"To promote the health and well-being of all Californians with developmental disabilities."

1999

Wellness Digest

Volume 2, Number 2

CALIFORNIA DEPARTMENT OF DEVELOPMENTAL SERVICES

BEHAVIORAL CHALLENGES

IN THIS ISSUE:

Some of our most troubling situations involve individuals who engage in behaviors that are serious enough to cause injury to themselves or to other people. These individuals typically require intensive treatment services and specialized interventions. Although the number of consumers identified as having severe behavior challenges is small (less than 7% of all consumers in the State of California), the clinical resources available for the services and supports they need are often costly and difficult to obtain. As a result, people with behavioral challenges are at greater risk for having limitations placed on where they live, work and recreate.

This issue of the Wellness Digest focuses on behavioral challenges. We present the assessment techniques and treatment strategies that are currently considered the best practices in this area. We also highlight the experiences of three individuals who have received the support, understanding and acceptance needed to overcome behavioral issues and maintain greater control over their lives.

THE WELLNESS DIGEST IS GRATEFUL TO:

DAVID

JENNIFER

JOSE

for sharing their experiences and giving us permission to publish their stories.

We also wish to thank the people who have provided support to David, Jennifer, and Jose. They, too, provided information about their experiences in helping people overcome behavioral challenges. We present these stories to exemplify the benefits of positive support and personal respect in helping people to gain greater independence and satisfaction in their lives.

FROM THE DIRECTOR

Wellness - A Way of Living

Cliff Allenby, Director

Cliff Allenby, Director

The Wellness Initiative continues to move forward with its mission to promote the health and well-being of all Californians with developmental disabilities. Much has been accomplished these past three years to ensure that individuals with developmental disabilities have access to quality medical, dental and mental health services. The Department of Developmental Services has formed new partnerships and sponsored a variety of new projects. These include:

- Partnerships with UCLA, UC San Diego and UC Davis medical schools to provide training to physicians and medical students about the health issues of people with developmental disabilities.
- Creation of a toll-free "warmline" to provide access to specialist consultants for community physicians through a partnership with UC Davis Medical School.
- Publication of an informational "medical access" booklet to assist case managers, families and care providers in accessing medical services for people with developmental disabilities.
- Funding of 76 regional projects related to wellness. These projects have generated a number of valuable resources to enhance the full range of health care services available to people with developmental disabilities. These resources include best practice guidelines, protocols, training videos and curriculum guides.
- Up to $1 million will be distributed for wellness projects in fiscal year 1999/00. Among the priorities for these funds are projects that will further enhance services in the areas of mental health, women's health, aging, medication and sexual abuse prevention. Additional funding will be allocated to enhance mental health services and dental care access throughout California.

In addition to these efforts, we continue to publish the Wellness Digest to share information on important health and wellness topics. This issue focuses on providing support for people with behavioral challenges, a topic of continuing concern and importance. Through increased awareness of the needs of persons with behavioral challenges, we hope to promote the services and supports necessary to assist these individuals in achieving maximum independence and quality of life.

Cliff Allenby

State of California
Gray Davis
Governor

Grantland Johnson
Secretary
Health and Human Services Agency

Cliff Allenby
Director
Department of Developmental Services

Julie A. Jackson
Manager
Program Services Branch

Rick Ingraham
Chief
Health and Wellness Section

Sue Boucher
Editor

Donald M. Hilty, MD
Consulting Editor

The DDS Wellness Digest is published by:
Department of Developmental Services
1600 9th Street MS 3-22
Sacramento, CA 95814
TEL: 1-877-377-4325 (Toll Free)
TTY: (916) 654-2054
FAX: (916) 654-3464
DDS Website at http://www.dds.ca.gov

More information about Wellness priorities and projects can be found on the DDS Home Page at http://www.dds.ca.gov/well01.htm

Subscriptions to the DDS Wellness Digest are available at no cost upon written request.

The DDS Wellness Digest provides tips, guidance and information on a variety of health issues. This newsletter is not intended to provide medical advice on personal health matters. Medical advice should be obtained from a licensed physician.

October 1999

INTERVENTIONS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES AND BEHAVIORAL CHALLENGES: A BRIEF HISTORY

In the late 1800s, psychiatrists were the primary diagnosticians and educators in the area of developmental disabilities. They were the early leaders and advocates for humane and education-oriented care for people with developmental disabilities. By the early 1900s, however, the treatment of individuals with developmental disabilities had shifted to the provision of custodial maintenance in large institutional settings.

Psychotropic medications were routinely administered in these settings. This practice was based on the widely held misconception that people with developmental disabilities typically engage in unusual and harmful behaviors. Such behaviors were assumed to be part of the disability. It was also believed that people could not benefit from treatment, other than medication, to change their behaviors. Psychotropic medications were administered without regard to psychiatric diagnosis as it was further believed that people with developmental disabilities could not experience mental illnesses.

It is now recognized that persons with developmental disabilities are vulnerable to the full range of psychiatric conditions. These conditions can be identified using standard diagnostic criteria and techniques. Unfortunately, the reliance on psychotropic medication to control behavior is still practiced in some settings. In a study conducted for the Department of Developmental Services in 1998, Citygate Associates found that approximately 12% of California's consumers were receiving psychotropic medications even though the diagnosis of a significant mental health condition had not been made. This finding was the same for people residing in the developmental centers, as well as for those residing in the community.

Clinicians now have a wide range of treatment alternatives to medication to assist people who engage in unsafe behaviors. In 1991, the American Psychiatric Association reported that individuals with developmental disabilities are known to benefit from a variety of psychotherapeutic interventions, including psychotherapy. Medications can be appropriate and effective in the treatment of some psychiatric conditions. But the most effective treatment-courses, in such cases, typically involve a combination of medication, education, behavioral therapy and counseling.

A psychiatrist with experience in developmental disabilities may be helpful for diagnosis and management of challenging behaviors. This should be done in consultation with the primary care physician or in collaboration with a multidisciplinary team of professionals, families and friends. For the purpose of diagnosis, specialists must consider the spectrum of causes for problematic behaviors, including medical and psychiatric disorders.

ASSESSMENT STRATEGIES: ALL BEHAVIOR IS MEANINGFUL

People engage in behaviors for a variety of reasons. A behavior can be learned in response to stressful situations. A behavior might also be symptomatic of a medical or psychiatric problem. It is not unusual that more than one type of condition is present at the same time or that an individual engages in the same behavior for different reasons. For example, an individual might hit their head in response to the pain of a headache. The same individual might also hit their head when they feel anxious or frustrated. Thus, an assessment to determine the cause of the behavior can be complicated and time consuming. This is especially true in those cases in which the individual does not use speech.

A thorough assessment is necessary for an accurate diagnosis. The diagnosis identifies the correct course of therapy to follow. Without an accurate diagnosis, an inappropriate treatment may result in side effects that are more severe and dangerous than the original behavior. One common mistake is to assume that a behavior is solely used as a method of control. This assumption overlooks other important issues and doesn't result in specific solutions.

A thoughtful and complete assessment preserves the dignity of the person involved. All participants in the assessment process must keep in mind that the objective is not to merely define and

Assessment Strategies: Continued on page 4

Assessment Strategies:
Continued from page 3

suppress the problem behavior. Instead, the objective is to understand the cause of the behavior so that alternatives can be taught and/or needed medical and psychiatric treatment can be provided.

Challenging behaviors must be systematically evaluated to determine the triggering cause(s). Some possible factors include medical disorders, medications, psychiatric disorders, substance abuse, cultural issues, social/environmental issues and individual differences. This newsletter will focus primarily on medical, psychiatric and social/environmental factors. What is important to remember is that a challenging behavior never occurs "just" because a person has a developmental disability.

BEST PRACTICES IN ASSESSING THE CAUSES OF BEHAVIOR

Develop an Assessment Team

- Team members typically include the individual, his/her service coordinator or case manager, family members, direct service staff who know the person well, primary care physician, behavioral specialist, and anyone else that the individual requests to be present. Other members may include a psychiatrist, pharmacologist, nurse and any other therapists involved in the person's life.

Involve the Individual

- Be positive. Discuss all issues candidly, but validate the person's feelings. Focus on the person's strengths.
- Be respectful. Always address the person directly, regardless of ability to use verbal communication. Request permission to include others for input and interpretation.
- Reduce anxiety. Avoid criticism and do not make accusations. Meet in a setting that is comfortable for the individual. Ensure there is adequate time and do not rush the process.

Identify All Behaviors of Concern. Define Each Behavior in Concrete Terms

- Define the behavior in terms of what the person does.
  Vague Definition: John is aggressive.
  Concrete Definition: John hits his co-workers during lunch break when it is noisy in the dining room.
- How long has the behavior occurred? What specific triggers are known?
- What interventions typically work and do not work?

Identify All Physical Complaints or Symptoms

- When did the complaints or symptoms begin?
- Are they new or recurring?

Obtain a Complete History of the Individual

- *Medical History*
  Include all current and past medical problems, including medications.
- *Family History*
  Include all known medical and psychiatric conditions, substance abuse problems and developmental disability of any biological family member.
- *Functional History*
  Include the following: skills and talents; preferred means of communication; positive personality characteristics; vocational experience.

- *Social/Emotional History*
  Include descriptions of family interactions, other significant relationships, daily activities, etc.

  Is there a history of trauma or abuse?

  Who knows the individual best? To whom is he/she closest?

  What kinds of events, situations or people are difficult for the person?

Complete a Functional Assessment

- Identify any situational factors for the behavior.

  Collect data on the target behavior to identify frequency, intensity, and situational factors.

Develop a Plan to Eliminate the Situational Factors and Provide Alternatives to the Problem Behavior

Evaluate Progress and Revise Plans

- Be flexible and willing to reassess when initial interventions do not seem to affect the behavior.
- Try to maintain a positive attitude.

Plan For Crises

- Everyone who has contact with the individual should be prepared to respond to dangerous situations if the identified behavior could result in self-harm, injuries to others or property destruction.
- Have a written plan. Carry emergency numbers.
- Ensure that substitute staff know and can implement the plan.

PSYCHIATRIC CONDITIONS

It has been estimated that between 30% and 70% of all individuals with developmental disabilities may also have a mental health condition and need psychiatric care. Although people with developmental disabilities can experience the full range of mental health illnesses, the conditions diagnosed most often are post-traumatic stress disorder (PTSD) and other types of anxiety disorders. There is a higher incidence of these conditions for this population than for the general population. The reason may be that individuals with developmental disabilities are often the victims of abuse, neglect, isolation, segregation, prejudice and other mistreatment.

To accurately diagnose an existing psychiatric condition, clinicians need to recognize that the standard criteria specified in the Diagnostic and Statistics Manual of Mental Disorders (DSM-IV) apply no differently to people with developmental disabilities than they do to people in the general population. Clinicians must also recognize that individuals with developmental disabilities can respond to most treatment approaches. A low IQ score does not automatically preclude the success of psychotherapeutic methods. Diagnostic and treatment techniques, however, may need to be adjusted to match the individual communication style of the person being assessed or treated.

One other consideration in the assessment and treatment of psychiatric conditions for people with developmental disabilities is the high incidence of concurrent medical problems. Behavioral symptoms related to medical conditions can appear to be psychotic in nature. Additionally, behavioral symptoms related to a psychiatric condition may become more severe when a medical condition is also present. Therefore, it is important that a complete medical evaluation is conducted to identify any medical conditions and non-psychiatric medications influencing behavior.

Indicators Of Psychiatric Conditions

Some behavioral symptoms are frequently associated with psychiatric conditions. A psychiatric assessment should be considered when an individual displays these symptoms. Because these behaviors may also be related to medical or environmental factors, the following criteria should be considered when speculating that the behavior is caused by a psychiatric condition:

- The behavior is consistent in all settings and situations.
- A consistent behavioral intervention has had little or no effect on the behavior.
- The individual does not appear to be able to start or stop the behavior at will.

BEHAVIORAL SYMPTOMS OF PSYCHIATRIC CONDITIONS

Changes In:	
Sleep Pattern	• Excessive sleep; Constant fatigue • Little to no sleep • Interrupted sleep
Appetite	• Lack of appetite • Intensely fearful of food; Inspects or refuses food
Excessive Moods:	
Worry	• Constant and excessive talk about particular daily events • Repetitive behavior rituals to either ensure or prevent an event
Anger	• Threatening or hostile to others • Agitated or irritable • Appears angry at strangers • Anger that is excessive for the situation
Happy	• Excessively elated over period of time • Grandiose thoughts and ideas
Sad	• Depressed mood over period of time that is not related to loss or grief • Loss of interest in pleasurable activities • Talks about death or hurting self • Change in sleep pattern • Change in appetite
Hallucinations:	
Hearing Voices	• Stares to side or corners and appears to be involved in conversation • Covers ears
Visual Hallucinations	• Appears to be shadow boxing • Covers eyes • Brushes unseen material off body
Appearance:	
Cleanliness	• Refuses to bathe or shower • Excessively showers or bathes
Clothing	• Wears multiple layers of clothing • Unusual wrappings around head • Uses wrappings to enclose openings such as collars, sleeves, ankles, etc.
Bruises/Cuts	• Accidental or purposeful self-harm

BEST PRACTICES FOR THE USE OF PSYCHOTROPIC MEDICATIONS

Rational Use of Medications

Follow Same Guidelines Used For People Who Don't Have A Disability

Medication Is Consistent With Diagnosis

Review Past History

Therapeutic Effects

Side Effects

Compliance

"Start Low.....Go Slow"

Initial Dosage.....When Changing Dosage

Medication Changes Can Result In Unmasking Of Symptoms And Other Side Effects

New Medications Or Dosages May Enhance Or Reduce The Effectiveness Of Other Medications

Implement Systems For Monitoring

Therapeutic Effects

Side Effects

Interactive Effects of Multiple Medications

Periodically Reduce Dosages

Can the symptoms be treated with a lower dosage of the medication?

Implement Other Types Of Treatment Applicable To The Diagnosis

For The Individual: Education and Behavioral Therapy

For Family And Care Providers: Education and Behavioral Plan

BEYOND MEDICATION: A PERSONAL SUCCESS STORY

David is an expressive and thoughtful man in his early 40s who receives services through Alta California Regional Center in Nevada County. He participates in a supported employment program through PRIDE Industries in Grass Valley and is known around his community as "Hydro Man." This is because of his passionately held belief in the health benefits of ingesting hydrogen peroxide. This belief has caused much concern for the supportive people in David's life. He talks about this belief frequently and with much enthusiasm. However, he has come to an understanding with his care provider that it is not acceptable to act upon this belief. The foundation of this understanding is the respect that David is shown in all other aspects of his life, something David hasn't always experienced.

When he first arrived at PRIDE 2½ years ago, David reported that he was so full of anger that he frequently hit his co-workers. He required the most intensive levels of staff intervention and supervision. "I had so much hatred inside of me, it's really hard to understand", David explained. "I had a hard time talking about my feelings. It's like I'm a completely different person today." Upon meeting David, a friendly and out-going person, it is hard to believe that he is describing himself in the not too distant past.

David was born in the Southern California community of Garden Grove. He doesn't like to talk about his childhood because of the abuse he received from his father and his siblings. There has been no communication with his family for years because it is just too painful. "I have to take care of my own needs", David said about the lack of contact with his family. "If I follow that path, it takes me right back and I don't need that." He did share that he left home as an adolescent and moved into the home of a friend named John. John was a person David got to know while mowing lawns and doing yard work in his neighborhood. John bought David his first bicycle and included David in his work at a local veterinary hospital where he helped care for sick and injured animals. They both made the move to Grass Valley after John retired in the late 1970s.

When John passed away some years later, David found himself looking for a new home. He decided to give living on his own a try so he rented an apartment in Grass Valley. His experience during this time was truly frightening. "The neighbors were pushing me around and I was doing some other things", David said. "It was scary. It's only by the grace of God that I got out of there." At one point, he ended up in the Nevada County jail, charged with assaulting a neighbor. There were growing concerns about David's safety and about the safety of others. Because of this, Angela Stewart from Alta California Regional Center helped David move into a board and home in Nevada City.

Following the move, David felt he had traded one set of problems for another. He wasn't accustomed to living with a group of people and he didn't like the restrictions placed on him in the care home. "I was upset and didn't feel good the whole time I was there", David remembered. "I didn't have my own room and I had to keep to their schedule. A home is supposed to be like a family, not like an institution." David was particularly disturbed by the different standards he felt were set for the consumers and the providers. There were separate areas in the house for the providers that were off-limits to the consumers. The consumers also had separate meal schedules, ate at different tables and were given fewer food choices. "It was like we weren't good enough and didn't deserve to share the space or to get a decent meal", David related. "They'd have steak or barbequed ribs, and we'd get tortillas and cheese...or bologna sandwiches. Lots of bologna sandwiches, and I just hate bologna."

David often protested about the things he did not think were right about the way he was being treated. He would also speak up for

Beyond Medication Continued on page 8

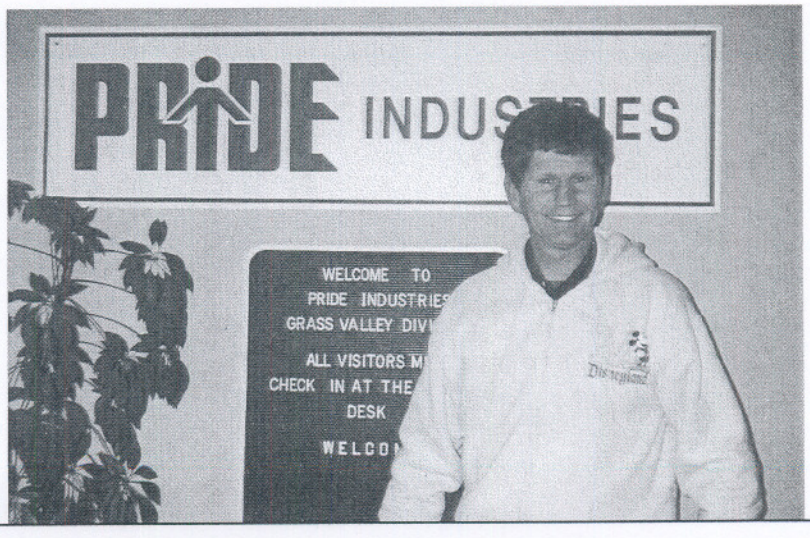
Beyond Medication
Continued from page 7

the other consumers living in the home who he felt were too afraid to speak up for themselves for fear of punishment. "I'd get put on restriction and not be able to go places or watch television", he recalled, "because I had an opinion and would speak out about it." His resentment and anger got him labeled as non-compliant and incorrigible by the care providers. As a result, he was referred to a psychiatrist. Based on this reputation, as well as a history of hearing voices while living on his own, the psychiatrist decided that David needed to be medicated. Although he was already taking a low dosage of Zyprexa, David started receiving Prolixin injections every two weeks. "The doctor only saw me for 5 minutes and decided I needed the shots", he said. "I never needed this drug before and I tried to tell people it wasn't helping me, but they just ignored me."

While on the Prolixin, David was sleeping most of the time. He was hardly able to function at home or at work. He began to have tremors, similar to the symptoms of Parkinson's disease. "If you would have seen me, you would have said 'oh my god!' ", David said about his situation at the time. "I was down in the dumps and I didn't want to come to work, but I knew I'd lose my self-esteem if I didn't. I think God kept telling me to not give up and to just hang on for one more day." After seven months on the medication, David was referred to Dr. Ruth Ryan of Consultative Mental Health Services to Persons with Developmental Disabilities. An expert on the assessment and treatment of behavioral issues, Dr. Ryan had been hired by Alta California Regional Center to provide training and consultation. "Dr. Ryan recommended that David be taken off the Prolixin and that he move out of the care home", Angela Stewart said. "And his situation made a 180-degree turnabout as soon as we implemented these recommendations."

David moved into a newly opened care home owned by Claudia Cook and her husband. Their two sons are the staff who live in the home with the consumers and the Cooks live nearby. "Our philosophy is that this is their home", Claudia Cook said about how the home is structured. "We respect their privacy and their choices." David described the move as "an energizer." He no longer feels like an outsider, but instead feels at home. "The people here believe in me, they believe that I'm a capable person", David said. "They treat me like I have a mind, a soul. Like I'm as good as anyone else. They boost everyone's morale." Claudia describes David as a very thoughtful and kind person. She has a difficult time believing some of the stories she has heard about his past. "We've been here almost a year, and David was one of the first people to move in. There's never been any problems this whole time. He's a very nice, very sweet person."

There are changes for David at work these days, too. He now has positive relationships with his co-workers and no longer needs intensive supervision. He works very independently in his job involving assembly and packing. But what he enjoys the most is the opportunity he has to help some of the other consumers at PRIDE. Every day he is relied upon to provide assistance to a small group of people who have complex medical conditions and communication or mobility challenges. "Some people look down on them because they can't talk or because it's hard for them to get around, but I know what it's like to have people look down on you", David said. "I believe in talking to them and treating them like anyone else. The most important thing is treating people the same way you want to be treated."



MEDICAL CONDITIONS

A change in behavior is often the first sign that a person has a serious medical condition. Unfortunately, such conditions are frequently undetected by a routine physical examination, especially when individuals are unable to verbalize their symptoms. Additional procedures and tests are typically required to locate and diagnose the problem. But many times primary care physicians are reluctant to order such procedures for fear that the individual will not be able to cooperate because of the behavioral issues. As a result, individuals are often seen repeatedly by their primary care physician or in emergency rooms before a medical diagnosis is determined. In the case of life-threatening conditions in which early detection is critical, such delays in diagnosis and proper treatment can have devastating consequences.

Medical procedures can usually be accomplished when the individual is helped to understand why the procedure is necessary and what to expect during the procedure. Family members, care providers and others in a supportive relationship can help prepare the person for the procedure by facilitating communication with the physician or technician. It is sometimes beneficial to visit the clinic or lab prior to the scheduled appointment to familiarize the person with the setting, the equipment and the clinical staff who will be involved. This also helps to reassure any clinical staff who have concerns about the individual's ability to complete the procedure.

BEHAVIORAL CLUES TO MEDICAL CONDITIONS

Observed Behavior:	*Medical Conditions To Consider:*
Self Injurious Behaviors	
Hand Biting, Chewing of Fingers	• Dental Pain • Nausea • Indigestion; Reflux • Local Infection
Hitting or Banging Head	• Headache; Migraine • Shunt Problems • Sinusitis • Dental Pain • Ear or Eye Infection
Scratching or Rubbing	
General	• Eczema; Other Skin Conditions • Scabies; Lice; Insect Bites • Sunburn • Liver or Kidney Disorder
Stomach or Abdomen	• Ulcer • Gastritis • Gall Bladder or Pancreas Problems • Menstrual Discomfort
Chest	• Pneumonia • Indigestion; Reflux • Angina
Rectum	• Constipation • Hemorrhoids

Observed Behavior:	*Medical Conditions To Consider:*
Aggressive or Violent Behavior	• Hypothyroidism; Hyperthyroidism • Temporal Lobe Seizures • Caffeine; Substance Abuse • Headache • Infection
Unusual Movements or Postures	
Rocking	• Back or Hip Pain • Indigestion; Reflux
Head Tilting or Waving	• Visual Problems • Sinus Infection
Sitting Sudden Sitting	• Vertigo • Cardiac Problems • Seizures
Other Unusual Posture	• Limb Fractures • Hip Pain • Rectal Pain • Genital Pain
Recurrent Masturbation	• Urinary Tract Infection • Vaginal Infection • Prostate Inflammation

(Based upon training materials entitled Medical Issues in Treating Individuals with Developmental Disabilities by Terrance Wardinsky, M.D., Medical Director at Alta California Regional Center)

RECOGNIZING CRIES FOR HELP: JENNIFER'S EXPERIENCE

Jennifer is a young woman who lives in Southern California and receives supported living assistance from the Institute for Applied Behavioral Analysis (IABA). She enjoys the privacy and independence she has in her current living situation. But Jennifer had to overcome numerous medical challenges before realizing this goal. Her story exemplifies the difficulties encountered in making an accurate medical diagnosis when the presenting symptoms are behavioral.

As an infant and toddler, Jennifer was healthy and reached the expected developmental milestones. Her father died suddenly when she was about 4 years old, and it was at that time that Jennifer lost the language skills she had acquired. She began to engage in both self-abusive and self-stimulating behaviors. Doctors diagnosed her as having autism. Within a few years Jennifer went to live in a community care home for children, the first of several homes she would live in as a child and adolescent.

Jennifer's self-abusive behavior grew more intense during her teen years. She would hit and bite herself, dig her fingernails into her stomach and force herself to vomit. She was repeatedly admitted to a local medical center for extended periods of time, but no physical problems were ever diagnosed. Instead, the doctors concluded that Jennifer's behaviors were related to her autism. She was given psychotropic medications to control her behavior. "The doctors put her on Haldol, Mellaril, everything", said Susan Sylvester, Jennifer's case manager at Westside Regional Center in Los Angeles County. But the medications didn't stop the behaviors. Jennifer eventually ended up in the emergency room at the county hospital where there was no bed available for her. She was 17-years old, and no one knew how to help her or how to ensure her safety. With no other options available, Jennifer was placed in a state developmental center.

Her stay at the developmental center lasted a little over two years and she was taken off all psychotropic medications. But Jennifer would isolate herself from her peers and spent most of her time alone. And she continued to hurt herself and force herself to vomit. At one point, Jennifer weighed less than 90 pounds and was very close to having a gastrostomy tube placed to ensure adequate nutrition. It was clear to her mother that Jennifer did not like living at the developmental center, but Jennifer was making progress and appeared to be getting healthier. It was in March of 1995, that Jennifer was considered healthy and stable enough to move out of the developmental center. She moved into the supported living situation with assistance from IABA.

"Initially, Jennifer was happy, thrilled," Susan Sylvester said of the new living situation. "But within 3 to 4 months the self-abusive behaviors and the vomiting started up again. Jennifer lost weight, began to act aggressively towards others and was often distraught and crying." A new behavior developed in which Jennifer would stand with her shoulders pushed flat against the wall. She would then

slide down the wall and crawl on her back under her bed. Susan was convinced that this was a symptom of a medical problem, so Jennifer was again referred to the local medical center. Again the doctors concluded that Jennifer's underlying problem was autism and more psychotropic drugs were prescribed.

Everyone involved with Jennifer was afraid that she would have to go back to the developmental center. But Jennifer was admitted to a different local hospital because she was vomiting blood. It was discovered during this visit that Jennifer was suffering from an ulcer. With treatment of the ulcer, Jennifer stopped the sliding down the wall behavior and her abusive behaviors decreased. It was now clear that Jennifer's behaviors were indeed in response to pain.

The next two years proved to be increasingly challenging for Jennifer, her mother, and the people in her life who provided support. She had one medical problem after another, including gastritis, internal and external hemorrhoids, impacted

wisdom teeth and recurring cellulitus. It was also discovered that she suffered from dysmenorrhea, or pain associated with her menstrual cycle. With every new condition, the self-abuse and aggression would return until a diagnosis was made and treatment provided. Diagnoses weren't easy because Jennifer could not verbalize what she was feeling. However, her behavior patterns provided a clear indication that something was wrong.

She was hospitalized numerous times during this period and, with each hospitalization, she was given additional psychotropic medications. "At one point, Jennifer was on 6 or 7 different drugs", Susan Sylvester shared. "She was literally falling over backwards because she was so over-medicated." Susan also related that the doctors treating Jennifer tended to minimize the severity of the pain that she was experiencing. "The doctors would say things like 'we've found that she has this problem, but it's really not that painful.' Then we'd talk to someone who had experienced the same condition and they'd tell us how excruciating it had been for them." It was as though these people, speaking about their own experiences, became Jennifer's voice in helping others to understand what she was really going through.

Eventually, each of the various medical problems that Jennifer experienced were diagnosed and treated. As her health stabilized, her behaviors improved. The people supporting Jennifer were pleased that their efforts were having such positive impact. During one especially difficult episode, six IABA staff members stayed overnight to provide the support Jennifer needed. And Susan Sylvester was able to advocate for a visiting nurse to monitor Jennifer's progress twice each week over an extended period of time. The nurse provided assistance to the IABA staff in monitoring and ensuring that Jennifer was drinking adequate amounts of water and getting pain medication when she needed it. More importantly, Jennifer learned ways to communicate when she was experiencing pain, such as laying her head on a staff member's shoulder or pointing to the Tylenol bottle.

Jennifer's situation has vastly improved. Although she still has good days and bad days, Jennifer has not had any major behavioral episodes for almost four years. She is fortunate to have the continued support of the IABA staff, her case manager Susan Sylvester, and her mother, whom she visits for dinner on a weekly basis. These are the people who know Jennifer best and who were able to advocate for her when the medical professionals had difficulty understanding and diagnosing her conditions. "I hope we helped the doctors establish new criteria when working with our consumers", Susan Sylvester says. "Based on their experiences with Jennifer, I hope they now ask themselves, 'What would I do for this person if he or she didn't have a developmental disability?'"

ENVIRONMENTAL FACTORS THAT INFLUENCE BEHAVIOR

We all engage in a variety of behaviors to help us cope with the circumstances and stressors we encounter on a daily basis. We use behaviors to communicate our feelings, to avoid threatening or unpleasant situations and to get our needs met. Verbal expression is the communication means that most people are accustomed to and use. Individuals who are not able to speak typically develop other ways to communicate their needs and to help them cope with environmental stressors. Often, these alternatives are behaviors that are maladaptive and seemingly unrelated to the situation at hand. Initially, these alternative behaviors may be merely unusual or disruptive. But such behaviors can develop into more aggressive and dangerous actions if the person becomes increasingly frustrated when their attempts to communicate are not understood. Likewise, it is not unusual for individuals who do use verbal expression to become frustrated and act in angry or aggressive ways when they are repeatedly ignored or discredited.

Positive behavioral support methods recognize that behaviors can be responses to environmental stressors and unfulfilled needs. These methods focus on eliminating or reducing these factors and assisting individuals in developing alternative coping and communication skills.

Environmental Factors Continued on page 12

Environmental Factors
Continued from page 11

Positive behavioral supports include:

- Teaching new skills
- Changing the environment to better fit the individual
- Ignoring non-dangerous behavior
- Substituting constructive activity
- Removing the individual from the situation

FUNCTIONAL BEHAVIORAL ANALYSIS

Accurate identification of the situational and environmental factors that influence behavior is essential to the success of a positive behavioral approach. Functional behavioral assessment techniques are generally considered to be most effective in identifying the environmental causes behind undesirable behavior. The individual who engages in the behavior, and those who know this person best, should collaborate with someone trained in behavior analysis to collect situational information about when, where and why behavior occurs. Based on this information, an intervention plan is developed to address the cause of the target behavior. The plan is then implemented to change the behavior.

COMPONENTS OF A FUNCTIONAL BEHAVIORAL ANALYSIS

- **Indirect Assessment: Structured interviews to obtain information about the behavior.**

  Settings in which the behavior does and does not occur.

  Others present when the behavior occurs.

  Activities or interactions prior to and immediately after the behavior.

  The individual's perceptions and feelings about their actions.

- **Direct Observation: Observing and recording situational factors.**

  In natural settings and conditions.

  Must not interfere with normal routines and activities over extended periods of time.

  Multiple observations of the behavior whenever possible.

Data Analysis: Comparison and analysis of the collected information.

  Identify any patterns associated with the behavior.

  Determine the relationship between the behavior and environmental events.

  Identify more acceptable alternatives to the behavior.

- **Hypothesis Statement: A plausible explanation for the behavior based on the data.**

  Predicts the conditions under which the behavior is most likely and least likely to occur.

  Predicts the likely consequences that motivate the person and maintain the behavior.

- **Hypothesis Testing: Confirms or disconfirms the hypothesis.**

  Systematic changes implemented to control conditions and consequences.

  Confirms hypothesis or identifies the need to formulate a new one.

- **Behavior Intervention Plan: Replace the behavior with positive or neutral alternatives that serve the same function.**

  Increase existing desirable behaviors.

  Encourage the development of additional desirable behaviors.

  Make environmental changes that reduce or eliminate the possibility of engaging the undesired behavior.

  Provide the supports necessary for the person to use alternative behaviors.

YOU WEREN'T LISTENING SO JOSE HAD TO GET YOUR ATTENTION SOMEHOW

Jose lives in his own apartment in Southern California and is very satisfied with his lifestyle. He has received assistance in reaching this goal from a supported living program in Los Angeles County called Avenues. Jose feels he has control over the decisions about his life and he is proud of his accomplishments. But in the past, Jose often felt others weren't listening to him and respecting his wishes.

At one time, Jose had a reputation for being a person who would get overly angry and frighteningly aggressive. "Jose is a big guy, so people would be afraid of him when he lost his temper", Lucilla Alvarez of Northern Los Angeles County Regional Center (NLACRC) explained. "His size had a lot to do with how people treated him. After he'd have a blow up, people would just give up on him and not deal with him anymore."

Both Lucilla and her co-worker, Patty Cardenas have worked with Jose as service coordinators at NLACRC. Each described Jose as a very independent person whose choices and priorities often differed from those of his mother. Lucilla and Patty both knew Jose when he was in his 20s. These were some tough years in which he moved frequently between his mother's home and various living arrangements. Jose has diabetes and maintains a routine appointment at a county mental health agency. Due to her concerns about Jose's health and safety, his mother expected the regional center and care home staff to place limits on Jose's choices and to rescue him from mistakes he made as he learned to take more responsibility for himself.

"Jose's mom often had ideas about what Jose should be doing that were different than Jose's ideas. She would try to get the people working with him to make Jose do what she thought was best for him", Patty Cardenas said. "So either Jose was angry or his mother was upset, and it just got to be too much for providers and program people to deal with." The dynamics between Jose and his mother made it difficult for regional center staff to find the right services and supports for Jose. "Jose blew-out of lots of programs and living arrangements. I was on the phone daily to Jose, his mother and to care home providers," Lucilla Alvarez recalled. "What would seem to be easy solutions for his mother or the care providers would not be the solutions Jose wanted.

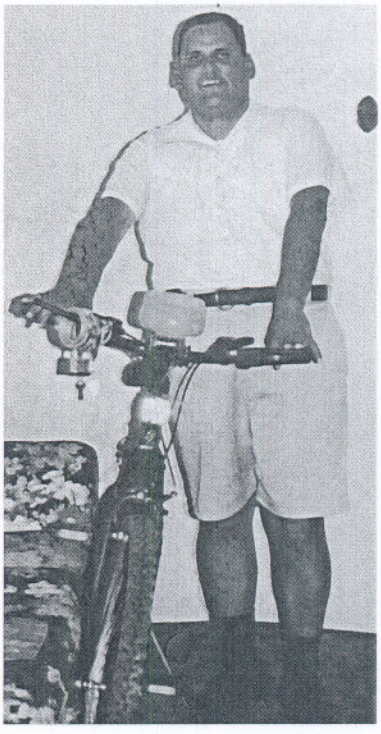
Over a period of about 10 years, Jose was constantly moving from one place to another, including a short stay at a state developmental center. Jose was eventually referred to Avenues. With the support of staff member, Scott Shepard, Jose has lived in his own apartment for almost 5 years. Both Jose and Scott agree that Jose's first attempt at supported living was "a disaster". But they stuck with it. "As service coordinators, we come and go", Patty Cardenas said, "but Scott has stood by Jose longer than anyone." "Scott has been wonderful", Lucilla Alvarez added. "He has a relationship with Jose that is based on trust. Jose knows he is heard and respected. Scott can set guidelines but is flexible so that Jose makes his own choices. If Jose doesn't make a great choice, Scott lets him take the consequences and doesn't rush in to rescue him."

As a result, Jose has learned strategies to help him succeed in making responsible choices and managing his own affairs. One challenging issue was Jose's difficulty with time concepts. This created problems with maintaining a work schedule and keeping appointments. In the past, his history of not showing up at scheduled times gained Jose the reputation of being noncompliant and uncooperative. Jose now has a speaking watch that literally tells him the time with the push of a button. Under an arrangement with Avenues, Jose receives a reminder call on the day before an appointment, and he also receives a call on the day of the appointment just prior to the scheduled time. In addition, he wears a pager so that he can return these calls when he loses track of time and is away from his apartment on the day of an appointment. These supports have enabled Jose to keep his scheduled appointments.

Scott also assists Jose in making plans for the future. This is done by taping large pieces of paper on the wall and writing down all the things Jose wants to accomplish. These plans include, among other things, the budgeting of his money, the

You Weren't Listening
Continued on page 14

You Weren't Listening
Continued from page 13



planning of a menu and finding a new job. Jose tracks how well he is doing by crossing out items as he accomplishes them. On April 4, 1999, Jose realized a major goal he had set for himself when he became a naturalized citizen of the United States. With pride he described how he dressed for the ceremony in his suit and tie and sang the Star Spangled Banner along with the other new citizens. Scott Shepard was at the ceremony with Jose, pleased to have the opportunity to share in this significant event.

At 35 years old, Jose now has control and stability in his life situation. Even though he knows that he can fire Avenues at any time, he has no plans to do so. He gives equal credit to Scott and to himself for what he has accomplished in the past few years. "I'm the boss", Jose said, "and I learned to take responsibility for myself." One great example is that he is working on his temper and is willing to accept responsibility for his anger. "Jose will apologize now when he does lose his temper", Lucilla Alvarez said. "He's learning how to make amends and move on after he gets mad about something. Scott has helped him realize that just because he's had a bad morning doesn't mean he has to have a bad afternoon."

PUNISHMENT AND COMPLIANCE TRAINING

Aversive methods that focus on behavior suppression rather than on the underlying causes have been utilized with varying levels of success. These methods involve providing a punishment when a person engages in an undesirable behavior and providing a reward when the person engages in an acceptable behavior. Punishment is the application of typically unpleasant elements. These might be loud sounds, isolation, removal of a desired object or sharp criticism. Problems identified with the use of aversive methods include:

- Changes in behavior are typically short lived with the challenging behavior re-emerging over time.
- Behavior can become worse as the individual reacts to, or attempts to avoid, the punishment.
- Punishment is damaging to self-esteem.
- The individual may acquire other undesired behaviors in response to the punishment, such as:
  - Fear of the person applying the punishment.
  - Fear of the setting, objects and events associated with the punishment.
  - Yelling or hitting, as modeled by the punishment, in response to a situation or event.
  - Engaging in the undesired behavior only when the person applying the punishment is not present (how "not to get caught").
  - Engaging in the undesired behavior to get attention or for the enjoyment experienced by making an authority figure upset.

Unfortunately, aversive methods have been widely used to make individuals with developmental disabilities more willing to adhere to the demands of family members, program staff, care providers and other support people. It is never acceptable to use aversive methods that make people more compliant solely for the convenience of others. Compliance training places arbitrary limitations on personal rights and choices, and it can also make people more vulnerable to abuse and exploitation.

OUR THANKS TO

Our consulting editor for this issue of the Wellness Digest is Donald M. Hilty, M.D. Dr. Hilty attended the University of Cincinnati College of Medicine and is now an Assistant Professor of Clinical Psychiatry at the University of California, Davis. His career interests include consultation-liaison psychiatry to primary care clinics, especially using telemedicine. He serves as the Head Psychiatric Consultant for the Department of Telemedicine at the University of California, Davis Medical Center in Sacramento. Dr. Hilty is also the Project Director for the Physician Assistance, Consultation and Training Network (PACT Net), a cooperative program developed by Department of Developmental Services and the M.I.N.D. Institute of the University of California Davis Health System to provide specialist consultations for community physicians treating patients with developmental disabilities and complex medical conditions.

SOURCES

The information presented in this issue of the Wellness Digest was compiled from the following sources:

Handbook Of Mental Health Care For Persons With Developmental Disabilities, by Ruth M. Ryan, M. D. Available through The Community Circle, PO Box 460651, Glendale, CO 80246.

Report Of The Task Force On Psychiatric Services To Adult Mentally Retarded and Developmentally Disabled Persons (1990).

Psychiatry and Mental Retardation: A Curriculum Guide (1995). Both are publications of the American Psychiatric Association (APA) and are available through the APA Office of Psychiatric Services, 1400 K Street N. W., Washington, DC 20005.

Positive Behavioral Support Web Page
www.lsi.ukans.edu/beach/pbs/pbs.htm
Valuable information and strategies on ways to support people with challenging behaviors.

Addressing Student Problem Behavior: An IEP Team's Introduction To Functional Behavioral Assessment and Behavior Intervention Plans
www.air-dc.org/cecp/resources/problembehavior/conducting.htm
A thorough overview of conducting a Functional Behavioral Assessment and developing behavior intervention plans.

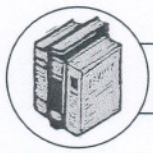
ANNOUNCEMENTS

Physician Assistance, Consultation and Training Network (PACT Net)

The Physician Assistance, Consultation and Training Network (PACT Net) is now available for physicians who are treating patients with developmental disabilities and complex medical conditions. PACT Net is a cooperative program developed by the State Department of Developmental Services and the M.I.N.D. Institute of the University of California, Davis Health System. It provides community physicians free consultations with U.C. Davis specialists. Community physicians can access the program by calling 1-800-4-UC-DAVIS and requesting a PACT Net consultation. Please note that the intent of this program is to provide consultations to physicians or nurses about specific patient concerns. It is not intended to provide consultations to other health care staff, families or other care providers.

We Welcome Your Comments

Use our toll free number, 1-877-DDS-Heal(th) (1-877-337-4325), to request subscriptions, change mailing information or to provide your comments about the Wellness Digest. Individuals using a TDD can contact us at (916) 654-2054. Letters may be addressed to Editor, DDS Wellness Digest, 1600 Ninth Street, MS-3-22, Sacramento, CA 95814.



RESOURCES

Recommended Reading

Developmental Disabilities Clinical Insights: The Use of Medications In Persons With Developmental Disabilities.

Written by Marc A. Schuckit, M.D. Published and distributed through San Diego Regional Center for the Developmentally Disabled. (619) 576-2996 (voice) or (619) 292-5821 (TDD).

OFF THE NET

Internet Mental Health www.mentalhealth.com

Comprehensive listing of information on mental health topics and issues. Includes details about the most common mental health disorders and psychotropic medications, as well as links to research articles and other current publications.

YEAR 2000 (Y2K) "MILLENNIUM BUG" ALERT

What's going to happen at midnight on December 31st? Are you prepared for the Year 2000 (Y2K) "millennium bug?" Do you know what to expect and how to prepare for possible problems? The Y2K problem results from the use of a two-digit number to represent the year in some computer chips. Chips created to interpret 00 as the year 1900 (rather than the year 2000) may fail to function after 1999.

Some medical devices have computer chips integrated into them. The majority of medical devices will function without any potential health or operational problem after December 31, 1999. Some may have a minor problem, such as displaying the year as 00 rather than 2000. A very small number of medical devices will encounter a real problem unless they are corrected prior to being used after December 31,1999.

All individuals receiving regional center services who also utilize a medical device are eligible to have that device assessed and replaced if necessary. Regional centers are identifying such equipment and the Y2K status is being assessed by an expert firm specializing in systems with embedded chips. For more information, contact your local regional center.

The Y2K problem may cause temporary disruptions to some services that depend on computers to function. Everyone should be prepared in the event that power, water, telephone and transportation and other services are disrupted. A special edition of the Wellness Digest will be released in the Fall of 1999 to provide tips for emergency preparedness planning. This information will help you be ready for potential Y2K problems as well as other emergencies situations, such as earthquakes or floods.

In addition, DDS has established a toll-free telephone line to provide Y2K information to the developmental disability community. The number is 1-800-909-6778. DDS has also established a Y2K section on its web site at www.dds.ca.gov. It provides information about the Y2K problem and how to be prepared. It also links to additional sites with information about emergency preparedness. Go to the Table of Contents and select **The Year 2000 Computer Problem**.

Printed on 80# Somerset Matte Book using Black and Pantone 300 Inks.

Department of Developmental Services
1600 9th Street
Sacramento, CA 95814