



# ***What Do I Do Next...?***

## **Supporting A Person With Difficult Behaviors After The Positive Approaches Workshop<sup>1</sup>**

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### **Introduction**

You know the feeling. You attend a workshop and you learn something new. Perhaps you now “see” an old problem with new eyes and you can’t wait to tell other people what you have learned. But as soon as you leave the front door, the ideas get fuzzy. Suddenly there is traffic on the road and bad news on the radio. Perhaps you race to pick up the kids and buy groceries. Once home, you find yourself on the phone, the kids are reluctant to do their homework, and you suddenly smell something burning on the stove. “Real life” is happening and the workshop now seems like a distant memory. You remember going to a workshop, you just can’t remember what the workshop was about.

What follows is a list of things you can do *after* the Positive Approaches workshop. Think of it as a prescription for the severely busy, or field notes for the forgetful. If you are worried about a failing memory, don’t worry. You may be fuzzy, but you will do everything you need to do as long as you are *personally* committed to making a difference.

- 1. Start Where You Are.** If you leave the workshop feeling that you have learned something new, that’s good. We can all benefit from new ideas. If you leave the workshop believing that the support you have been providing could be better, that’s good too. We can always find ways to improve our efforts. But if you leave the workshop feeling badly about yourself because you are not doing *all* you could be doing, stop worrying. There is only one place you could be right now, and that is exactly where you are.
- 2. “Go home” to the people you love. You can’t support another person unless you love the people right next to you.** When was the last time you kissed your honey like you used to always kiss your honey? When was the last time you stopped your busy schedule to *be with* your children? When was the last time you called your mother or your father on the telephone and reminded them about the good things they did for you when you were a child? When was the last time you called a good friend and told them how

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<sup>1</sup>This handout is an adapted from *Some Questions To Ask, Some Reasons for Asking* (1997). Both documents were prepared for and funded by the City of Philadelphia, Department of Public Health (v. 01 January 2005).

much they matter to you?

These questions are central for anyone who wants to *live* the principles of positive approaches. In fact, most of what we need to know about positive approaches can be learned when we “go home” to the people we love. Indeed, if you do not pay attention to the people who are closest to you, you will not be in a very good position to help a person who engages in difficult behaviors.

3. **“Going home” also means “looking in.”** Perhaps you have grown cynical and unhappy in your life. Try to remember the last time you felt hopeful. Try to remember the last time you experienced joy. What was happening then? What was important to you? Maybe you spend a good part of your life sacrificing for others. When was the last time you took care of yourself? There is a chance that the person you are supporting right now is missing some of the same things you are missing (the reason you can’t figure out what he or she may need is that you can’t figure out what you need). “Go home” to that place inside of you that used to be optimistic and hopeful. “Go home” to that person who once laughed and didn’t feel embarrassed or cut off. “Go home” to that person who knows how to rest and gain perspective. You’ll both be better for it. To paraphrase early educator Jean Clarke, “A person’s needs are best met by people whose needs are met.”
4. **Spend Time With The Person.** One of the most important (and pragmatic) things you can do to support a person who engages in difficult behaviors seems almost too obvious to state: *get to know the person!* It is too often the case that the people who develop interventions for the person don’t 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 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 what 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 sounding silly to the people who think the person cannot understand (they’re usually wrong).

If the person has no formal means of communication, tell the person that you would like to speak with other people. You might add, “If this isn’t OK for you, let me know the best way you can.”

You may wish to ask the person these questions posed by Mayer Shevin in his workshop *Negotiating and Discovering Positive Supports for People with Challenging Behaviors*<sup>2</sup>:

- a. *What's going well?*
- b. *What's not going well?*
- c. *What do other people think is the problem?*
- d. *Do you agree/disagree?*
- e. *What has helped in the past?*
- f. *What hasn't helped?*
- g. *Whom do you want help from?*
- h. *What do you want to learn to do?*

5. **Consider carefully your assumptions about people who act differently.** It is important to understand that everyone has biases. Each of us is affected by our upbringing and learning histories. Our biases may affect how we see someone who engages in difficult behaviors, and what we consider to be an appropriate response. Mayer Shevin, who is one of the most thoughtful people I know, states his assumptions about working with people “who act weirdly”:

- a. They already know they are acting weirdly.
- b. When it's not happening, they wish it wouldn't happen again.
- c. When it is happening, they either
  - i. Feel they can't stop it.
  - ii. Feel its the only thing they can do.
- d. After it happens, they feel embarrassed.
- e. They have lots of time to:
  - i. Develop an understanding of their behavior.
  - ii. Develop specific ideas about what it would take to change it.
- f. *People need to be supported in testing their own theories about their own behaviors.*

6. **Remember that relationships make all the difference in the world.** 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

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<sup>2</sup> If you would like to learn more about Mayer Shevin's work or contract with him directly, he can be reached at 210 Buckingham Ave., Syracuse, NY 13210; w: 315-443-5179 or by e: mshevin@mailbox.syr.edu.

knowing the person. Chances are the person has already made someone's life fuller. Be confident that she will make someone's life fuller again and again and again.

*Loneliness is the only real disability.*

7. **Become the person's champion (if you can't, help the person to find a champion).** We all need someone who thinks we are special. People with difficult behaviors often have no one who thinks about them with unconditional regard. Loneliness may be their most significant disability.

Become the person's champion. Make a commitment to help the person to find joy each day. Help others to see the person's strengths and gifts rather than limitations and shortcomings. Instead of being one more person who "works on" the person, be someone who "works with" the person. Speak about the person's struggles in a way that is respectful of those struggles. Let the person overhear you saying good things about him/her.

If you can't be the person's champion (for whatever reason), take responsibility for helping the person to find a champion. It's powerful medicine.

8. **Support the person in developing enduring, freely chosen relationships.** Although paid staff frequently develop meaningful relationships with an individual, they frequently leave. For this reason, it is critical to help the person develop relationships with people who are not paid to be in his/her life -- enduring, freely chosen relationships. Consider these ideas/strategies when helping a person to connect to others in the broader community:

- a. Never underestimate the corrosive influence of congregate models of care on your ability to help the person establish enduring, freely chosen, relationships.
- b. Move towards intimate housing arrangements and day supports.
- c. Make a list of the people who "hold the person's story." Help the person to make connections with these people.
- d. Be sure the person's story is told in a way you would want your own story told.
- e. Practice deliberate acts of kindness (in short, help the person to reconnect with these people with something to give).
- f. Make a list of the things a person loves to do.
- g. Find people in the broader community who love to do the same thing.
- h. Show up again and again...and again.
- i. Pay special attention to *who* goes with the person. The person providing support should ideally love the same activity.
- j. Get off the "disability dime."
- k. Help the person to make a contribution to the broader community.
- l. Never lose track of the importance of the mutual nature of relationships.

- m. Never lose track of joy (make fun a goal).
- n. Show up and be “present.” Show up again and again...and again.

9. **If the person continues to struggle with relationships, ask these questions from Linda J. Stengle’s book, *Laying Community Foundations for Your Child With A Disability*:<sup>3</sup>**

- a. Is the relationship between the person and the other person unbalanced?
- b. Are there too few mutual interests?
- c. Is this an activity that the person really wants to do, or is it something you want him/her to do?
- d. Is the activity long enough to encourage the development of a relationship?
- e. Is the other person afraid to get close to the person?
- f. Is the other person too busy to take time to get to know the person?
- g. Are needed accommodations being made to allow the person to participate fully in the activity?
- h. Could your presence be interfering with the development of friendships?
- i. Do the same people tend to participate, or are there different people every time?
- j. Are there breaks, joint projects, or committees which allow people to talk with each other freely?
- k. Is the other person in the relationship mainly out of a sense of charity?
- l. Is there enough structure to the activity?
- m. Is the person projecting an attitude that is keeping others away?
- n. Do you think that something is preventing the other person from seeing and appreciating the person’s good qualities?

10. **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<sup>4</sup>.

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<sup>3</sup>Adapted from Linda J. Stengle’s fine book “*Laying Community Foundations for Your Child With A Disability: How to Establish Relationships That Will Support Your Child After You’re Gone.*” You can purchase a copy by calling Woodbine House, Inc. at 1-800-843-7323.

<sup>4</sup>Consider how long you could live with people you would not choose to live with. Imagine how you would feel if someone made you live with other people who share certain characteristics. For example, imagine being told that you must live with people who have brown, or people who wear glasses, or people who are your height and weight. Assuming that people will ‘get along’ because they share a particular diagnosis is equally ludicrous. We choose our mates for far more complex reasons. When people with disabilities protest this kind of arbitrary selection

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.

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

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

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

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

- 13. Define the behavior so that your grandmother could see it.** It is important to describe the behavior in terms that your grandmother can easily understand; that is, the behavior should be written in everyday language that the dear woman could recognize. Avoid terms like “tantrum,” or “aggression,” or “self-injurious behavior,” or “self-stimulatory behavior.” Instead, describe what the person does (e.g., “hits the window,” “slaps

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of house mates, we put them on behavior programs or dispense psychotropic medications. When people without disabilities live with people they don't care for, they generally move!

people,” “bites his arm,” or “rocks back and forth”).

- 14. Ask, “Is this really a problem?”** Answering the question, “Is this really a problem?” may be relatively easy, or it may require some thought. It is quite possible the person does not consider “the problem” to be THE problem. Perhaps “the problem” is not the person’s problem at all. For example, Ruth refused to do tasks at the day activities center. When she attempted to leave the room, her care givers insisted that she sit down. They said that Ruth was “non-compliant.” But very few of Ruth’s care givers could or would tolerate hours of meaningless activity for little or no wage! It took time, but Ruth’s care givers 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 people, but hardly the kind of behavior that they would stick their nose into if the person did not experience a disability. Professionals often see it as their duty to “intervene,” even when a behavior is simply annoying or a part of a person’s personality.

Consider these questions adapted from the work of Ian Evans and Luanna Meyer (1985):

- a. *Is the behavior life threatening?*
- b. *Does this behavior provide a health risk to the person?*
- c. *Is the behavior more likely to become serious in the near future if the person does not change?*
- d. *Is this behavior serious to others?*
- e. *Is this behavior of great concern to the person’s friends, family, and care givers?*
- f. *Is this behavior getting worse and not improving?*
- g. *Has this been a problem for some time?*
- h. *Does this behavior result in damage to materials, furnishings, etc.?*
- i. *Does this behavior interfere with the person’s acceptance in ordinary community places?*

- 15. Ask, “What is the history of this behavior?”** Knowing when the person began to engage in the difficult behavior is a critical question. There is much to learn from identifying times when the behavior was not a problem and if life events are associated with the emergence of the problem. Life events can include the loss of a relative or favorite staff, the onset of a health problem, a change in the person’s place of residence or routine, etc. Consider these questions<sup>5</sup>:

- a. *When did the difficult behavior begin?*
- b. *What was going on in the person’s life when the behavior began?*
- c. *What was going on before the behavior began?*
- d. *Have there been periods of time when the behavior was more of a problem?*

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<sup>5</sup>Adapted from Al Vechionne’s (1997) *Trauma and Recovery Handbook: An Aide In Developing Programs for Individuals with Mental Retardation Who Suffer From Severe Emotional and Behavioral Disturbances*. Moretown, VT: Resources for Community Living.

e. *What was going on during these times?*

- 16. Ask, “Are there times during the day/week in which this behavior *never* occurs?”** If so, ask, “What’s happening? Is the person with people who she cares about? How do these people treat the person? Is the person doing things that she enjoys? Why do you think the person finds it enjoyable? Is the person being left alone? If so, why do you think that being left alone is helpful to the person?” Can you think of other questions? What are they?
- 17. Ask, “Are there times during the day/week in which this behavior occurs *often*?”** If so, ask, “What’s happening? Is the person with people who he does not care for? How do these people treat the person? Is the person doing things that he does not enjoy? Why do you think the person does not enjoy doing these things? Is the person being left alone? If so, why do you think the person is unhappy about being left alone?” Can you think of other questions? What are they?
- 18. Ask, “Is the person feeling well?”** 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’s health is deteriorating. Illnesses as common as a cold or seasonal allergy can result in behaviors as inconsequential as grumpiness or as serious as head banging. Consider these questions:

- a. *Is the person currently experiencing an illness? Are the person’s caregivers responsive to this illness or is the person expected to carry on as if nothing is wrong?*
- b. *Is the person comfortable? For example, is she or he hot or cold? Is she constipated? Does she have a tooth ache? How is her appetite? Is she sleeping well?<sup>6</sup>*
- c. *Does the person experience seasonal allergies?*
- d. *Does the person have a history of seizures or other underlying physical conditions that require ongoing medical attention?*
- e. *Are the person’s medications carefully monitored? Is the person experiencing any negative side effects from these medications?*
- f. *Is the person hurting herself? If so, what part of her body is she hurting and is it possible that this part of the body hurts?*
- g. *Are there other questions that can be asked? If so, what are they?*

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<sup>6</sup>An excellent resource for people with sleep problems is Mark Durand’s (1998) *Sleep better! A guide to improving sleep for children with special needs*. Baltimore: Paul Brookes. You can order the book directly from the publisher by calling 1-800-638-3775.

Perhaps one of the most important things you can do for a person who is experiencing medical issues is to help the person to establish working relationship with a primary health care physician. Although this is sometimes easier said than done, the person will need a good doctor to help sort through what can easily be a maze of symptoms.

If you are escorting the person to the doctor's office, be sure that his or her medical information is well organized. Don't be afraid to tell the 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 the absence of a disease or illness, and beyond therapeutic dosages of medication. "Feeling well" involves everything from a balanced diet to a good night's sleep. Help the person to achieve a state of "wellness."

**19. Ask, "Is the person experiencing a mental illness?"** Many people who exhibit difficult behaviors may do so because they are experiencing a mental illness. Illnesses such as depression, obsessive/compulsive disorders, and post traumatic stress disorder can play a significant role in the person's mood and affect. Consider these questions adapted work from Stephan Schwarz, M.D. and Stephen Ruedrich, M.D.<sup>7</sup>:

- a. *Is there a significant change in the person's behavior or mood which occurs in all settings rather than some settings?*
- b. *Is there little or no improvement in the person's behavior despite the availability of consistent, high quality supports?*
- c. *Has the person experienced a decreased ability to adapt to the demands of daily living (e.g., a deterioration in his or her ability to take care of himself or herself)?*
- d. *Has the person experienced decreased involvement with other people?*
- e. *Has the person lost interest in formerly preferred activities?*
- f. *Has the person shown some impairment in his or her perception of reality (e.g., responds to internal voices, displays beliefs which are obviously false)?*

**20. If the person has been given a mental health diagnosis, be sure you know what the diagnosis means to the person and the person's supporters.** People with difficult behaviors may have a legitimate psychiatric diagnosis. I say "may" because it is often assumed that a person has a psychiatric problem when, in fact, their behavior is a learned response to dysfunction in the environment. For example, Pamela learned, over the years, that biting the skin on her arms and hands was a powerful way to communicate her needs. Because she could not speak, people assumed she had nothing to say. They ignored or

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<sup>7</sup>Schwartz, S.A. & Ruedrich, S. (1996). Psychopathology update: On the distinction between mental illness and behavior problems in people with mental retardation. *Psychiatric Aspects of Mental Retardation Review* (15) 60-63.

misinterpreted her non-verbal attempts to communicate, *except* when she bit her arms and hands. In short, Pamela learned that the only way to get someone to listen is to engage in self-biting. The point of this story is that Pamela had several psychiatric diagnoses to explain her behavior. People saw the problem as an entity that resided inside of Pamela, but they never asked questions about the functions of her behaviors.

If a person has a *legitimate* mental health disorder, the following information should be available in his or her records<sup>8</sup>:

- a. the diagnosis (Axis I);
- b. the diagnostic criteria for this disorder;
- c. a description of how the person behaves when he or she exhibits the corresponding diagnostic criteria;
- d. a description of how the person might *feel* when experiencing the illness (whenever possible, ask the person to describe how he or she feels and/or read first-person accounts by people who experience the disorder);
- e. if the person is taking medications, a listing dosages, along with anticipated effects, and negative side effects;
- f. a plan for evaluating the effectiveness of the treatment and regular meetings to review progress.

If the above information is not available in the person's records, and/or, if the person and his/her supporters are unaware of the above information, take responsibility for organizing what needs to be organized.

- 21. Remember that when people are having a hard time, they generally need *more* support, not *less*.** It is generally true that human beings need *more* support, not *less* support when they are having a difficult time. And it is also true that how one person defines support can be different than how another person defines support.

Sadly, many people with disabilities are not supported when they are having a difficult time. Indeed, things that help them to feel better (we call them "reinforcers") are often denied the person needs them most. For example, Christopher is denied a chance to listen to his radio (his prized possession) when he has been "non-compliant." On the other hand, Carole -- Christopher's group home manager -- smokes cigarettes, lots of them, when she learns that the Agency is requiring her to do extra paper work. Not only does Carole drag her feet about the paper work (non-compliance), she "reinforces" herself over and over again (with cigarettes) while complaining to a co-worker.

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<sup>8</sup>Adapted from *The Six-Step Process* by Kathy Grasmeyer, Dina McFalls, David Molotsky, and David Pitonyak (1997). Philadelphia: Philadelphia Coordinated Health Care Services.

Make a list of the things that help the person to feel better when he is upset. Help the person to do these things more often. Next, make a list of things that make the person feel worse when he is upset. Do these things less often. Finally, compare the lists of things that help with the things that don't help with the current "behavior plan." Which list does the plan most look like -- the things that help or the things that don't help?

People may be concerned that supporting the person after he or she has engaged in the behavior may "reinforce" the behavior. They may be afraid, for example, that going for a walk with the person when he or she engages in head banging will teach the person that head banging leads to walks. Look them straight in the eye and say, "Well, yes, if the *only* way he can go for a walk is to bang his or her head, he will bang his head more often. The question is, 'Why does he have to go to so much trouble to do what we do every day?' (Tell the Carole in your life that these "reinforcers" help us to cope with life's ups and downs).

**22. Talk more when the person is on track. Talk less when the person is engaging in difficult behaviors.** If I were abducted by aliens tomorrow, the one thing I would want a person's supporters to know: talk more when the person is on track and less when the person is engaging in difficult behaviors. Tell the person that you want to help and then stop talking. Wait until the person begins to calm, or relax, and then provide the person with support (e.g., "That's great. I'm glad you're feeling better. How can I help you?"). And then, by all means, follow through on your promise to be helpful!

**23. Stop trying to fix the person. Help the person to add on.** It is critically important to show respect for a person's struggles<sup>9</sup>. Instead of "working on" the person, try "working with" the person to find a solution to the person's struggles.

Sometimes, the trick is to let go altogether of the need to "fix" the person. Help the person to "add on"; that is, rather than trying to stop the person's difficult behaviors, focus on teaching alternative skills. If *you* can't think of an alternative, chances are good the person will have trouble learning one!

Consider this simple, but elegant way of putting together the information you have learned, adapted from the work of Michael Smull and Susie Harrison<sup>10</sup>:

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<sup>9</sup>One of the best resources I know is Larry Brendtro, Martin Brokenleg, and Steve Van Bokern's *Reclaiming Youth At Risk*. You can order this fine book by sending \$18.95 to National Education Service, 1610 W. Third Street, P.O. Box 8, Bloomington, ID 47402. Be sure to include your name, organization, address and phone number.

<sup>10</sup>Michael Smull and Susan Burke Harrison's work on essential lifestyle planning and supporting people with difficult behaviors can be obtained by writing to the National Association of State Mental Retardation Directors, Inc., 113 Oronoco Street, Alexandria, Va. 22314.

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

**24. Build a support plan *with* the person.** 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<sup>11</sup>. 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?"

- a. *How can we help the person to achieve wellness?*
- b. *How can we expand and deepen the person's friendships and connections with family?*
- c. *How can we increase the person's presence in local community life? How can we help the person to have more fun?*
- d. *How can we help the person to have more control and choice in life?*
- e. *How can we enhance the person's reputation and increase the number of valued ways that he or she can contribute to community life?*
- f. *How can we assist the person to develop competencies?*
- g. *How can you build the support you need? How can you support the person's other supporters?*

**25. Build support 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 care-giver or teacher whose competence is being judged by this "compliance/ obedience" yardstick. The care giver/teacher often expends great energy trying to suppress the person's behavior in order to maintain "competence" (in many of our workplaces it is acceptable to share knowledge but not to share power).

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<sup>11</sup>These questions are adapted from John O'Brien and Connie Lyle-O'Brien's (1987) *Frameworks for Accomplishment*. Lithonia, GA: Responsive Associates. For additional information, call (770) 987-9785 or write: Responsive Associates, 58 Willowick Drive, Lithonia, GA 33038.

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

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

Ask yourself,

- a. *Am I comfortable with myself when this person is engaging in difficult behaviors?*
- b. *Am I happy with the way I conduct myself when I am doing my work?*

Allow yourself to dream about handling difficult situations in a way that feels supportive and constructive. Imagine a classroom or workplace that you are proud of.

- c. *Is there a difference between your vision and your reality?*
- d. *How is your vision different than your reality?*
- e. *What do you need?*

## Resources from the ANC Bookstore

***Learning to Listen***, Herb Lovett, Brookes, (1996). Herb's book is timeless. A joy to read. \$23.00

***Movement Differences and Diversity in Autism/Mental Retardation*** Anne Donnellan & Martha Leary, DRI Press, (1995). Appreciating and accommodating persons with communication and behavior challenges. The book that started the revolution. \$16.00

***Thinking in Pictures***, Temple Grandin (1995). Temple's latest - fascinating, insightful, upbeat, and informative. \$23.00

***Nobody Nowhere***, Donna Williams (1992). In her own unique voice Donna Williams speaks for thousands who have yet to be heard. \$10.00

***Somebody Somewhere***, Donna Williams, Random House, (1994). The continuing story of an extraordinary woman. \$14.00

The books listed above can be ordered from the AUTCOM Bookstore. Let AUTCOM know the number of copies of each title you need, total the cost, and add 10% shipping (min. \$2.00). Enclose a check, PO or credit card authorization for the amount to: ANC BOOKSTORE, PO 5202, Madison, WI 53705 (WI res. add 5% sales tax) TEL. ORDERS: 1-800-378-

0386. Be sure to include your name, address, and telephone number. If using MasterCard or VISA, include your card number and expiration date. Write for a complete listing!

## Other Helpful Resources

- Amado, Angela Novak (1993). *Friendships and community connections for people with and without developmental disabilities*. Baltimore: Paul H. Brookes.
- Arnot, R. (1997). *Dr. Bob Arnot's revolutionary weight control program*. New York: Little, Brown and Company.
- Chodron, P. (1991). *The Wisdom of No Escape And The Path of Loving-Kindness*. Boston: Shambhala.
- Chodron, P. (1994). *Start Where You Are: A Guide To Compassionate Living*. Boston: Shambhala.
- Copeland, M.E. (2000). *The loneliness workbook: A guide to developing and maintaining lasting connections*. Oakland, CA: New Harbinger Publications, Inc.
- Covey, S.R., Merrill, R., Merrill, R.R. (1994). *First Things First*. New York: Simon and Shuster.
- Flannery, R.B. (1998). *Post-traumatic stress disorder: The victim's guide to healing and recovery*. New York: Crossroads Publishing Company
- James, B. (1994). *Handbook for the treatment of attachment-trauma problems in children*. New York: The Free Press.
- Kasl, C. (1999). *If the Buddha dated: A handbook for finding love on a spiritual path*. New York: Penguin Books.
- Moore, R. (1991). *Awakening the Hidden Storyteller: How To Build a Storytelling Tradition In Your Family*. Boston: Shambhala.
- Prather, H., Prather, G. (1990). *Notes to Each Other*. Bantam Books.
- Prather, H. (1998). *Spiritual Notes to Myself*. Conari Press Books.
- Schaffner, C.B. & Buswell, B. E. (1992). *Connecting students: A guide to thoughtful friendship facilitation for educators and families*. Colorado Springs, CO: Peak Parent Center, Inc.

**The books listed above are widely available. You can visit a local bookstore and or visit one of the online book sellers such as [www.half.com](http://www.half.com), [www.powells.com](http://www.powells.com), or [www.amazon.com](http://www.amazon.com) . C. Beth Schaffner and Barbara Buswell's booklet, *Connecting Students* can be obtained by calling the Peak Parent Center in Colorado Springs. Call: 719-531-9400.**

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## Video Tapes & Study Guide:

**A 2 hour video with study guide** of David's presentation *Supporting A Person with Difficult Behaviors/Supporting the People Who Care* is available for \$10 from the Arizona Positive Behavior Support Project, Institute for Human Development, Northern Arizona University, Box 5630, Flagstaff, AZ 86011. Please make your check out to "Institute for Human Development." For additional information, call 520-523-8714.