspensions, out-of-school suspensions, detentions, expulsions, and truancies. Decreased time in instruction results in lower scores on academic achievement indicators (regardless of quality of instruction), and less time spent engaging in the learning process. Positive behavior supports result in significant reduction in truancy and referrals, and significantly increases time in instruction which, in turn, results in significant increases in academic indicators.

There are other variables that appear to positively affect achievement performance resulting from schoolwide PBS that are less well understood and stand in need of further research. Chief among these is “school climate.”

When urban teachers and administrators begin to understand why students present social challenges, they begin to develop increased respect for the students. When students show positive responses to PBS incentives, their social development process begins to accelerate. Schools with larger proportions of students that displayed negative behaviors literally become warmer, more nurturing environments, and the students respond.

Major questions for research remain, however. One is “how can schools that begin a PBS-driven social development process become self-sustaining over time, and thus avoid slipping back into negative, exclusionary discipline procedures?” In our research in Kansas City, we are investigating the use of empowerment evaluation as a critical feature of sustaining PBS capacity.

Positive Behavior Support (PBS) is providing new hope for schools facing multiple challenges to include those students that have been suspended, dropped out, and those prone to violent behaviors. PBS is a schoolwide systems change process that promotes the prevention of problem behavior for all students through comprehensive, proactive teaching of social skills and behavioral expectations.

School-wide PBS is a pathway to connecting the dots of a bigger picture of bringing together schools, parents and the community. PBS helps students develop social and communication skills, while creating a positive environment for learning and growth. PBS is reaching beyond the important aspect of applying individual strategies to reduce the challenging behavior of one child. School-wide PBS extends the framework of the field to examine the impact of analyzing larger contexts to ensure positive, proactive, safe schools, homes and community systems.

An urban middle school and an elementary school in Kansas City, Kansas have spent the past two and one-half school years systematically implementing PBS into their combined general and special education programs on a school-wide, targeted group and individual basis. These schools have introduced PBS and have customized its implementation and operation in each case, through the use of Empowerment Evaluation.
Using Empowerment Evaluation to Establish and Sustain Schoolwide Positive Behavior Support
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Empowerment Evaluation

With a foundation in community psychology and action anthropology, Empowerment Evaluation was developed by David Fetterman of Stanford University in order to facilitate the "voices" of those being served by others. Empowerment evaluation is a method of developmental, participation program evaluation intended to be used when a system (i.e., a business, a foundation, an agency, or a school) seeks to undergo a systems change process leading to a more democratic decision-making and administrative set of processes.

The term empowerment refers to the delegation of some measure of power and control in the system to line employees and consumers. Empowerment Evaluation promotes the self-determination of those involved in a school or community. For schoolwide PBS, Empowerment Evaluation enables the partnerships of school personnel, families, and community members to come to perceive ownership of the process, to take an active role in structuring goals and objectives for implementation of PBS and, over time, to become skilled in methods of data collection and evaluation.

Thus, Empowerment Evaluation addresses sustainability by assuring buy-in from all stakeholders, while at the same time assuring an exit strategy for the partner by helping the process to become self-evaluating over time. Additionally, Empowerment Evaluation allows key stakeholders to make important decisions about their processes while meeting shared goals.

Empowerment Evaluation facilitates school/technical assistance-provider partnerships by starting a dialogue between teachers, administrators, parents, students and community members in order to build communities and schools. It has an additional goal of enabling teachers and school administrators to make decisions based on evidence.

Empowerment Evaluation provides a source of data and a method for achieving ownership. Teachers, parents and administrators often discuss the strain on their time and resources in adequately supporting their children. Empowerment Evaluation builds a perception of ownership in the school, its students, and the community because the evaluative component is completely driven by the participants. It offers the opportunity to engage in a discourse that ultimately leads to buy-in, and generates networking among the participants.

Teachers in Kansas City, Kansas are voluntarily putting in additional time because they have an investment in the process. The participatory and data driven process that guide Empowerment Evaluation result in decisions based on clear information that can be essential for guiding schools to their outcomes. This process becomes embedded through systems change as a part of the climate of the school.

The school becomes self-evaluating and eventually self-reliant over time, reducing the need for outside support (i.e., consultants, outside meeting facilitators). Making schools a better place goes beyond disciplinary issues. PBS is a pathway to broader based school reform efforts with Empowerment Evaluation as the cornerstone with which to achieve those outcomes.

Steps of the process

There are three key steps to implementing Empowerment Evaluation, as shown in Figure 1 below. They include: (a) establishing a vision statement, (b) moving from the vision statement to standards that make the vision statement operational, and (c) using the standards to develop specific activities and objectives that will guide implementation.

Implementation of Universal PBS through Empowerment Evaluation

Urban Elementary School. This school (preschool through Grade 5) supports 278 students from diverse backgrounds, 46% of whom are economically disadvantaged, in an urban area of Kansas City, Kansas. The implementation team established a vision statement at the initial Empowerment Evaluation that was as follows:

“Our school has a caring, unified climate which supports diverse life long learners through high, clear, and consistent expectations. Staff members feel good about their instruction using a positive, proactive and evidence-based approach to teaching academic and behavioral standards, with the vital support and involvement of parents and the community.”

Urban Middle School. This school has 461 students enrolled in Grades 6 through 8. Of those 461 students enrolled, 56% are considered economically disadvantaged. Their vision statement, established at the initial Empowerment Evaluation session, is as follows:

“At our school, we are an extended family doing our part to achieve respect for one another; to care for all through a safe, consistent, and positive learning environment where everyone belongs; and to encourage students to explore and discover their diverse talents.”

Figure 1. Moving from vision statement to standards to activities and objectives.
Using Empowerment Evaluation to Establish and Sustain Schoolwide Positive Behavior Support

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Each school then creates guiding standards to be the basis for establishing specific activities. An example of those standards include: (a) fostering a caring climate, (b) developing a unified climate, (c) teaching academic and behavioral standards, (d) having high, clear, and consistent expectations, (e) using positive, proactive and evidence-based teaching methods, and (f) facilitating parent and community support.

From these standards which are drawn specifically from the vision statement, each Empowerment Evaluation team decides which specific activities they would like to work on over the next several months. Each member of the team is invested in the process because each member votes on the priorities and establishes the vision, the standards, the activities, and the objectives. The ownership grows as the process evolves. Initial reluctance that may be present by participants seems to diminish at each stage of development.

After the activities have been established based upon the standards and guided by the vision statement, each team clearly outlines the objectives of what must be accomplished to meet the desired outcomes. This includes timelines and specific names of people willing to take on these objectives. Since the objectives have been drawn from the group, rather than an outside evaluator, attendance and active participation in meeting the goals is usually excellent. The University partner provides training and technical assistance on PBS objectives and evaluation data collection and analysis.

Data Collection

All too often, evaluation of programs falls to outside personnel to identify programmatic strengths and needs and establish goals for schools to meet. Through Empowerment Evaluation that identification and goal setting is performed by school stakeholders and staff. Teachers, administrators, parents and the community are the ones who are most invested in their school and its outcomes. Additionally, they often know the most accurate picture of what is happening in the school, thus creating a unique opportunity for the design and evaluation of systems-change processes to occur simultaneously, and be accomplished by those who have the greatest stake in the process.

Teams are able to build their schools and their communities through a dialogue that empowers team participants.

Data from the schools on their goals established through Empowerment Evaluation

Urban Elementary School Implementation

Figure 2. Percentage of priorities implemented after two Empowerment Evaluations.

Urban Middle School Implementation

Figure 3. Percentage of priorities implemented after two Empowerment Evaluations.

Amy McCart and Wayne Sailor are with the Beach Center on Disability at the University of Kansas. Comments regarding this article may be sent to Ms. McCart at <ancmcart@kce.rr.com>
As a field, we are just beginning to fully appreciate through experience and research what many families have already known from years of challenges encountered in day-to-day life:

- the chronic problem behaviors that some children exhibit can produce deep and pervasive effects on all aspects of a family's life;
- most strategies of behavior support or behavior management that are advised and implemented by professionals have little to no impact on these family challenges, however;
- there are some approaches associated with positive behavior support that can be truly effective in helping families develop improvements in a child's behavior and an enhanced quality of life for all family members.

Our research group at the University of South Florida, in conjunction with many local families and national collaborators, has been involved in efforts to learn more about families affected by the occurrence of problem behavior in order to help develop more sensitive and effective programs of family-centered behavior support.

We have worked with many families from diverse communities that include children with a variety of disability labels and challenging behaviors ranging from aggression and severe self-injury to mild but persistent stereotypes that have the ultimate effect of excluding the child from opportunities for social engagement and community interaction.

The findings from our collaborative studies to date can be organized under three headings:

1. Problem behaviors can have effects on the family that are so pervasive that they impact virtually all aspects of the way a family functions;

2. Positive behavior support can be viewed as an approach that is highly congruent with the essential principles of family support and, thus, offers families a hopeful avenue for reducing some of the disruptions that problem behaviors exert on the family's quality of life, and;

3. There are certain practices that families find particularly helpful in the enterprise of family-centered positive behavior support.

The Effects of Problem Behaviors on Families

As researchers and program developers, we initially entered into our relationships with families with only a superficial understanding of their experience with problem behavior. It was only through many hours of working, talking, and spending time with families that we developed reciprocal and trusting relationships, and it was the quality of these relationships that provided us with a deeper appreciation for the impact of problem behavior on the lives of families (Fox, Vaughn, Dunlap, & Bucy, 1997; Fox, Vaughn, Wyatt, & Dunlap, 2002).

One of the first lessons we learned was that each family system uniquely defined their child's problem behavior. Acceptance or tolerance of behavior may be culturally defined and idiosyncratic to a family system or community (Chen, Downing, and Feckham-Hardin, 2002; Salend & Taylor, 2002).

Behaviors that we might identify as problematic may have been accepted or tolerated by family members who, instead, placed a priority on behaviors that we may have found to be relatively benign. Still, as a general rule, behavior that was considered by families to be problematic was behavior that isolated the child from the family's community (e.g., aggression toward peers), behavior that caused embarrassment to the family (e.g., public displays of inappropriate behavior), and behavior that compromised family routines (e.g., excessive unresponsiveness; disruption at meal time).

One of the findings that struck us as we processed data from a number of studies was the depth and pervasiveness with which serious problem behavior can impact the functioning of the family system. The problem behavior or problem circumstance that occasioned a referral was typically just the initial symptom of a much more comprehensive and serious pattern of tension and disruption within the full range of family routines.

One mother aptly described this phenomenon as a "24-hour, 7-day involvement" (Fox et al., 2002). Problem behavior in a family system has the potential to redefine family relationships, routines, sense of emotional well-being, social connectedness and friendship development, health, and perspectives about the future.

Problem behaviors rarely occurred in a single context. Most represented patterns of interaction that were shaped over time and multiple contexts by complex influences and reciprocal influences. Many of the families we supported had developed accommodations to problem behavior as a result of negative reinforcement (i.e., giving in to problem behavior to stop its occurrence).

For example, one family stored their food in an extra refrigerator in the garage in response to their child's insistence that only certain items belonged in the kitchen. Another parent continually sang "Old MacDonald" while shopping to prevent her child from scratching and banging his head. One mother described the family's response to problem behavior as if "you end up jumping through hoops to try to get it to stop and even when it doesn't work, you still do it" (Fox et al., 1997, p. 204).
The presence of problem behavior within family interactions can trigger other substantive changes in the family’s sense of well-being, emotions, comfort, self-efficacy, and patterns of interactions with others. For example, we came to learn that a boy who was never allowed outside to play with his siblings was restricted because he had repeatedly smeared his feces on a neighbor’s house. This behavior affected the child’s relationship with his siblings, the family’s relationship with their neighbors, the child’s independence, and contributed to a feeling of alienation. Here’s how the mother expressed it, “we are in our own world; we can’t expect others to understand.” Similarly, a number of families have expressed to us that they feel as if they are prisoners in their own home.

In our work with families, we have observed many impressive strengths within family systems, and we have often marveled at families’ ability to cope with the relentless demands of problem behavior. We have learned that a powerful impact of problem behavior is the emotional toll it can have on families.

One parent shared that she felt like “Jekyll and Hyde” in that she attempted to be cheerful and optimistic while she was “dying inside.” Another parent shared that “there are times that you feel so emotionally and physically exhausted...you just want to scream.” A parent we supported reported that she had anxiety attacks in anticipation of her son’s return home from school each day.

As we have worked with more and more families over many years, we have seen that these feelings and experiences are not unique, but instead are regrettably common. They emphasize how serious the challenge of severe problem behavior can be, and they underscore the importance of finding ways to assist these children and families with supports that are sufficiently effective that these poignant lifestyle indicators can be substantially improved.

Positive Behavior Support as Family Support

Historically, behavior management procedures, while effective in isolated circumstances, have not been successful in resolving serious problems in a comprehensive or sustained manner, nor have they been rich enough to offer a sincere promise to enhance a family’s quality of life.

The emergence of positive behavior support (PBS) as a distinct approach (Horner et al., 1990) offered a measure of hope that interventions could be constructed in a manner so as to produce a more meaningful benefit for children and families affected by problem behaviors. While research is still needed to fully evaluate the effects of PBS, and to refine its procedures in order to enhance their longitudinal impact, our data have suggested strongly that improvements in family functioning are reasonable outcomes of comprehensive, family-centered PBS (e.g., Clarke, Dunlap, & Vaughn, 1999; Dunlap & Fox, 1999a; Vaughn et al., 1997). This appears to be due to a number of critical features of the approach, including those described by Joe Lucysyn and his colleagues in a number of venues (e.g., Lucysyn, Dunlap, & Albin, 2002; Lucysyn, Horner, & Ben, 1997).

From the perspective of family functioning, the most important principle of PBS is that it is conducted in all phases as a partnership between individuals (usually professionals) with technical expertise and family members and others who are directly involved on a daily basis with the focus individual and who are affected by the presence of the behavioral challenges.

A commitment to partnership means that PBS steers clear of the traditional “expert model” of behavioral consultation in favor of a collaborative, team-oriented model that is centered around the family and the child. The child’s present and future quality of life is the commanding focus of the PBS process, and lifestyle enhancement is the universal goal. Because the child’s life is inextricably connected to the family’s, the well-being of the family is the central consideration.

In PBS, families are involved as essential contributors to the processes of functional assessment and development of the support plan. Family members are often the only team members with essential knowledge of the child’s home and community routines and the patterns of problem behavior and family interactions. Family members are also the best able to describe the potential fit between recommended support plan components and the values, cultural traditions, goals, habits, and inclinations of the family system. This fit is indispensable to the immediate and sustained implementation of the support plan because, in family contexts, family members are those who govern the implementation. An intervention cannot be effective if it is not used, and the partnership characteristic of PBS helps assure that planned strategies will, in fact, be employed.

An important feature of PBS is that it emphasizes the achievement of outcomes that involve quality-of-life enhancements that are judged as meaningful from the perspective of families and other essential stakeholders. This emphasizes that the PBS team is accountable primarily to the child and family for designing plans and producing changes that are important to the lives and well-being of the key participants.

At the same time, however, it is understood that such changes usually require a longitudinal involvement and periodic adjustments to respond to changing circumstances, opportunities, and challenges. Because people continually develop in many ways, and because family contexts are always in flux, no plan can ever be ideal for an extended period of time. For this reason, it is critical that PBS team members address responsibilities with humility and a recognition that occasional challenges must be confronted simply as signals that change is needed.

Family-friendly Practices of Positive Behavior Support

As we have worked with families in developing programs of positive behavior support (PBS), we have gained knowledge about the key practices that are necessary to produce optimal outcomes in family contexts. These practices have been described in more detail in other forums (e.g., Dunlap & Fox, 1999b; Dunlap et al., 2001; Lucysyn et al., 2002). We use this opportunity to summarize a few
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of the most pivotal guidelines. The practices are geared to family support in which a prominent concern is the presence of chronic and severe problem behaviors. When concerns are less serious, the recommendations would be mitigated in proportion to the circumstances, though they would still pertain.

Build Trusting Relationships with the Family

The key to a functional partnership is the presence of a trusting, reciprocal relationship between the family and the professionals and other individuals who are members of the behavior support team. Such a relationship is characterized by mutual understanding and respect, and the comfort and trust that comes with a shared investment in a common goal. It is critical that communication be conducted with language that is optimally efficient and familiar. Trusting relationships permit the exchange of personal and technical information that is crucial to the functional assessment and planning processes and, ultimately, the design of effective and contextually relevant support plans. The development of a trusting relationship often requires an investment of time with the family in their home and community, the development of relationships with all members of the family system, and demonstrations of genuine caring and commitment to the child's welfare.

Engage in Family-oriented Person-centered Planning

Person-centered planning is an extremely valuable process for developing a shared vision and action planning around individuals receiving team-based support (Kincaid & Fox, 2002; Mount & Zwerink, 1998). In family-centered PBS, the planning process revolves around many key aspects of family life. This is entirely appropriate as the family system constitutes the essential elements of the child's environment. The planning process should be conducted after some trust has been established and it should precede the development of the first comprehensive behavior support plan.

Assist families in gaining access to needed supports. Many families whose children have serious problem behavior may also be struggling with issues or concerns that affect the lifestyle of the family and the ability of the family to support their child's skill development. If a family is struggling with concerns about housing, health, difficult relationships or finances, the family will be less able to devote time and attention to PBS. Team members must be poised to address these types of concerns with the realization that a healthy, resilient family system is fundamental to success in the behavior support process. Though the capacity to address all of these challenges may not be present within the PBS team, team members can assist the family in gaining access to community resources that can address these broader concerns.

Encourage Family Involvement in Functional Assessment and Development of the Support Plan

All steps should be taken to facilitate active family participation in the process of functional assessment and plan development. Family members can and should be helped to understand the foundational principles of the process and they should participate in identifying the contexts for functional assessment activities, collecting the assessment information, and developing the behavior support strategies. It is extremely valuable for family members to engage in the process of connecting assessment information to the support plan design, including the selection of components that are most similar with the home and community circumstances in which they will be applied (Dunlap et al., 2001; Lucyshyn, Horner, Dunlap, Albin, & Ben, 2002).

Assure Technical Integrity of Implementation

PBS plans ordinarily include instructional components as well as strategies for arranging the environment to prevent occurrences of problem behavior. The components should be ones that can be easily implemented by pertinent family members. We have often found that it is helpful to demonstrate the components and sometimes to provide assistance and coaching until the procedures are used with fluency. This is particularly true when new procedures are used in public settings. It is vital that family members be fully comfortable with the procedures, and that they be simple to use, or it is unlikely that the strategies will be implemented for long.

Provide Efficient and Valid Procedures for Evaluation and Monitoring

It is necessary to have some strategies for evaluating the success of the PBS plan, but it is similarly essential that the strategies be easy for families to use. In our experience, families prefer data collection procedures such as brief telephone calls or simple checklists. It should be very obvious how the data pertain to the highest priorities of the family, and how they relate to the shared vision of the entire behavior support team.

1. Be sure family has basic needs met. If a family is struggling with day-to-day living, they may not be prepared to deal with the stress of change.

2. Celebrate even small successes. The family and the team need to believe that changes are happening and they are on the road to success.

3. Be sure the child has the services he/she needs (e.g., speech, OT, PT, etc.)

4. Return to the person centered plan to address the vision and quality of life.

5. Be sure parents have support for themselves and create time for themselves and for other siblings (Lucyshyn et al., 2000)

6. Get other service organizations involved.

7. Be sure the family has a circle of support outside paid providers.

Summary

The information we have gained in our years of program development and research is a function of the collaboration and generous sharing of family members and the shared observations of our colleagues around the country. Their contributions have encouraged us to appreciate the gains that have occurred, and to recognize the tremendous challenges that remain before us. There is a great deal that needs to be done to develop additional knowledge regarding the
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sustainability of PBS in family contexts and to build systems of support capable of delivering the team-oriented assistance that can enhance the quality of life for children and families affected by problem behavior.

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