

*When your child engages in difficult behaviors...*

# Notes for Parents

David Pitonyak

Several years ago I was asked to speak to a group of parents in Vermont. The title of the presentation was "Supporting Children With Special Needs." Five minutes into my talk, a parent stood up and interrupted me. She insisted that I stop referring to her daughter as someone with "special needs" (I had been using the term a lot).

"My daughter does not have special needs" she said. "My daughter has the *same* needs as anyone else. She has a need to live at home with her family. She has the need for a good education, friends, fun and a supportive family. Sometimes you professionals — in your efforts to provide special services to people — forget the ordinary, everyday things that people need."

She must have known that I was embarrassed. I'm sure I turned eighty shades of red as I muttered through the rest of my presentation. After it was over, she put her hand on my



shoulder and said, "You'll be fine."

As awkward as I felt about the evening, I felt grateful too. I learned one of the most important lessons I have ever learned as a professional: sometimes, in our efforts to provide "special" services to people, we often forget the ordinary things people need everyday: friends, family, interesting and fun things to do, safety and security, and a chance to make a contribution to the larger community (in short, a chance to belong).

What follows are 10 things to remember if your child, because he or she exhibits difficult behaviors, is at risk of *not belonging*. If you don't have the time or energy to read one more word, remember these two ideas:

*Taking care of yourself is one of the most important things you can do. If you don't, it will be very difficult to take care of anyone else.*

*Remember that your child's problem behavior(s) has meaning. Finding out what your child needs is the first step in supporting your child, and the people who love your child, to change.*

## 1.

### **Be mom and dad first.**

Chris Heimerl writes, "Of all the hats you must wear — advocate, care provider, therapist,

teacher — the most important is Mom and Dad. Your love is the most powerful treatment any of us can imagine. If all the other stuff you have to do first interferes with being a parent, stop. Someone else can help with the other stuff, but no one else can be Mom and Dad."

## 2. Think of challenging behaviors as "messages"

*Difficult behaviors result from unmet needs.* In a sense, difficult behaviors are "messages" which can tell us important things about your child and the quality of his or her life. Here are some examples of the kinds of "messages" your child may be conveying with their behavior:

### ***"I'm lonely."***

Michael's brother was invited over to a friend's house to watch television.. 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."***

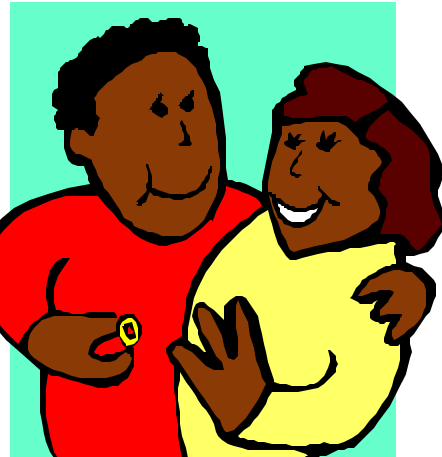
Roberta's sister is a doctor at the local hospital. She has her own house and is her parent's pride and joy. Roberta works all day at a sheltered workshop where she packages plastic forks and knives. She lives at home and is tired of packaging. She wants to get a real job. Roberta's case manager says she day dreams 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 desert when he gets home. John laughs when the bus driver threatens him with time out.

### ***"I don't feel safe."***

Conrad uses a wheel chair and is not able to defend himself from attacks. One of the people in his day program can be aggressive and Conrad



worries that he will be hurt.

### ***"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 her father's health. 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 did not know how to use words or sign to let other people know what she was thinking. She lives at home with her parents where she has learned that the best way to get be "seen" is to bite your arms. It hurts, but it is the only thing that "works."

### ***"My ears hurt."***

Walter hit his ears with his fists. His job coach wanted 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 stopped hitting his ears.

### ***"My body does not move like I want it to."***

Aron wanted to order a hamburger at a restaurant, but his mouth kept saying, "I want pizza." When the waiter brought him pizza, he became so upset he knocked it on the floor. Later, at home, he typed to his mom, "I wanted a hamburger but I couldn't stop saying, 'I want pizza.'" Aron experiences differences from other people in the way his body moves (see Anne Donnellan and Martha Leary's book, *Movement Differences and Diversity in Autism/Mental Retardation*:

*Appreciating and Accommodating Persons with Communication and Behavior Challenges* for additional information (ordering information on the last page).

Obviously there are many needs that your child might be expressing through his or her behavior. A single behavior can "mean" many things. The important point is that difficult behaviors do not occur by accident, or because someone has a disability. Difficult behaviors are expressions of real and legitimate needs. All behavior, even if it is self-destructive, is "meaning-full."

Ask yourself, *"Is my vision for my child similar to the vision I have for my other children? (or the vision other parents have for their children). When I think about what my child needs, do I focus on disability-related needs or do I think about things like friendships, fun, a sense of belonging?"*

### **3. Learn about person-centered planning.**

In the book, *A Little Book About Person-Centered Planning* Connie Lyle O'Brien, John O'Brien, and Beth Mount describe the powerful differences between traditional approaches and person-centered planning. Unlike traditional approaches to planning, which ask questions like, "What's wrong with you?" and "How can we *fix* you?", person-centered planning focuses on questions like "What are your capacities and gifts and what supports do you need to express them?" and "What works well for you and what does not?" and "What are your visions and dreams of a brighter future and who will help you move toward that future?"

Describing the roots of person-centered planning Lyle O'Brien, O'Brien, and Mount write (1998):

"Person-centered planning did not ignore disability, it simply shifted the emphasis to a search for capacity in the person, among the person's friends and family, in the community, and among service workers. A person's difficulties were not relevant to the process until

how the person wanted to live was clear. Then it was necessary to imagine, and take steps to implement, creative answers to this key question, "What particular assistance do you need because of your specific limitations (not labels) in order to pursue the life that we have envisioned together."

### **4. Don't assume anything.**

It is easy to make the mistake of underestimating your child's potential because of his or her labels or because he has failed to acquire certain skills. This is a tragic mistake. I have worked in the field for 15 years and I am less confident in my ability to predict how much a person understands or how much he will be able to accomplish with every passing day.

For example, the new AAMR definition of mental retardation states that an individual's success or failure in life is determined by the quality of his supports rather than a missing gene or "faulty" body chemistry. In short, professionals like me used to doom people because of an arbitrary diagnosis. What some of us have finally woken up to is the fact that nothing dooms people more than a lack of support.

You can speak volumes to your child about his self-worth by always including your child in conversations and explaining things as clearly as you can. Even if you doubt your child's ability to understand your words, know that at the very least your child will understand the tone of your voice; make sure it reflects dignity and respect as often as you can. Never speak about your child as if he was not in the room.

### **5. Remember that relationships can make all the difference in the world.**

Loneliness may be the most significant disability your child will ever face.

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.

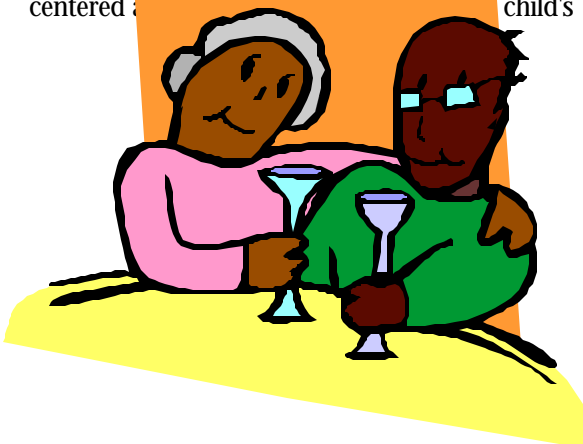
All too often, the only relationships people have are with paid staff. Although staff can offer a great deal, they change jobs frequently or take on new responsibilities. The resulting instability can be devastating to someone who is fundamentally alone.

Involve your child with other children at a young age (children with and without disabilities). It is easier to learn about the importance of relationships when their importance has been clear over a life-time.

It's easier to be a friend when you have friends who know something about friendship. Insist that your child be included in regular classrooms. Inclusion is a powerful way of building relationships.

And don't let anyone fool you into thinking that inclusion of children with disabilities in regular classrooms is a bad idea. Doing it poorly is a bad idea. Doing it well is good for *all* children.

Make a commitment to learn more about personal futures planning and other person-centered : child's



future. Do it today!

## **6. Help your child to have more fun.**

Fun is a powerful antidote to problem behaviors. Count the number of things your child enjoys, the number of places she likes to go. Compare this to the number of things other children enjoy, the number of places other children go. Ask yourself, "Is my child having fun? Is she experiencing enough joy? Is this an interesting life?"

People with substantial 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.

Sadly, many people with disabilities are put on reward schedules for good behavior. The very few things that they enjoy are used contingently to reinforce compliance (talk about spoiling a good thing).

Help your child to add on to her list of interesting (and really fun) things to do.

Spend time in regular community places where people hang out. Make fun a goal.

## **7. Take care of yourself, take care of your partner, and join with other parents to support each other.**

Many parents suspend their own dreams and

aspirations the day their child is born. They adopt an identity of "parent of a child with a disability," putting their own needs on hold like a video tape that can resume at the touch of a button.

Many parents feel isolated because their child has a disability. They feel obligated to suspend their relationships with other people because the work of parenting their child seems all-consuming. Or they feel that other people will have difficulty understanding their child's disability; there is a deep fear of rejection. As one parent put it, "It is better to be alone than to feel my child's hurt when he is rejected."

Chris Heimerl writes: "Take care of yourself, take care of your partner and join with other parents to take care of each other. Before you became a parent you were a partner in a relationship that had enough love, nurturing, and respect to want kids. Don't lose sight of that relationship. Before you were a partner, you were a person that someone found attractive, vital and loving. Don't lose sight of that person."

Get connected and stay connected with parents of children with and without disabilities. Join organizations made up of parents who fight for the inclusion of their children in every aspect of community life.

Remember that the vast majority of innovations that have taken place in our service delivery system happen because parents and their children have become dissatisfied with "what is." If you join forces with other parents you can make a significant difference in your child's life.

Learn about the laws and regulations that help and hurt your child's inclusion in community life. Speak up whenever your child's future is at stake. Above all, be respectful of people who disagree with you while remaining steadfast about your beliefs.

## **8. Help your child to make a contribution to others.**

Lou Brown has said that the least amount of difference between a child with disabilities and a child without disabilities may be the day that they are born, naked to the world. But then, because of the way our society separates the child with disabilities into "special services," he or she becomes "different."

Perhaps the most devastating effect of this separation is that the child with a disability does not learn what he or she can contribute to others. In a sad kind of way, the child becomes the "needy one." Being needy — all the time — is dispiriting. Making a contribution to others — to your family, friends, and the larger community — is good for you. It's good for the soul. It's good for the heart, the brain...it's probably a biological imperative to give. One day we may learn that the world actually revolves on its axis not because of the laws of physics, but because of the love we give to others. As John Bradshaw writes, "Our identity is the difference about us that makes a difference."

The real danger, of course, is that if enough people begin to think of you as "needy," you will begin to believe it too.

We all need to be needed.

It is my experience that people with difficult behaviors especially need to be needed.

Help your child to find a way to make a contribution to others. Start young because learning to give is a lifelong endeavor. Help your child 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?"). Things as simple as helping with household chores or helping out at church can teach your child that she *can* make a contribution.

## 9. Instead of ultimatums, give choices.

If it is 9 p.m. and you are sitting down to read these words, chances are good that you have made hundreds, if not thousands, of choices since 7 a.m.. You may have decided to wear blue socks when getting dressed. You may have decided to not to wear a heavy sweater, hoping the warmer weather would prevail. You may have decided to skip breakfast, buy unleaded gas, work on a report, clean the garage, take a hike, watch a football game, etc..

You may have made more monumental decisions: purchased on a house, stopped drinking, decided to remarry, purchased a major appliance, agreed to surgery, etc. The point is, we humans are decision making machines.

Many people with disabilities have little or no control over their own lives. Many of the decisions that we take for granted -- such as what to wear and whether or not to have a cup of coffee -- are made by other people. How would you feel if you lived such a life?

The mistake we make with children and adults who have disabilities is that we assume that because they don't always make good decisions about *some* things they ought not to make decisions about *anything*.

Always remember that our tendency is to become directive and negative when our children are engaging in problem behaviors. We tend to take control when our children are out of control. Ironically, our children may need more control not less when their behavior is disturbing.

Choice is a powerful alternative to punishment. If your child's behavior challenges you, help him or her to find more desirable ways to express the needs underlying his or her 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? That will give you a chance to calm down and then we can talk about what you need?").

Allow your child 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.

Make sure your child is invited to his or her IEP or IHP meetings. It is important that he/she have input whenever possible. This is especially true when a problem behavior is being discussed (imagine how you would feel if people were trying to change your behavior and never stopped to ask you what you think). It is also important that your child be able to say "no."

If your child does not speak, ask anyway (suggest that he find a non-verbal way of letting you know what's needed).

Don't assume that helping your child 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 children without their input, and if the limits are part and parcel of a life in which your child is powerless, even your best advice may even be interpreted as one more statement of "do it my way or else."

Expect a general disregard for advice when the

person receiving the advice is never heard. Rebellion may be a healthy strategy for someone who is out of power. As Tom Harris put it, "It's better to have bad breath than no breath at all.

**[Author's note: I heard the expression "Instead of ultimatums give choices" years ago, but I'll be darned if I remember where. My apologies to the author of this succinct phrase, wherever you are...]**

## 10. Establish a working relationship with a good primary health care professional.

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, 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 your child 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, your child, especially if he has difficulty communicating, will 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 your child'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 your child to learn about "wellness."

### References

Lyle O'Brien, C., O'Brien, J. & Mount, B. (1998) Person-centered planning has arrived...or has it?" In O'Brien, J. & Lyle O'Brien, C. (Eds). *A little book about person centered planning*. Toronto: Inclusion Press.

**Ordering Anne Donnellan and Martha Leary's book about movement differences.** Anne and Martha's book *Movement Differences and Diversity in Autism/Mental Retardation: Appreciating and Accommodating Persons with Communication and Behavior Differences* can be ordered through the Autism National Committee Bookstore (AUTCOM). Telephone orders: 1-800-378-0386. Online: [www.autcom.org](http://www.autcom.org)

**I can be reached at Imagine, 3694 Mt. Tabor Road, Blacksburg, VA. 24060 (w: 540-552-5629) or [Dimagine@aol.com](mailto:Dimagine@aol.com). You can also visit my web site: [www.dimagine.com](http://www.dimagine.com)**

