



NewsLine

The Federation for Children with Special Needs

617-236-7210 • 800-331-0688 • www.fcsn.org



Positive Behavior Supports

Excerpted from a Positive Behavior Supports Information Brief, courtesy of the PEER (Parents

Engaged in Education Reform) project at the Federation for Children with Special Needs, Boston, MA, 1999.

When the *Individuals with Disabilities Education Act* (IDEA) was amended in 1997, two key provisions related to positive behavioral support were enacted. First is a requirement that the Individualized Education Program (IEP) team address student behavior when it impedes their or other students' learning. IEP teams are to consider strategies, including *positive behavioral interventions*, to address the behavior.

Have you ever heard the phrase, "Treat the symptom, and ignore the disease"? Many people handle discipline that way. They try to eliminate disruptive or dangerous behavior without looking into why the behavior occurs.

Positive behavioral support is different—even revolutionary—because it is based on asking, "Why?" Why can't Pat sit in his seat at school? Why does Richard bang his head repeatedly? Why does Anastasia wander off?

Behaviors usually happen for a reason. For example, a student may use a specific behavior to seek attention. Other behaviors can be a form of communication, particularly for people with limited language capabilities, which may express

frustration, anxiety, physical pain, and other emotions, or needs.

It's not always simple to stop challenging behaviors. One goal of positive behavioral support is not merely to "eliminate" but to understand the behavior's purpose. Once the purpose of the behavior is understood, the individual can learn to substitute a more positive behavior that achieves the same desired outcome; people learn better ways to make their feelings and needs known.

FIRST STEPS

Before you can decide if positive behavior support is the right approach for your child and family, you need to collect some information. Figure out the purpose of your child's challenging

continued on page 5



Keynote Speaker Nora Wells

The Annual Conference— Another Record-Breaking Success!!!

"Creating A World of Opportunities," the Federation's annual conference drew a record crowd for the third year in a row with 681 participants. Parents, special education teachers, and health care professionals gave the conference rave reviews. Upon being asked about the best part of the conference, one participant noted "the wide variety of topics offered—there was something for everyone. You have done a great job!" This year's theme focused on empowering parents and their professional partners to have the tools they need to ensure high quality education and health care for all children, especially those with special needs, in these difficult economic times.

Taylor from the Office of Program Quality Assurance, Dept. of Education.

Keynote speaker Nora Wells, Family Voices at the Federation, gave a dynamic presentation focusing on the powerful stories of three families and their quests to gain access to appropriate supports and services. One parent commented, "It was uplifting to me and gave me some ideas of how I can help my child and others in my community." Another parent stated: "I liked the way she honored parents by re-telling their stories in a human way."

continued on page 4



Secretary Bob Gittens, Executive Office of Health and Human Services

Special guests included Bob Gittens, Secretary of Health and Human Services for the Commonwealth of Massachusetts; Gerry Morrissey, Commissioner of the Mass. Department of Mental Retardation; and Debbie Klein-Walker, Associate Commissioner of the Mass. Department of Public Health. Also in attendance were Joan Mikula, Associate Commissioner of the Dept. of Mental Health; Bob Wentworth, Director of Residential Services at the Dept. of Social Services; and Richard



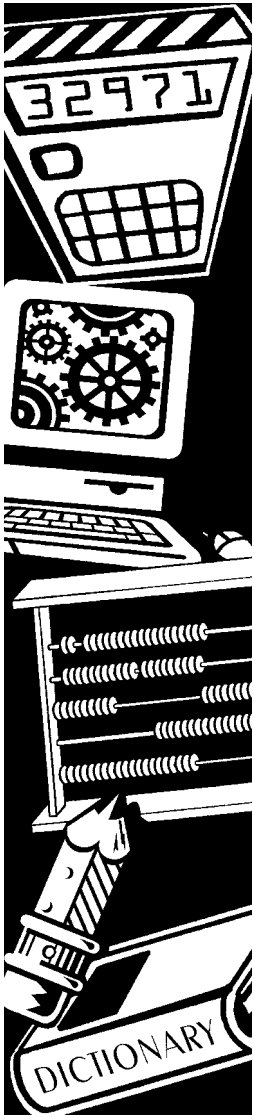
Federation staff member Diana Rocha and Benjamin Perez

CHECK IT OUT, INSIDE!



Bulletin

Parents Learning About Children's Education



Accommodation Vs. Modification

by Julie Sinclair, Director of FCSN—Western Region

Accommodations and modifications, or is it modifications and accommodations? What's the difference? Both parents and professionals often ask this question. Definitions and examples are presented below.

Accommodation is defined as a support or service that is provided to help a student fully access the general education curriculum or subject matter. An accommodation *does not change the content* of what is being taught.

Modification is defined as a *change to the general education curriculum* or other material being taught. The teaching strategies are modified so the material is presented differently and/or the *expectations of what the student will master are changed.*

2. Give the student credit for oral participation in class
3. Avoid pressure of speed and accuracy
4. Provide a scribe for written responses

Accommodations in materials

1. Simplify complex directions
2. Provide the same content with a lower reading level
3. Reduced homework assignments
4. Write due date in corner of assignments

Accommodations in instruction:

1. Provide study skills training
2. Use study guides
3. Provide concrete examples
4. Pre-teach vocabulary

Accommodations for test taking:

1. Open book exams
2. Oral exams
3. Allow extra time for exam
4. Read test item to student

Accommodations for help with organization:

1. Assign a homework buddy
2. Provide daily or weekly progress reports to parents
3. Provide a homework assignment notebook
4. Use a checklist to help student keep organized

Accommodations of behavior

1. Reward system for in-school work and homework completion (such as giving the student extra privileges)
2. Natural consequences for behavior
3. Allow breaks between assignments
4. Give the student an opportunity to verbalize his/her feelings

Accommodations for groups and peers:

1. Have cooperative learning groups
2. Provide a peer tutor
3. Ask a peer to take dictation
4. Peer modeling of appropriate responses

Here are some examples of modifications, taken from Margaret McLaughlin's book, *Accessing the General Curriculum*.

Modifications:

1. The student is taught something different from the rest of the class
2. The student is taught the same information, but at a different level of complexity
3. The student has a reduced assignment (for example, has fewer questions to answer)
4. Use a lower level reading text book, which covers similar subject content
5. Expectations of what the student learns will vary based on modifications agreed to on the IEP (Individualized Education Program)

Examples of different kinds of accommodations, taken from the Department of Education's Resource Guide, include:

Accommodations in scheduling

1. Changing the time of day for a subject or activity
2. Adjusting the length of time allowed for a task
3. Checking the student's understanding of the subject matter

Accommodations in settings

1. Working in a small group
2. Providing an individual work area
3. Reducing extraneous noise
4. Allowing movement to increase physical comfort

Accommodations of equipment:

1. Provide carbon copies of class notes
2. Allow use of a tape recorder
3. Allow use of a calculator
4. Allow use of a computer

Accommodations in responding:

1. Allow student to tape record responses for homework, tests, etc.

A Farewell To Margaret

by Mary Loughlin, Federation's Central MA office

Margaret Marotta Smith has left her position as Associate Director of Special Education Projects at the Federation to become the Evaluation Team Chairperson for the Peabody Public Schools. We wish her only the best in her important new role. We can think of no one more perfect for this position, for she brings not only technical expertise in understanding special education law and in writing IEPs (Individualized Education Programs), but also her tremendous empathy for families of children with special needs.

We will miss Margaret's expertise and special qualities. However, we know

that wherever she goes, she will carry forward the important work of the

Federation by providing information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. Whenever we see an IEP, we will think of how Margaret helped make positive changes to give parent vision added importance. Whenever we read *A Parent's Guide to Special Education*, we will hear Margaret's voice guiding us.



Margaret Marotta-Smith

From the Executive Director Still Waiting—After all these years

In 1962, thirteen years prior to the passage of IDEA (Individuals with Disabilities Education Act), the first ever President's Panel on Mental Retardation issued its report to President John Kennedy. This report entitled, *A Proposed Program for National Action to Combat Mental Retardation*, examined the scope, significance, and importance of addressing the needs of individuals with mental retardation and their families. The panel wrote, "mental retardation ranks as a major national health, social, and economic problem," affecting an estimated 3% of the general population, or at that time, 5.4 million children and adults in the United States. The panel enumerated 5 areas where there was an urgent need for extended or new services and urged the President to propose such programs. These proposals were:

1. **To enrich learning opportunities for preschool children.**
2. **To support state departments of education and universities to establish "instructional materials centers" in special education.** These centers would provide teachers and other education personnel with competent consultation and support.
3. **To develop state and local community leadership that would create new programs for school services for individuals with mental retardation.** In fact, they cite "the lack in many state and local school systems of staff experts as a major contributing factor to the general inadequacy of school services."
4. **To develop specialized classroom services to support all children, including those with mental retardation.** Despite the fact that special education programs had grown over 270% between 1948 and 1958, the number of programs was "grossly inadequate." The panel went on to say "it is doubtful that sound comprehensive programs will be developed in most communities without the incentive of external financial support, such as can be provided through general Federal assistance to schools." In addition, the panel found even new programs and existing services were "deficient" and many failed to accommodate the majority of children in their communities. Staff were inadequately trained, and most failed to provide for the full spectrum of intellectual abilities; and, finally, there were practically no programs, which existed to assist the adolescent or young adult to transition from school to work and community living.
5. **To expand or develop all community educational services which provide diagnosis and**

evaluation to enable the early detection of school learning disabilities.

Fast forward to the year 2002, 27 years after the passage of IDEA in 1975 and 40 years after the presidential report. Congress is required to reauthorize IDEA this year and many groups are identifying aspects of the law that need attention. Legislators on both sides of the aisle agree there are many problems that need to be addressed. At a recent hearing of the Senate Committee on Education, Robert Pasternak, Assistant Secretary of the U.S. Department of Education, testified about the need for **more highly qualified special education personnel** as well as the need to provide services to the "right children" (which addresses **evaluation and diagnosis** issues). The National Association of State Directors of Special Education identified 9 issues. Among them are the need to strengthen preschool services, school accountability, the need for a unified system of general and special education, coordination with other agencies, the need to address students with behavior issues, the need for a fairer dispute resolution system, the need for qualified personnel, and the need for full federal funding of IDEA.

The latest edition of the Massachusetts Special Needs Task Force Report, published by the Massachusetts Association of School Superintendents, identified challenges in five categories: 1) increases in the number of children and severity of disabilities of children served in early intervention and preschool programs, 2) numerous changes in the law that require additional paperwork on the part of special educators, 3) the costs of new programs and services, 4) the educational standard students are required to meet to graduate from high school, and 5) a lack of financial support to local schools from state and federal resources. The list of issues goes on, but at the root of many of them is the need for adequate federal financial support.

As many know the original promise of IDEA included the commitment of the federal government to provide "full" funding for IDEA. This was defined as providing 40% of the cost of special education services borne by cities and towns across this country. Most of us also know that this promise has never been met and was at the root of Senator



Richard Robison

Jeffords decision to realign his political party status. His heroic stance is a glaring reminder that the promise remains unfulfilled. As long as that is true, all children suffer.

Revising IDEA is always a difficult and politically charged issue with potentially high stakes for all involved, especially for parents and students with disabilities. The problems we face are not new, but they are complex. Let us learn from our predecessors and recognize that while problems persist, many accomplishments have been due to foresighted individuals and a prominent Presidential family that took up this cause 40 years ago. After all these years, it's time to end the waiting and see that the promise is fulfilled.

Richard J. Robison

**BARRIER
FREE LIFTS** **OF
NEW
ENGLAND**

Leader in Lift and Transfer Systems
1-800-987-6219
Call for Free Demonstration
www.bfl-inc.com



- LEXA 600
- Lifts Patients Weighing Up to 600 Pounds
- Reinforced Mast & Boom with X-wide Spreader Bar
- Capable of Lifting From the Floor



Ask an Expert!

Empowerment Through Information

by Phyllis Sneirson
Federation Information Specialist

Who Pays for an Independent Education Evaluation?

At times, parents may disagree with the school's evaluation of their child's educational strengths and needs and decide to have their child evaluated by an independent evaluator. Due to changes in the Massachusetts special education law, parents wonder if schools are still obligated to pay for independent educational evaluations. Generally, the answer is yes.

In order for a school to consider paying for an independent educational evaluation (IEE), parents must make their request within 16 months of the school's evaluation and the evaluators must meet state requirements for registration, certification and licensing, and provide assessments that are equivalent to the types done by the school district. Family size and income may also be used to determine whether or not the school district will pay for all or part of the cost of an IEE.

The school district is obligated to pay for an IEE when:

- The child is eligible for free or reduced cost lunch and/or,
- The child is in the custody of a state agency and has an appointed Educational Surrogate Parent and/or,
- The family's income is less than 400% of the Federal Poverty Guidelines. For example, a family of 4 whose income is less than \$68,200.

School districts may share the cost of an IEE with families, based on a sliding scale fee as follows:

- When family income is between 400% and 500% of the Federal Poverty Guidelines, the district pays 75% of the cost of an IEE.
- When family income is between 500% and 600% of the Federal Poverty Guidelines, the school pays half the cost of the IEE.
- If family income is greater than 600% of the Federal Poverty Guidelines, the school is not obligated to share the cost of the IEE with the parents.

Financial information that families provide to the school is confidential, will be returned, and families will be promptly informed about their eligibility for a free IEE or about their status for the sliding scale fee.

Families may choose not to share their financial information with the school and still request an IEE at the school's expense. In this case the school, within five days of the request, must either agree to pay 100% of the evaluation or initiate a hearing at the Bureau of Special Education Appeals (BSEA) to prove that their evaluation was comprehensive and appropriate. If the BSEA rules in favor of the school, then the school will not be obligated to pay. However, if a family chooses to pay for an IEE, the TEAM must consider the evaluation as they would any other evaluation.

Families can refer to the Massachusetts Special Education Regulation 28.04(5) for further clarification on independent evaluations.

Annual Conference

continued from page 1

A panel of experts, following the keynote, presented information about key strategies that families need to know. Dr. Richard Antonelli, a pediatrician, and Whit Garberson from the Mass Department of Public Health spoke of our state's new Medical Home Initiative. Attorney Tim Sindelar of the Disability Law Center, reminded us of the important laws that protect children's

rights. The "show-stopper," however, was Dalene Basden, a PAL parent support coordinator from Lynn. Dalene spoke of her own rise from desperation over her child not getting the services he needed to becoming a parent leader in her own community. All agreed, "Dalene was wonderful, a pleasure to listen to, she has a great sense of humor—humor helps!"

Participants selected from 30 workshops including autism, ADHD, legal advocacy, and a new assistive technologies strand. "All three workshops I attended were really good," wrote one parent. "They helped me a lot as a mother of a child with special needs and as a person." In addition to the workshops, over 45 exhibitors and tons of free resources filled the large ballroom. Participants remarked that "the time allotted for networking and exhibits was terrific. Baby-sitting was second to none! Thanks!" The Federation extends its thanks to all of those who made this year's conference such a success, especially its co-sponsors: Massachusetts Families Organizing for Change, Parent Professional Advocacy League, Family TIES, and the Boston Foundation.



Dalene Basden, PAL Format Coordinator, Lynn, MA



Lina Gutierrez



Workshop Presenters (left to right): Megan Rasbold-Gabbard, Sue Cusak, Denise Duhamel

Positive Behavior Supports

continued from page 1

behavior, what other behavior you can teach your child to attain the same goal, and to talk to the other people involved.

Ensuring Fit With Your Values

This approach focuses on rewarding good behavior, not punishing challenging behavior. Is this method consistent with your family's values? You must be able to take the lead and model this approach for others involved, custom fit the plan to your child, and anticipate and solve any additional problems that may arise.

Putting Together A Collaborative Team

You probably could do this yourself, but it is much more effective to involve your family, friends, professionals, and community members who are already familiar with your family's culture, skills, routines, and family values. Who works best with your child and has a true rapport? These connections can often be the miracle ingredient in effecting behavioral changes.

CREATING A VISION

This approach is not an overnight, silver bullet cure; it takes time and effort. Your vision of the ideal life for the individual with challenging behavior will sustain and help guide the journey. Typically, this vision begins with shared expectations and incorporates, to the maximum extent possible, the individual's preferences for inclusive activities, relationships, and daily/weekly routines.

Completing a Functional Assessment

Challenging behaviors do not happen repeatedly without reason. Finding out "why" the behavior occurs is the key to positive behavioral support. Technically, the finding-out process is known as a *functional assessment* and is a method of collecting and testing information. After you identify and clearly define the challenging behavior, check to make sure you are on target about the probable purpose(s) of the behavior (for instance, to quit doing a difficult task). Technical experts or someone who has knowledge of the person can do this.

STRATEGIES

The next phase of positive behavioral support begins with strategies to encourage behavioral changes. These include (in no particular order):

- **Teaching new skills**—Challenging behavior often occurs because the individual does not know a more appropriate way to achieve a result. Determine necessary skills, then work together to encourage their development. The new skill may successfully replace the behavior right from the start or it may take longer. When a flare-up does occur, ignore the behavior problem (in cases of

physical injury, it may be impossible and unethical to ignore behavior) and introduce known methods to promote good behavior.

- **Appreciating positive behavior**—You probably learned what the person views as a reward during the functional assessment. Use those rewards to reinforce the positive behavior. Remember to also recognize other appropriate behavior. This helps the individual to have a positive identity.
- **Altering environments**—If something in the person's environment triggers the challenging behavior, reorganize the environment for success. Try to make the environment as controlled as possible to decrease the occurrence of the challenging behavior. The goal is to create a rich pattern of preferred activities and relationships that encourage desirable, rather than undesirable, behavior.
- **Changing systems**—After working on the immediate environment, examine your system of services to see whether it is as responsive and personalized as possible. If not, do what you can to make those changes. Teachers can, for instance, request time for collaborative planning on behalf of the student with challenging behavior. A parent can explain positive support practices to school representatives. You may find that despite your efforts, the system is not changing directions quickly enough for your family. In that situation, you may need to change school systems.
- **Monitoring Improvement**—As the support program develops, devise a recording system to find

out what works and what doesn't. There will be fine-tuning and changes along the way. If the initial plan is not working, take some time to understand why. You can then use that information to design a new approach. For example, a person can get bored with the *same* people, and the *same* rewards. Creating variation may solve this problem. The second issue is that the people who oversee the positive behavioral support may get bored and become less responsive to the person and his or her communication efforts. Taking a break and adding variety help get past this roadblock.

- **Crisis Anticipation**—Right from the start, it is necessary to have a plan that anticipates dangerous situations. When someone has a behavioral challenge that results in property destruction, self-harm, or physical injuries, you can't be caught unaware. Devise a detailed, word-by-word script for how to respond to dangerous situations and distribute it to everyone in contact with the individual. Not only will this increase the plan's effectiveness, it will provide support persons with a security blanket.

END RESULTS

Positive behavioral support draws from teaching, systems design, behavior management, and social support to create environments where people succeed and feel good about themselves. The results of this evolving approach support the independence, productivity, and inclusion of people with disabilities. As one mom said, "It is about relationships as much as techniques."

Discover IDEA: Supporting Achievement for Children with Disabilities



Discover IDEA: Supporting Achievement for Children with Disabilities

A video produced by the IDEA Partnership Project and the Council for Exceptional Children

This 15-minute video lets you hear from educators, administrators, family members, and children themselves across the nation who attest to the impact of IDEA in ensuring that children with disabilities learn and achieve to their potential.

Discover IDEA:
Supporting Achievement for Children with
Disabilities received an Honorable Mention
in the 2000 Communicator Awards.



Available Now!

To order, call the ASPIRE and ILIAD Partnerships at the Council for Exceptional Children, 888-CEC-SPED (toll-free), 866-915-5000 (TDD), or e-mail service@cec.sped.org

www.ideapractices.org

Apoyos Positivos del Comportamiento



Reimprimido de Families and Disability Newsletter, Beach Center on Families and Disability, Universidad de Kansas con una introducción por Janet Vohs, PEER

Introducción

Cuando el *Acta para la Educación de Individuos con Discapacidades* (IDEA) fue enmendada en 1997, fueron establecidas dos provisiones claves relacionadas a los apoyos positivos del comportamiento. La primera es un requisito de que el equipo del Programa Educativo Individualizado (IEP) aborde el comportamiento de los alumnos cuando éste impide su aprendizaje o el aprendizaje de otros alumnos. Los equipos del IEP deben considerar estrategias, incluyendo las **intervenciones positivas del comportamiento**, para abordar el comportamiento.

¿Ha escuchado la frase, “Trate el síntoma, ignore la enfermedad?” Muchas personas abordan la disciplina de esa manera. Ellos tratan de eliminar un comportamiento disruptivo o peligroso sin investigar por qué ocurrió el comportamiento.

El apoyo positivo del comportamiento es diferente – aún revolucionario – porque está basado en preguntar “¿Por qué?” ¿Por qué Pat nunca parece estar sentado en su silla en la escuela? ¿Por qué Ricardo se golpea la cabeza repetidamente? ¿Por qué Anastasia se pierde?

El comportamiento usualmente ocurre por una razón. Por ejemplo, un individuo podría usarlo para atraer atención o auto-estimulación. El comportamiento puede ser una forma de comunicación – particularmente para las personas con una capacidad limitada del lenguaje – que puede expresar frustración, ansiedad, dolor físico, otras emociones, o necesidades.

Entonces trate de eliminar el comportamiento desafiante, ¿no es cierto? No es tan simple. El objetivo en el apoyo positivo del comportamiento no sólo es de “eliminar” sino que entender el propósito del comportamiento. El individuo entonces puede aprender a sustituir un comportamiento más positivo que logra la misma función. La gente aprende mejores maneras de hacer conocidos sus sentimientos y necesidades.

PRIMEROS PASOS

Tal como al comienzo de cualquier proyecto, primero obtenga los materiales necesarios. En el

apoyo positivo del comportamiento, esto incluye asegurar que este enfoque tiene sentido para su familia, juntar las personas que necesita, tener una idea de lo que desea, y averiguar el propósito que sirve el comportamiento desafiante.

Asegurar adaptación con sus valores. Si usted usa este enfoque, tendrá que estar listo para seguir avanzando (en lugar de esperar que otras personas dirijan). También tendrá que estar preparado para hacer un plan a la medida de la persona en la cual se está concentrando. Este no es un plan de que pueda ser aplicado a todos. En lugar de aceptar cualquier cosa que ocurra, usted tiene que estar preparado para activamente resolver problemas, aún anticiparlos. Este enfoque, también se concentra en premiar el buen comportamiento, no en castigar el comportamiento desafiante. Mantenga en mente estos valores al decidir si este enfoque funcionará con su familia.

Juntar un equipo colaborador. Usted mismo, probablemente podría realizar este enfoque. Pero las probabilidades de éxito no estarían a su favor. Una mejor manera es involucrar a la familia, profesionales, amigos y miembros de la comunidad. Aquellos sensibles a la cultura, destrezas, rutinas, y qué valoran al individuo y a la familia son ideales. También, encuentre aquellos que pueden trabajar mejor con el niño. Armonía – la habilidad de “conectar” – a menudo puede ser el ingrediente milagroso en los cambios del comportamiento.

Crear una visión. Este enfoque no es una curación de la noche a la mañana. Una visión de la vida ideal para el individuo con problemas de comportamiento será un incentivo y ayudará a guiar la jornada. Típicamente, esta visión comienza con grandes expectativas compartidas e incorpora a la extensión máxima posible las preferencias de ese individuo para actividades inclusivas, relaciones, y rutinas diarias y semanales.

Completar una evaluación funcional.

Problemas de comportamiento no ocurren repetidamente sin una buena razón. Averiguar “por qué” el comportamiento ocurre es la clave para el apoyo positivo del comportamiento. Técnicamente, el proceso de averiguar es conocido como evaluación funcional y es un método de coleccionar y examinar información. Después de identificar y claramente definir el comportamiento específico para que cualquier persona que observa pudiera saber exactamente lo que usted está diciendo, revisar para asegurar que usted dé en el blanco sobre los propósitos probables del comportamiento (por ejemplo, dejar de hacer una tarea difícil). Esto puede ser hecho por alguien que tiene conocimiento de la persona o por expertos técnicos.

ESTRATEGIAS

Ahora comienza la próxima etapa de este modelo del apoyo positivo del comportamiento: Estrategias para animar cambios del compor-

tamiento. Estas incluyen (en ningún orden particular):

Enseñar nuevas destrezas. El comportamiento difícil a menudo ocurre porque el individuo no conoce una manera más apropiada para lograr un resultado. Determinen las destrezas necesarias, y luego trabajen juntos para fomentar su desarrollo. Igual de importante, decida si la gente que trabaja con la persona que tiene el problema del comportamiento necesita aprender nuevas destrezas. Si es así, ellos, también necesitan comenzar a adquirir nuevas destrezas.

La nueva destreza puede reemplazar exitosamente el comportamiento desde el comienzo o podría demorarse más tiempo. Cuando ocurre un estallido, ignore el problema del comportamiento (en casos de herida física, podría ser imposible e inético ignorar el comportamiento) e introduzca métodos conocidos que promueven el buen comportamiento.

Apreciar el comportamiento positivo. Juntar información para la evaluación funcional ha causado que usted se concentre en el individuo. Durante ese tiempo usted debe haber aprendido lo que la persona considera premios. Usar esos premios cuando la persona exhibe comportamiento positivo objetivo refuerza la probabilidad de que aquellos comportamientos ocurrirán de nuevo. Al mismo tiempo que usted se concentra en premiar el comportamiento objetivo, recuerde de reconocer otro comportamiento apropiado y trabaje hacia animar al individuo a tener una identidad positiva.

Alterar los ambientes. Si algo en el ambiente de la persona influye el comportamiento difícil, es lógico organizar el ambiente para el éxito. Al ajustar el ambiente, concéntrese, también, en lo que ocurre entre incidentes de comportamiento difícil al igual que lo que pasa cuando ocurren estos comportamientos. Arreglar lo que ocurre durante el día, cuando ocurre, y cómo ocurre disminuye la probabilidad del comportamiento problemático. El objetivo del modelo de apoyo positivo del comportamiento presentado aquí es de no evitar todos los lugares donde el comportamiento difícil podría ocurrir o simplemente aprobar todos los pedidos del individuo. Al contrario, la meta es de crear un modelo rico en actividades preferidas y relaciones que fomentan un comportamiento deseable en lugar de uno indeseable.

Cambiar sistemas. Después de trabajar en el ambiente inmediato, examine su sistema de servicios para ver si es tan perceptivo y personalizado como es posible. Si no, haga lo que pueda para hacerlo de esa manera. Los maestros pueden, por ejemplo, solicitar tiempo para planificación colaboradora por parte del alumno con el comportamiento difícil. Un padre puede explicar prácticas

Apoio Positivo de Comportamento



Excerto do artigo Positive Behavior Supports Information Brief, uma cortesia do PEER (Parents Engaged in Education Reform), um projeto da Federação para Crianças com Necessidades Especiais, Boston, MA, 1999.

Quando a lei IDEA (Lei de Educação para Indivíduos Portadores de Deficiência) foi emendada em 1997, duas provisões chave, relacionadas ao apoio positivo de comportamento, foram promulgadas. A primeira é a de que a junta do Plano de Educação Individualizado (IEP) trate sobre o comportamento dos alunos quando este impeça a aprendizagem desses ou de outros alunos. As juntas do IEP (IEP teams) devem considerar estratégias, inclusive as *intervenções comportamentais positivas*, para lidar com o comportamento.

Alguma vez vocês já escutaram a frase “Trate os sintomas, ignore as doenças”? Muitas pessoas lidam com a disciplina dessa maneira. Elas tentam eliminar os comportamentos desordeiros ou perigosos sem procurar saber o porquê de tais comportamentos. O apoio positivo de comportamento é diferente—e até revolucionário—porque é baseado em perguntar “Por quê?” Por que Pat nunca fica sentadinha em seu canto na escola? Por que Ricardo bate em sua própria cabeça repetidamente? Por que Anastácia de repente vagueia?

Em geral, o comportamento acontece por uma razão. Por exemplo, pode ser que uma pessoa aja buscando atenção ou autopromoção. O comportamento pode ser uma forma de comunicação—em particular para pessoas com a capacidade de linguagem limitada—que pode expressar frustração, ansiedade, dor física, outras emoções ou necessidades.

Então, basta nos livrarmos do comportamento desafiador, certo? Não é assim tão simples. Um dos objetivos do apoio positivo de comportamento não é meramente “eliminar”, mas entender o propósito do comportamento. O indivíduo pode, desse modo, aprender a substituir um comportamento mais positivo que alcança a mesma função. As pessoas aprendem maneiras mais adequadas de fazer com que seus sentimentos e necessidades sejam conhecidos.

PRIMEIROS PASSOS

Exatamente como inicia-se qualquer projeto, primeiro obtém-se os materiais necessários. No apoio positivo de comportamento, isto implica em garantir que este procedimento seja adequado para a sua família, juntando as pessoas necessárias, tendo uma idéia do que vocês querem, e descobrindo com que propósito o comportamento desafiador é usado. Também que

outro comportamento seria mais apropriada para atingir o alvo determinado.

Garantindo a conformidade com os seus valores. Se usar esta abordagem, você terá de ir em frente, de ir à luta (sem ficar esperando que outros tomem a liderança). Também terá de estar preparada para adaptar o plano à pessoa que estará em foco. Este não é um plano do tipo “um modelo serve a todos”. E, ao invés de aceitar o que quer que aconteça, você deve estar pronta para resolver os problemas ativamente, e até antecipá-los. Esta abordagem também focaliza-se em premiar o bom comportamento, não em punir o comportamento desafiador. Mantenha estes valores em mente quando for decidir se esta abordagem funcionará com a sua família.

Agrupando um time colaborador. Provavelmente você poderia realizar esta abordagem por si mesma. Mas as chances de sucesso não estariam em seu favor. Um modo mais efetivo é envolver a família, os profissionais, os amigos e membros comunitários. Aqueles que são sensíveis à cultura, às habilidades, rotinas e valores do indivíduo e da família são ideais. Também, procure aqueles que lidam melhor com a criança. Empatia— a habilidade de “relacionar-se”— é, em geral, um ingrediente miraculoso nas mudanças de comportamento.

Criando um panorama. Esta abordagem não é uma cura da noite para o dia, rápida como uma injeção. Ela leva tempo e esforço. Um panorama da vida ideal para o indivíduo com comportamento desafiador abastecerá e ajudará a guiar a jornada. Tipicamente, este panorama se inicia com grandes expectativas partilhadas e incorpora, na maior dimensão possível, as preferências do indivíduo por atividades de inclusão, pelos relacionamentos e pelas rotinas diárias/semanais.

Completando uma avaliação funcional. Comportamentos desafiadores não acontecem repetidamente sem um motivo. Descobrir “por que” ocorre tal comportamento é a chave para o apoio positivo de comportamento. Tecnicamente, o processo de descoberta é conhecido como *avaliação funcional*, e trata-se de um método de coleta e teste de informações. Após identificar e definir claramente o comportamento desafiador, de maneira que qualquer observador saberia exatamente do que você está falando, cheque para ter certeza de que você está no alvo do(s) propósito(s) da ação do indivíduo (por exemplo, deixar de fazer uma tarefa difícil). Isto pode ser feito por alguém que tenha conhecimento da pessoa, ou por um perito em comportamento.

ESTRATÉGIAS

Agora, a próxima fase neste modelo de apoio positivo de comportamento se inicia: As estratégias para estimular mudanças de comportamento. Estas incluem (sem nenhuma ordem em particular):

Ensinando novas habilidades. O comportamento desafiador geralmente ocorre porque o indivíduo não conhece um modo mais apropriado de alcançar um resultado. Determine as habilidades necessárias e, então, trabalhem juntos para estimulá-las. Tão importante quanto isto, decida se aqueles que estão

trabalhando com a pessoa que tem o comportamento desafiador precisam aprender novas habilidades ou não.

A nova habilidade pode repor com sucesso o comportamento logo no início, mas também pode levar um pouco mais de tempo. Quando um ataque de raiva ocorrer, ignore esse problema de comportamento (em casos de danos físicos, talvez seja impossível e antiético ignorá-lo) e introduza métodos conhecidos para promover o bom comportamento.

Valorizando o comportamento positivo. Coletar informações para a avaliação funcional fez com que você se concentrasse no indivíduo. Naquele momento, você deve ter aprendido o que a pessoa vê como recompensa. Usando estas recompensas quando a pessoa exhibe comportamentos positivos almejados reforça a probabilidade de que esses comportamentos acontecerão novamente. Ao mesmo tempo em que você se concentra em recompensar o comportamento almejado, lembre-se de reconhecer outros comportamentos apropriados e de trabalhar para encorajar o indivíduo a ter uma identidade positiva.

Alterando os ambientes. Se algo no ambiente da pessoa influencia o comportamento desafiador, faz sentido organizar o ambiente para obter sucesso. Quando ajustar o ambiente, mantenha o foco, também, sobre o que ocorre entre os incidentes de comportamento desafiador, assim como sobre o que acontece quando os comportamentos desafiadores ocorrem. Relacionar o que acontece durante o dia, quando e como acontece, diminui a chance de um comportamento desafiador. O objetivo do modelo de apoio positivo de comportamento apresentado aqui não é de evitar todos os lugares em que o comportamento desafiador possa ocorrer, ou ceder a todas as solicitações do indivíduo. Antes, mais apropriadamente, o objetivo é criar um modelo rico em atividades e relacionamentos preferidos que estimulem um comportamento desejável, ao invés de um indesejável.

Mudando os sistemas. Depois de trabalhar no ambiente imediato, examine o seu sistema de serviços para verificar se ele é tão receptivo e personalizado quanto possível. Caso não seja, faça o que for possível para que passe a ser. Os professores podem, por exemplo, requisitar um tempo para um planejamento de colaboração da parte do aluno com comportamento desafiador. O pai ou a mãe pode explicar as práticas de apoio positivo para os representantes da escola. Você pode achar que, a despeito de seus esforços, o sistema planejado não está mudando as direções, ou não tão rápido o suficiente, para sua família. Nessa situação, você deve, literalmente, considerar a troca de seu sistema por outro (por exemplo, mudar de escola).

MONITORANDO O PROGRESSO

De acordo com o desenvolvimento do programa de apoio, conceba um sistema de registro para verificar o que funciona e o que não funciona. Por certo que haverá ajustes ao longo da jornada. Se o plano inicial não estiver funcionando, procure entender a causa. A partir daí, você pode usar essa informação para projetar uma nova abordagem para o plano.

Upcoming Federation Workshops

Please visit our website at www.fcsn.org for up-to-the-minute information or to register. Or call the Federation at 1-800-331-0688.

Call to find out about Basic Rights workshop in Portuguese. Ligue para informação sobre aulas iniciando em Português.

MAY 2002

- 2nd:** Shrewsbury, 7–9 pm, *Basic Rights*
7th: Dorchester, 8:30–10:30 pm, *Basic Rights*
8th: Brockton, 7–9 pm, *Basic Rights*
9th: Hanover, 7–9 pm, *Access to the General Curriculum*
14th: Methuen, 7–9 pm, *Access to the General Curriculum*
16th: Roxbury, 12–2 pm, *Basic Rights*
17th: Springfield, 10 am–12 noon, *Transition in Spanish*

- 18th:** Taunton, 2:30–3:30 pm, *Basic Rights*
22nd: Lincoln, 7–9 pm, *Basic Rights*
24th: Springfield, 10 am–12 noon, *Transition*

JUNE 2002

- 3rd:** Boston, 6:30–8:30 pm, *IEP 2000*

Federation Workshop Descriptions

Basic Rights covers basic information about state and federal special education laws to assist parents in the planning, decision-making and monitoring of their child's IEP. (Materials available in Spanish and Portuguese.)

Effective Communication offers communication skill building and conflict resolution for parents as members of the IEP Team.

IEP 2000 includes a walk-through of the new IEP with emphasis on IDEA '97 and the latest Massachusetts special education regulations, access to the general curriculum and writing curriculum-based, measurable annual goals.

Transition provides basic information on the state and federal laws that require the IEP to address goals such as competitive employment and independent living to assist students, 14 and older, with planning transition to adult living.

Access to the General Curriculum offers parent-friendly information on diverse learning styles and access to the general curriculum for all students. The workshop includes discussion and examples of modifications to content, delivery of instruction, and performance that will allow students with disabilities to more fully participate in the general curriculum.

Effective Inclusion of Students with Disabilities in the MCAS Testing System includes information on the IEP Team's determination of the appropriate method for an individual student to participate in the MCAS testing system. The workshop covers accommodations available to students with disabilities who take the standard paper-and-pencil version of MCAS as well as information on the MCAS Alternate Assessment.

Support Group in Spanish

Project COEP (Community Outreach and Empowerment Project), is a unique parent support project, funded by the Boston Foundation and operated by the Federation for Children with Special Needs. Staff of the COEP Project coordinates support groups for families of children with disabilities. One group, "Familias Latinas Unidas por el Síndrome de Down," (Latino Families United for Down Syndrome) is dedicated to sup-

porting and empowering families of children with Down syndrome. The group meets one Saturday a month from 10 am–12 noon at the Federation in Boston. For more information, please call Diana Rocha at 617-236-7210, ext. 171. In addition, Sandy Blanes and volunteer Rhea Tavares coordinate a second monthly support group for Portuguese-speaking parents who have family members with disabilities (see related article below). An English-speaking support group, with a similar format, is planned for the near future.

Grupo de Apoio em Português

O grupo de apoio para os falantes da língua portuguesa no estado de Massachusetts, com o patrocínio do Projeto COEP—Community Outreach and Empowerment Project—está aberto a todas as famílias que tenham crianças, jovens e adultos portadores de deficiência. O Projeto COEP é fundado pela Boston Foundation e operado pelo quadro de pessoal da Federação para Crianças com Necessidades Especiais. Uma vez por mês, as famílias se reúnem na Federação, em Boston, para trocar informações, saber das novas oportunidades e participar nas atividades sociais. Esses encontros

têm duas coisas em comum: a necessidade especial e a língua portuguesa. Independente de qual seja a necessidade especial, os falantes de língua portuguesa de todo o estado estão partilhando um lanche e informações sobre as suas deficiências e suas necessidades. Ao final do ano 2001, os membros do grupo de apoio se divertiram numa festa em que o jantar foi fornecido por um restaurante local, o Canestáros Restaurant. Dentre os planos para o ano 2002 estão incluídos: eventos sociais, eleição da administração, palestras informativas e, ainda, a realização de uma Central de Informações dos Membros e Colaboradores da Comunidade de Falantes da Língua Portuguesa com Necessidades Especiais. Maiores informações podem ser obtidas com Sandy Blanes ou Rhea Tavares, no tel. 617-236-7210, ramal 144.

Grupo de Apoio en Español

The community Outreach and Empowerment Project (COEP), patrocinado por Boston Foundation en La Federación para Niños con Necesidades Especiales apoya al grupo "Familias Latinas Unidas por el Síndrome de Down." El grupo se dedica a apoyar y aumentar el liderazgo de las familias que tienen niños con el síndrome de Down. Este grupo se reúne un sábado al mes, de 10 am a 12 pm en Boston. Para más información, llame a Diana Rocha al 617-236-7210, ext. 171.

HELP YOUR CHILD TO LEARN
With
AUDIOBOOKS
From



Recording for the
Blind & Dyslexic

Over 85,000 academic titles
in all subjects for all grades

For more information call:

617-577-1111 ex. 18

The Law is On Your Side

by Becky Rizoli



One afternoon last spring, I was reading a magazine that an acquaintance had lent me. One article, in particular, caught my

attention. It was about the various struggles that people with disabilities face. As I read on, I came to a statement that shocked and appalled me. It said that individuals with disabilities are the victims of more discrimination than any other minority.

I can't figure out why people are so intolerant and insensitive towards those with special needs. People with disabilities already have a difficult life, and society compounds their disability by treating them as if they were somehow worth less than other human beings. Why, in the 21st century, does this still happen?

We all know what racism, sexism, anti-Semitism, and homophobia mean. However, when I tried to come up with a similar word to describe discrimination against people with disabilities, I found myself drawing a blank. Although I have heard people call this kind of discrimination "ableism," I could not find it in the dictionary. The English language does not even have a word to describe discrimination against people with disabilities, even though it is a very real occurrence!

This kind of injustice angers me, not merely for social and political reasons, but for personal reasons as well. I have ADHD (Attention Deficit Hyperactivity Disorder), learning disabilities, and an anxiety disorder. Thanks to the laws that protect people with disabilities, I was able to attend my town's public school system, where I received special education services (at no cost to my parents) until I graduated from high school.

In elementary school, I spent the majority of my day in the resource room. I also received speech therapy, occupational therapy and counseling. By my senior year in high school, I was completely mainstreamed and only needed minor modifications to access the general curriculum, such as un-timed testing. I took a number of honors classes and even a few Advanced Placement courses. After high school, I went on to a competitive, liberal arts college, where I completed my Psychology degree in four years. I feel very thankful and fortunate that I was able to accomplish these goals.

However, I know that I could not have done it alone. Without the benefit of special education, I never would have made it to where I am today. Since my

parents and I understood my rights under the law, I was able to obtain the services I needed. My educational road was filled with obstacles. There were many times when a teacher or a professor did not want to make accommodations for me, or a supervisor was not supportive about my special needs. Yet, I realize that these obstacles are merely potholes compared to the "Big Dig" of discrimination that some other children and adults with disabilities face.

Discrimination occurs in many forms: from the child with learning disabilities who is denied admission to a private school, to the woman with cerebral palsy who is unable to attend religious services because her church is not wheelchair accessible, to the man with Down syndrome who is harassed by a co-worker. Despite both state and federal laws that prohibit "discrimination on the basis of disability," it continues to exist.

I would like to let all people with disabilities and their parents know that there is hope. I encourage parents of children with special needs to familiarize themselves with Chapter 71 B of the General Laws of Massachusetts (also known as "Chapter 766"), Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act. I also encourage them to learn as much as they can about their child's disability, and to let their children know what their rights are as well. Speak out when you feel that your child is being discriminated against and don't give up. Remember, discrimination on the basis of disability is not merely insensitive; it is **illegal**. The law is on your side!

Like Martin Luther King, Jr., I too have a dream. I have a dream that someday all people with disabilities will be treated with the respect and dignity. I have a dream that the work we do here at the Federation, and similar agencies, will continue to make a difference. And most of all, I have a dream that someday all people will be viewed not by what they can't do, but by what they can do.

Early Childhood Corner

Highlighting information of interest to parents of children under five and their professional partners, particularly Early Intervention service providers. Sponsored by the Federation's Early Intervention Training Center.



Early Intervention Training Center Workshop Schedule

May - September 2002

MAY 2002

May 15

Building a Community, Part 1
Stonehill College, Easton

JUNE 2002

June 5

Building a Community, Part 2
Reggie Lewis Center, Boston

JULY 2002

July 17

Building a Community, Part 2
Merrimack College, North Andover

SEPTEMBER 2002

Building a Community, Part 2
Date & Location TBA

Early intervention providers, families and other early childhood personnel are invited to attend these free workshops. Workshops are from 9 am to 3:30 pm. Snack and lunch is provided, parent stipends are available. For more information, call 1-800-331-0688, ext.159, or register on-line at www.eitrainingcenter.org.

The Early Intervention Training Center at the Federation is funded by the Massachusetts Department of Public Health.

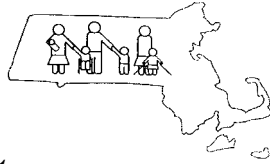


Health News

at the Federation for Children with Special Needs

Family TIES of Massachusetts

Together in Enhancing Support



GETTING ONBOARD THE 2010 EXPRESS

In December 2001, families of children with special health care needs, and professionals from all over the country, came together in Washington D.C. to launch an exciting new initiative called the 2010 Express. The Maternal and Child Health Bureau (MCHB) has collaborated with Family Voices, the American Academy of Pediatrics, the March of Dimes and many other private and public organizations to develop “A Ten Year Action Plan to Achieve Community-Based Service Systems for Children and Youth with Special Health Care Needs and Their Families.”

The plan is centered around six core goals :

- All children with special health care needs

will receive coordinated, ongoing, comprehensive care within a medical home

- All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
- All children will be screened early and continuously for special health care needs.
- Families of children with special health care needs will partner in decision making at all levels and will be satisfied with the services they receive.
- Community-based service systems will be organized so families can use them easily.
- All youth with special health care needs will receive the services necessary to make tran-

sitions to all aspects of adult life, including adult health care, work, and independence.

What does this mean for your family? It means opportunities for your voice to be heard and to make a difference. It means services for your children that are more accessible, more coordinated and more family centered. These six goals will enable medical practices to truly become “medical homes.” (A medical home is not a building, house or hospital, but rather an approach to providing health care services in a high-quality and cost-effective manner. Children and their families who have a medical home receive the care that they need from a pediatrician or physician whom they trust. Pediatric health care professionals and parents act as partners in a medical home to identify and access all the medical and non-medical services needed to help children and their families achieve their maximum potential.) Families will be partners in decision-making processes that affect policy as well as changes in service delivery.

What an exciting 10 years we are going to have! There are many ways for you, as a family member, to “get on board” the 2010 express. You can participate in focus groups, phone surveys, working groups and many other innovative ways of having your voice heard. For more information on the 2010 Express or the Medical Home, and to learn more about opportunities to be involved in these initiatives, call your regional Family TIES coordinator at 1-800-905-TIES. Don’t miss the chance to make a difference in the life of your child as well as the lives of all children with special health care needs.

Healthy People 2010

The above article “Getting Onboard the 2010 Express,” lists 6 core goals that specifically address needs and services for children and youth with special health care needs and their families. These 6 goals are part of a larger national initiative, Healthy People 2010, which addresses goals and objectives to determine and develop programs so that everyone lives a healthier life.

The two main objectives of Healthy People 2010 are to:

- 1) Increase an individual’s quality of life and years of healthy life.
- 2) Eliminate health disparities by improving health for those from varied racial and ethnic backgrounds.

The goals of Healthy People 2010 (HP2010) began in 1979 when the Surgeon General laid out health objectives for the nation to meet by the year 2000. The goals for the next 10 years were derived from this initial report. Public and professional opinion and guidance were used to

revise these goals to reflect today’s national health status and needs. Various federal agencies, including the Office of Disease Prevention and Health Promotion, and the U.S. Department of Health and Human Services coordinate the goals of the specific focus areas. More than 400 organizations—health departments, volunteer and private organizations, and businesses formed the 2010 Health Consortium. Consortium members commented on and redefined Healthy People 2000 into today’s goals. Other members bring the goals to life by incorporating them into their mission statements, developing health programs in the community, or assisting others to develop programs in their communities.

There are 28 focus areas that detail the specific health goals and objectives designed to meet the two main goals. These focus areas include: disability and secondary conditions, environmental health, family planning, maternal, infant, and child health, mental health and mental disorders, nutrition and overweight, oral health, and others.

The Maternal and Child Health (MCH) Bureau has developed six specific goals related to children with special health care needs. For more information, call Family TIES at

1-800-905-TIES or visit the MCH website at www.mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm.

To learn about specific activities, which are occurring in Massachusetts, contact the Massachusetts Consortium for Children with Special Health Care Needs. This consortium, part of New England Serve, holds bi-monthly meetings to assess how well the 6 goals for children with special health care needs are presently being met, and to devise plans to address next steps. A dynamic group of families, physicians, policymakers, and others, share ideas, information, and inspiration. If you’d like more information, please contact Alexa Halberg, at NE Serve at 617-574-9493.

As an individual, or a family, you can work to live a healthier lifestyle and/or choose a health care provider and health plan to meet your needs. Visit www.healthfinder.gov for information on health topics or health care organizations that can help you make healthy choices for yourself and your family. En español vaya a www.healthfinder.gov/espanol/.

MassCARE Honored at DPH Day Celebration

The MassCARE program was recently honored at the Massachusetts Department of Public Health's DPH Day Celebration. MassCARE was one of twelve programs from across the state chosen in recognition of its achievement.

The event took place on December 11, 2001 at the State Capital, and was attended by roughly 500 Department of Public Health Staff and community members. Dr. Howard Koh, the Commissioner of the Department of Public Health, praised the program for its longevity and dedication to families affected by HIV. He noted that many of the MassCARE staff members have been with the program through its entire 10-year history!

Many MassCARE staff members were able to attend the awards ceremony. Donna



Valerie Brown, Acting Director, MassCARE Program at the Department of Public Health presents an award to Fernanda Gudino-Valentin, Program Coordinator for MassCARE at the Federation.

Costa, Leticia Lopez, Donna Picard, Linda Besse, Fernanda Gudino-Valentin, Hayley Amett, Gayle Hearn, Valerie Brown, and Debbie Allen were all recognized. Donna Picard spoke for the group and told the audience about MassCARE's beginnings and the HIV+ children they treated years ago when the program was starting. Those children have now grown into healthy teenagers, and MassCARE continues to provide them services.

with groups already working on HP2010 projects. Become a HP 2010 partner by e-mailing hp2010@osophs.dhhs.gov.

For more information about Healthy People 2010 or the 2010 Health Consortium visit www.health.gov/healthy-people or call (800) 367-4725.

Update from Mass Family Voices

Massachusetts Family Voices provides support to parents as they seek to improve the quality of health care for their children with special health care needs. To follow up on the many parent activities in this state during the past year, and to provide continued support to parent leaders, Massachusetts Family Voices is planning a June meeting. Further information will be posted on the Mass Family Voices website (massfamilyvoices.org).

NEW PUBLICATIONS AVAILABLE

Last year parents in Massachusetts, along with parents in 11 other states, participated in a national Family Voices project. Parent interviewers met with staff of managed care organizations and spoke about programs and policies for children with special needs. Three reports on the interviews are now available. Contact Connie Sun at csun@fcsn.org for your copy.

- *From Conversations to Connections: A Report on Parent Interviews with Managed Care Plans in Massachusetts about Children with Special Health Care Needs.*
- *A National Dialogue: Families of Children with Special Needs and Managed Care Plans*
- *Parents Partnering with Managed Care Plans: A Discussion Guide on Services for Children with Special Health Care Needs*

RESOURCES FOR FAMILIES FROM THE DEPARTMENT OF PUBLIC HEALTH:

A series of TIP sheets for families (developed by the Division for Special Health Needs Care Coordination Program at the Massachusetts Department of Public Health), offer families important information about public benefits and support services to help families who have children with special health care needs navigate the system. These sheets can be accessed at www.massfamilyvoices.org/resources/dph.html

Healthy People 2010 continued from previous page

As a community or an organization, you can integrate goals into meetings, forums, publications or events, and/or collaborate

Music
Academics
Social skills
Life skills
Vocational preparation

Berkshire Hills Music Academy

A unique
post-secondary residential
Academy of Musical Arts
for young adults with
special learning needs

48 Woodbridge Street
South Hadley, MA 01075
Tel: 413-540-9720
www.berkshirehills.org
please contact us for application packets

KOTIN, CRABTREE & STRONG, LLP

Providing representation to children and adults with disabilities, their families, and non-profit service providers.

Kotin, Crabtree & Strong is a general practice law firm, one of whose specialties is in law relating to children, including education, special education and child care issues.

Areas of practice include:

- Education and Disability Law
- Business Law, including representation of private schools and programs, child care and other organizations
- Employment Law
- Civil and Criminal Litigation
- Personal Injury Law
- Estate Planning and Administration
- Intellectual Property
 - Real Estate
 - Taxation
 - Mediation

Please visit our Web Site at www.kcslegal.com
One Bowdoin Square, Boston, MA 02114
(617) 227-7031, Fax (617) 367-2988

When Choosing a Residential School— The Importance of Appropriate Licensing

by Andrea Watson, Project Coordinator PFRR, and Attorney Tim Sindelar, Disability Law Center, PFRR Advisory Board Member

When families place their child in a residential school or group home (group care), they are placing the life of their child in others' hands. Safety, as well as appropriate service delivery, should be their highest priority. Appropriate licensing is crucial when choosing a residential placement. The Office for Child Care Services (OCCS) should license all residential placements, even if they're 766 approved. This ensures that these facilities meet the same standardized objectives and criteria that other facilities, which serve children, especially children with special needs, must meet.

Even though PFRR would like to see an increase in these standards, an OCCS-licensed program at least meets minimum qualifications to serve this population of children. Programs without OCCS licensing may not be appropriate.

OCCS sets standards on restraint, medication,

staff qualifications, staff to student ratio, intake, service planning, nutrition planning, equipment, education services, behavior management, clothing, room assignments, grooming/hygiene, money, visiting, mail, telephones, runaways, transportation, building safety, physical plant and equipment, physical facility/architectural barriers, living units, access to records, criminal background checks for employees and much more. OCCS staff monitors the programs, and also provides information to parents and others, when requested. Complaints will be investigated. For more information, go to our website at www.pfrr.org, e-mail us at pfrr@fcsn.org, visit the OCCS web site at www.qualitychildcare.org or call them at 617-626-2000.

A residential school should also be 766 approved. This means the program meets the Massachusetts Department of Education (DOE) standards to provide special education services to your child on an IEP (Individualized Education Program), follows the curriculum frameworks, provides access to the general curriculum and also complies with standards for



Andrea Watson of PFRR

health, welfare, and safety. This approval is granted through Program Quality Assurance Services (PQA) at DOE. If you want information about a particular school, want to file a complaint of non-compliance of an IEP, or have health, welfare and/or safety issues to report, contact the PQA at 781-338-3300. The staff is always helpful and willing to provide assistance. You can also go to the DOE website at www.doe.mass.edu.

PFRR is now posting the most recent DOE progress reports about 766-approved residential schools on our site at www.pfrr.org. If you need assistance, or would like more information, please call our hotline at 1-800-672-7084 or e-mail us at pfrr@fcsn.org.

Selecting a Camp



This information was taken from The Parent Training Guide to Recreation developed by "LIFE: A New Direction"—a project sponsored by the Center for Recreation and Disability Studies Curriculum in Leisure Studies and Recreational Administration at the University of North Carolina at Chapel Hill.

Further information is available in Summer Fun 2002 available on our web site: www.fcsn.org.

What To Look For In Camp Programs

If you are considering sending your child to camp, you need to make some decisions about the type of camp that is most appropriate, and gather information about the camps that offer this type of experience.

Do you want a day camp or residential (sleep-away) camp experience for your child?

Day Camps

Day camps offer a wide variety of recreational activities, which may include music, arts and crafts, swimming and other sports, field trips, etc. These activities are designed to promote your child's mental, physical and social development. Programs may run all-day or half-day, five days a week, or two to three days a week, all summer or only a few weeks. Advance registration and a physical exam, with the child's complete medical history, are usually required. Day camps are generally designed for children, age 5 and older. Program offered by local community or municipal recreation departments usually charge a minimal fee. Most private agencies charge a higher fee, although they may be willing to reduce the fee based on financial need.

Residential Camps

Residential (sleep-away) camps are those in which your child may spend several days, two weeks, or the entire summer away from home. This type of

program can provide a unique living experience for a child with a disability. In addition to some of the same activities available to day camps, sleep-away camps enable children to live together in cabins under the supervision of qualified staff. A major emphasis of these programs is to increase the independence and self-help skills of each child. Ages tend to range from 5 to 16; most camps do not accept teenagers over 17 or 18. Advance registration and a complete physical examination are usually required; a formal interview may be necessary. Fees are generally charged; however, a scholarship program may be available to those with financial needs.

"Special" Vs. Integrated

There are day and residential camps only for children with disabilities and camps where a child with a disability is included with children who are non-disabled. The experience that is best for your child depends on his/her abilities and interests, social skills, and what you think the maximum benefit from each situation will be.

General Information

General information about a camp can be obtained by contacting the camp directly through mail, e-mail, by telephone, or by a visit to the camp's website. For your convenience, links for many camp websites are available at www.fcsn.org.

Book Review—

Rethinking Special Education for a New Century

Policymakers, especially those in Washington DC, are studying a recent book about special education entitled, *Rethinking Special Education for a New Century*. Edited by Chester E. Finn, Jr., et al. and published by the Fordham Foundation and the Progressive Policy Institute, the book features a preface by Madeleine Will, parent and former Assistant Secretary of Special Education and Rehabilitative Services.

This book is especially interesting and thought provoking because it takes a good look at special education from a somewhat distant vantage point, enabling the various authors to take a truly fresh look at special education as a national system. While I do not agree with every detail expressed, I do find much merit in the book; the editors urge us to shift from a “compliance paradigm” to a standard that emphasizes outcomes and accountability, without sacrificing the fundamental rights of the children and parents the law protects.

One of the six concluding recommendations presented by the authors includes, “Provide adequate funding to ensure the program’s success, assigning to Washington full responsibility for funding the

education of the country’s growing population of severely disabled students.” The first half of this recommendation is one that just about everyone agrees with, but the latter half probably stems from limited understanding of the complex interactions of child assessment, state and local funding mandates, rapidly changing educational practices, and uncertain definitions of such terms as “severely disabled.”

I am hopeful that the new Director of the Office of Special Education Programs at the U.S. Department of Education will use this book as a starting point to initiate a major review of the federal law, culminating two or three years from now with recommendations for change that will increase the quality of our children’s education and soften some of the backlash that periodically arises.

Meanwhile, I urge parents, teachers, administrators, and policymakers to read this important book. It is available on the Internet at www.edexcellence.net, or a free paper copy can be ordered by calling 1-888-823-7474.

Martha Ziegler, Founder
Federation for Children with Special Needs

Spontaneous Celebrations & Jamaica Plain Community Center presents:

Families Creating Together

An expressive arts workshop for participants of all ages and disabilities

Dates: May 11, May 25, June 1, June 15
Time: 2:00-4:00 PM

Location: Jamaica Plain Community Centers, Curtis Hall, 20 South Street, Jamaica Plain, MA
Suggested donations: \$5 for adults and child, \$3 each additional child
(Wheelchair accessible. If you need an American Sign Language interpreter, call us at 617-522-5286).

Project Description: Families Creating Together is a community-rooted expressive arts workshop series designed for the inclusion of participants with a wide range of abilities and ages. These workshops, taught in English and Spanish, include creating puppets, masks, magical environments, journal making, & poetry writing.

Cooperative Organizations: Jamaica Plain Community Centers, Federation for Children with Special Needs, Greater Boston ARC, the Disability Law Center, Camp Joy

FREE Workshops for Families

Sponsored by COEP and Parents’ PLACE
Open to all community members!

Things Kids Do That Drive Us Nuts: Understanding Motivation & Behavior

Wed, May 15 6:00 to 8:30 p.m.
(Register by Fri, May 10)

Self Esteem: How do Children Get it? How Do Parents Give It?

Wed, May 29 6:00 to 8:30 p.m.
(Register by Fri, May 24)

An Introduction to Recognizing, Understanding & Supporting a Child with a Nonverbal Learning Disability

Wed, June 12 6:00 to 8:30 p.m.
(Register by Fri, June 7)

Location for all workshops: The Federation for Children with Special Needs

Food and child care (ages 4-12) provided for those who pre-register.

To register or for more information: **Call Diana Rocha at 877-471-0980 x171**

COEP and Parents’ PLACE are projects of the Federation for Children with Special Needs. COEP is funded by the Boston Foundation; Parents’ PLACE is funded by the US Dept of Education, Grant #S310A990012A.

NewsLine

Guest Editor:
Beth Dworetzky
Production Manager:
Cara Donahue

Layout & Design:
Nummi Nummerdor

Advertising:
Brooke Heraty

Translators:
J. Nilson Melo (Portuguese)
Hosffman Ospino (Spanish)

Contributors:
Betsy Anderson, Brad Arndt, Sandy Blanes, Kathy Cruz, Peggy Curran, Cara Donahue, Beth Dworetzky, Brooke Heraty, Mary Loughlin, Barbara Popper, Becky Rizoli, Richard Robison, Diana Rocha, Carolyn Romano, Polly Sherman, Julie Sinclair, Tim Sindelar, Phyllis Sneiron, Joanne Spencer, Andrea Watson, Nora Wells, Martha Ziegler

NewsLine is a quarterly publication of the Federation for Children with Special Needs, 1135 Tremont St., Ste. 420 Boston, MA 02120.

NewsLine is supported in part by a grant from the U.S. Department of Education, Office of Special Education and Rehabilitative Services. The views and opinions herein do not necessarily reflect views or policies of the U.S. Department of Education, or of the Federation for Children with Special Needs. Ads herein do not constitute endorsement by the Federation for products, services, or organizations.

NewsLine contents are copyrighted by the Federation for Children with Special Needs; some material may carry other copyrights as well (noted where appropriate). Permission is granted to quote from us at length, while giving credit to *NewsLine*, a publication of The Federation for Children with Special Needs (and original author, if appropriate).

NewsLine’s mailing list is occasionally made available to organizations in which we believe our readers may have interest. If you wish your name to be withheld, please call or write the Federation’s Boston office to inform us.

The Federation for Children with Special Needs, Inc.

Our Mission:

To provide information, support, and assistance to parents of children with disabilities, their professional partners, and their communities. We are committed to listening to and learning from families, and encouraging full participation in community life by all people, especially those with disabilities.

Board of Directors:

Dan Heffernan, President;
Peter Brennan, Treasurer;
Miryam Wiley, Clerk
Ed DeNoble, Linda Downer, Jack Foley,
Robin Foley, William Henderson,
Anne Howard, Kim Yoshida

Executive Director:

Richard J. Robison

Apoyos Positivos

continua de página 6

de apoyo positivo a los representantes escolares. Usted podría encontrar que a pesar de sus esfuerzos, el sistema no está cambiando de dirección con suficiente prisa para su familia. En aquella situación, usted podría considerar cambiar su sistema por otro (por ejemplo, cambiar de escuela).

Vigilar el Mejoramiento. En tanto el programa de apoyo se desarrolla, crea un sistema de anotación para averiguar lo que funciona y lo que no funciona. Habrán ajustes y cambios a lo largo del camino. Si el plan inicial no funciona, cuídese de comprender por qué no está funcionando. Usted puede usar esa información para diseñar un nuevo enfoque para el plan.

Por ejemplo, una persona puede aburrirse haciendo las mismas tareas con la misma gente por los mismos premios a la misma hora del día. Crear una variación puede resolver este problema. El segundo obstáculo es que la gente que vigila el apoyo positivo del comportamiento puede aburrirse y responder menos a la persona y sus esfuerzos para comunicarse. Tomar una pausa y

agregar variedad ayuda a sobrepasar este obstáculo.

En algunas situaciones, usted podría encontrar que a pesar de sus mejores esfuerzos, el comportamiento no fue afectado. Pregúntese si le dió suficiente tiempo al plan, o si usted u otras personas criticaron a la persona exhibiendo el comportamiento o le rogaron a la persona para que se portará bien. Ambas tácticas pueden tener el efecto de aumentar el comportamiento difícil. El apoyo positivo del comportamiento podría también no ser efectivo en heridas propias que proporcionan al niño estimulación sensorial (por ejemplo, los niños podrían golpearse los ojos con la punta del dedo para hacer un efecto visual), o que responde a una insuficiente o demasiada estimulación. Las heridas propias o comportamientos agresivos pueden también ser iniciados o establecidos por condiciones psiquiátricas ocultas, tales como la depresión, desórdenes obsesivos-compulsivos, u otros desórdenes. Algunos científicos han sugerido que algunas heridas uno mismo se ha infligido (“self-injury”) pueden representar un tipo de comportamiento adictivo que proporciona un sentido de “altura.”

Anticipar Crisis. También es necesario desde el comienzo y a través del programa un plan que

anticipa situaciones peligrosas. Cuando una persona tiene un problema del comportamiento que resulta en la destrucción de propiedad, heridas que uno mismo se ha infligido, o heridas físicas, usted no debe ser sorprendido. Prepare una escritura detallada, palabra-por-palabra sobre cómo responder durante situaciones peligrosas y distribúyala a cada persona que tiene contacto con el individuo. Esta provisión aumentará la efectividad del plan, y proporcionará apoyo y seguridad a las personas.

RESULTADOS FINALES

Los apoyos positivos del comportamiento extraen de la enseñanza, diseño del sistema, manejo del comportamiento, y apoyo social para modelar ambientes en los cuales la gente tiene éxito y se sienten bien hacia sí mismos. Los resultados de este enfoque que está desarrollándose apoyan la independencia, productividad, e inclusión de las personas con discapacidad.

Sin embargo, una madre dijo, “Emplear el apoyo positivo del comportamiento no es como apretar algunas tuercas y tornillos. Es acerca de relaciones tanto como técnicas. Siempre importa quien hace la intervención al igual que lo que hacen.”

Apoio Positivo

continua da pagina 7

Por exemplo, a pessoa pode se chatear fazendo as mesmas tarefas, com as mesmas pessoas, pelas mesmas recompensas, na mesma hora do dia. Criar variações pode resolver este problema. Um segundo obstáculo é que as pessoas que supervisionam o apoio positivo de comportamento podem, igualmente, se chatear, tomando-se menos sensíveis à pessoa e seus esforços de comunicação. Dar uma pausa e acrescentar algum tipo de variedade ajuda a passar por este obstáculo.

Em algumas situações, você pode achar que, apesar de seus melhores esforços, o comportamento não foi afetado. Pergunte-se a si mesma se você concedeu tempo suficiente ao plano; ou se você, ou outros, criticaram a pessoa que exibiu o comportamento, ou pressionaram-na para se comportar bem. Ambas as táticas podem, na verdade, agravar o comportamento desafiador. O apoio positivo de comportamento pode também não ser eficiente nos casos de auto-agressão que dá à criança um estímulo sensorial (e.g., as crianças podem socar seus próprios olhos para fazer um efeito visual), ou que seja em resposta a um estímulo insuficiente ou excessivo. A auto-agressão, ou os comportamentos agressivos, também podem se iniciar ou serem causados por condições psiquiátricas básicas como depressão, desordens compulsivo-depressivas, ou outras desordens. Alguns cientistas têm até sugerido que alguns tipos de auto-agressão podem representar um tipo de comportamento vicioso que deixa a pessoa “alta”.

ANTECIPANDO UMA CRISE

Também necessário desde o princípio, e até o fim, é um plano que antecipe situações perigosas. Quando alguém tem um comportamento desafiador que resulta em destruição da propriedade, auto-ferimento, ou lesões físicas você não pode ser pega desprevenida. Invente um roteiro, palavra por palavra, de como responder a situações perigosas e distribua-o para todos os que mantêm contato com o indivíduo. Essa previsão não apenas aumentará a eficiência do plano, mas, além disso, fornecerá às pessoas que fazem parte do apoio positivo uma segurança extra.

RESULTADOS FINAIS

O apoio positivo de comportamento tem como método o ensino, o planejamento de sistemas, o gerenciamento de comportamento e o apoio social para construir ambientes onde as pessoas sejam bem-sucedidas e sintam-se bem a respeito de si próprias. Os resultados dessa abordagem envolvente apoiam a independência, a produtividade e a inclusão das pessoas portadoras de deficiência.

Entretanto, como disse uma mãe, “Empregar o apoio positivo de comportamento não é uma simples prática do tipo ‘toma lá, dá cá’”. Trata-se de relacionamentos, assim como de uma técnica. Sempre importa quem faz a intervenção, da mesma maneira que importa também como ela é feita.”

ESTRATÉGIAS PARA ESTIMULAR A MUDANÇA DE COMPORTAMENTO:

Ensinar novas habilidades. Algumas vezes, o comportamento desafiador ocorre porque os alunos não conhecem um modo mais apropriado de se expressarem, ou de obter os resultados almejados.

Adquirindo novas habilidades, o indivíduo pode, com sucesso, repor tal comportamento. O corpo de funcionários da escola talvez precise aprender novas abordagens e novas habilidades.

Valorizar o comportamento positivo. Uma vez que você saiba o que é recompensador para a pessoa com comportamentos desafiadores, utilize-se dessas recompensas para reconhecer e valorizar os comportamentos apropriados. Amplie o foco além do comportamento almejado, recompensando outros comportamentos adequados. Ajude o indivíduo a formar uma identidade positiva.

Alterar os ambientes. Organize ambientes para uma mudança com sucesso, através da criação de um padrão rico em atividades e relacionamentos preferidos que estimulem os comportamentos desejáveis.

Mudar os sistemas. Os pais e os professores têm um papel importante a desempenhar no desenvolvimento de sistemas que sejam receptivos e personalizados.

Monitorar o progresso. Conceba um sistema de registro para descobrir o que funciona e o que não funciona. Se o plano não estiver funcionando, verifique o porquê. Certifique-se de conceder o tempo suficiente para dar certo. Esteja disposta para projetar uma nova abordagem, se necessário.

Antecipar as crises. Invente um plano específico para responder às situações difíceis e distribua-o a todos os que têm contato com o indivíduo. Este tipo de previsão aumenta a eficiência do plano e fornece às pessoas do grupo de apoio uma segurança a mais.

**Summer
and fall programs
for teens in
Boston and Worcester**

Easter Seals Technology Centers

Opportunities for children and adults with all kinds of disabilities

- Try out the latest in hardware, software and computer adaptations
- Get expert advice from Easter Seals Assistive Technology Specialists
- Find solutions to computer access problems
- Benefit from a full range of computer-focused job training and employment services – including summer and after-school programs
- Explore career options

*All conveniently located at Easter Seals Technology Centers
in Boston and Worcester*

Questions?

Call **800 922-8290** for information on the Easter Seals Technology Centers and other resources for people with disabilities.

Or see **www.EasterSealsMA.org** for information on Easter Seals services.



Creating solutions, changing lives.

*Expanding independence
for people with disabilities*

**Easter Seals
can help with
school-to-work
prep**



Federation for Children with Special Needs

1135 Tremont Street, Ste. 420
Boston, MA 02120
617-236-7210 Voice/TDD
MA Toll Free 800-331-0688
email: kidinfo@fcsn.org
web: www.fcsn.org

Non-Profit
U.S. Postage
PAID
BOSTON, MA
PERMIT NO.
50539

Central Massachusetts (508) 798-0531 • Western Massachusetts (866) 323-0681

Welcome, Sara!

The Federation wishes to extend a warm welcome to its new associate executive director, Sara Miranda. Sara has a long history of involvement with the Federation, serving as a member of the Board for over ten years. She also brings to the Federation a vast knowledge of social services, especially as they pertain to children with special needs. Specifically, Sara has worked in the field of developmental disabilities and special health care needs since 1978. Sara trained as a clinical social worker at the Developmental Evaluation Center at Children's Hospital in Boston. She worked at the hospital for eleven years, directing the Down Syndrome Program, providing social work services for children with special health care needs and serving as the Director of Social Work for the Institute for Community Inclusion.

While at Children's, Sara also helped begin the Parent-to-Parent Program at the Center for Families. Additionally, Sara was a member of the Board of Directors for the

Massachusetts Down Syndrome Congress for twelve years and was involved in their First Call program, Brothers and Sisters Workshops and Young Adult Conferences. Sara was a co-founder of the Latino Down Syndrome Parents Group, which today meets monthly at the Federation. Sara has also worked with families involved in adoption of children with special needs.

Prior to accepting a position as an assistant executive director at the Federation, Sara worked at the North Shore ARC, managing the autism programs. These included an intensive early intervention program for children with autism/PDD, the Autism Support Center and an in-home behavioral and family support program. With this extensive array of experiences dedicated to improving the services available to families with children with special needs, Federation staff anticipates the wonderful contributions that Sara will make to the Federation, and looks forward to a long partnership with her.



To order this or other
FCSN publications, go
to www.fcsn.org or
call 800-331-0688

2002 Summer Camp Directory: A Listing of Day and Residential Summer Camp Programs

Published annually by the Federation, the Summer Camp Directory booklet provides information on 80 day and residential summer camps, plus a listing of local community resources. It provides guidelines for selecting a camp, and suggestions for including children with disabilities in regular camps.

59 pages. 2002. \$7.00

The Federation salutes all of the following contributors to and sponsors of this year's conference, "Creating a World of Opportunities."

Boston Foundation
Boston Public Schools
Noreen Curran—Advocacy Associates
Department of Mental Health
Department of Mental Retardation
Department of Public Health
Easter Seals
Fidelity
Gnomon Copy
Harvard Pilgrim Health Care Foundation

Pamela Jean Hausser—Pure Portraits
Massachusetts Behavioral Health
Partnership
Massachusetts Developmental
Disabilities Council
Regional Family Support Program,
Department of Mental Retardation
Video Master
Wayside Youth & Family Support
World Trade Center