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

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DRAFT

Version 22 October 2004
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 goodniss. 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 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).

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), “[w]e 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.

“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.

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.
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 is my job to help the person to find the support that he or she needs to be a son or daughter. It is not my job to make the person get along with his or her parents or agree with them.
4. It is 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 not 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 “non-compliant.” But very few of Ruth’s caregivers could or would 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 *Meaning* 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 you need to help the person and others to stay safe? What do you 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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All Behavior is Meaningful—20
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 **likely** 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 **unlikely** to occur?

- Note the times during the day/week without 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.
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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**

<table>
<thead>
<tr>
<th>“High pain tolerance”</th>
<th>Biting with back teeth</th>
<th>Intense rocking/preoccupied look</th>
</tr>
</thead>
<tbody>
<tr>
<td>• A lot of experience with pain.</td>
<td>• Dental</td>
<td>• Visceral pain</td>
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<tr>
<td>• Fear of expressing opinion.</td>
<td>• Otitis (ear)</td>
<td>• Headache</td>
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<td>• Delerium</td>
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<td>• Depression</td>
</tr>
<tr>
<td>• Neuropathy (disease of the nerves)/many causes</td>
<td></td>
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</tr>
<tr>
<td><strong>Fist jammed in mouth/down throat</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Gastroesophageal reflux</td>
<td></td>
<td></td>
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<tr>
<td>• Eruption of teeth</td>
<td></td>
<td></td>
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<tr>
<td>• Asthma</td>
<td></td>
<td></td>
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<tr>
<td>• Rumination</td>
<td></td>
<td></td>
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<tr>
<td>• Nausea</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Biting side of hand/whole mouth</strong></td>
<td><strong>Uneven seat</strong></td>
<td><strong>Won’t sit</strong></td>
</tr>
<tr>
<td>• Sinus problems</td>
<td>• Hip pain</td>
<td>• Akathisia (inner feeling of restlessness)</td>
</tr>
<tr>
<td>• Eustachian tube/ear problems</td>
<td>• Genital discomfort</td>
<td>• Back pain</td>
</tr>
<tr>
<td>• Eruption of wisdom teeth</td>
<td>• Rectal discomfort</td>
<td>• Rectal problem</td>
</tr>
<tr>
<td>• Dental problems</td>
<td></td>
<td>• Anxiety disorder</td>
</tr>
<tr>
<td>• Paresthesias/painful sensation (e.g., pins and needles) in the hand</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Odd un-pleasurable masturbation</strong></td>
<td><strong>Waving head side to side</strong></td>
<td><strong>Whipping head forward</strong></td>
</tr>
<tr>
<td>• Prostatitis</td>
<td>• Declining peripheral vision or reliance on peripheral vision</td>
<td>• Atlantoaxial dislocation (dislocation between vertebrae in the neck)</td>
</tr>
<tr>
<td>• Urinary tract infection</td>
<td></td>
<td>• Dental problems</td>
</tr>
<tr>
<td>• Candidal vagina</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Pinworms</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Repetition phenomena, PTSD</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Walking on toes</strong></td>
<td><strong>Walking on toes</strong></td>
<td><strong>Left handed or fingertip handshake</strong></td>
</tr>
<tr>
<td>• Arthritis in ankles, feet, hips or knees</td>
<td>• Arthritis in ankles, feet, hips or knees</td>
<td>• Frightening previous setting</td>
</tr>
<tr>
<td>• Tight heel cords</td>
<td></td>
<td>• Pain in hands/arthritis</td>
</tr>
<tr>
<td><strong>Sudden sitting down</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Sudden sitting down</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Atlantoaxial dislocation (dislocation between vertebrae in the neck)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Cardiac problems</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Seizures</td>
</tr>
</tbody>
</table>
### Common “problem” behaviors and speculations about their causes

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

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Speculation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Syncope/orthostasis</td>
<td>Gastroesophageal reflux</td>
</tr>
<tr>
<td>Vertigo</td>
<td>Costochondritis&quot;/slipped rib syndrome&quot;</td>
</tr>
<tr>
<td>Otitis</td>
<td>Angina</td>
</tr>
<tr>
<td>Waving fingers in front of eyes</td>
<td><strong>General scratching</strong></td>
</tr>
<tr>
<td>Migraine</td>
<td>Eczema</td>
</tr>
<tr>
<td>Cataract</td>
<td>Drug effects</td>
</tr>
<tr>
<td>Seizure</td>
<td>Liver/renal disorders</td>
</tr>
<tr>
<td>Rubbing caused by blepharitis</td>
<td>Scabies</td>
</tr>
<tr>
<td>(inflammation of the eyelid) or corneal abrasion.</td>
<td><strong>Self-restraint/binding</strong></td>
</tr>
<tr>
<td>Pica</td>
<td>Pain</td>
</tr>
<tr>
<td>General: OCD, hypothalamic problems, history of under-stimulating environments</td>
<td>Tic or other movement disorder</td>
</tr>
<tr>
<td>Cigarette butts: nicotine addiction, generalized anxiety disorder</td>
<td>Seizures</td>
</tr>
<tr>
<td>Glass: suicidality</td>
<td>Severe sensory integration deficits</td>
</tr>
<tr>
<td>Paint chips: lead intoxication</td>
<td>PTSD</td>
</tr>
<tr>
<td>Sticks, rocks, other jagged objects: endogenous opiate addiction.</td>
<td>Parasthesias</td>
</tr>
<tr>
<td>Dirt: iron or other deficiency state</td>
<td><strong>Scratching stomach</strong></td>
</tr>
<tr>
<td>Feces: PTSD, psychosis</td>
<td>Gastritis</td>
</tr>
<tr>
<td>Head banging</td>
<td>Ulcer</td>
</tr>
<tr>
<td></td>
<td>Pancreatitis (also pulling at back)</td>
</tr>
<tr>
<td></td>
<td>Porphyria (bile pigment that causes, among other things, skin disorders)</td>
</tr>
<tr>
<td></td>
<td>Gall bladder disease</td>
</tr>
<tr>
<td></td>
<td><strong>Scratching/hugging chest</strong></td>
</tr>
<tr>
<td></td>
<td>Asthma</td>
</tr>
<tr>
<td></td>
<td>Pneumonia</td>
</tr>
<tr>
<td></td>
<td>Gastroesophageal reflux</td>
</tr>
<tr>
<td></td>
<td>Hip/back pain</td>
</tr>
<tr>
<td></td>
<td>Back pain</td>
</tr>
</tbody>
</table>

Reprinted with permission from: Ruth Ryan, MD, Director of Clinical Services, Support Solutions, 56 Industrial Park Road, Saco, ME 04072 Telephone: 207-294-7458
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.
<table>
<thead>
<tr>
<th>When this is happening...</th>
<th>And the person does this...</th>
<th>We think it means this...</th>
<th>And we should....</th>
</tr>
</thead>
</table>

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

© David Pitonyak, Ph.D.  All Behavior is Meaning-full— 28
<table>
<thead>
<tr>
<th>How we will support the person’s supporters</th>
</tr>
</thead>
<tbody>
<tr>
<td>When this is happening...</td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

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

DR. DAVID STEIN
Attending Psychologist, Children’s Hospital Boston
Instructor, Harvard Medical School

David Stein, 2012
BRIEF BACKGROUND

- The year, 2000
- My job, “Child Behavior Specialist”
- My training, a degree in clinical psychology and child development
- My success rate, TERRIBLE
REMEMBER: THIS IS HARD work and nobody has 100% success. Our goal is NOT perfection, it IS improvement.
As parents, teachers, and providers, we have to keep our eyes on the long-term prize and remember to take care of ourselves.
HOW COMMON ARE BEHAVIOR PROBLEMS IN CHILDREN WITH DS?

- 30% of children with DS have diagnosable behavior condition
- Many more present with common behavior problems that can still get in the way, even without a diagnosis
- Behavior problems in childhood predict the same in adulthood
- Behavior problems in adults with DS can interfere with living in the LRE, working, and having a social life.
  - We need to intervene!
- 10% of typically developing children have diagnosable behavior condition, meaning children with DS are 3X more likely

McCarthy, 2008
Cuskelley & Dadds, 1992
Why do children with DS have behavior problems?

Brain Differences

- Reduced growth in the frontal lobe
- Smaller brain stem and cerebellum
- Problems in the temporal lobe and damage to hippocampus

Nadel & Fidler, 2007
WELL THAT’S A NICE PICTURE, BUT WHAT DOES THAT MEAN?

- **Social**
  - Often hyper-aware (remember this for later) and hyper-engaged
  - “Aggressive social problem solving”

- **Language**
  - Stronger receptive vs. expressive, difficulty with formulating ideas
  - Increased likelihood of frustration

- **Information Processing**
  - Less robust processing/memory for language
  - Very robust processing/memory for visuals

- **Motivation Differences**
  - Challenges in intrinsic motivation
  - Greater frustration, over time, can lead to greater avoidance

- **“Executive Functioning”**
  - May not see the stop signs (e.g., impulsivity)
  - May struggle to plan a behavior and/or consider its consequences

Nadel & Fidler, 2007
We live in a complex world with lots of demands, language, and other sources of frustration. This is a perfect storm for children with DS to be frustrated if not well-supported and understood.

David Stein, 2012
SO NOW THAT WE KNOW WHY BEHAVIOR PROBLEMS SHOW UP, WHAT CAN WE DO ABOUT IT???

The BIG Picture

1. Child-Parent Relationship
2. Behavioral Principles
3. Functions of a Behavior
4. POSITIVE Behavior Strategies
5. Focusing on and leveraging strengths
6. Effective Discipline

David Stein, 2012
THE RELATIONSHIP

Harry Harlow, 1959

When you don’t know what to do, consider what is best for your relationship.

David Stein, 2012
What to do about behavior.

1. Child-Parent Relationship
2. Behavioral Principles
3. Functions of a Behavior
4. POSITIVE Behavior Strategies
5. Focusing on and leveraging strengths
6. Effective Discipline
THE BASICS OF BEHAVIOR- EASY TO UNDERSTAND, VERY HARD TO DO.

- “Reinforce” what you want to see more of.

- Do NOT reinforce what you want to go away.

David Stein, 2012
**How do we Reinforce good behavior?**

- **Attention!**
  - Notice the behavior and react to it

- **Praise!**
  - Comment on the behavior and have a little party

- **Token Economy…**
  - Sounds much fancier than it is
  - Pick a few things you’d like to see more of, build a structure around them, and find a motivating reward.
  - It’s not only for children, it’s also a way to remind us adults to notice the good stuff
  - Complex ≠ effective. KEEP IT SIMPLE.
A Sample Token Economy for a Child with DS

<table>
<thead>
<tr>
<th></th>
<th>Pants on</th>
<th>Shirt on</th>
<th>Brush teeth</th>
<th>Prize!</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tuesday</td>
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<td>Wednesday</td>
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<td>Thursday</td>
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<tr>
<td>Friday</td>
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</table>
WHAT TO DO ABOUT BEHAVIOR.

1. Child-Parent Relationship
2. Behavioral Principles
3. Functions of a Behavior
4. POSITIVE Behavior Strategies
5. Focusing on and leveraging strengths
6. Effective Discipline
EVERY BEHAVIOR HAS A PURPOSE. IN ORDER TO ADDRESS BEHAVIORS, WE ALSO NEED TO UNDERSTAND WHAT THEIR FUNCTION IS.

The BIGGIES in DS

- **Attention-seeking**
  - E.G., These adults aren’t paying attention to me, and these toys stink. I’m going to turn the lights off in Dr. Stein’s office!
  - E.G., I don’t have the language to ask another child to play, so I am going to pinch him to get his attention.

- **Escape/Avoidance**
  - E.G., Math is hard, so I am going to run out of the classroom to avoid it.
  - E.G., I don’t want to leave the birthday party, so I will flop to the floor and refuse to move.
When attention seeking is driving a behavior, we have a very easy option for intervention.

An example:

- Joshua loves to go into his sister’s room and jump on the bed. When he does this, his sister and father run into the room and become very upset. Joshua laughs and laughs and continues doing this until physically removed by his father.

What is the function of this behavior?

What is reinforcing this behavior?

What could be done differently?
This seems very simple, but when we are in the moment, it is very difficult to remember this principle.
WHAT TO DO ABOUT BEHAVIOR.

1. Child-Parent Relationship
2. Behavioral Principles
3. Functions of a Behavior
4. POSITIVE Behavior Strategies
5. Focusing on and leveraging strengths
6. Effective Discipline
There are many positive behavior strategies and we cannot go through them all. Instead we will focus on a few of the most powerful tools for children with DS.

- **Choices**
  - “Brush teeth or potty first?”

- **Redirection**
  - “Please help me set the table”

- **Replacement behaviors**
  - Holding hands while walking down the stairs to avoid pushing

- **Providing the carrot (First-then instructions)**
  - “First do homework, then watch Cash Cab.”
WHAT TO DO ABOUT BEHAVIOR.

1. Child-Parent Relationship
2. Behavioral Principles
3. Functions of a Behavior
4. POSITIVE Behavior Strategies
5. Focusing on and leveraging strengths...to adapt the environment.
6. Effective Discipline
Let’s revisit the brain-based strengths and weaknesses in children with DS...

Strengths
- Visual
- Social
- Routine and predictability

Weaknesses
- Language
- Impulse Control
- Changes in routine
On a day to day basis, we can use this understanding to structure the environment and bring out the best in children with DS.

- Keep a routine that provides “sameness”
- Make that routine visual
STRUCTURING THE ENVIRONMENT, CONTINUED

- Use visual timers
- Use social motivators and rewards
  - Attention!
  - “First clean up, then play with mommy.”

David Stein, 2012
Sometimes, particular situations are hard for children with DS.

We can use the same ideas and add structure, visuals, and repetition for difficult situations with “Social Stories”
SOCIAL STORIES- THE BASICS

- Mostly pictures, few words
- Simple simple simple
- Shows sequence of events
- Shows DESIRED behaviors
- Lots of repetitions
- Read it as a bedtime story?
Knowing the strengths and weaknesses in DS, we also know what to avoid when structuring the environment

- “Blah, blah, blah…”
  - “Now Jonathan, there is no hitting in this household and if you do you will be in time out!”
  - Or….”No hit.”

- Inconsistency/unpredictability

- Social responses for behaviors we don’t want to see
WHAT TO DO ABOUT BEHAVIOR.

1. Child-Parent Relationship
2. Behavioral Principles
3. Functions of a Behavior
4. POSITIVE Behavior Strategies
5. Focusing on and leveraging strengths
6. Effective Discipline
NOTICE THAT DISCIPLINE IS LAST AND WE DISCUSSED MANY OTHER WAYS OF MANAGING BEHAVIOR?

- This is because children with DS respond far better to POSITIVE behavior supports than to discipline AND there are many ways to deal with behavior without disciplining.

“Positive reinforcement may be more productive, but, dammit... it’s just not as much fun.”
DISCIPLINE COMES BACK TO THE BASICS OF BEHAVIOR—
REINFORCE WHAT YOU WANT TO SEE MORE OF, AND DO NOT REINFORCE WHAT YOU WANT TO SEE LESS OF.

David Stein, 2012
When we do have to discipline, we need to consider how a child with DS thinks and learns, and adjust accordingly.

- What NOT to do…
  - DO NOT make eye contact
  - DO NOT make strong facial expressions
  - DO NOT yell
  - DO NOT use language to reason

- REMEMBER…
  - Each of these reactions can actually reinforce a behavior by making it FUN or INTERESTING!
So what CAN you do? Remember, if we want to make a behavior go away, we have to make it less fun and interesting. Rather than adding a response, we are TAKING it away.

- **Step 1: Ignore it...if you can...**
  - Basket 1- Safety issue, cannot ignore
  - Basket 2- Not a safety issue, but potentially problematic, MAY ignore or respond
  - Basket 3- Not a safety issue, and not that big of a deal, consider letting it go.
    - From The Explosive Child, By Ross Greene, PhD

- **Step 2: “RESPOND but do NOT REACT.”**
  - Remove any facial expression or eye contact
  - Remove a child from the situation
  - Remove others from the proximity of the child
  - Remove objects from the environment
SO, WHEN WE ARE DEALING WITH BEHAVIOR FOR ANY CHILD, WE MUST CONSIDER HOW THIS CHILD SEES THE WORLD AND LEARNS FROM IT. THIS WILL INFORM OUR APPROACH.

- For children with DS, we have, maybe, a greater understanding of how the brain works and therefore what strategies will work.
SOME CLOSING POINTS…

- Remember, focusing on your relationship, the positive, and the strengths of a child will help you choose and utilize the best behavior strategies.

- Remember, our goal is not perfection, our goal is improvement.

- Remember, our “endpoint” is not tomorrow or next month, it’s the individual with DS having a fulfilling adulthood and not being limited by behavior problems.
THANK YOU!

- Rosalie Forster and the MDSC
- My team at Children’s Hospital Boston
- All the wonderful children and families who have taught me so much and made my work life so fun and meaningful.
QUESTIONS?
BEHAVIOR AND DOWN SYNDROME: A PRACTICAL GUIDE FOR PARENTS

David Stein, PsyD
Parenting can be a bit like setting off on a journey without a map. With each unexpected fork in the road, the caring parent uses intuition informed by prior experiences to choose a path. For some families, this works out just fine. For most of us, a little extra guidance to understanding our children’s behavior can make a huge difference. While there are several very good books that address general child behavior, there is not much information available for families specifically designed to support positive behavior for children with Down syndrome. Dr. Stein’s guide fills this gap beautifully providing sound, practical advice for parents of children with Down syndrome. Recognizing that each child is unique but also that there are some common areas that can present challenges and also particular strategies that have proven successful, Dr. Stein gives advice that you can start using today. I am so pleased to recommend this guide to the families who come to the Down Syndrome Program at Children’s Hospital. I hope you find it sheds light on the road ahead for a more peaceful and fulfilling journey for your family.

Emily Jean Davidson, MD, MPH
Director, Down Syndrome Program
Developmental Medicine Center
Children’s Hospital Boston

The Down Syndrome Program at Children’s Hospital Boston offers specialized services for children with Down syndrome and their families. Program staff work closely with children, parents, medical specialists, community physicians, and educators. The program is a subspecialty service of the Developmental Medicine Center at Children’s Hospital Boston.

For more information or support, please call 857-218-4329 or visit our website at www.childrenshospital.org/downsyndrome

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WHY DOES MY CHILD WITH DOWN SYNDROME HAVE BEHAVIOR PROBLEMS?

Behavior problems are very common in ALL children. 1 in 10 children has behavior problems that are serious enough to be diagnosed by a professional.

Behavior problems are even more common in children with Down syndrome. 1 in 3 children with Down syndrome has behavior problems that are serious enough to be diagnosed by a professional. Even more children with Down syndrome have behavior problems that might not be diagnosed, but still cause problems for kids and their families.

SOME REASONS THAT KIDS WITH DOWN SYNDROME OFTEN HAVE BEHAVIOR PROBLEMS:

TROUBLE CONTROLLING IMPULSES
Children with Down syndrome often don’t notice the “stop signs” that tell them not to behave in certain ways.

TROUBLE COMMUNICATING
When people cannot express themselves or understand others easily, they become frustrated. Children with Down syndrome often have this difficulty.

TROUBLE RELATING TO OTHER CHILDREN AND ADULTS
Many children with Down syndrome are social and affectionate. But often, they may not know how to play efficiently with peers. This can be very upsetting to the child with Down syndrome, and can cause misbehavior.

TROUBLE MANAGING FRUSTRATION
We’ve already established that children with Down syndrome have reason to be frustrated. Unfortunately, many also struggle to calm down and feel better when frustrations come up. This can worsen behavior problems.

REMEMBER...

YOUR STYLE OF PARENTING DIDN’T CAUSE THESE PROBLEMS
But you can make a big difference by making some changes. That’s how this brochure can help you!

KEEP DOING WHAT WORKS
Parenting is a hard job. You are probably already going many things very well as a parent. Some of the tools in this pamphlet may help you do even better!
BE CONSISTENT
Behaviors can change quickly; the hard part is changing behaviors for the long-term. That’s why setting up a realistic plan is important. We’ll give you some ways to do that in this brochure.

KEEP YOUR EYE ON THE LONG-TERM GOALS
Making some changes now can make a big difference in your child’s future (e.g., level of independent living, ability to work, etc.), even you don’t see dramatic improvements right away. Remembering the big picture can help you get through daily frustrations.

BEHAVIOR IS A WAY OF COMMUNICATING
A child’s behavior—even really difficult behavior—can tell us that she doesn’t have a skill that she needs, that she is frustrated, that she is physically uncomfortable, or countless other important messages. Remembering that your child is trying to communicate something can make it easier to deal with difficult behavior.

SAME IDEAS, NEW APPROACH
Use the same approach you would with another child—and modify it. Many of the same behavioral techniques that work with most children are also effective for kids with Down syndrome. You just have to learn to use them in a way that fits your child.

YOU ARE NOT ALONE
Your child’s healthcare providers, school system, and community resources are available to give you information, services, and support.

This guide is designed to help you use proven behavioral techniques, with the unique needs of children with Down syndrome in mind. These techniques can help improve your child’s behavior. Some are ideas you might feel comfortable trying out on your own. For others, you might ask for help from a professional.

PEOPLE WHO CAN HELP

PEDiatricIAN
Your pediatrician can speak with you about behavior problems, and can help to rule out medical causes, such as poor sleep. Your pediatrician can also refer you to a mental health professional such as a psychologist, psychiatrist, or social worker.

A consultation with a professional will allow you to understand your child’s specific needs and how best to intervene. This might include looking at factors that affect your child’s behavior, such
as communication style, cognitive skills, academics, classroom setting, and social and emotional well-being.

SCHOOL
Today’s laws state that an education must address all areas of a child’s development. If behavior is a problem, it is reasonable to ask the school for some help.

You might ask the school to conduct an assessment of your child’s behavior. The formal version of this assessment is called a Functional Behavior Analysis (FBA). This should be conducted by an expert in behavior who can observe your child closely and determine what things come before behaviors, what behaviors are problematic, and what happens after behaviors to keep them going. A comprehensive FBA includes observation of your child at school, at home, and in the community.

STAY POSITIVE
Children with Down syndrome tend to respond to positive behavior techniques rather than discipline. So remember, stay positive and use other tools before resorting to discipline.”

THINGS TO TRY AT HOME
While there are many things that experts and professionals can help with, simple daily actions you take at home can also have a huge impact.

GIVE SIMPLE, CLEAR DIRECTIONS
Language is often difficult for children with Down syndrome. The more complicated your speech, the less likely your child is to do what you want. So directions should be specific, directive (a request, not a question), and contain the fewest steps possible.

For example, say: “Brush your teeth now, please.”
Don’t say: “Can you please go upstairs and brush your teeth before we have to leave for school?”

Say: “Please put your pajamas on.”
Don’t say: “I already told you it’s time to get ready for bed! If you put on your pajamas, I’ll come read you a story.”

You may wish to speak with your child’s school speech pathologist or with a private provider about other options, such as sign language or the use of a picture exchange system.

ESTABLISH A ROUTINE, AND STICK TO IT
Every morning, most adults do their routine in the same order. For
example: use the bathroom, take a shower, get dressed, have breakfast, brush teeth, get lunch ready to take to work. Having a routine makes life easier!

The same is true for children with Down syndrome, but routine is even more important. Your child is likely to do best when the day’s structure is the same as it was the day before. Try your best to make a routine and to help your child understand what that routine is.

**USE VISUAL SCHEDULES**

Many schools use this approach. Here is an example of an after-school routine shown visually. It tells a child that after she gets home from school, she needs to hang up her coat, have a snack, play, read a book, and then eat dinner.

<table>
<thead>
<tr>
<th>Hang up coat</th>
<th>Have a snack</th>
<th>Play</th>
<th>Read a book</th>
<th>Eat dinner</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Coat" /></td>
<td><img src="image2.png" alt="Snack" /></td>
<td><img src="image3.png" alt="Play" /></td>
<td><img src="image4.png" alt="Read" /></td>
<td><img src="image5.png" alt="Dinner" /></td>
</tr>
</tbody>
</table>

This chart was easy to make and is easy to follow. Something like this might help your child move more smoothly through his day without so much work on your part.

**PLAN FOR DIFFICULT SITUATIONS**

We all do better with structure, but we can’t always keep things the same. As a parent or caregiver, you know your child best. You probably are aware of some things that are difficult for your child. Anticipating these events can be helpful and you can help your child prepare for changes in order to reduce his or her worry or behavior problems.

One approach to getting ready for what’s coming is called Social Stories. This technique involves outlining coming events for your child using a book format. This is often through pictures, but may also involve some words. Social stories can help your child prepare for difficult or complex events such as having blood drawn, going to a new classroom, or having a birthday party.

For more information, see: [www.thegraycenter.org/social-stories/how-to-write-social-stories](http://www.thegraycenter.org/social-stories/how-to-write-social-stories)

**MAKE TIME FOR THE FUN STUFF**

When children are having behavior problems, they tend to get lots of negative attention. It is important to have positive interactions with your child, even when things are at their worst. Make time each day to play a game, read a book, draw, cook a fun dish, or watch a video with your child, even if things have been hard around the house.
REWARD GOOD BEHAVIOR

Set up a system to reward the behaviors you want to encourage. Start by answering these questions:

• What are two or three things you would like your child to do more often?
• Could your child do these things if he or she were willing?
• Does your child need to be rewarded right away to understand the connection between completing a job and getting a prize?
• Can he understand being rewarded later on for something he did earlier in the day or week? (This is quite difficult to do!)
• What does your child like that could be used to reward? Stickers? Poker chips? Quarters to buy something later on? Time to play a game with someone special?

Choose a few behaviors that are important to you, and use a chart to help your child achieve them (see below).

MAKING A GOOD-BEHAVIOR CHART

Children with Down syndrome often respond to visuals better than to being told what to do. Make a chart with pictures of what you’d like your child to do and put it up where he or she can see it, maybe on the bedroom wall or refrigerator. You can draw the pictures, cut them out of magazines, takes photos, or photocopy them from books.

When you’re starting out, make the goals really simple and positive. We want your child to like this so he keeps trying! It’s okay to help out at first, but encourage your child to do jobs independently to earn a prize after he has tried the chart out for a few days. As you go, add in some more difficult jobs to go with the ones your child has mastered. Remember, go slowly and keep it simple.

Be consistent with your use of the chart. This will not work if you stop doing it when it’s going well (or not so well). If you are having trouble keeping it going or are not having success, troubleshoot with a professional to figure out why.

On the following page is an example of a sticker chart to track your child’s progress on some morning jobs.

Many parents worry that creating a good-behavior chart is too much work. And it does take some effort. But remember, it also takes effort to instruct your child to do tasks each day and to fight, argue, or try to get her to do things against her will. Some upfront effort and time now can actually save you time later by setting routines that your child understands and will be willing to follow. Involving your child in making the chart can also be a fun activity.
Helping your child learn to complete jobs is not just to make your life easier. It is also important for his future. Children with Down syndrome tend to learn best through repetition and structure. If you can help teach these skills now, your child is more likely to be able to complete them independently as an adult. That can make a big difference in his life later on.

Charts have to be adjusted frequently to reflect new skills and changes. You may want to consult with a professional to help you do this.

**PICK YOUR BATTLES**

Wouldn’t it be great if we could make everyone in our lives behave exactly as we’d like them to? With other adults, you know that you can’t always get what you want. The same is true of your child. A lot of arguments, standoffs, and heartache can be avoided by simply choosing your battles. It is often beneficial to step back and consider whether a certain behavior is worth reacting to.
Consider the following when determining which battles to pick:

- Is the behavior dangerous? If so, then you need to intervene.
- If the behavior is not dangerous, is it one of the two or three behavior problems that you’d most like to decrease? If not, you might want to let it go...for now.
- If the behavior is not dangerous but is just bothersome, you might be best to ignore it. Not only will you save yourself some headaches, but this might even get rid of the behavior.

**AVOID POWER STRUGGLES BY OFFERING CHOICES AND EMPOWERING YOUR CHILD!**

Power struggles are very common between parents and children. A power struggle means that a child wants to do one thing, and a parent wants her to do another. And nobody wants to give in.

Power struggles can be very upsetting, and are often very hard on both parents and children. They can be particularly hard for children with Down syndrome, who are often social and affectionate and may find it very upsetting to be fighting with a loved one.

*When thinking about power struggles, keep these things in mind:*

- Just like you, your child would like some control over his or her life.
- You are the boss, but people tend to like bosses who listen to them and given them some power.
- When you offer people even a little bit of control, they tend to feel better.

*To avoid a power struggle, you might try the following:*

- Offer your child a choice. If there are three things that need to be done, allow your child to decide in what order he or she will complete those things.
- Provide your child with an “if-then” option. If she does what you want first, she can do something of her choosing next.

**MAKE HARD TASKS MORE FUN**

If a child struggles with bath time, bring a favorite toy to bath time to make it less challenging.

**DISARM AND DISTRACT**

Picture a two-year-old boy who is crying because his pacifier was taken away. This child is too young to respond to most forms of punishment, and this behavior is not something that
should be punished anyhow. Many parents, whether they know it or not, use the “disarm and distract” principle. That is, they would simply give this toddler a new toy to help him stop crying.

This same principle can be used to manage behavior problems or strong emotional reactions in older children and children with Down syndrome. Forget about the old behavior, or whatever triggered it, and introduce something new to help your child calm down and shift her focus.

**KEEP IT INTERESTING**
In the car you can sing, put on a DVD, look for letters outside the car. In the market, you can give the child a list or pictures of food items so they can find them.

**CORRECTING: MODEL A BETTER WAY**
Sometimes, children misbehave because they don’t have any other options to cope with a situation. For example, a preschool-age child who is struggling with speech might kick another child because he does not know how to ask that child to play.

In cases like this, it may still be necessary to discipline your child, but you should also consider doing some teaching or coaching. Your child’s teachers or healthcare providers may be able to help instruct you in this technique.

In the example presented above, you or your child’s teacher would tell your child that kicking is not OK. Then you might model how to ask another child to play. Since children with Down syndrome often learn best with repetition, this may need to be modeled many times. Schools are often willing to assist with this type of intervention.

Another option is “replacement behaviors”. This is another behavior the child can do to avoid a negative behavior. For instance, a child who pinches his peers might be taught to give high fives!

**THE POWER OF IGNORING**
Many children with Down syndrome are very social. They often love to receive attention, even if it is negative. If a behavior is not unsafe, try ignoring it and giving no feedback. Sometimes this is enough to get rid of a behavior!

**USE TIME-OUTS WISELY**
These days, most parents are familiar with the idea of a “time-out.” But many parents, teachers, and others working with children find time-outs difficult to use effectively.

To understand time-out, we have to think about why kids behave badly in
the first place. Most of the time, there is something that makes a difficult behavior fun or rewarding for the child.

For example, imagine that a child is in the doctor’s office with her parents and her pediatrician. In the middle of the conversation, the child turns out the lights in the office. The doctor and the child’s parents all jump out of their seats, run over to scold the child, and scurry to turn the lights back on.

Before the child turned off the lights, her parents and doctor were probably chatting away and not paying much attention to her. Turning the lights off changed that quickly!

Time-out is based on the idea that, in order to stop children from doing something, we have to make that behavior less fun and/or rewarding. In the case of turning the lights out, a good response would be to have everyone stay very calm, turn the lights back on, and go back to their conversation. This removes the motivation for the child to repeat this behavior.

The practice of time-out takes this one step further. In order to remove anything fun or interesting about a behavior, we find an area of the home or classroom that has nothing rewarding about it. This might be a corner of the room or a hallway. It is important that in the time-out space, there are no toys, television, or people to make it fun.

Reacting to your child’s bad behavior by yelling, crying, scolding, and becoming upset isn’t fun for you. But remember that these reactions (getting a rise out of you) can be interesting or rewarding for your child. When your child misbehaves, try to avoid these reactions. Keeping calm makes it less likely that your child will repeat the behavior in question. Stay calm, and feel free to use other terms like “take a break.”

**TAKE AWAY PRIVILEGES**

Another way to discipline effectively is to take things away from your child when he or she misbehaves. For example, if your son hits his sister, he may lose TV time.

Keep in mind that discipline is only going to work if your child understands it. Therefore, you should only take something away from your child for misbehavior if he or she understands the reason for this.

The solutions we’ve presented in this brochure are only some of the many ways you can help your child with Down syndrome improve his behavior. You’ll need to work with your family, school, and professionals to see what’s the best fit for you and what’s most effective for your child. For more information or support, please contact the Down Syndrome Program at Children’s Hospital Boston at 857-218-4329 or www.childrenshospital.org/downsyndrome.
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10 Things You Can Do to Support A Person With Difficult Behaviors

David Pitonyak

Supporting a person with difficult behaviors begins when we make a commitment to know the person. Sadly, it is often the case that the people who develop an intervention to stop someone from engaging in difficult behaviors do not know the individual in any meaningful sense. Instead, they see the person as a someone (or something) that needs to be fixed, or modified. But attacking a person’s behavior is usually ineffective and always disrespectful.

Think about someone you know who engages in difficult behaviors. Ask yourself, “What kind of life is this person living?” Consider how you would feel if you lived the person’s life. How would you behave?

What follows are 10 things you can do to support a person whose behavior is troubling you. It is not a list of “quick fix” strategies for stopping unwanted behavior. It is a list of ideas for uncovering the real things that a person might need so that you can be more supportive.

1. Get to know the person.

The first step in supporting a person with difficult behaviors almost seems too obvious to state: get to know the person! It is too often the case that people who develop interventions to eliminate unwanted behavior do not know the person in any meaningful sense. They know the person as the sum total of his or her labels, but know little about the person as a “whole” human being.

Make a point of spending time with the person in places that he or she enjoys, during times of the day that he or she chooses. It should be a comfortable place where both of you can feel safe and relaxed (e.g., a quiet room, a nice restaurant, a walking trail in a nearby park).

At a time that feels right (you will have to trust your intuition on this one), tell the person about your concerns and ask for permission to help (it’s rude not to). If the person has no formal means of communication, ask anyway. Sometimes people understand what is being said, but they have a difficult time letting
others know that they understand. The important point, always, is to ask the person for permission to stick your nose into their business, even at the risk of seeming silly in front of people who think the person cannot understand up from down (they’re usually wrong).

2. Remember that all behavior is meaningful.

Difficult behaviors are "messages" which can tell us important things about a person and the quality of her 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. Here are some examples of the kinds of the kinds of messages a person may be conveying with his or her behavior:

"I’m lonely."
Michael’s older brother was invited over to a friend’s house for a sleep over. Michael is never invited to the homes of children because he goes to a “special” school 35 miles from his neighborhood. Michael has no friends to play with.

"I’m bored."

Roberta’s sister is a doctor at the local hospital. She has her own house and is her parent’s pride and joy. Roberta works all day at a sheltered workshop where she packages plastic forks and knives. She lives at home and is tired of packaging. She wants to get a real job. Roberta’s case manager says she daydreams too much.

"I have no power."
John likes to sit down on the sidewalk when the bus arrives to take him to school. His mother becomes very angry and tells him that there will be no dessert when he gets home. John laughs when the bus driver threatens him with time out.

"I don’t feel safe."
Conrad uses a wheelchair and is not able to defend himself adequately from attacks by another man. Conrad worries that he will be hurt and often cries when left alone. Staff think he has a psychiatric illness.

"You don’t value me."
Gloria has a "severe reputation." People from all over the state have heard stories about her terrible tantrums. No one knows that she is a very caring person who worries about environmental issues. The only part of Gloria people pay attention to is her problem behaviors.
"I don't know how to tell you what I need."
June does not know how to use words or sign to let other people know what she was thinking. She lives in an institution where she learned that the best way to get people's attention was to hit her arms. It hurts, but it is the only thing that "works."

"My ears hurt."
Walter hits his ears with his fists. His job coach wants to stop and wrote a behavior plan for "not hitting." Weeks later, at a scheduled doctor's appointment, it was learned that Walter had a low-grade ear infection. Anti-biotics cleared up the infection and Walter has stopped hitting his ears.

Obviously there are many needs that a person may be conveying with her behaviors. A single behavior can "mean" many things. The important point is that difficult behaviors do not occur without reason. All behavior, even if it is self-destructive, is "meaning-ful."

Ask the person (and/or the person's supporters) what he or she needs to be happy. Find out who he or she counts on in a pinch. How often does he or she see loved ones and friends? What are his or her favorite activities? Where does he or she like to go? Ask the person what leads to unhappiness. Who are the people who the person does not like? How often does he or she see them? What are the person's least favorite activities? Since many people are experiencing physical and/or psychiatric distress, it's also important to know something about the person's physical and emotional health. Does the person have a way to let others know what he or she needs and feels? Is the person experiencing physiological or psychological distress? What kinds of medications is he or she taking? Do they help?

Finally, if you're stumped, ask, "Are there times when the person exhibits this behavior frequently?" and "Are there times when person exhibits this behavior infrequently or not at all?" Answering these two questions can tell you a great deal about the meaning of the person's behavior. With time, you should be able to see a discernable pattern.

For example, you might find that the person engages in the difficult behavior in the morning hours, but rarely in the afternoon. Ask, "What happens in the morning that might cause the person to behave this way?" or, conversely, "What is happening in the afternoon that causes the person not to behave this way?" (Hint: it often has something to do with the things a person is being asked to do, and/or who is asking the person to do it).

3. Help the person to develop a support plan.

People who exhibit difficult behaviors are usually subjected to a behavior plan at some point in their lives. It is rare that they are asked if they want a plan, let alone invited to the meetings where one is developed. Instead, a plan is developed by strangers (e.g., the agency behaviorist who has spent less than two hours "observing" the person).

Think about how difficult it would be to stop a behavior that a stranger thinks you should stop. It can be difficult enough to stop behaviors we choose to stop (e.g., smoking, excessive eating)!

Instead of a behavior plan to "fix" the person, help the person and the person's supporters to develop a support plan that reflects a real and authentic life. John and Connie Lyle O'Brien suggest the following questions for building a support plan. Note how different these questions are from those we typically ask, such as "How can we reduce this person's problem behaviors?" or "How can we manage this behavior?"

1. How can we help the person to achieve health and wellbeing?
2. How can we help the person to maintain his or her relationships and make new ones?
3. How can we help the person to increase his or her presence and participation in everyday community life?
4. How can we help the person to have more choices in life?
5. How can we help the person to learn skills that enhance his or her participation in community life?
6. How can we help the person to make a contribution to others?

The team can ask, "Is our vision for the person similar to the vision we hold for ourselves and each other? When we think about what the person needs, do we focus on "fixing" deficits or do we think about supporting the person in achieving a real life?"

4. Develop a support plan for the person's supporters

Just as it is simplistic to treat a person's behavior without understanding something about
the life the person lives, it is simplistic to develop a support plan without considering the needs of 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 caregiver or teacher whose competence is being judged by this "compliance/obedience" yardstick. The caregiver 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 "do as you are told" or suffer the consequences. Many of our human services environments are "toxic" with fear.

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 caregivers 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.

Take time with your colleagues to develop support plans for each other. For example, what can you do to increase each other's level of safety and comfort when someone is behaving dangerously? What can you do to have more fun at work? How can you have more control over your schedule and input into decisions? How can managers better support you?

A fundamental question is, "If you stopped responding to the person's difficult behavior the way you do now, who would you be?"

5. Don't assume anything.

It is easy to make the mistake of underestimating a person's potential because of her labels or because she has failed to acquire certain skills. This is a tragic mistake.

I have worked in the field for 15 years and am less confident in my ability to predict how much a person understands with every passing day. Recent developments make clear the folly of making predictions about a person's potential on the basis of diagnostic labels or past performance. Hundreds of thousands of people deemed "unfit" for society have left our institutions and now live in community. One hundred and twenty thousand people who were assessed "unemployable" because of the severity of their disability now work and pay taxes thanks to supported employment services.

The very definition of mental retardation itself has changed in recent years. The American Association for Mental Retardation (AAMR) has recently overhauled the definition. Gone are pessimistic predictions that saw little hope for the "severely retarded" and "profoundly retarded." The new definition eliminates such terms altogether and emphasizes the importance of our supports. In short, an individual's potential depends largely upon the adequacy of his/her supports rather than some inherent flaw or "defect."

Always remember that people are people first. Labels tell us nothing (in any real sense) about how we can be supportive. We need not forget the person's problem behaviors, but we must understand that people have gifts and capacities that eclipse our labels (or, as Herb Lovett has said, our "clinical accusations.") Always remember to speak directly to the person and explain things as clearly as you can, even if the person's labels suggest that he cannot understand (at the very least the person will understand the tone of your voice). Never speak about the person as if he were not in the room.

6. Relationships make all the difference.

Loneliness is the most significant disability of our time.
Many people with disabilities, young and old, live lives of extraordinary isolation. Some depend entirely upon their families for support. A brother or sister or mom or dad are the only source of company. Friends are often absent altogether.

All too often, the only relationships people have are with paid staff. Although staff can offer a great deal, they change jobs frequently or take on new responsibilities. The resulting instability can be devastating to someone who is fundamentally alone.

Remember that there are many people in the community who will benefit from knowing the person. Chances are the person has already made someone’s life fuller. Be confident that she or he will make someone’s life richer again and again.

Learn more about personal futures planning and other person-centered approaches to planning.

7. Help the person to develop a positive identity.

John Bradshaw writes, "Our identity is the difference about us that makes a difference."

Many people with disabilities develop identities as "problem people." They are segregated into "special" programs where they are treated as people who have little to offer. Soon their "treatment" becomes a kind of cage to protect them from themselves and others. The real danger is that if enough people begin to think of the person as a "problem," she will begin to believe it too.

We all need to be needed.

Help the person to find a way to make a contribution. Start when the person is young if you can. Giving is a lifelong endeavor.

Things as simple as helping with household chores or helping out at church can teach the person that she can make a contribution.

Pour over the newspaper and find the "Volunteers Needed" section. Talk to the person about joining an organization with you or with a friend (e.g., Habitat for Humanity, a local food shelter, an environmental group).

Help the person to learn how to support friends (e.g., an invitation to a sleep over, birthday cards, learning to ask "How are you doing?" or "What’s new?").

Remember that it is important to overcome the belief that the person has nothing to share. It takes time and determination to help the person and others to see strength and the capacity to give when deficits were all that anyone ever saw before.

8. Instead of ultimatums, give choices.

Choice is a powerful alternative to punishment. If the person’s behavior challenges you, help him to find more desirable ways to express the needs underlying the behaviors. Instead of ultimatums, give choices (e.g., "Bill, I know you’re upset. What would help? Would you like to go for a walk or take a ride? You need a chance to calm down.

Allow the person to make decisions throughout the day. If he has trouble making choices, find a way to help. Make sure there are at least three desirable outcomes to choose from. As Norman Kunc has said 1 option = tyranny; 2 options = a dilemma; 3 or more options = a real choice.

Don’t assume that helping the person to have more choices means letting him do whatever he wishes. Limit-setting is an important and fair part of any relationship. The real question is who is setting the limits and why. If limits are imposed upon the person without their input, and if the limits are part and parcel of a life in which the person is powerless, even your best advice may even be interpreted as one more statement of “do it my way or else.” You can expect a general disregard for your advice if the person on the receiving end of the advice is “out of power.”

Make a sustained commitment to the person and to “fairness” in the relationship. If the person has been on the outside of power for too long, you may need to bend more often than not for awhile. The goal is to teach the person that giving is a two-way street.

9. Help the person to have more fun.

Fun is a powerful antidote to problem behaviors.
People with significant disabilities often live in ghettos of reward. Indeed, it is often this poverty of reward, not a lack of skills, that keeps people separate from other community members. Many must endure reward schedules for good behavior. The very few things that they enjoy are used contingently to reinforce compliance (talk about spoiling a good thing!).

Count the number of things the person enjoys, the number of places she likes to go. Compare this to the number of things other people enjoy, the number of places other people go. Ask yourself, “Is the person having fun? Is she experiencing enough joy? Is this an interesting life with things to look forward to?”

Help the person to add to her list of interesting (and really fun) things to do. Spend time in regular community places where people hang out. If you feel compelled to take data on something, take data on the amount of fun you find. Make fun a goal.

10. Establish a good working relationship with the person’s primary health care physician.

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 the needs of others when you don’t feel well? When we are sick, we are not ourselves.

Many people who exhibit difficult behaviors do so because they don’t feel well. The sudden appearance of behavior problems may be a signal that the person does not feel well. Illnesses as common as a cold or ear ache can result in behaviors as inconsequential as grumpiness or as serious as head banging.

It is important to establish a working relationship with a good primary health care physician. Although this is easier said than done, the person will, especially if he has difficulty communicating, need a doctor who can help him to stay healthy and well.

Remember that physicians, like many other people who grew up in our “separate” society do not always understand (and may even fear) a person with substantial disabilities.

Don’t be afraid of telling the person’s doctor that you don’t understand a recommendation or finding. It is important to get a clear and straightforward answer to all of your questions.

Remember too that it is important to go beyond a concept of health as the absence of a disease or illness. “Feeling well” and “being healthy” involves everything from a balanced diet to a good night’s sleep. Help the person to achieve a state of “wellness.”


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