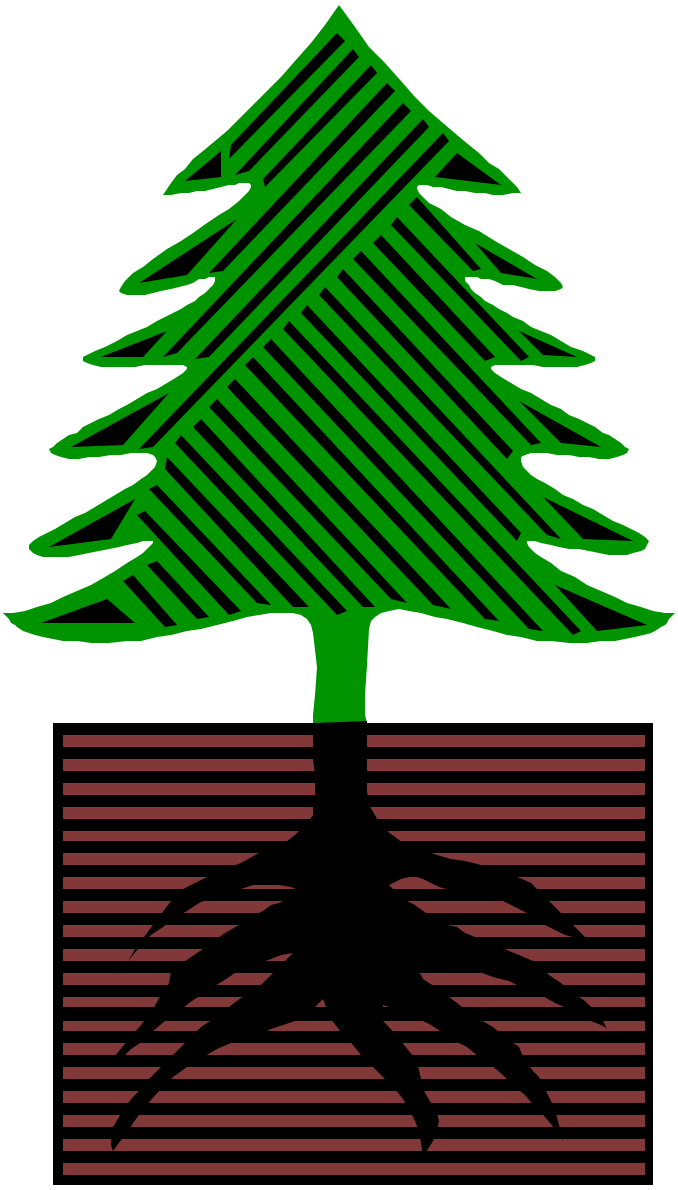

upside down and inside out

supporting a person in crisis/
supporting the people who care

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Portions of the handout appear in previous handouts including *Big Water: Helping People Overwhelmed by Fear and Anxiety to Find Solid Ground, Supporting a Person with Posttraumatic Stress Disorder, Loneliness is the Only Real Disability: Implications for Policymakers and Providers,* all available at www.dimagine.com

Printing Suggestions
Please, when making copies of *Upside Down and Inside Out*, save paper by using both sides. Check my web site for the most recent version (listed on the front cover, bottom right).

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☺ Click on "Links and Other Resources"

☺ There you will find links to web sites and information about a variety of topics, including:

- Advocacy
- Assistive Technology
- Books Worth a Look
- Communication Rights
- Emergency Preparedness
- Employment
- Family Support
- History of Disability
- Housing
- Inclusion
- International Support and Resources
- Medicine, Health and Well-Being
- Microboards
- Music
- Person-Centered Planning
- Policy Links
- Post Traumatic Stress Disorder
- Relationships
- Self-Determination
- Spirituality
- State-by-State Resources
- Storytelling
- Videos

- You may also wish to click on :
  - 7 Questions
  - Articles and Publications
  - Workshops/Presentations

overview

introduction

1.0 remember the fundamental importance of relationships and helping a person to achieve a real life

Relationships are critical to our well-being. In my experience, the most common reason for a crisis is a breakdown in relationships (the person loses someone important or becomes conflicted about a person they love). A person in crisis needs people who care, people who have hope about the future, people who take the long view.

A common mistake we make in trying to help people in crisis is that we forget their behavior may be their only way to communicate to us that something is fundamentally wrong with the life they are living. Sadly, many people exhibit problem behaviors *because* they receive services from organizations that are dysfunctional. Their behaviors may be "symptoms" of an entire service delivery system that is out of touch with people's needs. A person in crisis needs people who take seriously the question, "How can we help you to live a real life?"

2.0 check your assumptions

A person in crisis needs people who listen carefully and act with the belief that the person, no matter how confused or stressed, has wisdom. Before attempting to help, we must first check our assumptions about the person, his/her caregivers, and family members.

3.0 assure safety/minimize threat

It can be difficult to support a person who is upside down and inside out. A person may exhibit behaviors that are dangerous or threatening, or simply embarrassing. When a person cycles

from crisis to crisis (a sign that something is missing from the support plan), it is not uncommon for even the most well-intentioned care givers to burn out, give up, and/or resort to punishment.

Understanding the role of threat in crisis situations and how it affects our ability to think clearly and manage our emotions is a focus of this section, along with strategies for helping a person and his/her supporters to stay safe.

4.0 pay close attention to the person's health and well-being

One of the most common reasons why people engage in aggressive or self-injurious behavior is that they are in pain. Unfortunately, health care for people who experience disabilities is often woefully inadequate. Medical and psychiatric conditions are "over-shadowed" by the person's disability because it is assumed that a reason for problem behavior <u>is</u> disability (an erroneous but widespread conclusion). A person in crisis may need a medical "advocate" or "case manager" to organize all medical reports to help the individual and his/her team to advocate for appropriate health care.

A person in crisis <u>may</u> need medications if it has been determined that he or she is experiencing a medical or psychiatric issue. He or she <u>may</u> benefit from an experienced psychiatrist who knows that medical and psychiatric conditions can cause a person to experience distress, who will prescribe medications responsibly and monitor progress diligently.

5.0 <u>actively</u> support the person's supporters

The people who best know the individual and who provide support on a day-today basis need support. They may feel threatened by the person when he or she is "acting out," or inadequately prepared to respond in safe and helpful ways. It is not uncommon for caregivers who support individuals with trauma issues to be "vicariously traumatized." Every effort should be made to address the real and pressing needs of a person's supporters, both at work and at home. As Jean Clarke has put it, "A person's needs are best met by people whose needs are met."

6.0 determine the meaning of the person's behaviors

A crisis should be an infrequent event. If crises are occurring on a regular basis, something is wrong with the support plan. All too often, people in crisis are living lives that are devoid of important relationships, adequate health care, the power to make important decisions, joy , and a chance to be seen as someone who has a contribution to make to the larger community (to name a few). In this view, difficult behaviors are seen as "messages" which result from unmet needs.

7.0 tips for listening and communicating

No matter who offers their support, everyone on the team needs to understand that the person's input is critical to the long-term success of the plan. It is also important that close family, friends, and caregivers, be actively involved (with the person's permission). Once information has been gathered, each of us has an important obligation to communicate our findings and ideas in a way that are respectful of the person and the members of the team. No matter how well credentialed , it is important we be mindful of each other's values, unique perspectives, and capacity to assimilate information. Every effort should be made to communicate recommendations in ways that are clear (e.g., jargon free) and understandable (e.g., through graphic representation).

8.0 policy documents

references

What is a crisis?

A crisis is a sudden decline in typical functioning that can threaten a person with loss of place and opportunities in community life.

Examples of life-changing crisis include:

- A serious decline in health
- A profound loss
- The acceleration of a difficult or dangerous behavior beyond a bearable threshold
- The decline of necessary supports below a tolerable threshold

Living successfully through a crisis can give people with disabilities, their families, and key support workers three benefits:

- Stronger, more trusting relationships
- Better informed and more exact assistance
- Greater resilience and confidence with which to meet future difficulties.

Reprinted with permission. This is taken from the October 2006 Developmental Disabilities Network Incorporated Crisis Training Flyer. This summary resulted from several meetings and discussions held in Wisconsin and was summarized in full by John O'Brien.

introduction

People who are in crisis need support. It's that simple. They don't need people who are full of judgment, or inclined to "get tough" or "teach a lesson." They need people who understand that importance of safety and predictability. They need people who know the difference between setting respectful limits and asserting dictatorial control. They need people who have a sense of humor, people who take the long view, people who care.

You might say that every crisis is an opportunity to learn something important about the person (and, perhaps, an opportunity to learn something important about yourself). It is an opportunity to show the person the value of relationships -- safe, predictable, nurturing relationships.

Yet it can be difficult to support someone who is upside down and inside out. A person may exhibit behaviors which are dangerous, or threatening, or simply embarrassing. When a person cycles from crisis to crisis and seems unresponsive to support, it is not uncommon for even the best intentioned care givers to burnout, give up, and/or resort to punishment.

stop trying to "fix" the person

This workshop is based upon a simple idea: *difficult behaviors result from unmet needs.* In a sense, a person's difficult behaviors are messages which can tell us important things about a person and the quality of his or her life. People with difficult behaviors are often missing:

- Meaningful relationships
- A sense of safety and well-being
- Power
- Joy (things to look forward to)
- Relevant skills and knowledge.
- A sense of value and self-worth

These needs are usually minimized or ignored in educational or human services settings. As a result, people may become:

A crisis should be an infrequent event. Frequent crises are a sign that something is missing in the support plan.

- Relationship resistant
- Chronic rule-breakers
- Helpless and insecure
- Depressed and isolated

Supporting a person with difficult behaviors requires us to get to know the person as a complicated human being influenced by a complex personal history. While it is tempting to look for a quick fix, which usually means attacking the person and his or her behavior, suppressing behavior without understanding something about the life he or she is living is disrespectful and counterproductive. Difficult behaviors are a reflection of unmet needs. They are "meaning-full." Our challenge is to find out what the person needs so that *we* can be more supportive.

stop trying to "fix" the person's supporters

Our best efforts to support someone who engages in difficult behaviors will fall to pieces if the people who are asked to provide the support are not clear about their own needs. Whether you are a friend, a parent, or a paid care giver, there is a relationship between your needs and the needs of the person you are supporting. In my experience, a person's supporters often need:

- Support from friends, family members, and colleagues
- A sense of safety and well-being
- Power
- Interesting, meaningful, and challenging routines
- A sense of value and self-worth
- Relevant skills and knowledge

These needs are usually ignored by educational and human services organizations. People inside and outside of these organizations often feel that their needs are being ignored by an insensitive and uncaring bureaucracy. As a result, they often resort to their own difficult behaviors. They become:

- Resistant to new ideas and support
- Cynical and rebellious
- Overly controlling and punishing
- Depressed and isolated

While it is tempting to blame care givers for failing to "deal" with a person's problem behaviors, the vast majority of the people who are supporting a person are interested in helping not hurting. But helping another person is difficult when your own needs are ignored. Thus, it is critical that any effort to support an individual include support for the person's supporters. To paraphrase early childhood educator Jean Clarke, "A person's needs are best met by people whose needs are met."

beyond consequences

People who exhibit difficult behaviors are usually subjected to a behavior plan at some point in their life. It is rare that they are asked if they want a plan, let alone invited to the meetings when one is developed. The people who design the intervention are often strangers (e.g., the agency behaviorist who has spent less than an hour in the group home writes a behavior plan and conducts an in service training with staff who believe it will not work). Think about how difficult it is to change your own behavior when you want to (e.g, smoking, excessive eating). Imagine how difficult it would be to change a behavior that someone else, especially a stranger or

strangers, tell you to change!

My wife Cyndi, who trains teachers in our local school system about positive behavioral supports, suggests that there are three reasons why care givers continue to use restrictive procedures or punishing consequences to control unwanted behavior, even when there is no change in the behavior. First, because they believe these methods are necessary to achieve a positive result. But, even when these strategies fail to achieve a positive result, they continue for a second reason — to achieve a sense of control over a bad situation. And, third, even when it is clear the strategies are not leading to more control, they persist to demonstrate to anyone watching that they believe the behavior is unacceptable.

Sadly, many people exhibit problem behaviors *because* they receive services from organizations that are dysfunctional. Their behaviors may be "symptoms" of an entire service delivery system that is out of touch with people's needs. For example, Michael bangs his head at the workshop because the tasks he is expected to perform are meaningless and dull. His support staff, faced with their own meaningless and boring routines, felt ignored by the organization whenever they expressed their concerns. In one meeting, they described Michael's head banging as a clear "message" that he is bored, angry and in need of change, but their supervisors responded by insisting only that he continue his routine, referring him to the Agency Psychiatrist who prescribed a medication for "intermittent explosive disorder").

In short, instead of seeing that Michael *had* a problem, they decided that Michael *was* the problem.

Anne Donnellan has said, "We ask people who by definition have the fewest adaptive abilities to make the most adaptations all the time." We are asking people who might have a difficult time speaking, who might not be able to move about easily, or who might take a longer time to learn something new, to live lives we would find intolerable. Similarly, we are asking the least powerful staff in our organizations to empower people with disabilities. We are asking them to listen when they rarely have the opportunity to be heard. We are asking them to be supportive in a vacuum of support. Two fundamental questions should be asked, *"How can we help the person who engages in difficult behaviors live a life that makes sense?"* and *"How can we help the person's supporters to listen?"*

in a nutshell

It is simplistic to treat a person's behavior without understanding something about the life that he or she lives. It is equally simplistic to develop interventions that do not take into consideration the needs of a person's care givers. The challenge is to build support for the person and the people who care.
If you are too tired to read one more word (and the people busiest providing support usually are), I encourage you to get some rest and take time for yourself and your family. But, before you leave, consider these four simple ideas:

- *Difficult behaviors result from unmet needs*
- *Finding out what a person needs is an important step in helping the person, and the person's supporters, to change.*
- *Attempts to "fix" the person are misdirected. It is often the "system" that needs fixing.*
- *Taking care of yourself is one of the most important things you can do. If you don't take care of yourself, it will be very difficult to support someone else.*

Lessons from Minnesota

[Excerpted from *The Social and Policy Context of Community-Centered Behavioral Supports and Crisis Response* by K. Charlie Lakin and Sheryl A. Larson]

Recognize the high costs of inaction

If state institution depopulation continued in the absence of community alternatives for behavioral support and crisis response, the system would eventually experience very large increases in service expenditures and/or human costs...Denial of access to behavioral supports led to injury, homelessness, emotional impairment and other unacceptable costs.

Establish a foundation of efficiency and acceptability

It was important to recognize, value and include in the planning process people with high stakes in and capacity to contribute to a non-institutional approach to behavioral support. It is equally important to appreciate that all participants had insights, skills, and commitments to offer.

Base programs on valid and accepted treatment principles

Challenging behavior and behavioral crises are the product of a wide range of interactions between people [who experience MR-DD] and their social environments. An effective system would need to address a wide array of circumstances and needs, including not only those amendable to traditional behavioral analysis, but also, and more often, those requiring social-environmental changes, physical-medical assessment and treatment, communication development and augmentation, new ways of planning around specific personal preferences, and other responses to circumstances that may underlie challenging behavior and resulting crisis.

Be responsive to key consumers

An effective behavioral support and crisis response program must operate in a supportive partnership with the individuals, families, counties, private and public providers, mental health

Interventions with potential for long-term positive outcomes often require sufficient respect and skill to listen to individuals to understand and appreciate the extent to which their daily lives reflect their own personal goals, needs, and desires.

- K. Charlie Lakin and Sheryl A. Larson

providers, state agency representatives, and communities being served.

Integrate existing resources and expertise

In developing community supports, professional, economic, and political realities required integration of the resources, expertise, and experience of [various professionals]...Integrating them into a definable program with a single point of entry..[was an]...on-going challenge.

Change the culture of "easy out"

When public institutions functioned as places to send people who presented behavioral challenges, it became convenient for private service providers to take advantage of that function. Operating without public institutions and with a very limited "crisis bed capacity" requires that service providers stay engaged and work with behavioral support staff to respond effectively to people who once would have been remanded to the state institutition.

Stay on the "side" of people with disabilities

Many of the challenges in providing behavioral support and crisis response services derive from a serious mismatch between people and their environments. Too much of the history of behavioral treatment has focused on how to induce conformity to a "given" environment. Interventions with potential for long-term positive outcomes often require sufficient respect and skill to listen to individuals to understand and appreciate the extent to which their daily lives reflect their own personal goals, needs, and desires.

7 Ways to Cause a Crisis

- Peter Leidy

(based on Paul Simon's "50 Ways to Leave Your Lover")

The problem is sometimes with the system you don't know
Forgetting basic person-centered thinking as we go
If we don't get it right we make a person blow
There must be 7 ways to cause a crisis

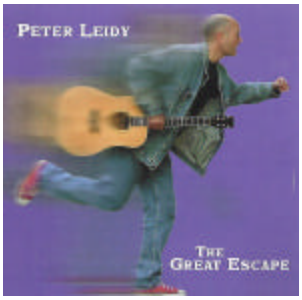
Control and power we neglect to recognize
One size does not fit all, all do not fit one size
So I repeat myself 'cause we need to realize
There must be 7 ways to cause a crisis
7 Ways to Cause a Crisis

> Just make a dumb plan, Stan, put 'em in a slot, Dot
> Make a bad match, Mitch, now dontcha forget
> Listen less, Tess, ignore her loneliness
> Don't train your staff, Jeff, and see what you get

Sometimes we're placing folks where they do not feel free
Where they live or where they spend the day is not what it should be
Just look around, and I think you might agree
There must be 7 ways to cause a crisis
7 Ways to Cause a Crisis

> Make a bad match, Mitch, take away control, Joel
> Ignore her needs, Rasheed, now dontcha forget
> Make a dumb plan, Stan, watch it all hit the fan
> Don't listen to him, Jim, and see what you get

> Just make a dumb plan, Stan, put 'em in a slot, Dot
> Make a bad match, Mitch, now dontcha forget
> Listen less, Tess, ignore her loneliness
> Don't train your staff, Jeff, and see what you get



Check out Peter's great web site where you can purchase music from his extensive catalogue: www.peterleidy.com

section 1.0: remember the fundamental importance of relationships and helping the person to achieve a real life

beyond coverage

I met a man once who was very much alone in the world. When he was a young boy, his family sent him to an institution. He had troubling behaviors that would not go away, regardless of the interventions or medications he received. He refused to do things with other people and preferred to isolate himself in his room, wrapped tightly in blankets. I believe his difficult behaviors and resistance to relationships were the direct result of the trauma he endured when he was separated from his family, and from the systematic abuse he suffered at the hands of his "care givers" over the years. When I suggested that loneliness and trauma might be at the root of his difficulties, one member of the team said, "He's not lonely. He has one-to-one coverage."

Portions of this text are taken from my chapter "Opening the Door" in John O'Brien and Connie Lyle-O'Brien's book *Implementing Person-Centered Planning: Voices of Experience.* and my handout *The Importance of Belonging* available online at www.dimagine.com

what matters most to

people's safety…

….is the extent and quality of their relationships. People are safer the more others care enough about their safety and well being to keep a close eye on their situation, to stand up to difficult situations with them, to act imaginatively in response to their vulnerabilities, to negotiate on their behalf with others who control important opportunities, and to struggle with them over situations in which they are contributing to their own problems. Many people with developmental disabilities are more vulnerable exactly because they lack opportunities and assistance to make and keep good relationships. But most current policies and practices ignore these vital relationship issues, and most service dollars are spent on congregating people with developmental disabilities in settings which segregate them. By suggesting that people could be kept safe and well in settings where strangers can drop in to check on quality of life, current approaches to safety fundamentally misdirect attention away from people's most important safeguard, the safeguard that most service settings are most likely to discourage or disrupt.

- O'Brien and Lyle-O'Brien (1993)
Assistance with Integrity

Photograph by Matthew Swarts,
New York Times Magazine, September 10, 2000

You can, of course, have ten-to-one coverage and be terribly alone. One way I like to explain the difference between coverage and relationships is to ask people to imagine that I have just returned from a road trip. I pull up into my driveway and discover that my wife Cyndi is not home. Another woman is standing at the door and I ask, "Where's Cyndi?" She replies, "Cyndi is not here, but don't worry. We have you covered."

People generally laugh at this scenario. It's silly. Preposterous, really. But it is exactly what happens to people who experience our services time and time again. The very fact that people laugh at the joke of another woman "covering" for my wife is an indication that they know there is a huge difference between "coverage" and "relationships." Our field keeps giving people coverage when the desperately need to belong.

the importance of belonging

Many people who experience disabilities live lives of extreme loneliness and isolation. Many depend almost exclusively on their families for companionship. Some have lost their connections to family, relying on people who are paid to be with them for their social support. Although paid staff can be friendly and supportive, they frequently change jobs or take on new responsibilities. The resulting instability can be devastating to someone who is fundamentally alone.

Bob Perske ( ) describes how a person whose life is devoid of meaningful relationships might feel:

> *We have only begun to sense the tragic wounds that so many [persons with developmental disabilities] may feel when it dawns on them that the only people relating with them -- outside of relatives -- are paid to do so. If you or I came to such a sad realization about ourselves, it would rip at our souls to even talk about it. Chances are some of us would cover it up with one noisy, awkward bluff after another. And chances are, some professionals seeing us act this way, would say we had "maladaptive behavior." Think about what it would feel like to have even one person come to us without pay, develop a reliable, long-term relationship with us because he or she wanted to...literally accept us as we are. Then think of the unspeakable feelings we might possess if -- when others were "talking down" to us and "putting us in our place" -- that kind person could be counted on to defend us and stick up for us as well! Most of us do have persons like that in our lives. But will the day come when [people with disabilities] have them too?"*

In my view, most people served by the human services industry are profoundly lonely. Loneliness is the central reason why so many people enter into crisis situations. It is not because our instructional strategies are ill-informed or because our planning processes are inadequate. It is not because our medications are in-potent or because staff are untrained. Their suffering results from isolation.

As Willard Gaylin (1990) has written, "To be vulnerable is not to be in jeopardy. To be vulnerable and isolated is the matrix of disaster."

the wrong questions

For years, the human services profession has been pre-occupied with three questions (Lyle-O'Brien, O'Brien, & Mount, B., 1998)):

1. What's wrong with you?
2. How do we fix you?
3. What do we do with you if we can't fix you?

The central function of our human services system, in my view, should be to help people who experience disabilities to develop and maintain "enduring, freely chosen relationships" (O'Brien & Lyle-O"Brien, 1987).

better questions

The field is now moving toward a much more promising set of questions than *What's wrong with you? How do we fix you?* And *What do we do with you if we can't fix you?* Processes such as person–centered planning pose a deeper more illuminating set of questions (Lyle-O'Brien, O'Brien, & Mount, 1998):

1. What are your capacities and gifts and what supports do you need to express them?
2. What works well for you and what does not?
3. What are your visions and dreams of a brighter future and who will help you to move toward that future?

In addition to these questions, I like those posed by Mary Romer. Mary's questions strike me as fundamental to anyone's success (Romer, 2002):

1. Are enough people engaged in the person's life?
2. Are there people who are imbued with the belief and hope for a brighter, better future for the person?
3. If not, how might such people be found or how might that sense of hope be instilled in those committed to walking with the person?

remember that *who* shows up matters

A person in crisis may benefit from the services of a qualified therapist who helps uncover dysfunctional patterns of thought that may have grown out of traumatic life experiences. Or help might come from a behavior analyst who "sees" the functional relationship between the person's behavior and events in the environment. With this information, a talented teacher may know which replacement skills to teach the person (and how) so that future conflicts can avoided or more peacefully resolved. But *who* shows up matters. It is not enough to provide a person services and assume that anyone will do. Every effort should be made to match the person providing support to the person receiving support.

remember the importance of authentic presence

Many professionals *do* take the time to get to know the people they are supporting. But some do not. For them, 'professionalism' is a kind of armor against the uncertainties of getting involved. When you get involved with someone, there is the risk that you will not know what to do, or that their behaviors will cause embarrassment or, perhaps, even be hurtful. But taking the time to get to know someone also offers the opportunity for great discoveries. I always find that I learn something important about myself when I make a commitment to know someone and let them affect me.

I like what John Welwood says in his book, *Awakening the Heart: East/West Approaches to Psychotherapy and the Healing Relationship:*

> "...I have found that I most enjoy my work and am most helpful to

others when I let them affect me. This does not mean that I should identify with their problems or get caught up in their neuroses. There are ways that clients try to draw the therapist into their world in a manipulative way which should, in fact, be resisted. Yet the therapist can still leave himself open to seeing what that pull or manipulation feels like, for this will provide essential clues to guide him in responding more helpfully to the person. What I am speaking of here is not losing my boundaries, but letting myself experience what the other person's reality feels like.

"If I can hear another person's words, not from a place of clinical distance, but as they touch me and resonate inside me, then I can bring a fully alive, human presence to bear on the other's experience, which is much more likely to create an environment in which healing can occur. Many other factors also determine the outcome of therapy, but without this kind of authentic presence on the part of the therapist, real change is unlikely to occur. Authentic presence is sparked in therapists when they let themselves be touched by the client, when they can really feel what it is like to be in the client's world so they can respond from a place of true empathy and compassion. (p. xi).

keep your promises

Many people who engage in difficult behaviors have too much experience with *broken* promises. Life has been full of tricksters -- people who say one thing and mean another. For example, Carl was told that he would be able to live in his own apartment if he improved his behavior. But the truth was much more complex. The funding streams which pay for the group home will not pay for his supports if he lives in an apartment or home of his own. In the *real* world, Carl lives in the group setting because people are unwilling to deal with the "politics" of funding streams and State regulations. In short, people don't want to deal with the *real* problems, so they make *Carl* the problem.

Teach the person that your word is good by following through on your promises. Give the person a chance to learn that you are trustworthy, but don't be surprised if the person is reluctant to trust you at first. It can take time for a heart that has been betrayed to open up one more time.

And remember, in the real world there will be times when you can't keep your promise (for reasons beyond your control); life happens. But it will almost certainly be easier for the person to accept the change in plans if, on balance, you keep your promises.

For additional information about the development of relationships, see my handout *The Importance of Belonging* (also available in Spanish) which can be downloaded from my web site: www.dimagine.com.

A community that excludes even one of its members is no community at all.

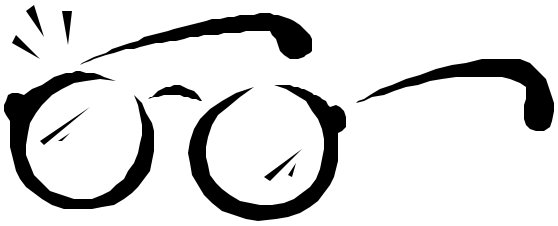
-Dan Wilkins

Indicators of a successful crisis support system:

- Less intervention by law enforcement
- Less use of emergency room services
- Less use of 911
- Less exclusion of people from residential placements
- Less use of medication as control
- Decrease in the use of restraint and other coercive control procedures
- More focused use of MH services (e.g., fewer days in hospital)

Reprinted with permission from John O'Brien (2006) Closing remarks at the Wisconsin Developmental Disabilities Network October 16, 2006 conference "Crisis: How do we define it? How do we prevent it? How do we successfully live through it?" at the Kalahari Resort in Wisconsin Dells, WI.

section 2.0 check your assumptions



about the person

It is important to understand that we all have biases. Our individual learning history affects how we "see" the world. These biases can be positive and they can be negative, but they are inescapable. We all 'see' the world the way we have learned to see it.

When I first entered the field, I was told that adults who experience intellectual disabilities are just children in grown-up bodies. "He is 49 in chronological years but functioning at a five year old level." I heard statements like these on a regular basis from co-workers, supervisors, speakers at conferences, and even family members.

Thanks to the help of many people, especially people who experience disabilities, I have learned that such a view of people is just plain wrong. In fact, there is very little, if any, empirical evidence for such claims. What we now know is that we really don't know what people can and can't do and we should never underestimate their potential. Even the American Association on Mental Retardation changed it's definition of mental retardation by including the idea that what people are capable of achieving depends on the quality of their support.

We now know that there is a huge difference between understanding an idea and being able to communicate that idea with words. Many people who we have assumed to be 'stupid' or 'retarded' are, in fact, of normal (or better than normal)

intelligence. What we have missed over the years is that people may experience difficulty 'moving' thoughts in their 'thinking brain', with support, can learn to accommodate these 'movement differences.' (For additional information about movement issues, see Anne Donnellan and Martha Leary's fascinating book *Movement Differences and Diversity in Autism/Mental Retardation: Appreciating and Accommodating People with Communication and Behavior Challenges* (available at the Autism National Committee Bookstore: www.autcom.org).

Mayer Shevin, who is one of the most thoughtful people I know when it comes to supporting people who exhibit difficult behaviors, states his assumptions right up front when he is offering support:

1. The person already knows that he/she is acting weirdly.
2. When it's not happening, they wish it wouldn't happen again.
3. When it is happening, they either (a) feel they can't stop it or (b) feel that it is the only thing that they can do.
4. After it happens, they feel embarrassed.
5. No matter how significant their disability or how difficult their behavior, they have lots of time to (a) develop an understanding of their behavior and (b) develop ideas about what it would take to change it.
6. The person needs to be supported in testing their own theories about their own behaviors.

[For additional information about Mayer Shevin and his work, visit his web site: www.shevin.org].

about the person's supporters

Just as it is important to consider carefully your assumptions about the focus person, so too is it important to consider carefully your assumptions about the person's supporters.

"As a first step," say Kathleen Ryan and Daniel Oestreich, in their book, *Driving Fear Out of the Workplace: How to Overcome the Invisible Barriers to Quality, Productivity, and Innovation,* (1985), "[we] can challenge the negative assumptions about employees and managers that are reinforced [in many work cultures]. Suppose, for example, managers assumed that employees:

1. Want to take responsibility for their work and want to do a good job.
2. Care about their work beyond the money they get to perform it.
3. Can consider the "big picture."
4. Are willing to take responsibility for their mistakes.
5. Are capable of establishing their own structures in order to maintain focus.
6. Want to contribute freely.
7. Are fully capable of understanding budgetary and political realities.
8. Do not just focus on their entitlements and rights.
9. Are intrinsically honest and trustworthy.

"Next, consider what might happen if employees believed that managers:

1. Are sensitive to the personal issues and interests of employees.
2. Enjoy open, participative problem solving.
3. Want the workload to be fair and reasonable.
4. Work to find solutions that are both technically and politically sound.
5. Pride themselves on working fairly and objectively.
6. Want input on decisions.
7. Are willing to put the success of the organization, welfare of the employees, and service to the consumers before private interests.

8. Do not think they are better than their employees.
9. Are honest and would consider retaliation a serious sign of weakness.

about family members

Any of the above assumptions about employees and employers can also be made about the person, the person's family, and the person's friends. I assume, for example, that parents who have institutionalized their children, if given the right information, can see the big picture and understand the need to help their child find support to live in ordinary, everyday places.

But parents are often assumed to *be* the problem in their child's life. For this reason, I would like to include a few assumptions that I make whenever I meet parents for the first time:

1. They are the best parents the person could ever have. No one can ever take their place, and no advice or medicine that I offer will ever be as potent as the medicine brought by the person's mother or father.
2. No matter how 'politically incorrect' a mother or father might be, their commitment to their child is timeless. It is my responsibility to make a commitment to 'know' them as deeply as possible, and when asked for advice, offer it honestly and with respect.
3. It <u>is</u> my job to help the person to find the support that he or she needs to *be* a son or daughter. It is <u>not</u> my job to make the person get a long with his or her parents or agree with them.
4. It <u>is</u> my job to help mothers and fathers to *be* mothers and fathers. They should not have to become researchers or advocates or behavior specialists because I have failed to do my job.
5. It is <u>not</u> my job to make mothers or fathers 'see' their child as I do. Their relationship with their son or daughter is *their* relationship and my relationship is *my* relationship. My responsibility is to remain mindful of a parent's gifts and to tell them what I believe to be true in ways that are respectful.

helpful resource

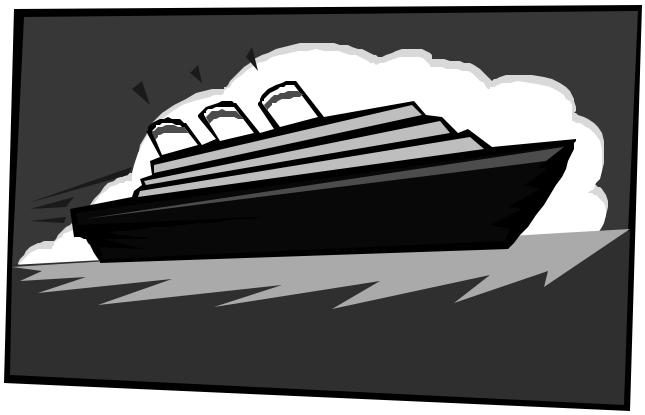
Years of experience working with people who exhibit challenging behaviors helped Wisconsin's Paul White create a five-stage framework for professionals to manage threatening confrontations. In the DVD, *Managing Threatening Confrontations*, participants learn to recognize the stages (adaptive, tension, emotional distress, physical distress and recovery) and respond appropriately.

For frontline staff in the fields of developmental disabilities and mental illness who deal with potentially explosive situations. Realistic scenes follow the five-stage process and show both unskilled and effective staff responses. Includes actors with developmental disabilities.

Available from:
Attainment Company, Inc., PO Box 930160, Verona, WI 53593
Call: 1-800-327-4269

www.AttainmentCompany.com

section 3.0 assure safety/minimize threat



Imagine finding yourself on board one of those impossibly large ocean liners, the kind that travel to places like the Virgin Islands or Alaska. There is a storm — a menacing storm — about to overtake the boat. You and dozens of other people are on deck, holding fast to anything that will hold, when, suddenly, a gust of wind blows a fellow passenger into the sea. He falls like a stone, disappearing the churning waters as if he were being swallowed. There is disbelief at first. Silence. No one can believe what has happened. And then someone yells, "Call a human services worker! Call a human services worker! This man needs crisis support!"

In what seems an age, a handful of professionals finally appear on deck. Dressed in business attire, they make their way to the railing and locate the man overboard who disappears repeatedly under churning waves. He is screaming and waving his arms frantically, but it is difficult to hear what he is saying — the waves are exploding beneath you, and he is getting further and further away as the ship, too heavy to stop, continues on its path. The only thing that is clear is that the man is terrified.

You watch helplessly as the professionals whisper to one another, nodding and conferring, conferring and

nodding. One of them, a well-credentialed looking fellow, finally picks up a mega-phone and directs it toward the man overboard. "Stop shouting and flailing!" he barks. "You are engaging in attention seeking behavior and we will not help you until you are calm in the water!"

It might seem odd to you that a professional would respond in such a way. But it happens all the time. The person overboard is terrified, and the guy with the megaphone barely seems to notice.

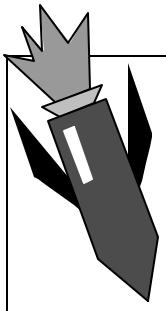
fight, flight, or freeze

You've probably heard of the "fight-flight-or freeze" response. It's what we do when we are overwhelmed by something scary or threatening.* Caroline and Robert Blanchard, researchers interested in how we defend ourselves when threatened, describe the response this way:

> If something unexpected occurs — a loud noise or sudden movement — people tend to respond immediately...staop what they are doing...orient toward the stimulus, and try to identify its potentiality for actual danger. This happens very quickly, in a reflex-like sequence in which action precedes any voluntary or consciously intentioned behavior. A poorly localizable or identifiable threat source, such as sound in the night, may elicit an active immobility so profound that the frightened person can hardly speak or even breath, i.e, freezing. However, if the danger source has been localized and an avenue for flight or concealment is plausible, the person will probably try to flee or hide... Actual contact, particularly painful contact, with the threat source is also likely to elicit thrashing, biting, scratching, and other potentially damaging activities by the terrified person (1989, p. 94-121).

Sound familiar?

Think of the last time you were with a person in crisis. Did they seem anxious or afraid?



"At the sound of the first droning of shells we rush back, in one part of our being, a thousand years. By the animal instinct that is awakened in us we are led and protected. It is not conscious; it is far quicker, much more sure, less fallible, than conscious. One cannot explain it. A man is walking along without thought or heed — suddenly he throws himself down on the ground and a storm or fragments flies harmlessly over him — yet he cannot remember either to have heard the shell coming or to have thought of flinging himself down. But had he not abandoned himself to impulse he would now be a heap of mangled flesh. It is this other, this second sight in us, that has thrown us to the ground and saved us, without our knowing how. If it were not so, there would not be one man alive..."

-Erich Maria Remarque
All Is Quiet on the Western Front

*The man overboard is undoubtedly preoccupied with beating back the waves (fight) and trying to escape (flight).

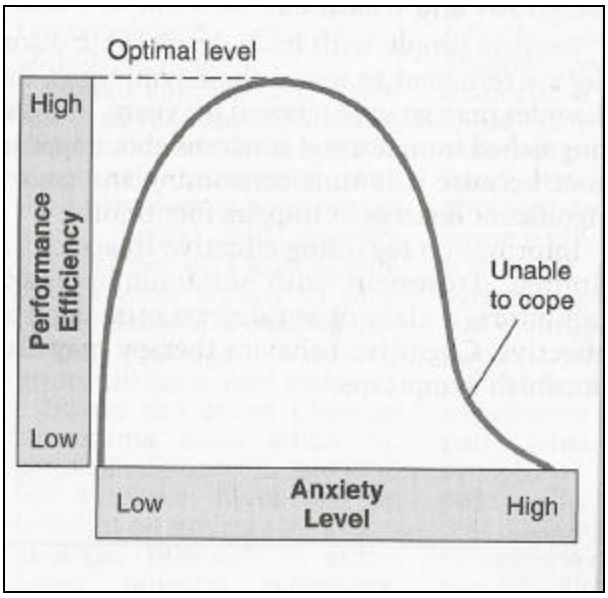
anxiety and fear

There is nothing wrong with a little anxiety. Anxiety, in the right dosage, can actually be a good thing. It can help to motivate us during challenging tasks. But too much anxiety can have devastating effects on our performance. See the graph in the lower right hand corner of this page (figure 3.1). You can see that a certain level of anxiety is good for performance. Performance improves when we are anxious, but only up to a point. When we become too anxious, our performance level drops off dramatically and we are quickly unable to cope.

"Anxiety and fear are closely related," according to Joseph LeDoux. "Both are reactions to harmful or potentially harmful situations. Anxiety is usually distinguished from fear by the lack of an external stimulus that elicits the reaction — anxiety comes from within us, fear from the outside world." He goes on to say that "fear and anxiety are normal reactions to dangers (real or imagined) and are not themselves pathological conditions. When fear and anxiety are more recurrent and persistent than what is reasonable under the circumstances, and when they impede normal life, then a fear/anxiety disorder exists."

A central premise of this handout is that fear and anxiety are central reasons why people who experience disabilities sometimes "act out." Their "difficult" behaviors may be normal reactions to everyday events (e.g., encountering people who are unkind or prejudiced, or having difficulty learning certain kinds of information, or expressing themselves in ways that accurately reflect their competence). Or, their behaviors may result from an underlying psychiatric issue. It has been demonstrated that "fear plays a central role in psychopathology" (LeDoux, 1996, p.130).

figure 3.1
how anxiety affects performance



The effects of anxiety on performance can be shown on a curve. As the level of anxiety increases, performance efficiency increases proportionately but only up to a point. As anxiety increases further, performance efficiency decreases. Before the peak of the curve, anxiety is considered adaptive, because it helps people prepare for a crisis and improve their functioning. Beyond the peak of the curve, anxiety is considered maladaptive, because it produces distress and impairs their functioning.

Source: Merck Manual of Health—Home Edition. Used with permission.

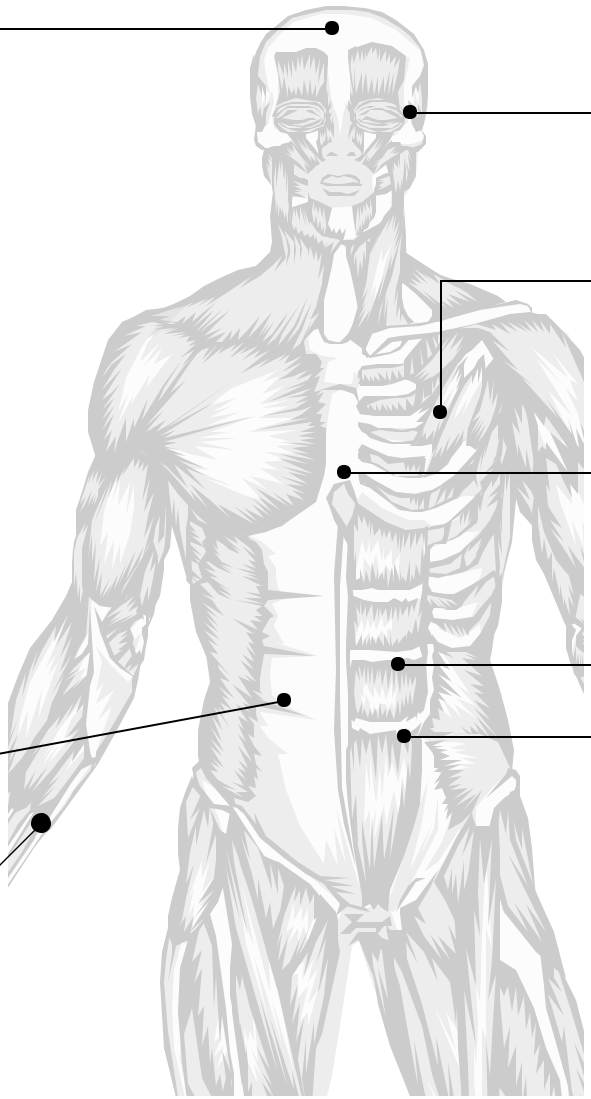
figure 3.2

the brain kicks into fear gear

When confronted with fear, the brain initiates a cascade of instantaneous biological reactions. What those reactions are and where they occur:

1 fear recognition
The body's alarm center, the amygdala, directs nerve impulses to initially freeze all function when confronted with fear. This freezing allows the body to direct every nerve impulse toward the ensuing biological response.

2 biological response
The brain then directs nerve impulses to many key areas of the body.



Adapted from graphic by Grant Jerding in article by Debbie Howlett in USAToday (November 9, 1999, p.06 D) *Loving a good fright: It's in our nature.* **Source:** Center for Neural Science, New York University and Laurence Gonzales *Deep Survival: Who Lives, Who Dies, and Why.* New York: W.W. Norton and Company

Whatever the source, our body changes in some predictable, but remarkably complex ways when we are afraid

the jockey and the horse

When threatened, our bodies change. Laurence Gonzales, in his book entitled *Deep Survival* , describes what happens to us physiologically when we encounter threat (see figure 3.2):

> During a fear reaction, the amygdala (as with most structures in the brain, there are two of them, one in each hemisphere), in concert with numerous other structures in the brain and body, help to trigger a staggeringly complex sequence of events, all aimed at producing a behavior to promote survival; freezing in place for example, followed by running away. When the reaction begins, neural networks are activated, and numerous chemical compounds are released and moved around in the brain and body. The most well known among them is the so-called adrenaline rush. Adrenaline is a trade name for epinephrine, and...epinephrine and norepinephrine, which come from the adrenal glands, are in a class of compounds called catecholamines, which have a wide range of effects, including constricting blood vessels and exciting or inhibiting the firing of nerve cells and the contraction of smooth muscle fibers. But it is norepinephrine (not adreneline or epinephrine) that is largely responsible for the jolt you feel in the heart when startled. Cortisol (a steroid), which is released from the adrenal cortex, also amps up fear, among its other effects. The net result of all the chemicals that come streaming through your system once the amygdala has detected danger is that the heart rate rises, breathing speeds up, more sugar is dumped into the metabolic system, and the distribution of oxygen and nutrients shifts so that you have the strength to run or fight. You're on afterburner. The knot [you

Definition:

The amygdalae are almond shaped groups of neurons located deep in the medial temporal lobes of the brain. Shown in research to perform a primary role in the processing of and memory of emotional reactions, the amygdalae are considered part of the limbic system.

From Wikipedia, the free encyclopedia online:
www.wikipedia.org

> feel]...in your stomach results from that redistribution (as well as the contractions of the smooth muscle tissue in the stomach), in which the flow of blood can be used elsewhere to meet the emergency.

Gonzales explains that our brains are "split" between two parts — cognition and emotion. "'Cognition' means reason and conscious thought, mediated by language, images, and logical processes. 'Emotion' refers to a specific set of bodily changes in reaction to the environment, the body, or to images produced by memory. Cognition is capable of making fine calculations and abstract distinctions. Emotion is capable of producing powerful physical actions" (p.33).

"The human organism" he goes on to write, "is like a jockey on a thoroughbred in the gate. He's a small man and it's a big horse, and if it decides to get excited in that small metal cage, the jockey is going to get mangled, possibly killed. So he takes great care to be gentle. The jockey is reason and the horse is emotion, a complex of systems bred over eons of evolution and shaped by experience, which exist for your survival. They are so powerful, they can make you do things you'd never think to do, and they can allow you to do things you'd never believe yourself capable of doing. The jockey can't win without the horse, and the horse can't race alone. In the gate, they are two, and it's dangerous. But when they run, they are one, and it's positively godly" (pps. 33-34).

what can you do to help?

Chances are good that the person you are trying to support is routinely overwhelmed by the horse — that powerful part of the brain ruled by emotions. You might say the jockey is no longer in control and it is your job to help the person regain control of the horse.

What kinds of things might cause a person who experiences disabilities to run, fight, or freeze?

- Simply experiencing a disability in a culture that can be exclusionary and prejudiced;
- difficulty understanding or learning certain kinds of things under certain circumstances;
- being exposed to insensitive, even inhuman practices, such as aversive treatment, separation from family at an early age,
- an underlying psychiatric issue such as an anxiety disorder (e.g., Post Traumatic Stress Disorder)
- An underlying medical condition (e.g., endocrine disorder) or a problem with medications (e.g., an inappropriate medication or dosage, withdrawal symptoms);
- movement issues that make it difficult to connect with others and inhibit certain behaviors.

Consider figure 3.3. It looks like a simple bell curve, but here it represents what happens to our bodies when confronted by threat. Sometimes referred to as the "assault cycle," the curve represents the way in which our bodies become charged with energy — we become aroused — and how the energy must move. As our bodies respond to threat, we experience a build up in arousal (a) . If we have good coping skills, we can manage the circumstance and avert a melt down (see next section for advice on building coping skills). But there is a line (b) that, once crossed, makes it difficult to contain the energy or

figure 3.3
the "assault cycle"

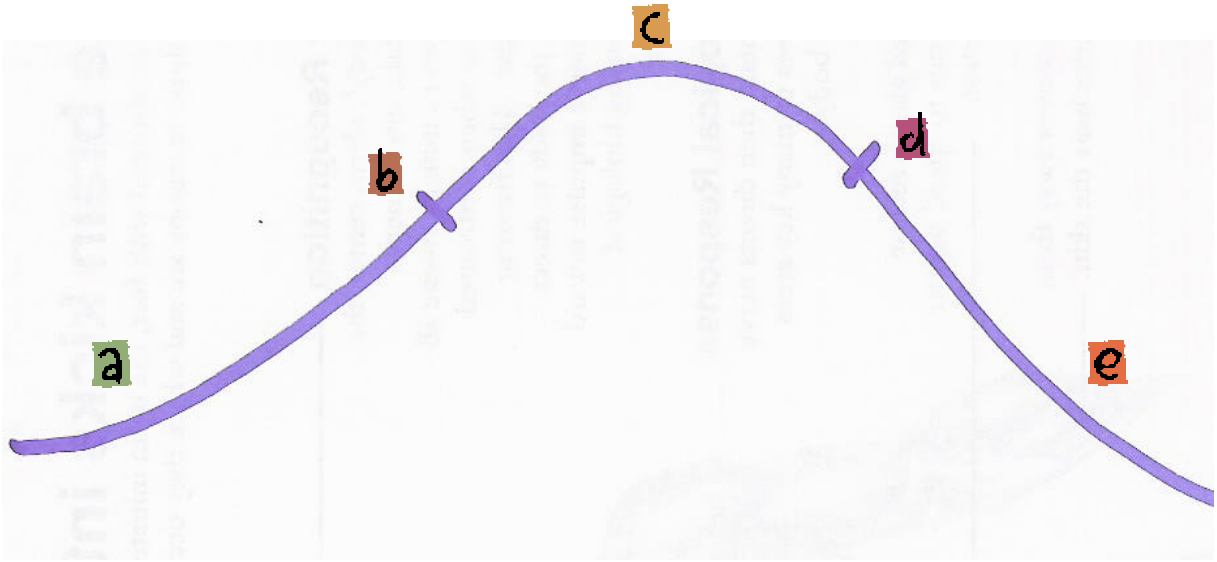


Figure 2.2 — Sometimes referred to as the "assault cycle" the above curve represents the manner in which arousal builds in the body. If we have good coping skills, we can avert a full-blown "tantrum." But once we cross over a certain line (b), we become overcome by energy — the "genie is out of the bottle" — and the energy must be expressed, or moved. A common mistake made by caregivers is to reintroduce the stimulus that caused the person to lose control when the person finally begins to calm down.

figure 3.4
"intermittent explosive disorder"?

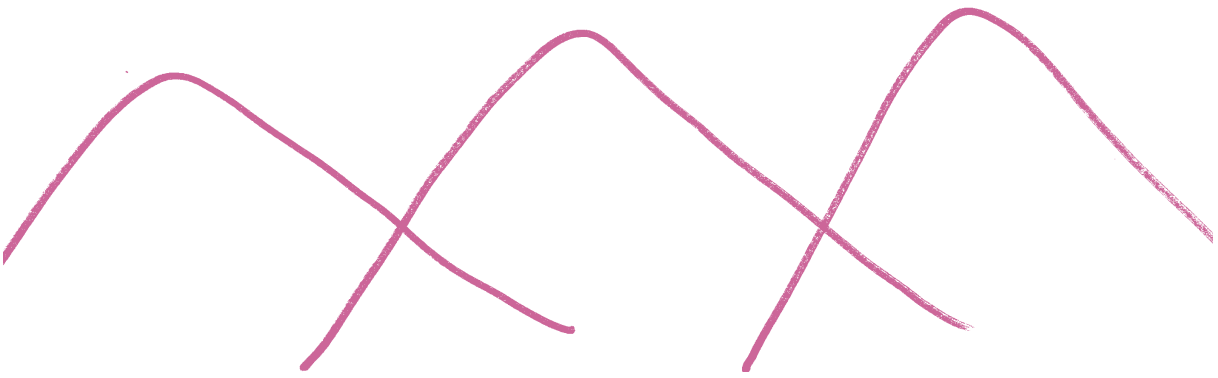


Figure 2.3— We often "teach" people to engage in crises behaviors by failing to recognize their need to develop coping skills and discharge unwanted anxious energy. The pattern that often emerges from this "instruction" looks like the above — crisis behavior, followed by short periods of calm, followed by additional crisis behavior. What makes it even more insulting? We have created a classification for the behavior that suggests it is a *thing* — "intermittent explosive disorder." We might as well develop a diagnosis called "intermittent getting out of seat disorder."

In the event that a restraint is used, this should be recognized as trauma to the individual. The restraint has the potential to affect an individual's short and long term mental health, manifest behaviors, affect the relationships they have with staff, and alter their overall care and needs. Recognition that past incidents of restraint should also be viewed as is essential in eliminating the need for restraint.

-Commonwealth of Pennsylvana
Mental Retardation Bulletin
Elimination of Restraints through Positive Practices

manage the situation. You might say it is the point at which the "genie is out of the bottle." Once we cross that line, we may stomp our feet and shout or lash out at the people around us, or run fast away. At this point, we are bundles of excess energy and the only way thing we can do is express the energy. Like water cascading down a creek, the energy must move. We can attempt to block the water, to dam up the creek, but the water — our energy — must move.

At some point, once the energy has peaked (c) , we begin the process of calming down. Sadly, it is often during the point on the curve when the person is beginning to calm down (d) that caregivers reintroduce the stimulus that provoked the person in the first place. Rather than waiting for the person to fully calm (e), we create a habit of downshifting which some have called "intermittent explosive disorder" (see figure 3.4).

set respectful limits

When I first meet a person who has a history of "losing control" I ask them to help me understand what is going on and how I might be helpful. If the person is unable to communicate in a formal way or lacks insight about the problem, I ask for permission to speak with people who know the individual best. Whenever possible, I let my actions be informed by what the person thinks is going on and what I should do. For example, if the person lets me know that a crowded room is upsetting, I am going to try my best to help the person find a way to proactively "escape" situations that are overwhelming. When efforts to prevent a crisis do not work and the person is "losing control," I try to remember the following:

1. Help anyone who is vulnerable to attacks to leave the room safely.
2. Remove any objects which might be easily broken or thrown to prevent injury.
3. Every effort should be made to avoid restraint. Restraint can be traumatizing both to the individual and his/her care givers. If the use of restraints has been sanctioned, every effort should be made to eliminate the need for restraints as quickly as possible. For information regarding the use and elimination of restraints, see an excerpt of Commonwealth of Pennsylvania Bulletin on the Use of Restraints in the policy section (Policy Document 8.1).

4. There is no one strategy that helps all people to calm down. Different people need different things. For example, some people do better when they have time by themselves to calm down. Others do better when you stay present with them, avoiding things that might make them feel worse (e.g., talking too much or presenting demands). One way to determine what best works for the individual is to ask team members to imagine that s/he is having a very difficult day (usually not hard for them to imagine). Next, I ask them to imagine that I will give them each $500 if they can help the person to calm down within a short time. Someone almost always says, "Nothing we do works all the time." I respond by saying "Of course. But if I were going to give you $500 there are some things you would try and some things you would avoid like the plague." After we have made the list of things that "might work" I ask them to imagine that I would reward them with $500 if they made the person feel worse. No one ever says, "Nothing we do works all the time" because everyone generally has very good ideas for making the person feel worse. After this part of the exercise, we have two lists — things that help and things that make matters worse. It is this first list that I try to rely on when a person is in crisis.
5. If the person is attacking me, or others, I may use things like pillows to hold in his/her way, blocking the blows. It can take some time for the person to calm, but it is worth waiting, especially if the technique helps you to avoid restraints.
6. The person is probably threatened by something internally or externally. Anything I can do to help reduce threat (e.g., get them something soothing to drink or ask the person they are angry with to leave for a short time) will be useful. I myself must avoid any threatening or aggressive behavior.
7. If the person is overwhelmed by internal stress, such as pain or an illness, it helps to try and sooth the person by making the environment more comfortable (e.g., reduce the number of people present, remove potentially harmful objects). It is also necessary at times to consult with the person's primary care physician/psychiatrist should a serious medical/psychiatric condition be suspected (see section 4.0 for additional information)
8. I use as few words as possible when a person is upset. Because s/he has probably "downshifted" to the emotional brain, in all likelihood her/his hearing centers have shut down and, if able to hear sound, is probably unable to process language. When s/he begins to calm (figure 3.3, c-d), I begin to say encouraging things (e.g., "I'm glad you are feeling better," "What do you need?" "How can I help?).
9. It is also important to convey to the person that I am not overwhelmed. In my experience, the people who are <u>most</u> helpful during a crisis are people who have honestly and forthrightly asked for what they need and are supported by organizations or systems that take their needs seriously (see Section 5.0 for additional information). They are people who know the difference between "being present" and "being all things to all people." They are not easily overwhelmed because they are prepared for the worst and know what to do when things get tough. They are able to remain calm even when the person is coming undone, conveying verbally and non-verbally that they are OK and will do what is needed to make sure no one gets hurt They are often people who have been through tough times before and have seen tremendous progress after very trying times. They almost always have a sense of humor, but

would consider jokes at the person's expense a serious character flaw. Above all else, they project a sense of hope to the person about the future.

10. I do this by preparing myself for as many possible contingencies as possible and asking "What would I need, should this happen, to be OK?" More often than not, it is easy to take steps that assure my own safety (e.g., making sure someone is present should I need assistance).
11. I follow the stages for "building emotional alliances" developed by Al Vecchione, Ph. D. found on the next two pages.

when a person has "offended"

On occasion, I meet people who have a history of "offending" and who have been adjudicated by the criminal justice system. Individuals who might harm others in malicious ways need us to take special precautions while remaining respectful and supportive. You can find an outline of a "community safety plan" developed by the Vermont Division of Disability and Aging Services in Section 8 (Policy Document 8.2).

teach coping skills

A common problem for someone who repeatedly "loses it" is that they lack coping skills. Coping skills are those things we do for ourselves when we are experiencing discomfort or stress. They help us to "get over the hump." Many people who experience disabilities have been subjected to behavior plans that actually discourage the development of coping skills. How? By contingently withholding reward from people when they "misbehave," we are actually denying them access to things that may help them deal with life's ups and downs. For example, I have several coping skills, some of them healthy, some of them not so healthy. I enjoy a good hike (healthy) when I am stressed. I also enjoy beer (potentially unhealthy). It is sometimes useful for me to discuss my problems with good friends who know how to give me sound advice without sounding judgmental (healthy). Sometimes I like to drink beer... Oh yes, I said that.

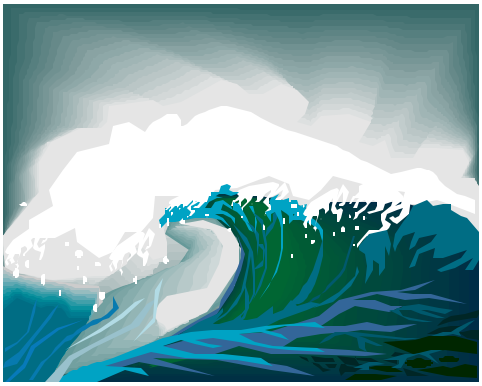
The coping skills that I might use to help me through tough times are often withdrawn or denied to people who experience our services. In their case, we call them "reinforcers":

- *You can't go for a walk because you have been hateful to your roommates!*
- *No, you cannot smoke. Smoking is bad for your health!*
- *We are not going to give you attention now…*
- *...and so it goes.*

At times, our emphasis on behavior modification (which is often about control), and our own learning histories in which punishment was the pre-potent response to problem behaviors, leads us to believe that withdrawing support from someone in crisis is the only thing that works. But is that really true? The vast majority of humans I know need <u>more</u> support not less during difficult times. Why should it be any different for people experiencing disabilities?

One answer I receive to the question *Why should it be any different?* is that people will take advantage of the kindness of others and act out just to get their support. In short, their inappropriate behavior will be <u>reinforced</u>. For example, I met a man named Michael who was routinely banging his head against hard objects, such as table tops and walls. When I met him, he was sitting at a table and he thrust his head toward the table but stopped just short of striking it. I asked him if it would be OK to talk. "How about a coke?"

`Later, after Michael and I had spent



Building Emotional Alliances

—Elia Vecchione, Ph.D.

Step 1: Manage Your Own Behavior

a. Hold on to your first reaction
b. Evaluate the situation
c. React according to the plan
d. Eliminate any threat

Step 2: Listen and Find a Way to Agree or Acknowledge: Stay with Feelings

a. Listen actively.
b. Agree whenever possible.
c. Acknowledge emotions, needs, desires, competence and authority
d. Find their point
e. Talk, reflect, paraphrase.
f. Explore their position with them
g. Express views without provoking.

Step 3: Help the Person to Examine the Situation and Think Through It

a. Ignore and reframe attacks
b. Look for some reasonable alternative explanations
c. Ask open ended questions
d. Get advice from the person
e. Go from you and me, to we.

Step 4: Help the Person Generate Solutions and Resolve the Problem

a. Go slow
b. Take it step by step

c. Start from where the person *is* (not where you think they should be)
d. Make sure needs are met
e. Offer choices
f. Accept criticism

Step 5: Help the Person Understand Consequences and Take Personal Responsibility

a. Be realistic about limits
b. Help the person evaluate outcomes
c. Help them clean up the emotional and instrumental mess

Step 6: Put the Relationship Back Together

a. Forgive and forget
b. Re-establish the relationship
c. Be real about how you feel, but at the right time

Special note:

For individuals who experience movement differences, spending too much time discussing an incident can trigger further incidents because the person has difficulty inhibiting the response once he/she has thought about it. For these individuals, it is generally best to spend move on to other things. For additional information, see Donnellan and Leary, 1995 and Donnellan, Leary and Patterson Robledo, 2006).

some time with one another, a staff voiced concern. "I'm afraid that if I give Michael a coke whenever he bangs his head, then he will bang his head every time he wants attention."

Putting aside the possibility that Michael was banging his head for reasons other than coca-cola (e.g., a sinus infection, ear ache, seizures), let's imagine that the only reason that he banged his head was to get coca-cola and attention. In this case, the only question anyone should ask is, "Why does this poor guy have to go through so much trouble to get coca-cola and attention?" A more thoughtful approach would be to find ways to help Michael have coke more often and time to sit down with people he enjoys!

Most efforts to teach coping skills fail for three reasons:

1. We attempt to teach coping skills to the person during a crisis.
2. We do not include the person in planning.
3. We are not concrete enough.

Remember: You don't teach swimming lessons to a drowning man. Because a person in crisis has probably "downshifted", it is unlikely that he/she can hear information, let alone process it. Once a person has left their upper brain for their "fight-flight-or freeze" brain, it is largely about energy; what the person most needs to do is move the energy. What's probably missing for a person who moves from one crisis situation to the next is the capacity to engage in behaviors (coping skills) that help to diffuse the stress before it builds up. For this reason, it is necessary to practice and rehearse coping skills times of reduced stress, when threat is minimized, for a period of at least 3 weeks. . By doing so, you will help the person to "re-wire" their brain. With your assistance, the person will literally be creating new pathways in his/her neo-cortex that make it easier to avoid

strategy:
teach the person coping skills

The basic steps for teaching coping skills:

1. Teach coping skills during non-crisis times ("You don't give swimming lessons to a drowning man").

2. Make a list of things a person loves, things that bring joy, comfort. Build a book with the person in which each of these things is listed. Use words for people who can read, photos for people who do not read. Encourage the person to practice going to the book and choosing one of the items at least 5-10 times per day. Note: Items/activities that have a clear beginning, middle and end work best (e.g., preparing and drinking herbal tea, listening to a favorite CD).

3. At least three weeks after rehearsing step #2, make a second list of things that tell you the person is beginning to get stressed. Help the person to recognize these early signs by suggesting he/she go to the book and choose an item/activity that brings joy. Support the person each step of the way.

4. Congratulate the person on making better choices!

5. Give the person lots of opportunities to practice the new skill.

a full blown crisis (avoiding (b) in figure 3.3) .

Remember: Involve the individual in planning and be concrete. Caregiver efforts to teach coping skills also fail when the individual is left out of the process for deciding what to do. It is critical that the person play an active role in deciding what brings joy or relief from stress and that the steps for letting caregivers know what strategies the person would like to practice must be as concrete as possible (See Strategy: How to Teach Coping Skills, previous page).

Helpful Resource:

Aerobic exercise is one of the most effective treatments for depression and PTSD available. A helpful resource is Keith Johnsgard's 2004 book *Conquering Depression and Anxiety Through Exercise.* Available through Prometheus Books:

www.prometheusbooks.com

section 4.0: pay close attention to the person ’s health and well-being

Mark Durand has said, “People tend to get immature when they don’t feel well.” How often have you experienced a general decline in your mood or your ability to empathize with others when you did not feel well? When we are sick, we are not ourselves.

Many people who experience disabilities exhibit difficult behaviors because they do not feel well. The sudden appearance of behavior problems may be a signal that the person’s health is deteriorating. Illnesses as common as a cold or seasonal allergy can result in behaviors as inconsequential as grumpiness or as serious as head banging. Ruth Myers, MD, James Salbenblatt, MD, and Melodie Blacklidge, MD provide helpful examples of difficult behaviors and potential physiological or psychiatric causes (see tables 3.1 and 3.2).

is the person experiencing a physical illness?

1. *Are the person’s caregivers responsive to this illness or is the person expected to carry on as if nothing were wrong?*
2. *Is the person uncomfortable? For example, is she hot or cold? Is*

Table 4.1

Common "problem" behaviors and speculations about their causes

Ruth Ryan, MD, James Salbenblatt, MD, Melodie Blackridge, MD

"High pain tolerance"

- A lot of experience with pain.
- Fear of expressing opinion.
- Delerium
- Neuropathy (disease of the nerves)/ many causes

Fist jammed in mouth/down throat

- Gastroesophageal reflux
- Eruption of teeth
- Asthma
- Rumination
- Nausea

Biting side of hand/whole mouth

- Sinus problems
- Eustachian tube/ear problems
- Eruption of wisdom teeth
- Dental problems
- Paresthesias/painful sensation (e. g., pins and needles) in the hand

Biting thumb/objects with front teeth

- Sinus problems
- Ears/Eustachian tubes

Biting with back teeth

- Dental
- Otitis (ear)

Uneven seat

- Hip pain
- Genital discomfort
- Rectal discomfort

Odd un-pleasurable masturbation

- Prostatitis
- Urinary tract infection
- Candidal vagina
- Pinworms
- Repetition phenomena, PTSD

Waving head side to side

- Declining peripheral vision or reliance on peripheral vision

Walking on toes

- Arthritis in ankles, feet, hips or knees
- Tight heel cords

Intense rocking/preoccupied look

- Visceral pain
- Headache
- Depression

Won't sit

- Akathisia (inner feeling of restlessness)
- Back pain
- Rectal problem
- Anxiety disorder

Whipping head forward

- Atlantoaxial dislocation (dislocation between vertebrae in the neck)
- Dental problems

Left handed or fingertip handshake

- Frightening previous setting
- Pain in hands/arthritis

Sudden sitting down

- Altlantoaxial dislocation (dislocation

Table 4.2

Common "problem" behaviors and speculations about their causes

Ruth Ryan, MD, James Salbenblatt, MD, Melodie Blackridge, MD

between vertebrae in the neck)
- Cardiac problems
- Seizures
- Syncope/orthostasis (fainting or light-headedness caused by medication or other physical conditions)
- Vertigo
- Otitis (thrown off balance by problems in the ear)

Waving fingers in front of eyes

- Migraine
- Cataract
- Seizure
- Rubbing caused by blepharitis (inflamation of the eyelid) or corneal abrasion.

Pica

- General: OCD, hypothalamic problems, history of under-stimulating environments
- Cigarette butts: nicotine addiction, generalized anxiety disorder
- Glass: suicidality
- Paint chips: lead intoxication
- Sticks, rocks, other jagged objects: endogenous opiate addiction.
- Dirt: iron or other deficiency state
- Feces: PTSD, psychosis

General scratching

- Eczema
- Drug effects
- Liver/renal disorders
- Scabies

Self-restraint/binding

- Pain
- Tic or other movement disorder
- Seizures
- Severe sensory integration deficits
- PTSD
- Parasthesias

Scratching stomach

- Gastritis
- Ulcer
- Pancreatitis (also pulling at back)
- Porphyria (bile pigment that causes, among other things, skin disorders)
- Gall bladder disease

Scratching/hugging chest

- Asthma
- Pneumonia
- Gastroesophageal reflux
- Costochondritis/"slipped rib syndrome"
- Angina

Head banging

- Pain
- Depression
- Migraine
- Dental
- Seizure
- Otitis (ear ache)
- Mastoiditis (inflammation of bone behind the ear)
- Sinus problems
- Tinea capitis (fungal infection in the head).

Stretched forward

- Gastroesphageal reflux
- Hip/back pain
- Back pain

she experiencing constipation? Does she have a tooth ache?
3. *Is the person eating well?*
4. *Is the person getting a full night's sleep?*
5. *Does the person have a history of seizures that demand regular attention?*
6. *Are the person's medications carefully monitored? Is the person experiencing any negative side effects from these medicines?*
7. *Is the person hurting himself? If so, what part of the body is the person hurting? Is it possible that part of the body hurts?*
8. *Does the person have a good working relationship with a primary health care professional?*
9. *Has anyone taken the time to organize the person's medical information in an accessible and complete way?*

Consider these additional questions, offered by David McDonald or Oregon's Disability Activists Work Group (DAWG):

10. *Has the person had all of the recommended screenings for serious medical conditions (e.g. cancer)?*
11. *Does the organization employ a person who has enough medical background to know which tests should be conducted and how to interpret the results?*
12. *Has the person been denied important screenings because of a refusal by the funding source to cover it?*

Can you think of other questions? What are they? Make a list of questions and try to answer each one of them very carefully.

If the person is experiencing a physical illness and you need help understanding what the illness is and how to treat it, check out the Merck Manual Online, a helpful resource for medical conditions of all kinds.

In February 2002, Surgeon General David Satcher, MD released a scathing report about health care in America for people who experience developmental disabilities. The report can be downloaded by clicking here — *Closing the Gap.* An updated report by Surgeon General Richard Carmona, MD, can be downloaded by clicking here — *A Call To Action.*

does the person have a mental health diagnosis?

People who experience disabilities are no less likely to experience mental health issues as anyone else. In fact, in some cases, people may be *more* likely to experience a mental health diagnosis (e.g., depression) than most other people in the general population.

A mental health issue may be at the root of a person's difficult behaviors. Consider these questions adapted from the work of Stephan Schwarz, M.D. and Stephen Ruedrick, M.D. (1996):

1. *Is there a significant change in the person's behavior or mood which occurs in all settings rather than some settings?*
2. *Is there little or no improvement in the person's behavior despite the availability of consistent, high quality supports?*
3. *Has the person experienced a decreased ability to adapt to the demands of daily living (e.g., a deterioration in his ability to take care of himself)?*
4. *Has the person experienced decreased involvement with other people (by her choice)?*
5. *Has the person lost interest in formerly preferred activities?*
6. *Has the person shown some impairment in his or her perception of reality (e.g., is responding to internal voices, or shows beliefs which are obviously false)?*

Can you think of other questions? What are they? Make a list of questions and try to answer each one of them very carefully.

neuroleptic malignant syndrome

–

- A state of unresponsiveness caused by use of certain antipsychotic drugs.
- Develops in 3% of people treated with antipsychotics, usually within the first few weeks of treatment.
- Most common in men, who, because they are agitated, are given rapidly increased doses of the drugs or high doses initially.

- Symptoms:

  --Muscle rigidity
  –High temperature
  –Fast heart rate
  –Fast breathing rate
  –High blood pressure
  –Comma
  –Brown urine (myogloginuria; protein excreted in the urine; can cause kidney damage/failure)

- People must be treated immediately, usually in the intensive care unit.
- 30% of people die.
  –Fever is controlled with ice baths, wet towels, cooling blankets
  –Muscle relaxants are given
  –Sodium bicarbonate helps prevent myoglobulinaria by making the urine alkaline.

Check out the Network of Care and Supports for Behavioral Health and Mental Retardation Services web page for great links to various mental health sites.

Is the person experiencing Post Traumatic Stress Disorder?

I believe that a significant number of people who experience disabilities are experiencing PTSD. Ruth Ryan, M.D. (1994) estimates that 61% of the people with developmental disabilities living in a hospital setting met the criteria for PTSD.

According to Al Vechionne, Ph.D., traumatic events may include one or more of the following:

- Separation from primary relationships at an early age.
- Frequent moves from residential placements.
- Institutionalization.
- Physical abuse.
- Verbal abuse
- Neglect
- Degradation
- Loss of parent, sibling, or significant other
- Significant medical problems/procedures
- Extended hospitalizations

Additionally, in the hands of professionals, people may have been exposed to one or more of the following procedures:

- Time out
- Over correction
- Physical Restraint
- Facial screening
- Ammonia or other aversive substances

According to Legare, Ryan and Lewis Herman (1998), typical reasons for referral include:

1. Unexplained (inexplicable) bouts or episodes of anger;
2. Inexplicable episodes of screaming, throwing things, or destruction of property;
3. Out of proportion kinds of reactions to normal changes or stressors. (People who have an out of proportion reaction to a moderately stressful but not catastrophic situation may have had something worse happen to them in the past that is stirred up by the event);
4. Rage attacks;
5. Abrupt physical assault (often toward the people they like the most);
6. Being extremely afraid (terrified) at times of people they know and trust;
7. Calling someone they know by a different name;
8. Appearing unfocused or "not with it" (sometimes it is thought that people are having seizures);
9. Sometimes behaving like they are somewhere else;
10. Dissociative experiences; an inability to respond to people during these experiences.

Sound familiar?

If you suspect the person you are supporting is experiencing PTSD, it is very important to seek qualified help. You will need the support of a good psychiatrist who has an understanding of PTSD and the implications of PTSD for people with developmental disabilities. You may also wish to obtain a copy of my handout entitled, *Supporting a Person with Post Traumatic Stress Disorder* which can be downloaded from my website: www.dimagine.com. The handout contains information about the causes and symptoms of PTSD, strategies for supporting people with developmental disabilities who also experience PTSD, and other resources.

From Joan B. Beasley and Jeri Kroll of the Sovner Center:

four effects of an intellectual disability on the accurate diagnosis of mental illness

Renowned psychiatrist Robert D. Sovner helped us to understand that people who experience intellectual disabilities are as likely, if not more likely, to experience a mental health issue. At the same time, he cautioned against the over-diagnoses of mental health issues to explain people's emotional distress or "aberrant behavior.". In 1986, he outlined "four effects of mental retardation that affect diagnosis of mental illness, summarized here by clinicians Joan B. Beasley and Jeri Kroll of the Sovner Center in Danvers, Massachusetts (pp. 97-98):

Intellectual Distortion

Sovner (1986) refers to intellectual distortion as the inability of an individual with developmental disabilities to think abstractly and communicate verbally. Intellectual distortion undermines the results of a diagnostic interview because a person with developmental disabilities may be unable to respond to questions accurately...The inability to articulate internal abstract experiences, as well as the experience of concrete thinking, aphasia, limited vocabulary, and hearing deficits — all these greatly hamper a clinician's ability to use these tools effectively in diagnosing a specific disorder, especially because so much is weighted on the clinical interview.

Psychosocial Masking

Sovner (1986) uses the term *psychosocial masking* to describe the effects of developmental disabilities on the content of psychiatric symptoms. The limited knowledge of the world along with the limited life experience of an individual with mental retardation may restrict the detail, range, and richness of delusions and hallucinations they experience. This makes it difficult to determine whether or not someone with developmental disabilities is experiencing a "fear" or a "delusion."

Cognitive Disintegration

Sovner (1986) uses this term, *cognitive disintegration,* to describe the tendency for some individuals with developmental disabilities to become confused when experiencing serious emotional distress. Unrelated to a mental disorder, individuals with developmental disabilities are predisposed, by organic deficits and concrete coping skills, to become confused when under severe stress. At times, they may regress in their behavioral presentation, because they cannot express their needs.

Cognitive disintegration may foster a misdiagnosis of a mental disorder, because individuals may present chaotic thinking, assaultive behavior, and an inability to be in the presence of others, resulting in complete withdrawal. Individuals with mental retardation are often misdiagnosed as suffering from atypical psychosis or schizophrenia because they cannot cope with stress in more acceptable ways. When antipsychotic drugs are

Joan Beasley and Jeri Kroll *continued*-

prescribed under these circumstances, they may induce behaviors resulting in the further misdiagnosis of mental health symptoms.

Baseline Exaggeration

Baseline exaggeration is an increase in the severity of preexisting maladaptive behavior due to periods of stress. In a person with mental retardation, a diagnostician may overlook symptoms of a mental disorder, because the symptoms exist to a lesser degree at the person's baseline level of functioning. However, the increase in severity may very well be a symptom of a mental disorder.

As Sovner indicated, it is important to note that the diagnosis of a mental disorder cannot be based soley on the presence of aberrant or maladaptive behaviors. Although symptoms of mental illness are often manifested in maladaptive behaviors, a distinction exists between mental illness and behavior problems.

Skill Development and Behavior Problems

Behavioral problems or maladaptive behaviors can occur as a result of limitations in an individual's skill development without underlying psychopathology (i.e., symptoms of a mental illness). For example, physical discomfort in a nonverbal individual can result in aberrant behavior. In this case, the behavior is eliminated once the physical discomfort is resolved. In this example, the cause of aberrant behavior is unrelated to mental illness.

Excerpt from Joan B. Beasley and Jeri Kroll (2002). The START/Sovner center program in Massachusetts. In R. Hanson, N. A. Wiseler, K.C. Lakin (Eds). ***Crisis prevention and response in the community.*** **Washington, DC: AAMR**

section 5.0: actively support the person 's supporters

"A Person's Needs Are Best Met By People Whose Needs Are Met"—Jean Clarke

Imagine, for a moment, that there is nothing you can do right now to help the person. Imagine that there isn't *anything* that *anyone* can do to help the person feel better right now. Just for a moment, give up the need to figure out what's wrong.

Ask, What do you need to feel safe when the person is upset? What do you need so that you can go home tonight and not have that sinking feeling in your stomach? What do you need so that you can go home to be with your children and not worry?

- Do you need back up that shows up?
- Do you need to know that the people "on call" actually know the person (as opposed to strangers that come as a part of the agency's generic crisis team?
- Do you need to meet with the team tomorrow morning instead of this afternoon?
- What do you *really* need?
- A glass of wine?

Whatever you need, write it down. And ask your fellow team members what they need. Write that down.

You're now on your way to helping the person. You're taking care of your needs, and it's always true — "a person's needs are best by people whose needs are met."

get involved and stay involved

The first step in supporting a person's supporters seems too obvious to state: *spend time with them!* Many professionals act aloof or distant from a person's friends , family members, and primary caregivers. Some believe they should stay distant in order to maintain objectivity (a rare achievement). Objectivity can be helpful, of course, particularly in situations where there is a lot of stress and complexity. But for some, "objectivity" is really an excuse for remaining "uninvolved." Without taking the time to connect with the individuals involved, one might lack a *real* understanding of what people are feeling and what 's needed.

build support for the person's supporters

Many of our school and human service delivery systems are based on the idea that a few people with greater knowledge and power should bestow care and skills to a larger number of people with lesser knowledge and power. "Success" is based on compliance or obedience. A person who engages in difficult behaviors presents a real threat to a care-giver or teacher whose competence is being judged by this "compliance/ obedience" yardstick. The care giver/teacher often expends great energy trying to suppress the person's behavior in order to maintain "competence" (in many of our workplaces it is acceptable to share knowledge but not to share power).

Punishment or the fear of punishment (coercion) may be the primary means of "motivating" staff. Many approach each day with a mixture of fear and dread. If they make a mistake, they could be "written up," demoted or fired. If they try something new, it may violate a policy or procedure. The unspoken message is "stay the course" or suffer the consequences.

It is in this context that human services workers are "told" to be supportive. Workers are trained in positive approaches when the underlying organizational message is "maintain obedience." Under the deadening weight of these systems, even the kindest and most respectful of care givers may begin to exhibit their own difficult behaviors. They become excessively controlling and resistant to change. They begin to believe that individuals are worthy of their labels and "beyond hope." They may even resort to forms of punishment procedures that the average citizen would find repulsive and unacceptable.

spend time in everyday routines

I find it helpful to spend time with a person's supporters in their routines. As Yogi Bera once said, "You can see a lot by looking." Often, the most important information to be learned in a situation is learned by *being there.*

You might ask a person's primary caregivers if you can help them in their work routines when they are resistant to change. There is a good chance they are feeling under-supported, or perhaps frightened that they will not know what to do when the person is having a difficult time. The important point is to get to know people and let them get to know you.

Consider asking the person's supporters these questions (adapted from the work of John O'Brien, Jack Pierpoint, and Marsha Forest):

1. *What do you consider to be the person's most*

Laurie Ann Pearlman, Ph.D. and Karen W. Saakvitne

vicarious traumatization

what is it?

> "Vicarious traumatization refers to a transformation in the therapist's inner experience resulting from empathic exposure to clients' trauma material. That is, through hearing clients' personal accounts of traumatic interpersonal experiences in the context of a therapeutic interpersonal relationship, the therapist is vulnerable through his or her empathic openness to the emotional and spiritual effects of vicarious traumatization. These effects are cumulative and permanent, and evident in both a therapist's professional and personal life."

what are the effects?

> "By definition the effects of vicarious traumatization resemble the effects of traumatic experiences upon an individual ..."These [effects] include shifts in the therapist's identity and world view; ability to manage feelings, to maintain a positive sense of self and connection to others; and spirituality or sense of meaning, expectation, awareness, and relationship; as well as alterations or disruptions in basic needs for and schemas about safety, esteem, trust and dependency, control, and intimacy. In addition, the therapist is vulnerable to intrusive imagery and other post-traumatic stress symptomatology as s/he struggles to integrate trauma material and these profound personal changes.

what helps?

> **Personal Strategies**: (1). Maintain a personal life; (2) Use personal psychotherapy; (3) Identify healing activities; (4) Tend to your own spiritual needs.
>
> **Professional Strategies:** (1) Arrange supervision; (2) Develop professional connection; (3) Develop a balanced work life; (4) Remain aware of your goals.
>
> **Organizational Strategies:** (1) Attend to the physical setting; (2) Arrange for adequate resources; (3) Create an atmosphere of respect; (4) Develop adjunctive services

Source: Pealrlman, L.A. & Saakvitne, K.W. (1995). Treating therapists with vicarious traumatization and secondary traumatic stress disorders. In C. Figley (Ed.)., ***Compassion fatigue: Coping with secondary traumatic stress disorder in those who treat the traumatized.*** **New York: Brunner/Mazel.**

vicarious traumatization

finding support

1. In my organization, who can provide information, advice, help or support? (Example: administrator, mentor, employee assistance program, ombudsman)

   Who Kind of help

2. Among my colleagues, how can I get information, advice, help, or support? (Examples: trainings, staff support groups, case supervision and consultation).

   Who Kind of help

3. In my personal life, who can give me information, advice, help, or support? (Examples: family, friends, church, community organizations).

   Who Kind of help

Source: Pealrlman (2005). Training guide: Vicarious traumatization. Nevada City: Cavalcade Productions, Inc. To purchase a copy of the DVD and training guide, call 800-345-5530.

difficult behaviors? Does the person agree? If not, why do you think there is a disagreement?
2. *What are you doing well right now?*
3. *Are there aspects of the person's current support plan that are not working? If so, what?*
4. *Are there things that you could be doing differently in the next 24 hours?*
5. *Are there things you could be doing differently in the next 6 weeks?*
6. *What do you need? Who can support you best?*

Do the person's supporters feel safe?

When a person engages in dangerous and even life-threatening behaviors her supporters need special support. It is frightening to be with someone who engages in eye gouging or someone who is aggressive. In these circumstances, a person's supporters need specific action plans that help them to foresee a crisis and fend it off, or to create safety when a crisis is full blown. People also need to discharge their feelings over and over again. In all probability, caregivers will feel angry and/or frightened when the person exhibits serious behaviors. It is important for them to have the opportunity to express these feelings openly and constructively (generally, for obvious reasons, this can be done most constructively when the person is not present, especially when the feelings are negatively charged). It is more important to act upon staff needs once they have been expressed; a constructive way to prevent future crisis situations and deal more positively should be the primary objective.

Ask, "Is there a crisis plan in place? Does the plan clearly describe the behavior (s) of concern and describe exactly what people should do in an emergency? Do people feel comfortable with the plan? Do people feel safe? What can you do to assure the plan is implemented correctly? You may wish to use the checklist on the following two pages, adapted from the Vermont Positive Behavior Support Guidelines, as a tool for assessing the effectiveness of the crisis plan.

a role in decision making

Support for staff also includes steps to assure they have an active role in decision making. In all too many human service organizations, the people providing day-to-day support have little or no input into the decision-making process; they are struggling to listen deeply to the individual because they are not heard. Some organizations employ outdated management practices that rely on fear as a way to motivate staff. The result is diminished creativity, innovation, and commitment. High turnover is often assumed to result from "the nature of the work" (a highly insulting thing to say about people who experience disabilities), or inadequate wages. I think the number one cause of high turnover is that we are not involving people in the decision-making process and we are not treating them with due respect (for additional help in developing a workplace culture, see my paper *Toolbox for Change* available online at my web site: www.dimagine.com).

helpful resource

Laurie Anne Pearlman and Karen Saakvitne's DVD: *Vicarious traumatization.* Available from Cavalcade Productions, Inc. PO Box 2480, Nevada City, CA 95959. To purchase a copy of the DVD and training guide, call 800-345-5530.

A Crisis Support Plan Checklist* (Part One)

The crisis support plan includes:		Do people feel safe when the person is having a difficult time? If not, what can be done to help people to feel comfortable even on the most difficult of days?
____Summary of who the person is as a person. ____Summary of what the person likes and what makes life worth living. ____Summary of the crisis behavior(s) and a rationale for needing a plan. ____Probation/parole status. ____Guardianship status. ____Summary of court ordered restrictions. ____Summary of supervision and lead agency's responsibility for community safety ____Personal risk factors (e.g., alcohol, drugs, impulsivity) ____a description of each behavior of concern, written in clear, observable terms	____a description of conditions/circumstances associated with high levels of the behavior and strategies for re-direction; ____specific steps for intervening when the behavior(s) occur to assure safety for the individual and others; ____a description of stabilizing factors which reduce risk; ____a description of various treatments and therapies and goals; ____a description of restrictions for community safety and individual safety; ____should restraints of any kind be in use, the plan includes a specific protocol for use and a plan for their elimination; ____specific steps to support staff ____a process for monitoring the overall progress.	Be specific. What supports will help people to feel safe?

***Adapted from:** State of Vermont (2004) *Behavior support guidelines: For support workers paid with developmental services funds.* Waterbury, VT: Division of Disability and Aging Services, Department of Disabilities, Aging and Independent Living. The entire document is available on my web site (www.dimagine.com). Click on Links and Other Resources—Policy—Behavior Support Guidelines.

A Crisis Support Plan Checklist* (Part Two)

Are there concerns that the plan, no matter how well laid out, may not be implemented correctly? What can you do to make sure the plan is implemented with fidelity?	NOTES
Be specific. What will <u>you</u> do?	

***Adapted from:** State of Vermont (2004) *Behavior support guidelines: For support workers paid with developmental services funds.* Waterbury, VT: Division of Disability and Aging Services, Department of Disabilities, Aging and Independent Living. The entire document is available on my web site (www.dimagine.com). Click on Links and Other Resources—Policy—Behavior Support Guidelines.

section 6.0: determine the meaning of the person ’s difficult behaviors

difficult behaviors as “messages”

Difficult behaviors are “messages” which can tell us important things about a person and the quality of his life. In the most basic terms: *difficult behaviors result from unmet needs.* The very presence of a difficult behavior can be a signal that something important that the person needs is missing.

For example, Walter hits his ears with his fists. His job coach wants Walter to stop this behavior and has threatened to have Walter fired unless he stops. Weeks later, at a scheduled Doctor’s appointment, it is learned that Walter has a low-grade ear infection. She treats Walter’s infection and he stops hitting his ears.

Obviously, there are many needs that a person might be conveying with his or her behavior. A single behavior can “mean” many things. The important point is that difficult behaviors do not occur without reason; all of our behavior is -- intentionally or unintentionally -- communicating something important. All behavior, even if it is self-destructive, is “meaning-full.”

get to know the person

The first step in finding out what a person needs seems almost too obvious to state: *spend time with the person!* Sadly, it is too often the case that people who develop plans or interventions do not know the person well. They know the person as the sum total of her labels, but know little about the person as a human being.

Make a point of spending time with the person in places that she enjoys, during times of the day that she chooses. It could be in a quiet room, or in a nearby park. It could be shopping or volunteering time together at a local food bank. The important point is to find a way to spend time with one another so that a relationship, based upon a *mutual understanding* of each other, can form.

Ask the person to tell you something about her life. What is her story? Who are her people? Find out what she is good at and what she enjoys doing for fun. Find out something about her dreams. Tell her something of your story. Tell her of your people, your talents, your joy. Let her know at least one of your dreams.

Even if you suspect the person has a difficult time understanding words, speak to her as if she can understand most of what you are saying. It never ceases to amaze me how many people really do understand what others are saying when it has been assumed, historically, that they cannot understand.

ask the person if it's ok to talk about the problem

When you find a comfortable time to discuss the individual's difficult behavior(s), you might consider these questions suggested by Mayer Shevin :

1. *What's going well?*
2. *What's not going well?*
3. *What do other people think is the problem?*
4. *Do you agree/disagree?*
5. *What has helped in the past?*
6. *What has not helped?*
7. *Whom do you want help from?*
8. *What do you want to learn to do?*

You might ask the person if you could speak with friends, family and caregivers. She may not want you to "snoop around," and by all means honor her wishes. She may smile to let you know it's OK, or she may shake her head "No!" to let you know you're being too nosy. The point is, even if you suspect she doesn't understand your words, it's worth giving her feelings the benefit of the doubt. An honest attempt to honor the person's opinion is often the first step towards establishing a relationship based on healing.

remember grandma's law

It is important to describe the behavior in terms that your grandmother can easily understand; that is, the behavior should be written in everyday language that the dear woman could recognize. Avoid terms like "tantrum," or "aggression," or "self-injurious behavior," or "self-stimulatory behavior." Instead, describe what the person does (e.g., "hits the window," "slaps people," "bites his arm," or "rocks back and forth").

insert the word 'need' into all questions of 'why'

People frequently ask me questions like, "Why does she slap herself?" or "Why does he run away?" As mentioned above, difficult behaviors result from unmet needs. It can be helpful to insert the word *need* into questions of *why*. For example, instead of "Why does

she slap herself?" ask, "Why does she *need* to slap herself?" or, instead of, "Why does he run away?" ask, "Why does he *need* to run away?"

what is the history of the problem?

Knowing when the person began to engage in the difficult behavior is a critical question. There is much to learn from identifying times when the behavior was not a problem and if life events are associated with the emergence of the problem. Life events can include the loss of a relative or favorite staff, the onset of a health problem, a change in the person's place of residence or routine, etc. (see figure 6.1 and 6.2 and worksheet 6.1)

are there times during the day/ week when the behavior is <u>most likely</u> to occur?

If so, ask, "What's happening? Is the person with people who she cares about? How do these people treat the person? Is the person doing things that she enjoys? Why do you think the person finds it enjoyable? Is the person being left alone? If so, why do you think that being left alone is helpful to the person?" Can you think of other questions? What are they? (worksheet 6.2 and 6.3)

are there times during the day/ week when the behavior is least likely to occur?

If so, ask, "What's happening? Is the person with people who he does not care for? How do these people treat the person? Is the person doing things that he does not enjoy? Why do you think the person does not enjoy doing these things? Is the person being left alone? If so, why do you think the person is unhappy about being left alone?" Can you think of other questions? What are they? (worksheet 6.2 and 6.3)

build a support plan based on what you believe the person <u>needs</u>

Instead of a behavior plan designed to "fix" the person, develop a plan to <u>support</u> the person. Consider this simple, but elegant way of putting together the information you have learned, adapted from the work of Michael Smull and Susie Harrison (see worksheet 6.4).

When this is happening _____
[describe what is going on when the person begins to exhibit difficult behaviors];
And the person does this _____
[describe the behavior so that your grandmother could understand it];
We think it means this
_____[describe the "message" the person may be conveying with his or her behavior];
And we should
_____[describe what you will do to be supportive].

additional information

For additional information on conducting a functional assessment, see the Vermont Division of Aging and Disability recommendations in the Section 8 (Policy Document 8.3).

figure 6.1

Was there a time when the person exhibited significantly fewer difficult behaviors than now?

Using even intervals (e.g., days, weeks, months, years), use the timeline below to indicate the last time you remember the person do-

The last time we remember that things were good (date):

Today's Date:

_____

figure 6.2

Ask, "What happened next?"

Was there a change in important relationships?
Did someone important to the person leave?
Did someone new arrive?

Was there a change in the person's health status or emotional well-being?
Has there been a change in the person's health status?
Has the person experienced any unusual trauma?

Did joy leave the person's life?
Has the person stopped doing something that he or she loves?

Was there a change in the person's power and control?
Has there been a change in the person's control over day to day events?

Was there a change in the person's capacity to contribute to others?
Has there been a change in the person's status?

Has the person lost important skills or do new circumstances require different?
Has the person lost skills? Are new skills needed?

Possible Sources:

Interviews with the person.

Interviews with people who know the person well.

A review of the person's records

Worksheet 6.1

After reviewing the history of the person's behavior….

What did you find?	Based on what you have found after examining the history of the behavior, are there ways that you 'can be more supportive in your day-to-day interactions with the	Are there changes that can be made to the person's schedule based on what you have found?
Be specific.	Be specific. What will you do.	Be specific. What will you do.

Are there times during the day or week when the three behaviors are likely to occur?

- Spend a week observing the person and make notations on the sheet that follows of when the behavior occurs.
- Make a notation for each behavior in a box that corresponds to a time/day when the behavior is likely to occur, using one of the three symbols (triangle, box, circle) from page 19.
- After a week, do you notice a pattern? Do some shapes show up time and time again? Do two or all three of the shapes cluster together?
- Where was the person?
- Who was present?
- What was happening just before the behavior occurred?
- Was there a specific activity going on that the person did not feel comfortable doing?
- Was something said to the person?
- Was the person feeling well?
- How did people respond? What happened next?
- Is it possible the person was trying to communicate something? If so, what do you think they were trying to communicate?

Are there times during the day or week when the three behaviors are unlikely to occur?

- Note the times during the day/week without notations (triangle, box, circle).
- Do you notice a pattern?
- Where was the person?
- Who was present?
- Is the activity a favored activity? Is the person with favorite people?

Worksheet: 6.3

After examining the person's daily/weekly schedule….

What did you find?	Based on what you found after examining the person's daily/ weekly schedule, are there changes that can be made that will be helpful?	Are there ways that you 'can be more supportive in your day-to-day interactions with the person based on what you have found?
Be specific.	Be specific. What changes can be make to the schedule?	Be specific. What will <u>you</u> do?

worksheet 6.4

How <u>we</u> will support the person

When this is happening...	And the person does this...	We think it means this...	And we should….

Adapted from the work of Michael Smull and Susie Harrison, The Learning Community for Person-Centered Practices (www.learningcommunity.us).

section 7.0: tips for listening and

It is critically important that anyone who gets involved with the person understand that his/her input is critical to the long-term success of the plan. It is also important that close family, friends, and caregivers, be actively involved (with the person's permission). Once information has been gathered, each of us has an important obligation to communicate our findings and ideas in a way that are respectful of the person and the members of the team. No matter how well credentialed , it is important we be mindful of each other's values, unique perspectives, and capacity to assimilate information. Every effort should be made to communicate recommendations in ways that are clear (e. g., jargon free) and understandable (e.g., through graphic representation). This section also includes information from Peter Senge, et al (1995) on how to listen in meetings.

9 Tips for Listening During A Meeting

1. Stop talking. To others and yourself. Learn to still the voice within. You can't listen if you are talking.

2. Imagine the other person's viewpoint. Picture yourself in her position, doing her work, facing her problems, using her language, and having her values. If the other person is younger or more junior, remember your early days in the organization.

3. Look, act, and be interested. Don't read your mail, doodle, shuffle, or tap papers while others are talking.

4. Observe nonverbal behavior, like body language, to glean meanings beyond what is said.

5. Don't interrupt. Sit still past your tolerance level.

6. Listen between the lines for implicit meanings as well as explicit ones. Consider connotations as well as denotations. Note figures of speech. Instead of accepting a person's remarks as the whole story, look for omissions -- things left unsaid or unexplained, which should be logically present. Ask about these.

7. Speak only affirmatively while listening. Resist the temptation to jump in with an evaluative, critical, or disparaging comment at a moment a remark is uttered. Confine yourself to constructive replies until the context has shifted, and criticism can be offered without blame.

8. To ensure understanding, rephrase what the other person has just told you at key points in the conversation. Yes, I know this is the old "active listening" technique, but it works -- and how often do you do it?

9. Stop talking. This is first and last, because all other techniques of listening depend on it. Take a vow of silence once in a while."

Senge, P. et al. (1995) *The fifth discipline field book: Strategies and tools for building a learning organization* (p. 391). New York: Doubleday
Artist: Helen Cordero. Cochiti, Male storyteller (4 children). From Douglas Congdon-Martin (1999): *Sorytellers and Other Figurative Pottery*. Atglen, PA: Schiffer Books

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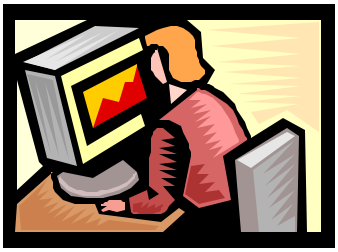
section 8.0: policy documents



This section (still under construction) contains excerpts from a variety of policy documents related to crisis support. You access and download the complete policies through my web site: www.dimagine.com. Click on Links and Other Resources, scroll down to Policy Links.

Policy Document 8.1

Commonwealth of Pennsylvania Department of Public Welfare

the use of restraints

reducing restraints and restrictive procedures

"Restraint is not treatment or a substitute for treatment. The use of restraints for punititve purposes, discipline, staff convenience, retaliation, or coercion is considered abuse. Each provider is asked to pursue alternative strategies to the use of restraint. For example, physical restraints are used only as a last resort safety measure when there is a threat to the health and safety of the individual or others, and only when less intrusive measure such as redirection, reflective listening, and other positive practices are ineffective in each situation. In the event that a restraint is used, this should be recognized as trauma to the individual. The restraint has the potential to affect an individual's short and long term mental health, manifest behaviors, affect the relationships they have with staff, and alter their overall care and needs. Recognition that past incidents of restraint should also be viewed as is essential in eliminating the need for restraint. In order to support this goal OMR recommends that the following measures be implemented as part of all behavior support plans:

- *Seclusion is not used.* Seclusion is defined as placing an individual in a locked room. A locked room includes a room with any type of engaged locking device, such as a key lock, spring lock, bolt lock, foot pressure lock or physically holding the door shut.

- *Chemical restraint is not used.* Chemical restraint is a drug used to control acute, episodic behavior that restricts the movement or function of an individual and is not a standard treatment for the individual's medical or psychiatric diagnosis.

- When a physician orders a medication that is part of the ongoing individualized plan and has documented as such for treating the symptoms of mental illness, the medication is not considered a chemical restraint.

- The use of Pro Re Nata (PRN) medication will be done in accordance with procedures outlined in MR Bulletin 00-02-09 entitled *"Pro Re Nata Medication Usage for Psychiatric Treatment—Clarification of Interpretation."* When utilized, it shall include a post review protocol by the provider's quality improvement/ risk management committee to ensure that use of the medication was consistent with the Bulletin's expectations.

- *Mechanical restraint is not used.* Mechanical restraint is a device used to control acute, episodic behavior that restricts the movement or function of an individual or portion of an individual's body. Examples of mechanical restraints include anklets, wristlets, camisoles, helmets with fasteners, muffs and mitts with fasteners, poseys, waist straps, head straps, restraining sheets and similar devices.

- When a physician orders a mechanical device to protect the individual from possible harm following surgery or an injury, it is not a mechanical restraint.

Source: Excerpted from the Pennsylvania Mental Retardation Bulletin entitled, *Elimination of Restraints Through Positive Practices"* available at the Office of Mental Retardation Web site: http://www.dpw.state.pa.us/General/Bulletins/003673169.aspx?BulletinId=1408

Commonwealth of Pennsylvania Department of Public Welfare
bulletin on the use of restraints *continued* -

Examples of mechanical devices that are not restraints include a device used to provide support for functional body position or proper balance and a device used for medical treatment, such as sand bags to limit movement after medical treatment, a wheelchair belt that is used for body positioning and support or a helmet for prevention of injury during seizure activity, are not considered mechanical restraints.

- Manual restraints, also commonly referred to as physical restraints, are used only as a last resort safety measure when the individual is in imminent danger of harming oneself and/or others and other measures are ineffective. Manual restraint is currently defined per 55 PA Code 6500.172, 6400.202, 2308.161 as a hands-on technique that lasts more than 30 seconds. When a hands-on technique occuriring for less than 30 seconds is used to guide or redirec t the individual away from potential harm/injury, it is not a physical restraint.

- Certain manual restraints or specific techniques are considered especially problematic and known to increase the risk of injury and death. Given the potential danger and liability related to these actions OMR recommends that the following be implemented:

- Prone (face down) manual (physical) restraint is not used.

- No manual restraint that inhibits the respiratory and/or digestive system is used.

- No manual restraint that involves compliance through the infliction of pain, hyperextension of joints, and pressure on the chest or joints is used.

- No use of 'takedown' techniques in which the individual is not supported and/or that allows for free fall as the individual goes to the floor.

- An individual's physical condition is evaluated throughout the restraint in order to minimize the potential of individual harm or injury.

- Manual (physical) restraint does not exceed 30 minutes within a two-hour time period, per 55 PA Code 6500.172, 6400.202, 2380.161 part (d)

- An individual is immediately released from physical restraint when they no longer present a danger to self or others.

- Support staff monitor the individual for signs of distress throughout the restraint process and for a long period of time (up to two hours) following the application of a restraint.

Source: Excerpted from the Pennsylvania Mental Retardation Bulletin entitled, *Elimination of Restraints Through Positive Practices"* available at the Office of Mental Retardation Web site: http://www.dpw.state.pa.us/General/Bulletins/003673169.aspx?BulletinId=1408

Policy Document 8.2

Vermont Division of Disability and Aging Services

community safety plan

sample outline for use with offenders

Date plan was developed.
Summary of who the person is as a person.
Summary of what the person likes, what makes life worth living.
Summary of offenses and dangerous behavior/rationale for needing a plan (when it happened, info source such as police affidavit or SRS report, victim age, gender, relationship, circumstances when offense occurred, location, duration and frequency of offenses, consequences of being caught , criminal conviction, change of placement).
Probation/parole status.
Guardianship status.
Summary of court ordered restrictions (if offender is not supposed to have contact with a specific person, name the person).
Level of supervision and level of agency's responsibility for community safety.
Assessment information.
Personal risk factors (alcohol, drugs, impulsivity, etc.).
High risk situations.
Target populations.
Other problematic behaviors which are not criminal offenses.
Stabilizing factors which reduce risk.
Intervention/treatment information.
Group therapy, treatment goals and techniques.
Individual therapy, treatment goals and techniques.
MH/Psychiatrist/Chemotherapy, treatment goals and techniques.
Interactional guidelines for direct support workers (how should people structure their interactions and reactions in a non-punitive fashion, how to be friendly but maintain boundaries, etc.; how to have a successful shift/day with the person).
Contracting for safety.
Risk plans.
Teaching emotional regulation skills.
Other coping skills, relapse prevention, social competence.
Restrictions of Rights for community safety or the person's safety:

a. Home location
b. Vocational settings
c. Community activity settings
d. Curfew
e. Alarms, monitors
f. Room searches

Source: State of Vermont (2004). Behavior support guidelines: For support workers paid with developmental services funds. Waterbury, VT: Division of Disability and Aging Services, Department of Disabilities, Aging and Independent Living. The entire document is available on my web site (www.dimagine.com). Click on Links and Other Resources—Policy—Behavior Support Guidelines.

g. Personal searches
h. Eye contact
i. Body contact
j. Intimate relationships
k. Phone use
l. Mail
m. Contact with family

Travel Restrictions
Media Restrictions

a. Pornography
b. Music
c. Video Games
d. Internet Access
e. TV

Other Restrictions

a. Contact with victim
b. Alcohol
c. Driving
d. Riding a bus
e. Possession of/access to wheeled vehicles (bike, four wheeler, snowmobile)
f. Animals
g. Binoculars/telescopes
h. Cameras
i. Walkie talkies

Crisis or Re-Offense protocol (how to respond)
Data collection procedures and responsibility
Review process
Required Signatures

a. Individual and date individual signed
b. Guardian (if there is one) and date guardian signed
c. QDDP and date QDDP signed

Source: State of Vermont (2004). Behavior support guidelines: For support workers paid with developmental services funds. Waterbury, VT: Division of Disability and Aging Services, Department of Disabilities, Aging and Independent Living. The entire document is available on my web site (www.dimagine.com). Click on Links and Other Resources—Policy—Behavior Support Guidelines.

Policy Document 8.3

Vermont Division of Disability and Aging Services

instructions for conducting a functional assessment

A comprehensive functional assessment must be conducted by or under the supervision of a person with training and skill in behavior analysis and positive behavioral supports. It must be based on direct observation of the individual, interviews with the individual and significant others, including family members where possible, caregivers and team members, and review of available information such as assessment reports and incident reports.

A comprehensive functional assessment includes:

a. A review of records for psychological, health and medical factors which may influence behaviors (e.g., medication levels, sleep, health, diet, psychological and neurological factors);
b. An assessment of the person's likes and dislikes (events/activities/objects/people);
c. Interviews with individual, caregivers and team members for their hypotheses regarding the causes of the behavior;
d. A systematic observation of the occurrences of the identified behavior for an accurate definition and description of the frequency, duration and intensity;
e. A review of the history of the behavior and previous interventions, if available;
f. A systematic observation and analysis of the events that immediately precede each instance of the identified behavior;
g. A systematic observation and analysis of the consequences following the identified behavior;
h. Analysis of functions that these behaviors serve for the person;
i. Get/obtain: interaction, reaction, desired activity, self-stimulation, other;
j. Escape/avoid/protest: an emotional state, demand/request, activity, person, other;
k. An analysis of the settings in which the behavior occurs most/least frequently. Factors to consider include the physical setting, the activities occurring and available, degree of participation and interest, the nature of teaching, the schedule, routinees, the interactions between the individual and others, degree of choice and control, the amount and quality of social interaction, etc.

Synthesis and formulation: All the above information should be gathered and reviewed as part of the functional assessments to formulate a hypothesis regarding the underlying causes and/or function of the target behavior. (It is recognized that not all behavior has a "purpose," and also that we cannot always determine the purpose of cause of behavior). The hypothesis should lead logically to the development of the plan.

Source: State of Vermont (2004). Behavior support guidelines: For support workers paid with developmental services funds. Waterbury, VT: Division of Disability and Aging Services, Department of Disabilities, Aging and Independent Living. The entire document is available on my web site (www.dimagine.com). Click on Links and Other Resources—Policy—Behavior Support Guidelines.

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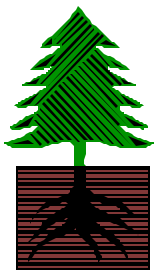

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