PREMIERE ISSUE

THE PENNSYLVANIA JOURNAL ON

POSITIVE APPROACHES

A quarterly publication dedicated to helping people with developmental disabilities and challenging behaviors live fulfilling EveryDay Lives.

Volume 1 ▾ Number 1 ▾ Summer 1996

POSITIVE APPROACHES

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Through case studies, Positive Approaches practices & tools, book reviews, interviews, policy & regulation reviews, and articles, the following Positive Approaches continuum of supports will be highlighted and explored:

- ▼ **Values and Changes in Environment**
- ▼ **Effective and Enhanced Communications**
- ▼ **Appropriate Specialized Assessments & Interventions**
- ▼ **Wrap Around and Extraordinary Supports—Hanging in There**

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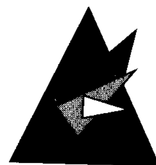

Positive Approaches
1996, Vol. 1, No. 1

The Pennsylvania Journal on Positive Approaches: An Overview

by Beth Barol, MSS

Pennsylvanians have been very successfully learning positive, new ways to help people overcome their challenging behaviors. We are still struggling, however, to find ways to help everyone in the Commonwealth understand and apply the principles and practices behind Positive Approaches.

In essence, Positive Approaches is a worldview, in which all individuals are treated with dignity and respect, in which all are entitled to "Everyday Lives." This journal focuses on how this principle plays out in working with individuals who have developmental disabilities and who present challenging behaviors. In coming issues we will present philosophies, practice techniques, tools, and case studies that mesh well with the Positive Approaches paradigm. The case studies and most of the articles will be presented by Pennsylvanians. The effort is to build a resource network across the state and to build the expectation that "YES! We can do it here!"

In recent years we have been trying to conceptualize the Positive Approaches paradigm in terms that are relevant to all of us who interact directly with the people we serve. Many of us have found it helpful to think about Positive Approaches in terms of four major areas: Environment, Communication, Assessment, and Hanging in There.

Environment

Most of the time, when people exhibit challenging behaviors,[1] we discover that a close look at that person's environment shows us why the person is having difficulty. In roughly three-quarters of the situations in which we have been asked to consult, a person's behaviors change for the better when they are helped to live in a manner that better meets their needs. Rather than using interventions and sedating medications to "control" the person's behavior and cause them to behave as if adapting to an environment that causes distress, we advocate altering the environment to meet the person's needs. In many cases, the distress and the related "maladaptive" behavior are alleviated.

For example, many people in group homes and institutions don't get along with their roommates. People with very different biorhythms, interests, and needs are often required to live together. The daily irritation, sleep problems, and experiences of personal space being violated will often lead to aggressive or self-abusive behavior, sleeping problems, and general irritability. Changing roommates or arranging for individuals to have their own rooms are appropriate solutions rather than trying to force incompatible roommates to coexist.

The environment creates challenging behaviors:

- Meal times that don't meet the person's needs
- Lack of access to snacks when hungry
- No choice of menu
- Lack of exercise
- Limited opportunities for fun
- Few loving relationships
- Lack of hobbies or the opportunity to develop interests
- Few reflections of being valued
- Isolation from the community
- No way to earn money
- Limited transportation and access to friends and activities

Such problems are endemic in the system, and are frequently mentioned as quality indicators for services in general. But it is surprising how frequently these environmental issues are ignored when investigating a person's challenging behaviors.

Many environmental-based areas of conflict begin as a small issue which grows into a relationship-destroying juggernaut.

I once worked with a young man, Mark, who wanted to take his shower in the morning. He would say, "That is when grown men take their showers, and I am a man."

[1] Challenging behaviors include but are not limited to: acts of verbal and physical aggression, self-abuse, property destruction, temper tantrums, isolation, and pica.

The staff found it more convenient to have him take his shower in the evening. Fights over the shower occurred every evening as a result. When asked why they wouldn't modify their schedule to accommodate Mark, the staff explained that they didn't want to give in to him. They said that they were afraid that if they changed their practices, he would think that it was his fighting that got them to change their minds. They were afraid that they would set a precedent that would guarantee that he would fight for everything. So they refused to change the shower time and continued the nightly fights.

The fights continued into the daytime hours due to the breakdown in the relationship between Mark and the staff. Eventually the house felt like a war zone. Mark felt a need to prove that he was a man, and the staff felt a need to prove that they were in control of the situation. Mark would hit, bite, scream, and kick. The staff would take away Mark's privileges and physically restrain him. They said that he was irrationally explosive.

Eventually, in desperation, and on the advice of a consultant, the staff allowed Mark to shower in the morning. The evening fights stopped. Staff could focus on building a positive relationship with Mark rather than on defending themselves against him. As the staff started seeing Mark as a man with needs and images of how he wanted his world to be, they were able to make small alterations in their schedule and in their style of interacting that made for a rewarding relationship. A complete change in relationships occurred, and no additional expense was incurred as a result of using a Positive Approach.

Communication

In this case all involved were fortunate that Mark possessed communication skills so he could let the staff know what he wanted. The people working with Mark just had to develop the capacity to hear what he was saying.

Often the person challenging us to understand cannot articulate wants and needs. Positive Approaches obliges supporters of a person with challenging behavior to do whatever is possible to enable the individual to communicate. Communication, then, is the second major area of concern when we are working with a person with challenging behaviors. We must continually ask ourselves how we know what a person is communicating. Those with difficulty expressing themselves must be offered any tool available that might enable communication: tools such as language boards, liberators, and Facilitated Communication should be tried. The people closest to the person we are trying to serve must be consulted with, since these individuals are the ones who can most often read the person's body language enough to tell us what the person is trying to say. This is especially important when all other attempts to augment communication have been unsuccessful.

Assessment

It is now common knowledge that when a person cannot communicate, frustration becomes part of every interaction. When a person can communicate, the frustration disappears, and often, so does the problematic behavior.

Here in Pennsylvania, we are finding more and more places where Positive Approaches to challenges are commonplace, and indeed, far more people are living happier lives as a result. However, even after environmental and communication needs have been addressed, some individuals still evince challenging behaviors. The search for ways to help these folks must never cease. And, in fact, we are learning more each day about ways to help people with extraordinary challenges. We are learning more, for instance, about the high frequency of mental illnesses among individuals with developmental disabilities. These illnesses must be accurately diagnosed and treated in order for other Positive Approaches pertaining to environment and communication to be fully successful. Prompt assessment, diagnosis, and syndrome-related treatment are vital tools in the Positive Approaches repertoire. (But using medication simply to control symptoms and to sedate is not a Positive Approach.)

Every concern that is relevant to typical citizens is also relevant to people with developmental disabilities. Problems such as trauma, loss, sexuality issues and abuse, loneliness, powerlessness, and addiction should be assessed. Relevant interventions should be offered.

Positive Approaches practitioners take advantage of the ever-widening repertoire of tools becoming available to help individuals in distress. Accounts of such interventions and their results will be highlighted each month in this journal.

Hanging in There

Even with all of the needed supports, opportunities, and conditions in place, a person who has lived a life full of hardship, isolation, stigma, and sorrow may have problems that continue for a long time. The person we are trying to help needs to have the opportunity to develop trust, often for the first time, needs to learn new ways of being in the world that can meet her/his needs, needs to experience over and over the goodwill and positive regard of others. For those with the most serious challenges, finding someone to persevere with them has proven difficult. Once found, that person often has more impact on their lives than any thing, or any one, else. This journal will relate in-depth stories about people who have hung in—in order to inspire hope in the rest of us as we each sign up for the long haul.

Beth Barol is the Clinical Training Director of the OMR Statewide Training Initiative. Harrisburg, PA.

Positive Approaches
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The Road To Positive Approaches: An Anecdotal History

by Kathy Lee

"Restraint! Restraint!" or, "Before Positive Approaches"

Before Positive Approaches there existed a world of consequence and punishment. I learned early on that the system smiled on and left alone those people who did not rock the boat. Ah, compliance, a client's best friend. Unfortunately for those people who challenged the status quo there were and I guess still are "things" that can happen. These "things" are prescribed by people who know you and by some people who you may never know. When I first worked in a sheltered workshop I learned about the "things" that can happen if you don't act accordingly.

Steve was a person with autism. Steve had bitten several of the staff people at the workshop. He was also known as a pincher. Steve would get agitated after lunch and start to jump up and down. He would get louder and louder and then he would grab someone. This is when his "plan" was put into effect. Three or four staff members would surround Steve and maneuver him into a chair. It was my job as program specialist to apply a poesy restraint so that Steve could not get up. This effectively tied Steve to the chair where he could not hurt himself or others. We would wait for his mother to come and give him some tranquilizers and then we would send him home. We were quite happy with this plan because it was quick and very effective. A person can't do much harm when tied down as long as no one gets near him/her. I felt useful—a vital part of the team: I knew I was keeping people safe.

One day we got word from the new behavior specialist that we could no longer use the restraint. It was getting too hard to get the people that approved these plans to sign off. We were devastated. Didn't they know that this was the only way to keep him safe? We knew that this was the only way that Steve could continue to attend. We had tried "everything" (although I could not recall anything else we had tried). We firmly believed that this was the only solution. We did not brainstorm, think about, or even consider anything that was less restrictive. We had to discharge Steve. His family moved away and I never saw him again.

The Behavior Mod Squad

Behavior modification is a series of techniques that are applied to people to help them be more "normal." The unfortunate part of behavior mod (as we hip people call it) is that many times the techniques that are applied are not themselves "normal." As an equation, this would appear something like: weird behavior + weird treatment = normal human being. The following story illustrates this.

Bill attended the sheltered workshop. He was small in stature but large in voice and personality. Bill liked to repeat certain phrases and names over and over again. He also liked to ask a lot of questions of his staff and get out of his seat. When Bill was having a really bad day he would hit himself and leave red marks on his arm. Bill loved Kenny Rogers' music, especially the song "Lucille." We wanted Bill to decrease his negative behaviors. We set up a plan that provided Bill a token for every five minutes during which he did not exhibit one of his more annoying behaviors. If he had enough tokens at the end of the day his reward was to listen to the song "Lucille" until his van picked him up.

This plan had a few problems. My office was the designated listening place for this song. This meant that every day that Bill got his reward I also was rewarded by not only getting to hear Kenny Rogers sing, "You picked a fine time to leave me Lucille," but also by getting to hear Bill's very loud voice. There were days when I could not take it, so I sabotaged the token count. I still have a strange aversion to anyone named Lucille. Another downfall was the "language" that was used to encourage Bill to get this reward. We would say, "You want Lucille, don't ya?" or "Sand that piece of wood so you can have Lucille at the end of the day!" or "Bill, you don't have enough tokens. There will be no Lucille today." I am sure the workers in the complex who did not understand behavior mod often wondered what kind of service we provided. An end note to this story is that Bill continued displaying these annoying behaviors. He would have good days and bad days and I am not sure if they were at all related to Lucille or her four hungry children or the crops in the field.

"These Boots Were Made for Kicking" or, "The Times They Are A Changin' "

I made a cosmic switch in the way I think about things long before I noticed that I had changed. Someone pointed out that people seemed happier at my workshop. People with behavior problems seemed calmer and less likely to hurt people. There was a woman named Marilyn who had been in trouble all her life. She had hurt or had attempted to hurt almost everyone. I genuinely like Marilyn. She had never hurt me. When someone asked me why, I realized that I had changed somewhere along the way: I came to realize, with the help of Marilyn, that if you give people what they want, they usually won't hurt you. I am not keen on getting hurt. Self-preservation has always been a high priority. Marilyn would wear high heels or boots to work on the days that she was planning to kick someone. When I saw this footwear I began to notice her moods. At just the time that she would be planning her attack, I would try and make her laugh. I would spend positive time with her. I would give her some extra coffee. I would let her stop work early. One day when she was trying to kick a staff person I mentioned that she really looked strange trying to run and kick at the same time. She did not want to look strange, and my opinion meant something to her. Her aggressive behavior decreased and she seemed happier. I realized that most of the workshop staff wanted people to be happy, and we realized that different people needed different support. Of course this did not happen overnight, and we missed the boat completely on some people. For the most part we were coming to understand the importance of giving up control and allowing people to express themselves. We were still doing strange "behavior" things to people in the name of rehabilitation, but I confess feeling uneasy every time I tried to "change" someone else.

There's a Place for Us

I had the opportunity to help create a small agency to support people who had been labeled "behaviorally challenging." There were no restrictive procedures at our new place. We began with the person, not with the problem. We created teams of support people who were responsive and caring. We were flexible, nurturing, and kind. Everything was individualized. We saw behavior as communication, and when in doubt, we applied good relationships and consistency. We had fun and celebrated whenever we could. Everyone responded to our philosophy. People with challenging behavior became less challenging when they felt loved and respected. Employees and family members were happy. We were all on a mission to free people from oppression. We were about choice, community, and acceptance.

And Then Came Betty

When we met Betty she was living in a state hospital. She had been sent to an institution at the age of 11, and she was 21 when we met her. Betty had several diagnoses. What got her in trouble the most was her obsessive talk and aggressive behavior. She was very strong and had seriously hurt herself and others many times. Her reputation was very bad. We liked her. She loved to smoke cigarettes, and this touched the heart of our director, who was an avid smoker herself. When we learned that one of the consequences of being noncompliant in the institution was to have her cigarettes taken away we were moved to action. The other thing that moved us was Betty calling on the phone and begging for our help so she could "get out."

We advocated for her release, and after many tense meetings and letters we were granted the opportunity to work with her. We were ready to welcome her into our positive family. We wanted to nurture her and let her know us personally. We worked hard to plan and create the right kind of support and eventually found a lovely woman for Betty to live with. A week after getting out of the institution Betty wanted to go back. We would meet with her and try and soothe her. She beat up her day staff person. We had meetings to continue to plan positively for her support. She used the phone as a weapon to call us repeatedly and make demands and threats. We searched everywhere for anyone with ideas of how to support this person. She called 911 when things got slow and she wanted someone to talk to. She took an overdose of her mother's medication and then a few months later took an overdose of her own medication. Finally she jumped out of a third-story window and shattered her right ankle. We were getting pressure from every direction to return her to the institution. We would defend her right to be in the community even when she was saying that she wanted to go back. We sacrificed family time, holidays, and vacations. We ended up hating her and fighting amongst ourselves.

Our seemingly impossible task was to continue to believe that Betty belonged and deserved to live in our community. Betty was saying in so many ways that she couldn't take the freedom, choice, and love. What she wanted was boundaries and consequence because that is how she felt safe. We reached a critical point when she beat up the woman that she lived with and the woman quit. Betty ended up in jail and then in the inpatient unit of our local hospital. We found ourselves saying, "Maybe there are people that should live in institutions where they can have structure, consequence, and punishment." We drew our first free breath when the doctors said that they would keep her for 30 days. What a relief to be rid of her. We now could make some decisions. We certainly had tried harder at this than anything before, and now we felt we had failed.

We called our work family together to decide what should happen next. There were those of us who were so burnt out that putting Betty in an institution seemed the only answer. A small contingent saw things another way—they saw a new life where Betty could live in her own apartment and have a different kind of support during the day. We knew that our agency was Betty's only chance to live in the community. We decided together to continue to try. We created a crisis team so that everyone could get a break. We worked hard with local law enforcement so that she would have some natural consequences and not just be taken to the hospital. We continued to believe that someday she would be a valued member of our community. We pointed out all of the small improvements that she made. We agreed to weather the next storm and the next and the next.

The truth is that it was a very stormy two years and that bad things continued to happen. The other truth is that good things started to happen, too, and pretty soon the good outweighed the bad. Today, three years later, Betty has become a friend, girlfriend, and neighbor. She lives in her own apartment with her boyfriend. She has not hit anyone in two years. She says that she never wants to go back to the state hospital. She can still be annoying but we believe that she will not hurt us because we care for her and she cares for us. Supporting Betty has been really hard work. Making her a part of our community has been incredibly rewarding.

This is the Song That Doesn't End

So what do I know about Positive Approaches? I know that it is an ongoing process of learning about the best in people and supporting them through the worst. I know that it is a "we" thing and not a "me" thing—I could never do it alone. I know that it is not a technique or method but more a way of thinking and acting—about trying and trying and trying again and not accepting the unacceptable. I know that Positive Approaches is based on a system of values that begins with the fact that everyone's life has meaning and purpose. I know that whatever we are doing in the name of helping people, it has to be real and respectful. I know that it has something to do with putting myself in a person's shoes and asking, "Would I want people to be doing this to me?"

Looking back at this chronology of stories I am filled with gratitude. I am thankful to those people who have helped me move from punishment, consequence, and pain to a Positive Approach. I am grateful that I never have to hurt anyone again in the name of human service. I look forward to the stories that are yet to come.

Kathy Lee is the co-founder of Supports, Inc. Meadville, PA. She is also a mentor for people who coordinate circles of support.

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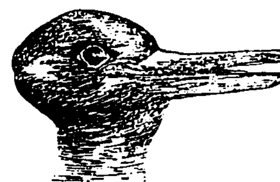
I know you know what I said; But do you know that what I said is not what I meant?

Bernie Fabry, PhD

When supporting troubled/troublesome people it can be hard to understand why they behave as they do. It is natural to focus on eliminating troublesome behavior. But a Positive Approach would instead look for the adaptive function a behavior serves, or its meaning, and teach a more acceptable but functionally equivalent alternative response. Techniques have been developed that allow us to understand the meaning of the behaviors of troubled/troublesome people. And when we can teach functionally equivalent responses, responses that achieve the same functional outcome, troublesome behavior will decrease.

Mary was placed in an institution when she was 12 years old. She was believed to be extremely suicidal. While living in the institution she frequently talked and wrote about suicide. She lived there for four years, until a community-based residential program agreed to accept the challenges she presented. At the community-based site she lived with teacher/counselors who worked a four-days-on, three-days-off tour of duty. So the same people were with her around the clock. At first they responded to her suicide threats literally—as if she would act as she talked. They talked with her about why she was so upset and why she wanted to hurt herself. As they got to know Mary more and saw her in different situations, they began thinking of the suicide threats in a different way. Since the teacher/counselors were living with Mary, they knew what was happening throughout her day. Each time she began to talk about suicide or wrote a suicide note, they did not talk to her about suicide or about feeling bad about herself, but instead thought about the circumstances surrounding the occasion and asked her questions about what had been happening. They discovered that Mary had some problems that she didn't know how to solve, and to get people to help her she would talk or write about suicide. They discovered that she didn't know how to problem solve. So instead of talking about feeling suicidal, they coached her on how to identify her problem, choose an effective solution, and act on it. It was then that the suicide threats stopped.

Most of us have learned that people literally mean what they say. When someone says she is feeling depressed and wants to hurt herself, she is in fact actually depressed and might really hurt herself. When someone says he is hungry, he in fact is and wants to eat. We learn to expect a predictable correspondence between behavior and purpose, or meaning. There is an old saying, "If it looks like a duck, walks like a duck and talks like a duck, then it must be a duck."



For troubled/troublesome people, and especially for those with disabilities that interfere with communication, there can be a variety of circumstances that confound things. We assume that all behavior has meaning, but meaning for a troubled/troublesome person may not be what our experience would lead us to think. So it becomes important for us to learn new ways of discovering the meaning of behavior. Look again at the duck, but in a different way. Could it be a rabbit? Consider the beak to be the ears of a rabbit and the indentation of the head the mouth of a rabbit. Just because it looks like a duck, walks like duck, and talks like a duck, doesn't necessarily mean it is a duck. When looked at from a different perspective it looks like a rabbit. There is an old mind teaser expression:

> I know you think you know what I said, but what you don't know is that what I meant is not what I said.

A respectful relationship involves starting with the assumption that we cannot take for granted what behavior means and that we need to discover the adaptive purpose of even the most troublesome behavior. Phil Quinn (1984) wrote about his experiences growing up in abusive families. He started his story as follows:

> Most people who knew me as a child and adolescent thought my behavior deviant, maladaptive, or pathological. By their standards they were right.

[1]Attneave, F. (1971). Multistability in perception. Scientific American, 225 (6), 63-71.

By most standards they were right. But by the only standard that mattered to me then—the standard of survival—they were wrong. Given the circumstances in which I lived, most of my thinking and behavior was not only appropriate, but a necessary adaptation for self-preservation. (p. 11)

To understand the meaning of another's behavior, we must first learn to look at that person's behavior from his or her perspective. "You never really understand a person until you consider things from his point of view—until you climb into his skin and walk around in it" (Lee, 1960). Given a troubled person's unique life experiences and learning style, how can we interpret his or her behavior? When we are not sure what a person means, or what purpose the behavior serves, there is a group of techniques that we can use to discover the meaning of the behavior. These techniques have been referred to as *hypothesis testing*. The best-known examples are *active listening* and *functional analysis*. To understand how hypothesis testing is used, it may be useful to look at how the techniques are related to one another and to review examples of each. Hypothesis testing involves three steps:

- Assess: Look for occurrences of a behavior and the circumstances surrounding the behavior's occurrence
- Hypothesize: Speculate about the meaning of the behavior, or the adaptive function it serves
- Test: Set up test situations in which the behavior should occur if the hypothesis is correct, and test situations in which the behavior should not occur if the hypothesis is correct. If the behavior occurs when you predicted that it would not, or if it doesn't when you predicted it should, the hypothesis is wrong

To assess the meaning of behavior we find instances of the behavior by:

- Questioning others who have spent a lot of time with the person and have been able to observe the person in lots of different situations
- Questioning the person directly about the behavior
- Directly observing the person engage in the behavior

When trying to discover the meaning of behavior, we start out by collecting information about the behavior so that we can form a hypothesis about what the behavior means. Sometimes this comes from being with a person, observing behavior over time, and slowly beginning to form an opinion that some actions may mean something different than what we would typically expect. At other times, hypothesizing may be instantaneous. A person does or says something, and we immediately have an opinion about what was meant. In these cases we have directly observed the person engage in the behavior.

At other times the function of a behavior may be elusive to those who have directly observed it. When we are puzzled by or disagree on the function of a behavior, a structured interview with people who have spent a lot of time with the person and have been able to observe the person in lots of different situations can make generating hypotheses easier. O'Neill, Horner, Albin, Storey, and Sprague (1990) developed a functional analysis interview that includes questions designed to identify the context in which a challenging behavior occurs. The questions elicit (1) a careful definition of the relevant behavior; (2) items that potentially may affect the behavior (e.g., medications, medical complications, sleep cycles, diet, daily schedule, predictability, personal activities, presence of other people, outcomes of actions); (3) circumstances that seem to predict the behavior (e.g., time of day, setting, with whom, during what activity); (4) what happens for the behaving person when the behavior occurs (possible functions of the behavior); (5) how efficient the behavior is; (6) what the primary methods used by the person to communicate are; (7) what events, actions, objects are thought to be positive for the person; (8) what "functionally equivalent alternative" behaviors are known by the person; and (9) the history of the undesired behavior and the strategies that have been used in an attempt to deal with it. Participating in this interview can help the respondent(s) hypothesize what function a troublesome behavior may serve for the individual.

Sometimes it is possible to talk directly with the person engaging in the troublesome behavior. Examples of this strategy are presented later.

Assessment gives us the information on which to base a *working hypothesis* or "best respectful guess" concerning what purpose a challenging behavior serves. A use-

ful hypothesis can be stated in terms of what a behavior accomplishes (the outcome) for an individual in a given situation (antecedent events). For example, "When a stranger gets too close to Joe, he engages in self-abuse until the stranger moves away." Sometimes it is more helpful to phrase a hypothesis as if there is a communicative function for the behavior. For example, "Joe's head banging means that you are physically too close to him and he wants you to move away." Phrasing the hypothesis as if there is a communicative function helps us to more readily identify what behavior to teach the person. But before assuming that we understand the purpose of a troublesome behavior, we need to confirm that the hypothesis is correct by testing it.

To test our hypothesis we can use a *passive* strategy such as naturalistic observation, in which we identify different situations that allow us to answer the question, "Does the behavior only occur in the context we thought it would, and not in other contexts?" Then we can observe what the person does when the context is present.

Or we can use *active* strategies such as active listening (ask the person questions like, "Do you mean...?") and functional analysis.

The passive strategy of *naturalistic observation* involves careful observation of what a person does in situations that can be crucial to the validation of the hypothesis. Joe is a young man who was banging his head and grabbing others' hair. After observing him for some time, the people around him formed a working hypothesis that both of these behaviors functioned to control who was around him and how close they got to him. To confirm their hypothesis, they then paid careful attention to what happened in contrasting situations. They observed that Joe banged his head in the presence of strangers but not when with people with whom he was quite familiar. They also observed that if anyone came close to him suddenly and without warning, he would bang his head or reach out quickly and grab their hair. But if people approached Joe gradually and started a conversation before getting too close, he did not bang or grab. Observation of these consistent correlations led people to accept the hypothesis that head banging and hair pulling served as ways to escape social encounters with "strangers" or sudden social encounters; they could be thought of as communicating, "Stranger, you're too close," or, "Oh, you frightened me."

Naturalistic observation is a passive strategy and does not directly confirm or validate a hypothesis. For example, there may be subtle aspects of a situation that observers miss because they focused on identifying situations that confirmed a strongly held but incorrect hypothesis. An active test of a hypothesis provides a more definitive answer. One strategy, active listening, depends upon an individual's communication skills, while the second strategy, functional analysis, does not and is particularly useful when a person's communication skills are not effective for others.

Thomas Gordon (1970) has described active listening as using many of the skills counselors have developed—not to counsel an individual, but to understand the meaning of the individual's behavior. Active listening involves repeating back to a person your interpretation of his or her actions or words and asking for some form of agreement or disagreement. While active listening can take many forms, it is most simply described as a question in the form of, "Do you mean...?"

For example, a teacher/counselor described the case of Tom, a boy she was caring for, who would come into the house from playing outside after school and ask, "When are we eating?" Initially, the teacher/counselor assumed that Tom literally meant what he said, and would answer, "In a few minutes." Tom would become upset and repeat his question over and over, until the teacher/counselor told him to stop repeating himself.

Active listening involves not acting on an assumption or an interpretation of what was meant but instead presenting the assumption to the child to determine if the teacher/counselor understands. Instead of immediately answering Tom, the teacher/counselor learned to ask questions for clarification, e.g., "Are you hungry now? Are you asking how long can you play outside? Do you want to go somewhere?" This gave Tom the opportunity to tell her whether she understood correctly. He might have answered, "I want to do something fun." Given this description of what the child meant, the teacher/counselor was able to provide an answer that better met his needs: "Dinner will be ready in a few minutes, and after we have finished dinner and cleaned up the kitchen, we can go to the park." When the teacher/counselor used active listening, not only did she better understand Tom, but he no longer became upset, and he stopped repeating himself. Active listening is different from the passive listening we

typically engage in and involves actively questioning our interpretation of what we heard or saw.

Horner (1996) has described a somewhat more structured interviewing strategy. Through a sequence of questions the person is asked to identify when he or she engages in the troublesome behavior, what happens at those times just before the person engages in the troublesome behavior, and what the outcome of engaging in the behavior is (what happens immediately afterward). Some people are able to self-observe and analyze the function their own behavior serves when guided through the analysis with the right questions.

Even when a person cannot answer because of a communication disability or heightened emotional arousal that is disruptive to the person's communication skills, we can still use active listening and watch the person's reaction. Many people can understand what is said to them even when they are not able to express themselves clearly. Changes in their actions may provide us with answers to our questions. For example, Dave gestures and makes vocalizations that are difficult to understand. At first his teacher/counselor made assumptions, e.g., that he was hungry, and gave him something to eat. He might start to eat it but would then throw the food at the person feeding him. When active listening was used, the situation looked something like this: When Dave gestured and vocalized, a teacher/counselor thought about what he wanted and asked him by both stating a question and showing him what she meant. She said something like, "Are you hungry? Do you want a banana?" and handed him the banana. If he didn't reach for the banana or show any other sign of wanting it, she speculated that he might not be hungry but wanted something else. She then asked him if he wanted a drink and showed him something to drink. If he again showed no interest in the drink but continued to gesture and vocalize, she would have realized that she still did not understand what he wanted and tried something else. She might have asked him if he wanted to go outside and taken him to the door. If he then went outside and seemed content, she might assume that was what he wanted. While the teacher/counselor cannot be positive that Dave was trying to communicate that he wanted to go outside, his behavior indicated that it was the better choice among those that she presented. And she was teaching him that she was willing to listen *actively* to his communication efforts.

Conducting a functional analysis in the form of *function probes* (Evans and Meyer, 1985) can prove informative when a person does not provide a useful response to the kind of questioning just described. Function probes involve arranging for the occurrence of contrasting situations to actively test the function of a behavior. For example, when asked to complete chores, Mike would throw his toys and swear at his foster parents. Generally he was very sullen and would not answer when asked why he was upset. The typical routine was that when Mike came home from school there was a set of chores that he needed to complete. The foster parents began testing a series of hypotheses for the functions of these "tantrums." They started with the assumption that he did not like the parent who was making the requests. (Troublesome behavior often feels like an attack on the caretaker and it is easy to assume that the function of the behavior is to get the caretaker to back off.) To test this hypothesis the parents took turns asking Mike to do his chores. Mike demonstrated that he was just as likely to swear at either parent and invalidated the initial hypothesis. The parents then speculated that the chores were either too difficult, or too time consuming, or too numerous. They tested each of these possibilities by alternating their requests to do one chore versus many chores, to do easy chores versus difficult ones, or to do time-consuming chores versus quickly performed chores. They discovered that Mike was capable of completing his chores whether requested in isolation or as a group of tasks to be completed. The foster parents next speculated that Mike didn't like to be disrupted from a play activity by a parental request. To test this hypothesis, the parents created a list of chores and required Mike to choose which ones to complete each day and when. They alternated this arrangement with their own requests to do chores. They discovered that there were many fewer outbursts when Mike chose when to complete the chores assigned him. They learned that they needed to teach him to negotiate what was being requested of him (functionally equivalent behavior) rather than throw toys and swear.

One behavior can often serve many functions. For Mike one function was to escape or delay disruption in his play. Since the tantrums continued to occur occasionally in other contexts, the parents continued to identify other functions that tantrums served for Mike. They discovered that Mike would sometimes engage in a tantrum as he came in the door from school. Initially the parents speculated that these particular

tantrums were associated with poor scores on his daily school report, but his behavior proved not to be consistent with this hypothesis. Upon further questioning, the parents discovered that Mike was being teased by older boys on his school bus when they found out that he had a school report with poor scores. This was a negative experience for Mike, and through passive observation the parents discovered he would throw a tantrum at home once he was out of harm's way of the older boys. His tantrums only occurred when he was teased on the bus. A functionally equivalent response for Mike was learning to describe negative experiences to adults who could advise him on new ways to act when negative experiences (e.g., teasing) occurred.

Our typical experiences may lead us to see a duck when something walks like a duck and talks like a duck. Our experiences may lead us to assume that a troublesome behavior "means" for another what it would mean for us. A respectful relationship with a troubled/troublesome person starts with "walking in his shoes" and is based on the assumption that challenging behavior serves a useful, valid function for that person. Our role is to understand that function and help the person learn a more acceptable but functionally equivalent response.

Duck, it's a rabbit.

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Escaping the Glass Bubble through Facilitated Communication

by Mary Lapos, M.S.

Imagine yourself as the person you are now and then imagine yourself not being able to speak or move the way you presently do. Imagine that you have had a stroke or have developed Parkinson's disease or some similar disorder. It wouldn't take you long to figure out that when you can't speak either clearly or at all, and when you move in different or unusual ways (or don't move at all!), it is very difficult to help other people come to know who you really are.

If you have had something go wrong with your health as an adult which affects your speech and movement, at least some people had a chance to get to know you before these important circumstances changed. Those people have a "picture" of you that they hold in their mind even when your talking becomes unclear or when you can't control your hands and your body. That "picture" allows people around you to continue to think of you as a competent person.

But when you are born with difficulties in the areas of speech and motor or movement control, people come to know you in a very different way. They see you, perhaps, as incompetent or less capable. The trouble is, there is no chance to convince them otherwise if you can't speak and don't move very well. The labels "mentally retarded," "autistic," "developmentally delayed," and the like frequently result.

Recent research efforts and articles in professional journals (Leary & Hill, 1996; Williams, 1994) suggest that (contrary to what we have always thought) some people who don't develop speech and who don't "respond" to their environment and other people in typical ways may not always have mental retardation. They may be competent people who just can't speak or physically respond to their world in typical ways. This is truly a trap for the affected person, like being frozen in a glass bubble. You see and understand everything going on around you and everyone can see you, but you say very little or nothing and your movement is very limited. Others can't understand who you really are.

For some people who have been known as mentally retarded, autistic, or developmentally delayed, all this is changing. Through a process which supports communication in a different way, we are beginning to understand who these people truly are. That process is known as facilitation or, in this instance, facilitated communication training.

Facilitation provides necessary physical support so people can move in purposeful ways. Typically, for people who can't speak and who don't have reliable hand movement, that means physically supporting them so they can point to or select in some fashion with their hand or fingers desired pictures, words, or letters. In this fashion, some people effectively communicate by pointing to pictures or whole words. Others are capable of typing complex thoughts.

In the early stages of using facilitation, the most frequent type of physical support involves stabilizing the hand and forearm of the new communicator. The person who does this stabilizing is called a facilitator. The facilitator uses various hands-on techniques to enable the person to reliably point to symbols, words, and letters in order to communicate. As the training progresses and the person gains skill, the objective is to reduce the support offered by the facilitator and for the person to gain independent physical control of their own movement so they can select pictures, words, or letters by themselves.

Early research into this process suggested that there was a strong possibility that letter selection on keyboards was more a product of the facilitator's intent than a product of the person with the communication difficulty. The facilitators appeared to be creating the typed messages. Reports quickly circulated via media "exposés," suggesting that there was little benefit to be derived from involving people in facilitated communication training.

That was then (1992–1993); this is now. Recent research (Cardinal et al., 1996; Sheehan & Matuozzi, 1996), which is essentially quite different in form than earlier efforts, has discovered that, under specific conditions, some people are indeed able to produce typing that is authentic—produced by the user, not the facilitator. The new research has shown us that facilitation is very sensitive to the conditions under which it is tested.

Simple things like:

- Practice of the process
- Accommodating sensory issues
- Providing wait time
- Creating supportive relationships

all appear to be important variables to successful communication attempts.

These newer findings in people who are described as developmentally disabled parallel the literature from other disciplines such as neurology and neuropsychiatry (Damasio, 1994; Rogers et al., 1991; Sacks, 1995; Sacks, 1990; Sacks, 1987). Work with patients who are described as having Parkinson's disease, Tourette's syndrome, catatonia, among others, informs us that these groups of people can be observed to engage in very similar behaviors and have many of the same issues as many people with the labels of autism, Down syndrome, and PDD (Pervasive Developmental Delays). Not surprisingly, they respond in much the same way to their environments and the people around them and they benefit from many of the same adjustments that have been incorporated into the newer research around facilitation.

Developmental disability has always carried with it the inference of mental retardation, which has created major barriers for supporters in their relationships with people who might benefit from facilitation. However, learning, motivation, and physical control issues present in much the same way in all these people, whether they are known as developmentally disabled or neurologically impaired.

Research is beginning to support the concept of facilitation as a viable process for people with severe communication disorders, and in fact increasing numbers of people have achieved independent communication after several years of practice. These individuals are able to type their thoughts completely independent of any involvement from a facilitator. I have worked with a young woman who now produces and edits her own newsletter–independently. I know a young man who has undertaken his own research into the difficulties experienced by people with severe communication disorders similar to his own. He has gradually become able to type his responses to research questions independently. Many others, of school age, are finishing up their elementary and high school studies and taking their exams–independently. However, all began their journey toward full communication and self-determination with the support of a facilitator and continued the trek, putting in the long hours of hard work necessary to achieve independence.

Jennifer, who is a young adult with autism, has been the key person in developing her own behavioral support plan. She has been able to be very specific in describing her internal perceptual circumstances. Some of Jennifer's suggestions to her supporters involved major life changes; others involved seemingly insignificant factors which were supporting her difficult behaviors. Armed with that information, those working with her have been able to significantly reduce many of her major behavioral problems. Concurrently, after only 14 months of facilitated communication training, Jennifer is approaching independence. Her desire to achieve that goal is tremendous, as is her willingness to make the effort that it requires.

In addition, Jennifer's new-found communication skills and the accompanying boost in confidence they have given her have spilled over into other areas of her life. She is now printing independently, playing board games independently, and trying out new activities. She is clearly a bright, energetic young woman who has finally escaped the glass bubble and some of the labels which had been her life until 14 months ago.

If her communication had been stopped when some called her method of communicating a hoax, Jennifer might well have gone on being viewed as a less-than-thinking being; instead, she is now seen as the vibrant, funny, and intelligent person that she really is. How many other Jennifers exist out there, living their lives frozen in glass bubbles, waiting for an opportunity, waiting for the rest of us to see them for who they truly are?

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Medication That Affects Behavior

by Christopher P. Gorton, MD

A critical issue in supporting some individuals who exhibit challenging behavior is the role of medication. It can be stated categorically that under no circumstances is medication alone a sufficient response to challenging behavior. Environmental supports are always necessary. That is not to suggest, however, that medication should be reserved as an intervention of last resort, only to be employed when all other interventions have failed. Individuals have a clear cut right to timely access to appropriate care. If that appropriate care involves medication, it should be begun as soon as the need is recognized. Failure to provide appropriate medication is no less morally unacceptable than willful overmedication.

With these caveats in mind, there are three scenarios in which medication can be appropriately employed to benefit individuals with challenging behaviors. These scenarios involve: (1) behaviors resulting from or exacerbated by a treatable, biologically based psychiatric disorder, (2) behaviors resulting from or exacerbated by a treatable general medical disorder, and (3) short-term management of behaviors which endanger the health or safety of the individual or other persons. These scenarios are outlined in greater detail below. The guidelines given are designed to be a general rubric for psychopharmacologic interventions, not an all-encompassing paradigm defining appropriate care. The expert members of an interdisciplinary team (IDT), such as the psychiatrist, primary care physician, and clinical psychologist, are, in consultation with other team members, the appropriate people to determine the specific details of an individual's medication regimen.

1. Behaviors resulting from or exacerbated by a treatable, biologically based psychiatric disorder:

In the past, it was believed that individuals with developmental disabilities were incapable of being affected by the mental illnesses that afflict the rest of the population. Therefore, any difficult behavior they exhibited was not a symptom of treatable diseases: It was a problem to be suppressed. Antipsychotic medications (known previously as "major tranquilizers") were quite useful in stopping these unwanted activities through the secondary effect of sedation, and they were widely employed.

Subsequently it was realized that this was flawed thinking. Individuals with mental retardation and developmental disabilities are subject to mental illness, and they have the right to receive appropriate medications for their psychiatric problems. Thus, leaders in the field have embarked on a major undertaking–promoting the end of the inappropriate and potentially dangerous use of sedation to suppress unwanted behavior and offering, instead, definitive therapy through the use of appropriate medication.

Providing definitive therapy requires characterization of an individual's mental health problem in the form of a psychiatric diagnostic formulation. Teams working with individuals with developmental disabilities are strongly encouraged to use the latest version of the *Diagnostic and Statistical Manual of Mental Disorders* of the American Psychiatric Association *(DSM-IV)* to guide the diagnostic process. These criteria remain valid as a general guide for individuals with developmental disabilities, although they may require some modification to accommodate the challenges many individuals face in defining and expressing their thoughts and feelings. Individuals and people who care for and about them (particularly family members) should be integrated into the diagnostic process to the greatest extent possible. Managers and supervisors at provider agencies should recognize that this involvement is critical to achieving a positive outcome and should take all reasonable steps to facilitate this involvement.

Once consensus has been reached on a psychiatric diagnostic formulation, the expert members of the interdisciplinary team such as the psychiatrist, primary-care physician, and clinical psychologist can recommend a course of medication tailored to the neurochemical abnormalities associated with a particular *DSM-IV* disorder (or group of disorders). Information regarding the expected treatment response time, the anticipated changes in target symptoms, and plans for evaluating the outcome of the medication trial should be discussed and documented. In addition, possible adverse outcomes, particularly in terms of potential medication side effects, should be reviewed with the individual (when this can be done in a meaningful fashion) and all other concerned parties and then documented.

In order to ensure that individuals receive high-quality care in a timely fashion, it will at times be appropriate for the expert members of the IDT to recommend initiation of more than one medication in either a sequential or concurrent fashion. It may be beneficial for agencies to develop basic medication protocols for frequently encountered diagnoses which outline the spectrum of acceptable initial approaches to therapy. The treatment team can then tailor an individual's therapy within the rubric of the general protocol. Conditions under which it may be acceptable to exceed the conservative treatment parameters outlined in reference manuals such as the *Physicians' Desk Reference* can be defined. This approach will allow the treatment team to craft an individualized medication regimen with reasonable confidence that it will be acceptable to the reviewing bodies. Reviewers, particularly those with little or no clinical experience, can be confident that the approach is appropriate for the diagnosis. The level of understanding engendered by this approach should facilitate timely completion of the review process and allow the individual access to appropriate care in the shortest possible time frame.

When initiating a new medication, it is important that all members of the treatment team understand what constitutes an adequate therapeutic trial. Medications should be used in adequate dosage for sufficient periods of time before the individual is labeled a nonresponder. Blood levels should be followed if appropriate and may need to be in the high therapeutic range before a response is seen. It should be recognized that some medications may initially make symptoms incrementally worse at low dosage. The treatment team should prospectively identify and implement additional environmental supports which may become necessary during periods of medication change. The potential for drug–drug interactions should be closely monitored, and other medications may need to be eliminated in order to facilitate use of an indicated psychiatric drug. The individual should be monitored for side effects and, when possible, be supported through them, as in many instances they are transient or self-limited. In instances where significant side effects necessitate discontinuation of a medication, a detailed description of the reaction should be documented in the permanent record. In some cases, a team may legitimately undertake a second trial of a medication to see if a previously reported response recurs. This approach may be necessary in individuals reported to have had vaguely characterized adverse reactions to multiple medications in the past.

In order to prevent problems due to sketchy record-keeping, it is essential that a detailed summary of the results of a medication trial or series of medication trials be documented in the individual's record. Agencies should designate which team member(s) is responsible for this task and monitor compliance. Information included in such a summary would probably include (1) the diagnostic formulation at the time of the trial, (2) the type of medication, dosage, length of trial, and blood levels achieved, (3) narrative and data detailing response to therapy, (4) any adverse effects noted, and (5) the reasons for discontinuation of medication, including potential confounding factors such as other medications, intercurrent illness, and changes in environment. In some cases, detailed summaries of collected behavioral data with supporting progress notes may be sufficient documentation. Alternatively, agencies may consider developing a specific form to consolidate this information in an easily accessible location in the record.

Once the treatment team has formulated a working diagnosis and treatment plan, most agencies require an independent review panel to authorize the intervention prior to implementation. It is essential that these reviews occur in a timely fashion and do not impede an individual's right to treatment. Processes should be in place that allow a highly expedited review when circumstances warrant an urgent or emergent intervention. In some cases this may require emergency implementation with a retrospective review. In the majority of cases, the review process should be able to be completed within a time frame that allows for diligent review but does not significantly delay initiation of therapy.

Review panels should review the technical aspects of a medication plan at the time it is initiated and then at regular intervals. These administrative reviews should serve as a forum for frank and objective technical discussion of the proposed plan. Strict standards of confidentiality must be maintained to protect individuals' rights and to allow the treatment team to receive candid collegial feedback from an outside objective source. One primary function of this review process is to examine plans for internal congruence. The diagnostic formulation, proposed medication, and level of symptoms

should be consistent with one another. Target symptoms being tracked should be specifically defined and relevant to the diagnostic formulation. Dosage ranges and target blood levels should be consistent with current standards of care. Monitoring strategies for commonly encountered adverse effects should be outlined. The proposed length of the trial should be consistent with the known pharmacokinetics and response time of the medications. Finally, the plan should include a detailed summary of concurrent environmental supports and interventions designed to optimize the chances for a successful medication trial. As stated above, medication alone is never a sufficient intervention to address a mental health problem.

2. Behaviors resulting from or exacerbated by a treatable general medical disorder:

Not uncommonly, an individual may exhibit a problem behavior which, on further evaluation, is seen to result from a general medical disorder. In some cases, such as hypothyroidism or lupus, the general medical condition may have a direct effect on the central nervous system. In other cases, individuals may exhibit unusual behaviors because of pain or discomfort. Still others may develop irritability or distractibility leading to aggression or self-injurious behavior because of sleep disturbances or general malaise associated with being chronically or acutely ill. Finally, some individuals may be affected by all of these factors. Treatment teams should attempt to identify these situations as soon as possible.

The primary focus for the treatment team in these cases should be the identification and treatment of the general medical condition. Environmental supports should be in place to help the individual be as comfortable and content as is possible during the course of the illness. The treatment team should work aggressively to identify pain or discomfort in individuals who cannot or will not express it. Pain controlling interventions, including (but not limited to) narcotics or other medications where clinically appropriate, should be vigorously implemented to limit an individual's suffering. All agencies should have clearly stated policies which ensure that all individuals have access to any and all clinically appropriate care, regardless of their age, race, gender, or level of cognitive or physical disability.

It is likely that behaviors that are manifestations of physical illness will subside with treatment of the general medical condition. Some behaviors may have been long-standing problems arising from inappropriately conditioned responses or untreated psychopathology and will return to pre-illness levels of intensity. It is also possible that a period of physical illness may trigger the new onset of mental health problems. The treatment team must keep all these possibilities in mind as they continue to tailor the behavior support plan to meet the individual's changing needs.

It should be clear that medications that lead to an improvement in behavioral manifestations secondary to treatment of a general medical condition should not automatically be defined as psychotropic medications. Psychotropic medications are those whose primary use is to treat diagnosable neuropsychiatric conditions or maladaptive behaviors that cannot yet be adequately characterized in diagnostic terms. A reasonable rule of thumb is that if a medication is being instituted and adjusted based on outcome measures related to a general medical condition (e.g., number of seizures or blood pressure elevation) it is not a psychotropic medication.

3. Short-term management of behaviors which endanger the health or safety of the individual or other persons:

Individuals may at times exhibit behaviors which endanger the health or safety of themselves or of others around them. Some of these episodes may be predictable, as in the case of scheduled medical or dental procedures. If the treatment team agrees by consensus that sedation is an appropriate intervention in this context, it should be given and the fact should be documented in the record. It is important to record the response to sedation as this may become important at a future date.

In other situations, emergency sedation may be necessary to safeguard the health and safety of the individual and other persons. Procedures should be in place to meet these emergency needs. All such interventions should be retrospectively reviewed in order to develop a plan to address the individual's needs in such a way as to minimize or eliminate the need for emergency medications in the future. The treatment team should in particular focus on whether or not the behavior was symptomatic of an unrecognized and/or partially treated mental health or general medical disorder.

If this is a possibility, aggressive steps should be taken to proceed with evaluation, diagnosis, and initiation of appropriate treatment and supports. The treatment team should thoroughly document this process in the individual's record and where appropriate submit addenda to the individual's behavior support plan for review and approval.

In conclusion, people who care for and about individuals with developmental disabilities need to be aware of the situations in which the use of medication may be beneficial to an individual. Certain principles must be adhered to when medication use is considered:

- Medication use should be diagnosis-driven. Medication should be used to treat illness rather than to suppress behavior.
- Medication should never be employed as an isolated intervention. Appropriate environmental supports should be developed and put in place.
- Individuals with developmental disabilities have a right to high quality care. No person should be denied access to appropriate medication on the basis of a developmental disability.

By following these principles, treatment teams should be able to provide individuals access to potentially beneficial medications without subjecting them to the excesses of the past. As we work to support individuals with developmental disabilities we must maintain our commitment to provide them with the finest care available. Judicious use of medication can help them lead fuller, more satisfying lives—and that is the ultimate goal.

MEDICATION UPDATE: ANTIPSYCHOTICS

Antipsychotic medications have historically been used in developmental centers to regulate problem behavior. Commonly used medications include Thorazine, Mellaril, Haldol, and Navane. Widespread, chronic use of these medications, which can produce serious irreversible side effects, is no longer thought to be appropriate. This change in thinking has led to close scrutiny of such use at Hamburg Center and other facilities across the state and country.

One important reason to wean a person off antipsychotic medication is to decrease the risk of devastating side effects. Possible side effects include Parkinson's disease, blindness, dysphagia, major depression, and tardive dyskinesia (an irreversible motor disturbance which causes constant involuntary movements that can disrupt ability to participate in normal activities). Risk factors for these side effects include length of treatment, size of dose, age, and gender.

Halting these medications also can "unmask" symptoms—such as sleep disturbances and mood swings—that may give clues to the true psychiatric diagnosis. With an accurate diagnosis in hand, the clinical team can offer the individual a rational, focused approach to therapy.

Unfortunately, the discontinuation of these medications have negative consequences as well. Although usually temporary, these can be quite troubling. First, the problem behaviors that were being suppressed may recur. This may be useful diagnostically, but it can be emotionally painful and in some cases physically dangerous. Intensive support is needed to get the individual, family, and staff through this difficult period. Experience shows us that the process is usually worthwhile, but that does not make the behaviors any easier to tolerate while they are playing out. Second, these medications cause significant changes in brain chemistry. Even gradual step-wise reductions may provoke withdrawal symptoms, which will tempt caregivers to discontinue the weaning. The withdrawal symptoms include poor appetite, weight loss, sleep disturbances, motor problems, and new behavioral symptoms. Most of these symptoms are temporary, and some are responsive to treatment. Unfortunately, the withdrawal syndromes can persist for a number of weeks. Experi-

ence shows that with patience and determination, 75% of individuals can be supported through this unpleasant transition and successfully weaned from these dangerous medications. The remainder have become so physically dependent on the medication that it cannot be discontinued.

In summary, individuals and those who care for and about them are left with a hard reality: We owe it to the individuals to try to get them off dangerous medications that are not appropriate for the problems they face, but the cost of doing so includes the risk of a period of significant emotional and physical distress. Considering the potentially devastating consequences of remaining on an antipsychotic medication, however, we really have no choice but to try.

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