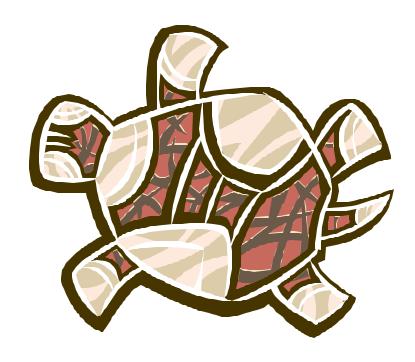
All behavior is Meaning-full Supporting a Person With Difficult Behaviors/Supporting the People Who Care



David Pitonyak, Ph.D.

DRAFT

imagine

David Pitonyak, Ph.D. 3694 Mt. Tabor Road Blacksburg, VA 24060

540-552-5629 VOICE 540-552-1734 FAX

For additional information, visit the imagine web site:

www.dimagine.com

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Part One Introduction

Key concepts:

Difficult behaviors result from unmet needs.

A person's needs are best met by people whose needs are met.

Difficult behaviors are almost always political.

Stop trying to fix the person and/or the person's supporters. Offer your help.

Taking care of yourself is one of the most important things you can do if you want to help someone else.

Difficult behaviors result from unmet needs

My practice is based upon a simple idea: difficult behaviors result from unmet needs. In a sense, difficult behaviors are messages which can tell us important things about the person and the quality of his or her life. In my experience, people with difficult behaviors are often missing:

- Meaningful relationships
- A sense of safety and well-being
- Power
- Things to look forward to
- A sense of value and self-worth
- Relevant skills and knowledge

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

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

Supporting a person 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 the person is living is disrespectful and counterproductive. In summary, 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.

A person's needs are best met by people whose needs are met

Our best efforts to support someone will fall to pieces if the people who are asked to provide the support are not supported. Whether you are a friend, a parent, or a paid caregiver, 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 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 challenging 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 caregivers 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 is difficult when your own needs are being ignored. It is a central contention of this paper that many human services workers are under-supported; some contend every day with fear-provoking management practices that discourage and even destroy their goodness. When people do not feel supported, when they feel afraid, they have a difficult time being supportive. 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."

Difficult behaviors are almost always political

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 dull routines (e.g., completing paperwork), feel ignored by the organization's managers. One expressed it quite clearly, "Michael is banging his head because he is bored and he feels like we don't listen. Staff want to

bang our heads for the same reason."

It's true. Michael is rarely asked what he would like to do, and when he does things "right" hardly anyone notices. Staff are rarely asked for their input and, like Michael, they rarely receive support for their efforts. Much of the paperwork that they complete each day is as meaningless as the packages that Michael packs and unpacks for hours and hours. It is not uncommon to hear staff make sarcastic remarks about their jobs and their managers, or to mutter hopelessly, "a pat on the back every now and then would be nice."

In one meeting, staff described Michael's head banging as a clear "message" that he is bored, angry and in need of change. Their supervisors, facing extreme pressures and a lack of support for *their* efforts, responded by insisting that Michael continue with his "program." They referred him to the Agency Psychiatrist who prescribed a medication for his "explosive disorder."

In short, instead of seeing that Michael *had* a problem, the organization's leadership decided that Michael *was* the problem.

If and when it becomes apparent to an organization's leadership that problem behaviors may be symptomatic of larger issues, they must ask, with unblinking honesty, "How can we be truly helpful, not only to the people who receive services, but also to the people who deliver them.

Stop trying to fix the person and the person's supporters

Connie Lyle O'Brien, John O'Brien, and Beth Mount (1998) point out that a significant shift is taking place in the field of human services. Historically, the questions that we have asked are:

- What's wrong with you?
- How do we fix you?
- What do we do with you if we can't fix you?

The field is now moving toward a much more promising set of questions that seek a deeper understanding of the person:

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

I would add these questions:

- What are the capacities and gifts of the person's supporters and what do they need to express them?
- What helps the person's supporters to sustain their support and what does not?
- What are the visions and dreams of a person's supporters and who will help them to move towards that future?

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 caregivers. The challenge is and always will be to build support for the person and the people who care.

If you're too tired to read one more word (and the people providing support usually are), I encourage you to get some rest. Before you sleep, I will leave you with these four simple ideas:

- Challenging behaviors result from unmet needs.
- Finding out what a person needs is the first step in helping the person, and the person's supporters, to change.
- Attempts to "fix" the person may be 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 can't take care of yourself, it will be very difficult to care about someone else.



Part Two

Getting to Know the Person and His/Her Supporters

Key concepts:

Knowing the person is critical if you are going to help in a meaningful way. Knowing the person's supporters is equally important.

Sometimes professionals over-complicate things. Forming a meaningful relationship with someone is pretty straightforward.

It is critical that you keep your promises and ask the person for permission to help.

It is OK to "get close" to the person.



Molly's Rules

- 1. He looked at me when he was talking with me.
- 2. He made me laugh.
- 3. He talked to me about things that are interesting.
- 4. Sometimes he just smiled and listened.

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.

Remember Molly's Rules

Professionals have a habit of making things overly-complicated. Starting a relationship with a person can be pretty simple. When my friend Dennis and Mary Jane's daughter Molly was 9 years old, she told her mother and father that she enjoyed meeting their friend Al at a party. When they asked her why she liked him, she offered four ideas that seem pretty sensible for anyone who is hoping to establish a relationship with someone else:

- 1. He looked at me when he was talking with me.
- 2. He made me laugh.
- 3. He talked to me about things that are interesting.
- 4. Sometimes he just smiled and listened.

I would add one more: keep your promises.

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 is much more complex. The funding streams which pay for the group home will not pay for an apartment. In the *real* world, Carl lives in the group setting because people are unwilling to deal with the "politics" the organization, 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.

Ask the person if it's OK to talk about the problem

If and 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.

Get to know the person's supporters

The first step in supporting a person's supporters also 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 an effort to stay uninvolved in a situation can also have a serious downside. 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.

For example, Katie, who does not speak, was refusing to get on the school bus each morning. Her mother was perplexed and growing more frustrated with each and every passing day. The school psychologist told Katie's mom that Katie was resisting the bus ride because she wanted "attention." Katie's after-school aid was skeptical about this hypothesis and she asked Katie and her mom if she could visit the house over several mornings. They agreed. There seemed to be

little out of the ordinary about the morning. It was a busy household, but Katie seemed ready and eager to start her day. The aide told Katie that she would ride the bus with her to see if there was trouble on the bus. but the rides seemed pleasant and uneventful. Where she did notice trouble was in the school yard. A young boy teased Katie in a way that Katie did not enjoy. He even pushed her to the ground on one occasion and launched her back pack into the swings. Instantly, the after-school aide could see the source of Katie's hesitation about the bus — fear. After a brief consultation with teachers from the school, the boy was told that his behavior was unacceptable. He later apologized to Katie (he was actually quite nice about it), and Katie seemed relieved. She gradually warmed up to the idea of coming to school on her own.

The point is simple: Katie's psychologist assumed Katie's refusal to sit on the bus was motivated by her mother's attention. Because he did not take the time to follow Katie in her routine, he missed the chance to see that her behavior was motivated by fear.

But that is not the end of the story. On top of everything else, the psychologist conveyed less than helpful information to Katie's mom about *her* behavior. He assumed that she was over-compensating for Katie's behavior because she was "guilty" about her daughter's disability. Although he never said so directly, his body language and tone communicated, "You're a big part of the problem."

"Who does he think he is?" Katie's mom asked her husband, "Sigmund-fricking-Freud?"

As Katie's mom got angrier about the psychologist's unwillingness to *know* Katie, and as he got more and more convinced that his hypothesis about attention-seeking behavior was correct, their dislike for one another grew. Sadly, the relationship never improved. It never had the time to improve (or get worse). He left town and started a new practice elsewhere.

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 questions posed by Jack Pierpoint and Marsha Forest (plus one):

- 1. What are you doing well right now?
- 2. What could you be doing better?
- 3. What could you be doing differently?
- 4. What can you do within the next 24 hours to do things better or differently?
- 5. What can your supervisor or friends do for you to help?

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 and insecurities 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 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 work through my apprehension and make a commitment to know someone and let them affect me.

Here's 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 Many other factors also can occur. 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).

Welwood, J. (1985). Awakening the heart: East/west approaches to psychotherapy and the healing relationship. Boston: Shambhala.



Part Three Checking Assumptions

Key concepts:

It is critically important to check your assumptions about the person, his or her supporters, and most especially — Moms and Dads.

Make sure the "problem" is really a problem.



Mayer Shevin's Six Assumptions

- 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.

www.shevin.org

Consider carefully your assumptions about the person

It is important to understand that we all have biases. Our individual learning histories affects how we "see" the world. Our biases may affect how we see someone who engages in difficult behaviors and what we consider to be the "right way to behave." Mayer Shevin, who is one of the most thoughtful people I know, states his assumptions right up front when he is offering support (see previous page).

Consider carefully your assumptions 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.
- Are honest and would consider retaliation a serious sign of weakness.

Be especially careful in considering your assumptions about Moms and Dads

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.
- 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 <u>is</u> not 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 <u>is not</u> my job to make mothers or fathers 'see' their child as I do or to treat them as I would.

 Their relationship with their son or daughter is *their*

relationship and my relationship is my relationship.

Ask, "Is this really a problem?"

Answering the question, "Is this really a problem?" may be relatively easy, or it may require some thought and judgment. It is quite possible the person does not consider "the problem" THE problem. Perhaps "the problem" is not really the person's problem at all. For example, Ruth refused to do tasks at the day activities center. When she attempted to leave, her caregivers insisted she sit down. They said that Ruth was "noncompliant.." But very few of Ruth's caregivers could or would tolerate tolerate hours of meaningless activity for little or no wage! It took time, but Ruth's caregivers finally came to see that Ruth's behavior was not the problem. Ruth had a problem.

It is also possible that the behavior is annoying to some, but hardly the kind of behavior that they would try to change if the person did not experience a disability (e.g., smoking). A behavior may be a part of a person's personality. It may even be annoying. But that does not mean it is anyone's business to "intervene."



Ask, Is this really a problem?

- 1. Is the behavior life-threatening?
- 2. Does this behavior create a health risk to the individual?
- 3. Is the behavior more likely to become serious in the future?
- 4. Is the behavior serious to others?
- 5. Is this behavior of concern to the person's friends, family, and caregivers?
- 6. Is the behavior getting worse or not improving?
- 7. Has the behavior been a problem for some time?
- 8. Does this behavior result in damage to materials, furnishings, etc.?
- 9. Does the behavior interfere with their acceptance in ordinary community settings?

Adapted from the work of Ian Evans and Luanna Meyer (1985)



Part Four

Tools for figuring Out the <u>Meaning</u> of a Person's Difficult Behaviors

Key concepts:

Define the difficult behavior (s) in terms your grandmother would understand.

Before you get too far ahead of yourself, find out how you can support the person's supporters.

Create a timeline of the behavior.

Ask, "Are there times during the day or week that this behavior is likely/unlikely to occur.

Ask, "What happened next?"



Grandmother's Law

Define three of the person's most troubling behaviors, using words your grandmother could understand:

1.

2.

3.

Support for a person's supporters.

It often takes time for an individual to change his or her behavior. Imagine that nothing you (or anyone else) can do right now will help the person to change. What do <u>you</u> need to help the person and others to stay safe? What do <u>you</u> need to maintain your hope about the person's future?



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

Use the timeline below to indicate the last time you remember the person doing well. Using even intervals of days, weeks, months, or years, plot what happened next by answering the questions below.

The last time we remember that things were good (date):	Today's Date:

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Notes



What happened next?

A change in relationships

Did someone important to the person leave? Did someone new arrive?

A change in health and well-being

Has there been a change in the person's health status? Has the person experienced any unusual trauma?

A change in joy

Has the person stopped doing something that he or she loves?

A change in power and control

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

A change in the person's capacity to contribute to others

Has there been a change in the person's status?

A change in the person's skills/overall skill level

Has the person lost skills? Are new skills needed?

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

• Make a notation for each behavior in a box that corresponds to a time/day when the behavior is likely to occur.

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

Note the times during the day/week <u>without</u> notations.

Do you detect a pattern?

- 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?
- If a behavior occurs during different times of day, across all kinds of activities, with different people, the root cause of the behavior may be physiological or psychological.

Notes:

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	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
7:00 AM							
8:00 AM							
9:00 AM							
10:00 AM							
11:00 AM							
12:00 NOON							
1:00 PM							
2:00 PM							
3:00 PM							
4:00 PM							
5: 00 PM							
6:00 PM							
7:00 PM							
8:00 PM							
9:00 PM -							



Part Five

Health Care Considerations

Key concepts:

As Mark Durand has said, "People who don't feel good tend to get immature."

The sudden onset of a difficult behavior, or the presence of the difficult behavior across settings and times, suggests an underlying physiological/psychological problem.

When necessary, secure the services of a competent health care professional.

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 between vertebrae in the neck)
- Cardiac problems
- Seizures

Common "problem" behaviors and speculations about their causes

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

- 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

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Part One

Building a Positive Behavior Support Plan

Key concepts:

A support plan should not be about how the person will change his/her behavior. It should be about how you will change yours.

A support plan should be based upon "respectful guesses" of why the person is engaging in the difficult behavior.

A support plan should include specific action steps for supporting the person's supporters.

When this is happening And the person does this And we start the start this this this this this this this thi	

Adapted from the work of Michael Smull and Susie Harrison, ELP Learning Community (www.allenshea.com).

How we will support the person's supporters				
When this is happening	We need the following to feel safe and hopeful about the person's future			

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Linda Stengle's Problem-Solving Questions

- 1. Is the relationship between the person and the other person unbalanced?
- 2. Are there too few mutual interests?
- 3. Is this an activity that the person really wants to do, or is it something you want him/her to do?
- 4. Is the activity long enough to encourage the development of a relationship?
- 5. Is the other person afraid to get close to the person?
- 6. Is the other person too busy to take time to get to know the person?
- 7. Are needed accommodations available to allow the person to participate in the activity?
- 8. Could your presence be interfering with the development of friendships?
- 9. Do the same people tend to participate or are there different people every time?
- 10. Are there breaks, joint projects, or committees which allow people time to communicate freely?
- 11. Is the other person in relationship with the person out of a sense of charity?
- 12. Is there enough structure to the activity?
- 13. Is the person projecting an attitude that is keeping others away?
- 14. Do you think something is preventing the other person from seeing and appreciating the person's good qualities?

Adapted from Linda J. Stengle's book, Laying the Foundation For Your Child With A Disability: How to Establish Relationships that Will Last After You Are Gone.. New York: Woodbine