



# North Dakota Parent to Parent Program Guide

North Dakota Parent to Parent (NDP2P) supports and connects families of individuals with special health care needs and disabilities.



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## ND Parent to Parent Program

Parents who have just learned of a child's diagnosis with a disability or special health care need often feel helpless and alone. Talking with another parent who has experienced a similar situation can help families to feel less alone and more hopeful.

Parents may want to talk to someone who can give specific guidance about care for their child and day-to-day coping with the effects and life changes of living with a disability or special health care need. Sharing ideas and specific suggestions can bring a sense of security to families who wonder what to do when their child does not fit the usual patterns of growth and development. By sharing ideas, the Referred Parent develops concrete skills and suggestions as well as hope for the future.

Children with special needs may require special services. Locating and negotiating one's way through a maze of needed programs and interacting with a range of professionals are skills that Support Parents can teach. The Support Parent who has successfully learned how to be an advocate for their child has a unique and valuable set of skills to share with another family.

“Experienced parents understand that the event that has altered their lives is painful. Parents do not have the power to change the event, but they can change the way they think about it. Parents have the power to choose to live a joyful life; they are not compelled to live in constant grief. They have a choice for life and celebration. New parents may not know this. Experienced parents are not saying it is easy, but they can teach this. Supporting parents can plant the seed.”

-Janice Wright



*Bloom Where You  
Are Planted*

## History of ND Parent to Parent

The Family Involvement Subcommittee of the Interagency Coordinating Council on Early Intervention spent several years, from late 1993-1998 researching, gathering information, resources and partnering with other parent to parent programs across the country. Through their foresight, strength and oversight to pursue a parent to parent program for ND we proudly identify them as the founding mothers of the ND Parent to Parent Program: Donene Feist, Tammy Stuart, Deb Clarys, Jane Nelson, Kathy Desjarlais, Twyla Bohl, Ruth Antal, Evy Jones Hartson, Yolanda Fransen, and Rosa Backman.

Additionally, we acknowledge the professional partners who provided guidance and support: Deanne Horne, Rob Graham, Deb Baldson, Keith Gustafson, Tammy Gallup Milner, Mary Lindbo and Alan Ekblad.

Lastly, we acknowledge the woman who provided guidance and mentorship throughout this time and beyond to develop a parent to parent program to North Dakota. *The late Betsy Santelli, the Beach Center at the University of Kansas, worked many years assisting and guiding us, and connecting us to other programs and their mentor directors across the country as we pursued this journey. She worked for over 25 years for and with children with special needs and their families.*



***For all those who worked tirelessly to achieve this dream for ND families we dedicate this manual.***

Join the Family Voices of North Dakota  
Parent to Parent Program at BigTent.com  
going to the link below

[www.bigtent.com/groups/ndp2p](http://www.bigtent.com/groups/ndp2p)

This site will:

- Give you the opportunity to chat and connect with other parents 24/7, post questions, get answers, meet new people, get helpful tips from others, as we are all in this together.
- Allow you to view a calendar of events for ND families.
- Allow you to add events to the calendar.
- Allow you to share photos with other parents.

Big Tent is very interactive, fun and secure!

If you have any questions about BigTent,  
please call Missi at 290-8711



## North Dakota Parent to Parent Program

Family Voices of ND PO Box 163  
Edgeley, ND 58433  
1-888-522-9654  
[www.fvnd.org](http://www.fvnd.org)

Thank you for showing interest in the Parent to Parent Program. Your participation is vital and very much appreciated. It will prove to be greatly rewarding. Email and internet access have opened new opportunities for parents to locate information, but the personal contact that we can offer each other is important. Emotional support is crucial and must be recognized and validated.

This Parent to Parent Guide is designed to introduce you to the ND Parent to Parent program and to acquaint you with roles parents play in supporting each other. Good listening skills are imperative and we will be offering suggestions on how to enhance your skills. The guide also provides helpful tips and information about supporting other parents.

Lastly, this manual is designed to serve as reference to you as you support other parents. If you feel you need assistance or have any questions or concerns please feel free to contact me.

Once again, thank you for your support. We look forward to having you in our Parent to Parent Network.

Sincerely,

Missi Baranko  
NDP2P Coordinator

# Parent Support 101

## What is a Support Parent?

NDP2P has trained volunteers called Support Parents. They are raising children with special health needs. They have participated in training preparing them to be "matched" or connected with Referred Families also raising children with special health needs.



## What is taught at training workshops?

The workshop covers things such as communication skills, listening skills, and the grief process. Time is also spent covering what it means to be a Support Parent.

## What are the responsibilities of a Support Parent?

When NDP2P connects a Support Parent with a Referred Parent, the Support Parent is expected to call or email their match as soon as possible, preferably within 48 hours. The Support Parent should take the time to listen and be supportive. The Support Parent calls the NDP2P staff if any problems arise.

## What if NDP2P asks a Support Parent to take a match at a bad time?

A Support Parent can always decline to take a match - if your child has the flu, or if you don't feel like talking on the phone, or for any reason at all. We all have times when we just need to say no - it is OK.

## How often is a Support Parent called upon to take a match?

Some Support Parents are called fairly often; others are seldom called. It depends upon the disabilities or health conditions that NDP2P is asked to address.

## Will I have to attend meetings or pay dues?

NDP2P does not mandate that you attend regular meetings. From time to time, we may try to organize educational or social gatherings for Support Families and Referred Families, but attendance is not required.



## How does it work?



A parent is referred to the North Dakota Parent to Parent (NDP2P) Program or a parent contacts the program requesting to be matched with another family.

NDP2P Program gathers all pertinent information from parent requesting to be matched with another family.

NDP2P staff selects or locates appropriate match for requesting/referred parent.

NDP2P calls the selected Support Parent to see if they can assist the requesting parent. If it is not a goodtime for the volunteer Support Parent to provide support, they may refuse any referral at any time with no questions asked. If the Support Parent accepts the referred parent....



NDP2P gives the Support Parent the referred parent's information and asks them to contact the family within 48 hours. NDP2P contacts the requesting/referred parent and gives them the Support Parent's contact information and tells them they should expect contact soon from the Support Parent.

NDP2P follows up with both referred and support parents two weeks after the information is shared. NDP2P also asks both parents to fill out a survey 2 months after the first connection is made. If the parents are not able to connect they are asked to contact NDP2P.



# Philosophy of ND Parent to Parent

NDP2P believes in the innate strength of families. Therefore, our services affirm families' strengths and enables families raising children with special health needs to obtain for themselves the services and support they need. We believe that professionals can give a family direction and ideas, but in order for families to become empowered, they need the confidence to explore and discover their own personal strengths. Trained Support Parents can assist Referred Families facing this process of discovery, as their support helps Referred Families to develop strong self-



esteem, a positive attitude toward their children and a feeling of being "connected" with community resources and supported and affirmed by their peers.

Families need support from other families. To sit back and pity a family doesn't help them to help themselves. The best we can offer families is a positive self-esteem, pride in themselves and in their families and the ability to seek the service they need. NDP2P contact can help families to regain their sense of strength, purpose, and independence.

## ND Parent to Parent Goals:

- ♦ To decrease family stress and isolation by matching experienced Support Parents with families whose children have a special health care need or disability.
- ♦ To increase families' knowledge and use of community resources.
- ♦ To increase the confidence and skills of families by providing emotional support, positive parenting models and ongoing opportunities to acquire specific information and /or training.
- ♦ To be an ongoing resource to families, health care providers, educators, policy makers, agency directors and others in the design, implementation and evaluation of programs for families.

# Privacy Policy

*(For all FVND Staff and Volunteers - to include Support Parents)*

- ⇒ ND Parent to Parent is dedicated to maintaining the privacy and health information that individuals disclose to coordinators and volunteers of our programs.
- ⇒ We understand that information about an individual and their family is personal. We will safeguard and respect the privacy of individuals and their families.
- ⇒ We will protect all information that is provided to Parent to Parent including names, addresses, birth dates and medical information.
- ⇒ ND Parent to Parent will disclose information only with specific permission from a parent or guardian of a child or when mandated by law.
- ⇒ An individual has the right to confidential communication and the right to request that our office communicate at a particular location or in a particular manner.
- ⇒ Any authorization provided to us regarding the use and disclosure of identifiable health information may be revoked at any time.

If an individual believes their privacy has been violated,  
they may file a complaint.

To file a complaint with our organization, contact  
Donene Feist, Director, Family Voices of ND,  
PO Box 163, Edgeley, ND 58433



## Role of the Support Parent

As a Support Parent, you are being asked to provide support, comfort, reassurance and hope to parents who are confronting the challenges of raising a child with special health care needs and disabilities. It is most important that you ***be yourself***. Be spontaneous, genuine, relaxed and informal.

While sharing your personal knowledge and experience, the following statements will serve to guide you in your role as a support parent.

1. In your first contact with the parent, allow them the first opportunity to talk. If the parent seems reluctant to talk, offer to share your own experiences in an attempt to "break the ice". Once the parent begins to talk, sit back and listen to what they have to say. Reassure them, if you can, that you understand why they feel the way they do (as opposed to "I know how you feel" since that is unique to each individual). Allow the parent to express his/her feelings and concerns.
2. Don't be overly positive in your attitudes about having a child with a disability. It may be some time before they accept the thought that raising a child with a disability does have its very own pleasures and rewards.
3. Avoid being judgmental. Although you may not agree with what the parent says or how he/she feels, it is more important that you are accepting and compassionate.
4. Do not give advice. You may wish to share suggestions, experiences and offer options, but do not instruct or insist. Leave the decision making to the parent. For example, rather than saying, "You should...", instead say, "Have you considered...?" or you may prefer to say, "I found it helpful to...have you considered trying...?". By being indirect, you relieve yourself of any responsibility resulting in advice that failed to work.
5. You can help parents with understanding medical and rehabilitative terms and vocabulary, but do not attempt to interpret diagnoses or offer medical advice.

6. Don't be critical about the services or care the parents have chosen for their child. If the parents are satisfied with the services their child is receiving, don't intervene. There may be unknown reasons, such as cultural or religions.
7. If you visit the parent, be sure to relate to the child by holding, playing with or talking to him/her. You may be the first person outside the family who relates to the child in a positive manner. You may want to bring along pictures of your child. It may help to make your contact more genuine. Use your judgment about showing these pictures on your first visit.
8. Be a strong support for your new parents in the beginning. Allow the parent to lean on you by offering the support needed until they are able to cope with the situation. However, care should be taken to discourage an unhealthy dependence.
9. Discuss any challenges you may be having in your relationship with the new parent with the Parent to Parent coordinator. You are in no way expected to maintain a strained or uncomfortable relationship.
10. If you feel uncomfortable or need assistance, call the Parent to Parent coordinator. The coordinator is there to assist you with any difficulties, problems or questions that you may have. You are not alone.
11. If it is a bad time for you to talk with another parent, feel free to just say "no". Parent to Parent understands that life sometimes gets crazy and you can't be all things to all people. Your "no" will be respected.





# Guidelines for Telephone/Email Contact

**PURPOSE:** *To offer emotional support by providing an accepting, honest, caring atmosphere, which gives the referred parent an opportunity to discuss feelings, concerns or difficulties that they might be having. Also, to share information about the child's special needs, parenting and appropriate resources and services.*

**HOW:** By being an effective, non-judgmental listener. Communication skills, including "active listening" will help you to convey:

- You care and you are concerned
- You are there to listen and talk about their concerns
- You will do your best to understand

## Getting Ready to Call

1. Be relaxed and ready to listen.
2. You will probably be nervous beforehand; most are.
3. Set aside enough time for the call. The first contact with a family might take just a few moments or the conversation might last for an hour.
4. Consider whether the time will be convenient for your referred parent.
5. Refer to information given to you about the family.
6. Focus on the basic areas you want to cover. Try to keep a balance between interests in the parent and interest in the child. Don't forget the spouse, siblings or significant others. Fathers need support also, so don't assume you must talk to the mother only.
7. Be sensitive to what your attitudes and verbal cues are conveying.

# The First Contact

## 1. When to contact

- At your earliest convenience after receiving the referral (preferably within 48 hours) If the parent is difficult to reach, try calling at several times of the day. You may also email them if that is what the referred parent prefers.
- If you cannot reach the parent after several days, call your Parent to Parent coordinator and tell her so she can contact the parent directly.

## 2. Introduction

- Introduce yourself by name and as a Parent to Parent Support Parent.
- Say that you are the parent of a child with special needs.
- You may mention the name of the person who referred the family in order to remind them how their request for support came to you.
- If calling, ask if this is a good time to talk. If not, ask when you can call back and also leave your name and phone number. Invite the parent to return your call, but don't expect they will. They may not have the time or may be too nervous to initiate contact.
- Ask if the parent is familiar with Parent to Parent. Emphasize that we provide parent to parent support and mention the resources (website, e-newsletter, BigTent etc.) available.

## 3. Door Openers – finding common ground

- Mention your own experience very briefly, noting what you share with the referred parent: "My son, Frank, also has cerebral palsy and we attend the same clinic you do." Remember that every child is unique and that a diagnosis does not define a child or a family. While there may be similarities between your children, no two family situations are identical.
- When a child has just been diagnosed, the family most likely is not thinking about what classroom setting will be appropriate three years from now. They are dealing with the immediate practical and emotional concerns raised by their child's diagnosis and situation.
- Refrain from mentioning serious problems or complications, which do not surface for every child, such as diabetes, which affects only some children with cystic fibrosis.
- Suggest that sometimes it is helpful to talk with another parent who has gone through a similar experience.
- Ask the parent about her/himself, the child, and the feelings they are experiencing. Use open-ended questions beginning with "how", "what" and "when". Avoid "why" questions that might make the parents feel they are being judged. Use statement beginning with "Tell me about..."

## 4. Listening

- Take cues from the parents about where they are, and validate their statements.
- Avoid long responses.
- Don't be afraid of silence. Parents will sometimes welcome an opportunity to compose themselves.
- Note a parent's concerns, questions and requests for information.
- Focus on what the parent is feeling, rather than problem solving.

## 5. Support

- Reassure the parent that all emotions are valid and that other parents, including you have shared those feelings.
- "Can I help you?" gives permission for the referred parent to involve you.
- "What can I do for you?" helps to define a need.
- False reassurances or clichés are not helpful, as you may remember. Listen and reflect back. You may be tempted to say, "Everything will be all right." Don't! Instead, share what helped you.
- Your area of expertise is in your practical and emotional experiences, what you've learned, what helped you. When parents seek specific medical information, encourage them to consult with medical professionals.
- Your own memories may come back to you, particularly during your first few contacts with referred families. Be prepared for occasional strong feelings. You might find it helpful to talk with other support parents about their experiences.
- Before saying goodbye repeat back any specific requests the parent has made, such as for addresses or literature, and give a timeframe for getting the information to the parent.
- Many referred parents do not feel comfortable calling their support parents even when you have encouraged them to do so.
- If you haven't heard from your referred parent in a while, sometimes it can be helpful to make another call.
- Remind the family that Parent to Parent can help them to identify and access community resources (see New Beginnings Guide for ND Resources)
- Make an extra effort to stay in touch during any potentially stressful times you may be aware of, such as hospitalizations.





## Things to remember

- ⇒ Remember that whatever a family shares with you is **confidential** and not to be discussed with anyone except to Parent staff.
- ⇒ Some parents may not respond to you openly, especially during the first call. Don't take it personally. You are support, which they may not be ready to receive. Let the parents know that you would like to share their experiences, as another parent who has "been there", but don't be pushy.
- ⇒ Don't hesitate to let the Parent to Parent staff know if you are uncomfortable with a match, or if you sense the referred parent may be uncomfortable as well.
- ⇒ Recognize that there are times when you will have other commitments and cannot be available as a support parent.
- ⇒ Parent to Parent staff are available to you if you have concerns or questions, or are unsure how to respond to a particular family situation or crisis. Keep in touch so that we can support you.
- ⇒ Be yourself. Feel good about what you are doing and the valuable support you have to offer.





# People First Language: It's the Person First, Then the Disability

## What do you see first?

- The wheelchair?
- The physical problem?
- The person?

If you saw a person in a wheelchair unable to get up the stairs into a building, would you say, "There is a handicapped person unable to find a ramp?"

Or would you say, "There is a person with a disability who is handicapped by an inaccessible building?"

## What is the Proper Way to Speak to or About Someone Who has a Disability?

Consider how you would introduce someone - Jane Doe - who doesn't have a disability. You would give her name, where she lives, what she does or what she is interested in: She likes swimming or eating Spanish food or watching Robert Redford movies.

**Why Say it Differently for a Person With Disabilities?** Every person is made up of many characteristics - mental as well as physical - and few want to be identified only by their ability to play tennis or by the mole that's on their face. These are just parts of us. In speaking or writing, remember that children or adults with disabilities are like everyone else - except they happen to have a disability. Therefore, here are a few tips for improving your language relating to disabilities and handicaps.

## Tips.....

- Speak of the person first, then the disability.
- Emphasize abilities, not limitations.
- Do not label people as part of a disability group - don't say "the disabled," say "people with disabilities."
- Don't give excessive praise or attention to a person with a disability: Don't patronize them.
- Choice and independence are important; let the person do or speak for himself as much as possible.
- A disability is a functional limitation that interferes with a person's ability to walk, hear, talk and learn. Only use the word handicap to describe a situation or barrier imposed by society, the environment or one's self.

### Say . . .

child with a disability  
person with cerebral palsy  
without speech  
developmental delay  
emotional disorder, mental illness  
deaf, hard-of-hearing or  
uses a wheelchair  
person with retardation  
person with epilepsy  
has a learning disability  
non-disabled  
has a physical disability  
congenital disability  
condition

### Instead of . . .

disabled or handicapped child  
palsied, CP, spastic  
mute or dumb  
slow  
crazy or insane  
deaf and dumb  
confined to a wheelchair  
retarded  
retarded epileptic  
is learning-disabled  
normal, healthy  
crippled  
birth defect  
disease (unless it IS a disease)

## Etiquette

An individual with disability is a human being. It's as simple as that.

**Treat people as people:** Treat everyone the way you'd want people to treat you.

**It is okay to offer assistance.** Here are some tips:

Always ask first.

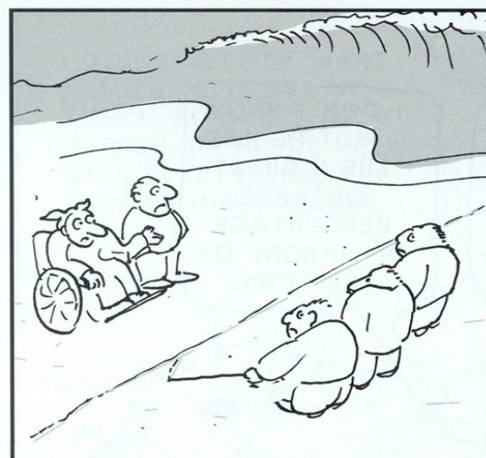
Understand the clarified assistance.

Realize that different people have different preferences.

Some people don't want or need help... accept "no" to your offer.

**Make a mistake?** Apologize, correct the error, learn, and move on.

**RELAX!** It is okay to say to a person who is blind, "I'll see you later," or ask a person in a wheelchair to go for a walk. It's part of our everyday language and not always taken literally.



MARC GIVES  
NEW MEANING  
TO DRAWING  
A LINE IN THE  
SAND.



© 1998 MICHAEL F. GIANGRECO. ILLUSTRATION BY KEVIN RUELLE  
PEYTRAL PUBLICATIONS, INC. 612-949-8707





## Part 2

# Communication Skills

### My Gift

*As a Support Parent my message is:*

*"I am a stranger to you now, but let me walk with you for a while. Because I have been where you are, and where you are about to go. I have no answers. I offer instead my hand, my heart, my listening ear, my time, and my experience...so that one day you can turn to another and say....."*

Alice P.



**Support Parents** already have the most important qualifications for helping Referred Parents: Our experiences with our own children and families. Some of the benefits of working with Referred Parents often happen without the Support Parent being aware of it. When we share our own parenting experiences and demonstrate enjoyment of our children and pride in their accomplishments, we show Referred Parents by our example that it is possible to survive grief and live a happy and productive life. This is a powerful message. It is one of the ways in which we bring strength and hope into the lives of Referred Parents.



Another way we help Referred Parents is by using the active-listening and problem-solving approaches outlined in this section. These methods have been used for many years by mental health professionals. However, participants in Parent to Parent networks throughout the country have adapted these techniques to our unique situation as equals and friends, rather than as professional helpers. Because we have "been there," we often can establish an almost-immediate rapport with Referred Families.



## Good Listener Checklist

### Attitudes

	Almost Al- ways	Usually	Occasionally	Seldom	Neve r
1. Do you like to listen to others?	5	4	3	2	1
1. Do you encourage oth- ers to talk?	5	4	3	2	1
1. Do you listen even if you do not like the person who is talking?	5	4	3	2	1
1. Do you listen well whether the person is a man or woman, young or old?	5	4	3	2	1
1. Do you listen equally well to a friend, an acquaintance or a stranger?	5	4	3	2	1

### Actions

	Almost Al- ways	Usually	Occasionally	Seldom	Neve r
1. Do you put what you have been doing out of sight and out of mind?	5	4	3	2	1
1. Do you look at the speaker?	5	4	3	2	1
1. Do you ignore distractions?	5	4	3	2	1
1. Do you smile, nod, encour- age the speaker to talk?	5	4	3	2	1
1. Do you think about what the speaker is saying?	5	4	3	2	1
1. Do you let him or her finish what the speaker is trying to say?	5	4	3	2	1
1. Do you try to figure out what the speaker means?	5	4	3	2	1
1. If the speaker hesitates, do you encourage him or her to go on?	5	4	3	2	1

## Attitudes

	Almost Always	Usually	Occasionally	Seldom	Never
14. Do you like to listen to others?	5	4	3	2	1
15. Do you withhold judgements about the speaker's idea until he or she has finished?	5	4	3	2	1
16. Do you listen regardless of the speaker's manner of speech and choice of words?	5	4	3	2	1
17. Do you listen even though you anticipate what the speaker is going to say?	5	4	3	2	1
18. Do you question the speaker in order to get him or her to explain an idea more fully?	5	4	3	2	1
19. Do you ask the speaker what the words mean as he or she uses	5	4	3	2	1

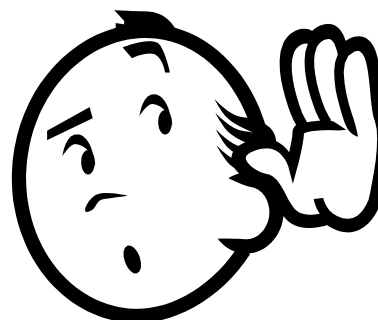
### Scoring:

If your score is 75 or better, you are a **GOOD** listener.

If your score is 50-75, you are an **AVERAGE** listener.

If your score is below 50, you are a **POOR** listener.

**Notes:**



# Active Listening

Active listening is a way of listening and responding to another person that improves mutual understanding. Often when people talk to each other, they don't listen attentively. They are often distracted, half listening, half thinking about something else. When people are engaged in a conflict, they are often busy formulating a response to what is being said. They assume that they have heard what their opponent is saying many times before, so rather than paying attention they focus on how they can respond to win the argument.

Active listening is a structured form of listening and responding, which focuses the attention on the speaker. The listener must take care to attend to the speaker fully, and then repeats, in the listener's own words, what he or she thinks the speaker has said. The listener does not have to agree with the speaker—he or she must simply state what they think the speaker said. This enables the speaker to find out whether the listener really understood. If the listener did not, the speaker can explain some more.

Often, the listener is encouraged to interpret the speaker's words in terms of feelings. Thus, instead of just repeating what happened, the active listener might add, "I gather that you felt angry or frustrated or confused when...[a particular event happened]". Then the speaker can go beyond confirming that the listener understood what happened, but can indicate that he or she also understood the speaker's psychological response to it.

Active listening has several benefits.

- ♦ **First**, it forces people to listen attentively to others.
- ♦ **Second**, it avoids misunderstandings, as people have to confirm that they do really understand what another person has said.
- ♦ **Third**, it tends to open people up, to get them to say more. When people are in conflict, they often contradict each other, denying the opponent's description of the situation. This tends to make people defensive, and they will either lash out, or withdraw and say nothing more. However, if they feel that their opponent is really attuned to their concerns and wants to listen, they are likely to explain in detail what they feel and why. If both parties to a conflict do this, the chance of being able to develop a solution to their mutual problem becomes much greater.

## Tips for Effective Listening

- Work through feelings and find solutions
- Be patient and allow plenty of time
- Don't prepare answers while the person is talking
- Avoid premature conclusions and interpretations
- Empathize with the person and put her/him at ease
- Don't try to change a person to your way of thinking
- Hold your temper; think constructively
- Stop talking and listen
- Ask appropriate and open-ended questions
- Don't interrupt
- Take mental notes (writing notes can be distracting)
- Have desire to hear what is being said and to be helpful
- Recognize that feelings are transitory and change over time
- Be alert for your own negative feelings
- Trust in the person's capacity to handle his/her feelings

**"Listening is a magnetic and strange thing, a creative force. When we really listen to people there is an alternating current, and this recharges us so that we never get tired of each other. We are constantly being re-created." Brenda Ueland**

# Active listening

*First seek to understand, then to be understood.*

Stephen Covey

## Elements of Active Listening

### 1. Be Attentive

Pay close attention to what is being said; demonstrate that you are listening through attentive body language.

### 2. Be Impartial

This is perhaps the most difficult of elements—it means not agreeing, disagreeing, or stating any opinion about what is being said. Remember, the purpose of active listening is to understand the other person.

### 3. Reflect Back

Use the same or similar words to reflect the speaker's idea back to him or her. For example—Speaker: "I'm really unhappy about the meeting we had today."

Listener: "It sounds like you have some concerns about how it went." This technique helps both to convey your interest and to elicit more information.

### 4. Listen for Feelings

If something is important to the speaker, he or she will have feelings about it. Often, the feelings themselves are the most important part of the message. Acknowledge the feelings the other person is conveying to you. For example: "It sounds like you have some concerns about how it went," or "From the way you describe the situation, it sounds like you're very frustrated."

### 5. Summarize

Pick out what you think were the most important parts of the speaker's message. Summarize them back to the speaker, to be sure you understand and to convey your understanding to the speaker.

# Guidelines for Active Listening

- ◀ Put yourself in the Referred Parent's shoes.
- ◀ Don't make judgements. There is no right or wrong.
- ◀ Accept the Referred Parent's feelings; they may be different from yours.
- ◀ Feel confident in suspending your feelings and judgments in order to be completely open to what the Referred Parent is communicating.
- ◀ Trust in the Referred Parent's ability to handle their feelings, to work through them and to find solutions to their problems. You are there to support them in this process.
- ◀ Be patient. Allow plenty of time. Don't interrupt or be in a hurry to give answers.
- ◀ Be flexible.
- ◀ Avoid arguments and criticism.
- ◀ Know that feelings change over time. Allow Referred Parent's to experience feelings in their own way and at their own pace.
- ◀ Listen closely to the Referred Parent. Be sure you know what they are asking or describing.
- ◀ Do not prepare your answer while someone from the Referred Parent is talking.

## Active Listening Starters

Below are a variety of ways to start a response which sounds spontaneous, some of which are listed below. The feeling word is underlined and can be changed to fit your message.

"I see, you meant that you hoped she would..."

"That sounds to me like you are sad about..."

"You feel upset about..."

"You mean you're afraid of..."

"I'm not sure I understand. Do you mean you're disappointed that..."

"You're really clear about..."

"You wish your husband/wife would..."

"I'll bet it is frustrating when..."

"That's really important to you. You want..."

"When that happens, your unhappy..."



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# Open Ended Questions

Questions are a critical piece of any conversation and there is an easy way to use them to build better conversations and depth while communicating. That method is simply by using **Open Ended Questions**.



## Open Ended Versus Closed Ended

There are two types of questions that are important to know in order to keep your conversations going and to build more rapport with others in conversation. They are open ended and closed ended questions.

**Closed ended questions** can be answered with a single one or two word response. They are often a yes or no question and don't leave much room for elaboration, interpretation or opinion.

**Open ended questions** on the other hand are questions that cannot be answered with one word responses. They require some thought and some details to reasonably answer the question.

## Build a Conversation

Simple response closed questions don't leave much room for elaboration or really a full response. These are often question using phrases like, did you, when, do you want to, will you, have you, etc. Each of these just need a couple words to answer and they don't transition well from one topic to another in a conversation.

They leave little room for new ideas and they don't spark much creativity or imagination which leads to new questions. That is where open ended questions excel. They provide much more detail, thoughts, comments, and bits of information that can more easily form into new ideas and transitions.

Here are some examples of typical questions in an open format:

- ♦ Tell me what you think about that?
- ♦ What is it you like about the idea?
- ♦ Why would you suggest that?
- ♦ How do you plan to achieve that?

## Let Others Talk more than You

Open ended questions also ensure that you give others a chance to talk more than you. It forces you to listen more in any conversation because you have to wait for a longer response with these questions. You can still lead a conversation by steering with your questions but at least the open questions will allow room for more elaborate response.

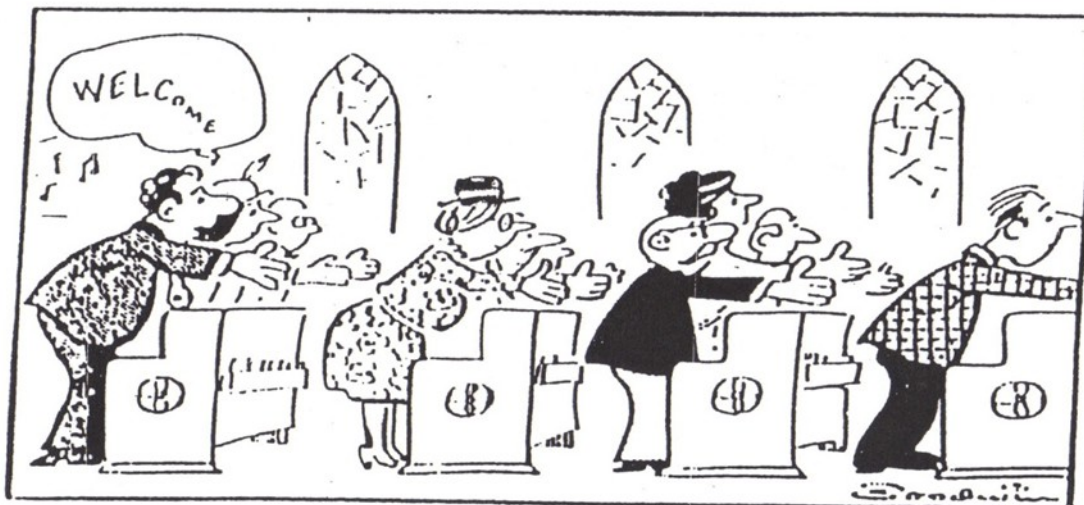


OPEN-ENDED QUESTIONS Worded to Encourage the Broadest Possible Response	
<p>What's on your mind?</p> <p>What would you like to achieve?</p> <p>What do you want?</p> <p>How do you want to get it?</p> <p>What would you like to happen?</p> <p>What do you see happening?</p> <p>What do you want to see by the end of the meeting?</p> <p>What ideas do you have/want to share?</p> <p>Can you help us understand your thoughts on that?</p> <p>Anything else?</p> <p>Can you tell me more about that?</p> <p>Is _____ what you are talking about?</p> <p>What is your reaction to that suggestion?</p> <p>What are your thoughts?</p>	<p>Is this idea closer to what you want to see happen?</p> <p>What would work for you?</p> <p>Would that work for you?</p> <p>... Have I got it?</p> <p>Do we have all your ideas on the table?</p> <p>What would be the benefits of _____?</p> <p>What benefits do you see?</p> <p>What outcomes do you want?</p> <p>How does _____ feel to you as an option?</p> <p>If _____, what would you get that you need?</p> <p>Your child needs?</p> <p>How do you see that working?</p> <p>As I understand it, your interests are _____. Have I understood correctly?</p> <p>Are there other important points?</p>
QUESTIONS USING STATEMENTS	
<p>Say more about that.</p> <p>Tell me your concerns.</p> <p>Tell me more.</p> <p>Talk to us about your concerns / vision / desires / wants.</p> <p>Describe what that looks like/feels like.</p> <p>Describe your thinking about _____.</p> <p>Tell me what you want.</p> <p>Help me understand . . .</p>	<p>Elaborate on that . . .</p> <p>Give some examples of what you want.</p> <p>Given _____, tell me what you want to see happen.</p> <p>Say more about your non-negotiables.</p> <p>Help me understand the specifics of your request.</p> <p>Looking forward, tell me what would work for you.</p> <p>Go on.</p>

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# COMMUNICATING

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## Tip of the Day:

Don't forget to take care of yourself. As support parents, it is important for us to also seek support from others.

## Problem Solving

We know that the presence of a child with a disability or chronic health need changes a family in important ways. Once a child's condition is recognized, roles and relationships must change to meet changing circumstances. No family is ever the same again.

The pressure to change familiar ways of behaving and to make immediate decisions about their child's treatment is very stressful for families. When Referred Parents must make important decisions or face problems in managing daily routines, Support Parents can help by guiding them through the problem-solving process.

In a calm, matter-of-fact manner, Support Parents can help Referred Families to define the problem, consider the options, make a decision, carry it out and evaluate the results. In this way, Support Parents pass along the skills Referred Parents need to view themselves as experts on the needs and care of their own children and families and engage in successful collaboration with professional service providers.



# Problem Solving Techniques

## Step 1: Identifying Needs

### Goal:

- Help the Referred Parent to identify **one** immediate need which can be resolved successfully.
- Express the need in behavioral terms - i.e. describe what must happen in order to take care of the problem.

### Action

- Using active listening techniques, allow Referred Parent to express their feelings and concerns.
- Focus on the present.
- Point out the strengths and coping abilities of various family members - both parents and children.

### Tips:

- **Focus on the present:**  
"How are things going today?"  
"How can I be helpful to you today?"  
"Tell me more about your worry about the baby."
- **Point out strengths:**  
"You seem to know just what to do when..."  
"You can tell \_\_\_\_\_ really loves you when he....."



## Step 2: Discussing Options

### Goal:

- Help the Referred Parent to identify possibly course of action that fit their unique family situation.
- Find out whether the Referred Parent may be ready for help in solving problems or need more supportive listening.

### Action:

- Explore with the Referred Family possible solutions within their existing network of friends, family and professional service providers.
- Give examples of practical solutions that have worked for other families.
- Provide information about community resources and how to use them.

### Tips:

- The purpose is to present options or choices not to give advice.
- Words to use:  
"What have you tried in the past?"  
"Whom have you asked for help?"  
"How has it worked?"  
"Have you considered trying..."  
"Some parents in similar situations have found that..."

### **Step 3: Making a Decision**

**Goal:** Referred Parent chooses a course of action.

- Make sure the Referred Parent understands any laws, practices, responsibilities, etc. that might limit their choice.
- Be sensitive to the diversity of family values and customs that shape Referred Parent's choices.

**Action:**

- Ask the Referred Parent what they want to do. They are the experts on the needs of their own children and family.
- Provide information, based on experience, about the pros and cons of each option the family is considering.
- Always be ready to step back and be there just to listen if the Referred Parent needs more time to express feelings before deciding.

**Words to use:**

- "What do you think will work best for you?" "What do you think is best for your child?"
- "What would you like to do at this point?" "Keep in mind that....."

### **Step 4: Taking Action**

**Goal:** The Referred Parent Takes Action

- Help the Referred Parent to be as successful as possible in meeting their goal.

**Action:**

- Find out how comfortable the Referred Parent is about taking action. Help them to plan what they are going to do, building on their strengths.
- Pass along practical tips other families have found helpful, role-play, inform the Referred Parent about their rights and responsibilities.

**Words to use:**

- "How do you feel about taking this action?"
- "Is there any way I can help you to plan what you will do?"
- "Let me tell you about your rights and responsibilities as a family in this situation."

### **Step 5: Evaluating the Results**

**Goal:**

- Help the Referred Parent review the experience.
- Plan ways to act even more effectively in the future.

**Action:**

- Listen closely to the Referred Parent's account of their experiences.
- Point out the family's strengths.
- Ask the Referred Parent how it might go even better next time.
- Contact families after important appointments, meetings, etc. to ask how things went.
- As the Referred Parent becomes more confident in advocating for their family's needs, the Support Parent can remain available for emotional support and further problem-solving when needed.





## Part 3

# Grieving Process And Coping

*"I wondered how to break the news to causal friends and acquaintances, whether to send birth announcements and most importantly when I should feel better again?  
I still remember some of the answers to my questions, but mostly, after talking to another parent, I remember that I felt less alone, less different from everyone else I knew and more hopeful that I wouldn't feel this way forever."*

# The Feeling States of Grieving

*Grief is a normal, natural part of life. It is important that grief be regarded as a healing process. There are different grief stages. An individual may experience each stage during their grief; however, it may not be in order and some stages may be visited more than once and for different amounts of time.*

## Denial

People who deny are often considered stupid, obstructionists, dull or deliberately irritating by many who have to deal with them. **None of that is true.** Parents of children with special health care needs may manifest denial as a normal course of trying to deal competently with loss. It is impossible to live

life fully while maintaining an awareness of the awful things that can happen to people. Most people routinely shield themselves with such thoughts as "The terrible things that happen to other people can't happen to me, because..."

### *Grieving:*

***It is not about pretending everything is OK, it is about finding joy where you can.***

This system works fine as long as nothing terrible happens, but when it does, no one is prepared to deal with it. This is where denial in the service of grieving comes in. Denial buys the time needed to blunt the initial impact of the shattered dream, to discover the inner strengths needed to confront what has really happened, and to find the people and resources needed to deal with a crisis for which one could not be prepared.

## Anxiety

When a person loses a dream that is central to their being, they are forced to make major changes within themselves and within their environment. To face the challenges needed to be faced with a child with special needs or a disability, parents go through dramatic changes that affect their attitudes, priorities, values, and beliefs, as well as altering day-to-day routines. Such changes require a great deal of energy. Anxiety mobilizes the energy needed to make these changes. Further, it gives focus to that energy so that the changes can be actualized. Anxiety is the inner source of the need to act.

Anxiety is often seen as hysterical, inappropriate, and unacceptable. The culture's message is clear. As a rule we advise anxious people to "calm down." To take



medication, or to use alcohol as a “solution” for the “problem” of anxiety. These “solutions” keep the parent from changing and often make things worse for all concerned. Realities must be faced, stressful as they might be. It does not take long for most parents to become aware that they, not some professional, are their child’s medical, educational, and therapy managers, even though they may have minimal knowledge of these areas. That alone should drive home the urgent need for energies to be mobilized and focused by the crucial feeling of anxiety.

## **Fear**

As anxiety mobilizes people to deal with change, fear is a warning that alarms the person to the seriousness of the internal changes that are demanded. One’s sense of balance and order are dramatically challenged when one confronts a meaningful loss. Parents may experience the terror of knowing that they will be required to change on a fundamental level, against their will, with full understanding that the process of internal change is very difficult.

Significant losses produce a profound sense of abandonment and vulnerability. We have a number of sayings to cope with this level of fear, e.g., “It is far better to have loved and lost, than to have never loved at all.” Each person must find their own words to confront the sense of abandonment and vulnerability generated by a significant loss. Many parents experience the fear of vulnerability about having more children after they have had a child with a disability or special health care need, or about “overprotectionism,” the gut-wrenching fear of permitting their child to do anything that feels risky. Given the ways that this part of grieving is manifest, it should not be difficult to see that fear is the medium that encourages the struggle to reattach, to love again in the face of a loss.

## **Guilt**

Parents of children with disabilities manifest guilt through the normal course of grieving and are often criticized for doing so. Guilt is a feeling state that has become so identified with being neurotic that people feel guilty about feeling guilty. Since sharing such feelings often evokes negative judgments, it can be difficult for a sophisticated parent to talk about guilt freely. On the surface, guilt-ridden people may appear not only neurotic, but superstitious, ignorant and primitive. They are often viewed as unpleasant, uncomfortable people to be with and therefore are dismissed or treated harshly by friends, family, and professionals.

Generally, parents of children with disabilities or special health care needs express guilt in one of three ways.

- ♦ One way is by telling a story that explains how they are responsible for their child's disability. Their story is often accurate and, on the whole, persuasive. The current emphasis on the prevention of birth defects has brought many parents to feel that they caused their child's impairment. The issue is not the logic, but the feeling of guilt.
- ♦ Another way that guilt is manifested is in the conviction that the child's special health care need is punished for a past inappropriate thought, feeling, or action. One of the more common "guilt thoughts" is regretting the pregnancy sometime during gestation. When something goes wrong after that thought occurs, "it's all my fault" becomes a natural outcome.
- ♦ Lastly, guilt can be expressed through the parent's belief that good things happen to good people, and bad things happen to bad people. Because they have a child with a disability or special health care need, they must be bad people and consequently feel shame and guilt. How can such painful explanations of tragedy be useful to bereaved individuals? Simply by being explanations. Guilt "explains" the unexplainable.

Human beings begin to question the "why" of things from very early on in their lives. What are the rules which govern the way of things: cause and effect as well as right and wrong? A most important "why" concerns how one's "right" or "wrong"



actions effect one's life. What difference does it make that a person is moral, ethical, legal, caring, ambitious? How is it that one does or does not influence the events of one's life? Some of us found early and easy answers to these questions and have not considered them since. After a loss, such questions cannot be answered in an ordinary fashion. Rather, they must be addressed through the kind of grief-related struggles addressed here. When people

confront a loss, the beliefs they held regarding cause and effect, right and wrong, and their impact upon life are deeply shaken. The order of things is totally upset when an innocent child suffers. The parent experiences deep pain, pain that can be used to reorder the rightness of the world. Guilt is the feeling state that facilitates this struggle to reorder. Basically the guilt-ridden person is saying that they are accepting responsibility for everything. It feels better to do that than to be-

have no influence on anything! Guilt, in this sense, helps one to redefine the issue of cause and responsibility in the light of loss.

## **Depression**

A common response to loss is often characterized by profound and painful sobbing. Parents report that at times it feels as though the tears will never stop. There is a rest, but then for no apparent reason, waves of despair and anguish wash over the parent once more. Between the tears, one can sit alone, staring silently. Those periods of silence can last well beyond the periods of tears. The thoughts of depression take over, thoughts like: "What's the use of trying, it's all over." or "Nothing I do matters, because nothing will change what has happened to my child!" Depression is subtly rejected and judged as pathological by much of our culture. When people display such feelings, they are often told to "cheer up", given medication, or offered distractions. Such responses are inappropriate, for depression is part of normal, necessary, and growthful grieving. It attends to another aspect of a basic human struggle that loss stirs.

As we mature, we develop and modify our definitions of the following words: competence, capability, value, and potency. They are words of profound personal significance. They are the criteria that people use to decide if they are OK or not. What criteria does a person have to meet to feel like a competent parent, a capable worker, a valued friend, or a strong person? Each person determines these standards privately, even secretly. When parents are confronted with a child with a disability or special health care need, whatever definitions they held for competency, capability, value, and potency usually no longer apply. Out of this struggle of defining one's worth come the frightening feelings of helplessness, hopelessness, and haplessness. Faced with loss, a parent feels unable to act effectively (helpless), unable to imagine that things will ever get better (hopelessness), and unable to believe that their lives are touched by good luck (hapless).

Such feelings can be terrifying for both the parents and those around them. For that reason, it is hard to see that depression is a normal and necessary part of the grieving process. Depression is the medium that helps parents come to new definitions of what it takes to be a competent, capable, valuable and strong people, even though their child has health care needs that they cannot cure.

## Anger

Anger, for many people, is the most disconcerting of the feeling states. It too is a natural and necessary part of the grieving process. Parents feel anger at the harm done to their child and the shattering of their dreams. When one encounters a significant loss, it is likely that one's internal sense of justice is severely challenged. To continue to trust in the world, one must have a sense of justice that confirms an orderliness and fairness to the way the world works.

A parent can righteously demand to know why he or she has a child with a disability or special health care need: "Why me, why not you!" Implicit in the question is the notion that there must be good reason that such a thing happens to one parent and



not to another. A parent's concept of justice, like value and worth, is another unique product of that individual's thinking and development. When confronted with the traumatic loss of a dream, that internal sense of justice is violated. Crying out in the face of injustice, the parent develops new ways to look at justice in the world. "What, after all, is fair, if this can happen?" Anger is the medium through which a parent redefines fairness and justice. It integrates new beliefs within the deepest emotional levels of the grieving parent.

Unfortunately, anger is an emotion that is actively rejected by the culture at large and by people closest to the parent. The angry parent experiences rejection by others, confusion about feeling anger and acting out the feeling, the feeling of being out of control. All of this makes it very difficult for this important feeling to run its course.

Anger also poses other dilemmas. Unlike the other feeling states of grieving, anger is directed toward someone or something. Who (or what) is the object of parental anger? This question deeply distresses most parents, because the honest answer is often so troubling that many people avoid asking themselves the question. The unacceptable answer, of course, is that the child with the disability or special health care need is the object of anger. After all, who has entered this parent's life, disrupted it, caused immeasurable pain, and drained the parent's time, energy, and money.

Many parents were raised to believe that feeling and expressing negative feelings about one's child is taboo. "The child never asked to have disabilities, let alone to

be born. How can one be reasonably angry at this child?" If the child is blameless, this manual is produced by Family Voices of North Dakota for the North Dakota Parent to Parent Program

then it must be unreasonable to feel anger toward the child—even though one does! The conflict between what parents feel and what they can permit themselves to express can cause a return to denial. Another outcome of this conflict is that the parent can displace the anger onto others. Spouses, siblings, and professionals are all possible targets of this displaced anger.

When considering the feeling states of grieving, especially the feeling state of anger, logic and reason are irrelevant. Where is the logic behind cursing a twig that one has just tripped on? What is the purpose of kicking a flat tire? What good does it do to admonish anyone after they have already done the wrong thing? Expressing simple anger clears the way to getting on with the task at hand. Expressing anger opens the way to address the meaning of justice (though enacting angry behavior sidetracks the parent from the task at hand). While there is no logic, there is purpose and function to the expression of angry feelings. As events occur that violate one's sense of justice, the outrage must be expressed. Those expressions help to redefine one's concepts of fairness and justice.

The parent of a child with a disability or special health care need separates from dreams that were shattered through grieving. Denial, anxiety, fear, depression, guilt and anger all emerge. If they are shared with other people, these feelings help parents grow and benefit from what might be the worst tragedy of their lives. Grief must be shared deeply and fully until the underlying issues are revealed. The reopening of these issues changes the parent's world view. New perceptions of themselves and their world serve as a solid foundation for coping with the disability and for personal growth.

Yielding to the grieving process helps parents find the inner strength and external support needed to face profound loss', to mobilize and focus the energies needed to change their lives; to reattach to new dreams and loves in spite of feeling abandoned and vulnerable; to redefine their criteria for competence, capability, value, and potency; to reassess their sense of significance, responsibility, and impact upon the world around them; and to develop new beliefs about the universal justice system that makes the world a tolerable place to live, even though terrible losses can occur. The culturally rejected feeling states of denial, anxiety, fear, depression, guilt, and anger may be used in surprisingly positive ways when the feelings are fully shared.



# The Grieving Process

For the parent of a child with special needs grief can be a lifelong experience. The emotions involved in this process do not move in a straightforward progression through orderly, predictable "stages", but may surface in no particular order, in any combination, and with varying intensity throughout the parenting experience.

There are no right or wrong ways to move through these feelings, or any sure cure for them. Powerful, intense feelings are natural and common responses to living with your child who has a disability or chronic illness. The "states" of grief (**Shock, Panic, Denial and Disbelief, Anger and Fear, Sadness and Despair, Hope, and Acceptance**) can be revisited throughout life.

## **SHOCK**

### **How you may feel**

Numb  
Detached  
Unaffected

### **How you may act**

Withdrawn  
Quiet and non-responsive  
Distracted or uncaring

### ***Ways to cope***

- Recognize the numbness and detachment can be valid defense mechanisms, which give you time to absorb difficult news or information.
- Be patient and gentle with yourself.

## **PANIC**

### **How you may feel**

Overwhelmed  
Confused  
Very anxious

### **How you may act**

Disorganized  
Forgetful  
Unable to think about the future  
or to make plans

### ***Ways to cope***

- Accept your feelings and find outlets for them.
- Try to take time for some relaxing activities such as listening to music, or take a walk outside.
- Allow others to help out with household and daily responsibilities.



## **DENIAL AND DISBELIEF**

### **How you may feel**

Full of doubt

Helpless

Argumentative

Attacked

### **How you may act**

"Doctor-shop"

Resist making child's appointments

Refuse to talk about the situation

Sleep a lot without feeling rested

Talk a lot about minor problems

Keep yourself very busy

### ***Ways to cope***

- Allow yourself to delay talking about the situation, especially to people outside of your immediate circle of family and friends, until you're ready.
- Take care of yourself.
- Begin to search out factual information.

## **ANGER AND FEAR**

### **How you may feel**

Generalized anger

"Mad at the world"

Frustrated

Afraid of the anger's intensity

### **How you may act**

Abrupt and cold

Blame others

Blow up over trivial problems

Lash out at family, doctors, anyone  
who is available

### ***Ways to cope***

- Accept your anger and find outlets for it, including physical activities.
- Try not to personalize your anger by blaming others, and recognize that the person you're tempted to shout at may not be the source of your anger.
- Apologize if you know you have hurt someone's feelings.
- Understand that other people may have good intentions, but simply don't know the right words to say to you.
- Your sense of humor can be a lifesaver.

## **SADNESS AND DESPAIR**

### **How you may feel**

Guilty  
Ashamed  
Empty  
Isolated  
Like a terrible parent

### **How you may act**

Blame yourself  
Criticize yourself  
Cry often  
Experience changes in your appetite  
Avoid friends who have typical children  
Have trouble making decisions

### ***Ways to cope***

- Remind yourself as frequently as necessary that you are not to blame.
- Talk to someone who understands about your feelings.
- Let yourself cry.
- Let others help out with your child or with other responsibilities.

## **HOPE**

### **How you may feel**

Encouraged  
Concern about the future  
Belief that you can cope  
Other feelings are still present,  
but less intense

### **How you may act**

Talk more easily about your child  
Willing to accept information and support

### ***Ways to cope***

- Enjoy your child.
- Seek out information and support from all available sources.
- Begin to make some decisions about your child's day-to-day needs.
- Be prepared for all of the feelings described above to resurface, knowing now that you will get through them.

## **ACCEPTANCE**

Acceptance is not a final product or the end to your emotional journey. How fully you accept and are at peace with your life as the parent of a child with special needs may vary even day-to-day. Most parents reach an emotional balance, not through being "adjusted" or having "adapted", but with getting to know and enjoy their child. As you become comfortable and confident in your parenting skills, identifying and appreciating your child's strengths and lovable traits becomes an easier, more natural process.

Most likely, the time will never arrive when you are finished with all the emotions described above, when you've completed your climb up a ladder of predictable stages. However, as you begin to recognize and understand these feelings as common and necessary aspects of your parenting experience, you will develop your own coping strategies and your own individually defined sense of acceptance.

# THE FOUR STAGES OF ADAPTATION

- Surviving
- Searching
- Settling In
- Separating

From "Nobody's Perfect – Living & Growing with children Who Have Special Needs"  
By Nancy B. Miller, Ph.D., M.S.W. adapted by Laura J. Warren

# SURVIVING

- What you do to keep going when you are feeling completely overwhelmed because something totally out of our control has taken away your child's equal chance at life.
- First time through survival is the longest.
- Ways to ease the Surviving Process:
  - Understand that your feelings are normal.
  - Try to make time for yourself.
  - Create and use your support system.

# SEARCHING

- Some leap frog right into this stage.
- What you do when you are looking for answers for your child. You will probably have periods of Searching during your whole life with your child.
- Will learn to recognize what you can control and what you cannot.
- Two kinds of searching:
  - Outer Searching: Looking for a diagnosis or services such as Family Support.
  - Inner Searching: Trying to find your identity as the parent of a child with special health care needs. (Why did this happen, what does this mean for me).

# SEARCHING (CONTINUED)

- Things you may become aware of during your inner search:
  - Life is not fair.
  - If you devote all your time, energy and thoughts to your child, someone will pay the price, and that someone may be you or your child.
  - Being realistic about your child's abilities and limitations does not mean giving up hope.
  - How your child feels about his/her abilities and limitations is more important than what he/she can or cannot do.
  - Things will change. Some will become harder and some will become easier, but things change. It is how you deal with the change that matters.

## SETTLING IN

- Seeing the world for what it is and seeing yourself for who you are.
- It is moving beyond the intense emotions of surviving and urgency of searching into a greater sense of control and balance in life.
- What you do when the frantic pace of Searching lets up. You begin to choose your battles and balance your child's schedule and your family life. Not only has your Outer Searching subsided for a while, but more important, your attitude about it settles down.
- You will see a shift in your balance as well as in your attitude.

# SETTLING IN (CONTINUED)

- Some families are not able to enjoy the normality of feeling Settled In or this stage is delayed due to:
  - Continued medical crisis
  - Lack of financial resources
  - Marriages or relationships that are unable to survive the change.
  - Single parenting resulting in juggling all the responsibilities.
  - Old Surviving or Searching issues that come back into the foreground.

## SEPARATING

- What you do as a normal, gradual process that occurs in tiny steps throughout childhood. When a child has special needs, the process may need to be altered or slowed down. Extra parenting may be required – you may have to initiate separation, plan it, find it and make it happen.
- Letting go on your part is also necessary.
- Letting go means giving up some control.
- Letting go feels like you are losing something – and you are.



# REMEMBER

- Everyone passes through these periods in their own way and at their own time.
- There is no “right way” to adapt.
- The tasks in each stage may overlap. They actually have more of a circular quality than a linear one.

From “Nobody’s Perfect – Living & Growing with children Who Have Special Needs”  
By Nancy B. Miller, Ph.D., M.S.W. adapted by Laura J. Warren





## Part 4

# Family Centered



**"I guess we'd be considered a family. We're living together, we love each other, and we haven't eaten the children yet."**

# Family



**We all come with families.**

Families are big, small, extended, nuclear, multigenerational,  
with one parent, two parents and grandparents.

We live under one roof or many.

A family can be as temporary as a few weeks, as permanent as forever.

We become part of a family by birth, adoption, marriage  
or from a desire for mutual support.

As family members, we nurture, protect and influence one another.

Families are dynamic and are cultures unto themselves,  
with different values and unique ways of realizing dreams.

Together, our families become the source of rich heritage and  
spiritual diversity.

Each family has strengths and qualities that flow from individual  
members and from the family as a unit.

Our families create neighborhoods, communities, states and nations.

*-Adapted from New Mexico's Memorial 5 Task Force on Children and Families and the Coalition for Children, 1990*

## Family Centered Support

*Support that is offered to the family as a whole, rather than to the child with a disability alone, and is based on the priorities and concerns that are identified by the family, rather than by professionals.*

Early Care and Education Committee

*Recognizes and respects the pivotal role of the family in the lives of children with special health care needs; promotes normal patterns of living at home and in the community; and that views parents and professionals as equals in a partnership committed to excellence at all levels of health care.*

Association for the Care of Children's Health

# The Effect of a Disability on the Family

Family members each cope with a child's disability or illness in their own way. Each member must adapt to the new situation. Relationships within the family, along with previously defined rules, values and roles, must be adapted, also. Such tremendous changes on everyone's part can cause much stress on the family unit, as well as on individual members.

## Mothers

In the initial crisis period, mothers may react differently from fathers or significant others. Mothers may be more emotional and may voice concerns about their ability to cope with the additional tasks of child care. Usually, mothers are more encouraged socially to express their feelings, and they also receive the majority of support offered to the family.



Because mothers usually are the traditional caretaker in the family, they assume most of the additional work in caring for their child with special needs. They must learn how to make it all work together within the household routine. And, because they are doing much of the daily care, mothers may recognize and feel the reality of their child's special needs earlier than the father. With the responsibility for daily care often comes an additional role in the medical world, taking the child to clinics, school evaluations, consultations and other services. Thus, mothers become the primary information giver and taker for their family.

## Fathers

Fathers may respond less emotionally at first than their partners, concentrating more on long-term concerns, such as prognosis, social stigma, financial effects and the child's future as an adult. It is not unusual for fathers, because of cultural and family beliefs, to cope by trying to be what society expects men to be: "Strong and silent." Thus, dads are discouraged from confronting and expressing their feelings. Fathers may be expected to assume the role of family leader, "the fixer," and the person in control. These roles may be difficult to maintain, adding to the stress





created by such expectations. Fathers traditionally are the “breadwinners”: That is, their primary role in the family is making money to provide the family with what it needs.

They may feel a tremendous responsibility for the financial burden that may accompany the disability, especially if the mother must quit her job to care for their child with special needs. More hours working means more hours spent away from the child, less time for receiving information and less opportunity to initiate professional and/or supportive relationship. It is, therefore, not unusual for fathers to deny their child’s disability for a longer time.

## Mother-Father Relationship

The relationship between the mother and father usually is the initial bond within the family. That relationship is a partnership, one that sets the rules and roles for the family. Still, each parent is an individual who reacts uniquely to the crisis, and, in fact, each may define the loss differently. These individual responses or reactions can cause a crisis in itself.



When a parent utilizes his or her own coping skills in the crisis, the other parent may misinterpret this behavior. He or she may judge the partner’s response as inappropriate within the situation, because it is different from the way they reacted. At times, mothers may label their partner’s behavior as “cold” or “uncaring,” when fathers are perceived to deal with their child’s situation in an “objective” manner. Fathers may judge their partners as “overly-emotional” or “weak.” Fathers may feel that they must take care of their partner in spite of having unmet needs of their own; mothers may feel the same way. Each partner may be unable to see beyond his or her own needs. Each can be unaccepting of the other’s ways of coping. Each may become angry at the other for adding to the stress in an already-stressful situation.

Parents may have difficulty communicating with each other about their child's disability. One parent may want to share his or her feelings, but the other parent may be unable to or unwilling to do so. This difference may set up a communication block and one-sided discussions. Fathers may have to rely on their partners to relay information from professionals, but the information they need may not be forthcoming. Mothers may understand what they heard but be unable to explain it fully. At times, parents may be reluctant to express their concerns to each other, fearing that such concerns only will add to the worry or depression for their partners. Consequently, each may attempt to protect the other by avoiding such discussions.

Each parent has his or her own value system, which was handed down from their childhood family. Differences in value systems may contribute to conflicts within the relationship regarding decision making and the outlook for their child. Thus, the parental unit may become overwhelmingly burdened, and it may take much compromise to keep it intact. The mother-father relationship can survive the many changes it must endure, but parents must work to:

- Find a way to communicate feelings and concerns in a productive manner. They may need to seek guidance in this area, especially if effective communication has not been well established.
- Develop a respect for each other's coping style. This, too, may require professional guidance.
- Re-examine individual roles and rules within their family and together develop a new plan to meet their child's needs as well as needs of the other family members.
- Maintain their relationship as partners, apart from their relationship as parents. Parents need to have quality time together.

Sometimes, the stress of coping with a child's disability becomes too much for the mother-father relationship; parents may not be able to resolve their differences and may decide to dissolve their relationship. The stress of their dissolved relationship will "ripple" through the family. The family will change from a two-parent family to a single-parent family, and perhaps, over time, stepparents may be added.



## Single Parents

Because single parents may not have a consistent person to depend on or to share responsibility for their children, they often feel like they “do it all.” They may be overwhelmed with the additional tasks and time demands a disability can bring. Daily activities can turn into chronic stressors when there are no other adults to share the work and the feelings that accompany such work.

Single parents may experience financial problems. It is difficult to care for a child with a disability while earning an income for the family. Single parents may be more apt to be unemployed and supported by others.

Finding child-care to enable single parents to have private time is a big concern. Such respite opportunities may depend heavily on extended family and friends. However, many single parents do not have others who are willing or who feel sufficiently trained to assist them. Thus, the single parent has limited opportunities to renew his or her energy or to be able to spend quality time with their other children.



When only one adult is in the household, roles will have to be adjusted. Responsibilities the absent parent might have shared now must become the responsibility of the existing members - parent, siblings, extended family, significant others. Some single parents live with their parent(s), which may ease some problems and increase others.

Single parents may share responsibility for their children with the noncustodial parent, who may provide some financial support and respite care. However, without effective communication, such “sharing” may add stress by having two separate parents with differing opinions on how care and management should be done and with differing needs, trying to care for a child with a disability or chronic illness in two separate households.

## Step-Parents

When joining a new family, stepparents encounter major issues, such as attaching to the new stepchild and defining and being accepted in their role as a stepparent. Stepparents of a child with a disability not only have the "usual" issues of stepparents, but they also have to learn new aspects of physical care as well as deal with concerns never experienced before.

They may also have to struggle to attain a role with the child, since roles probably already have been firmly defined.

## Grandparents

Grandparents have an especially hard role. They, like other family members, grieve for their "dreamed of" grandchild. Grandparents often look forward to a new grandchild, envisioning themselves as a nurturer and mentor for the child; they are eager to watch them grow and develop into adulthood. Grandparents may see the child's disability or illness as an obstacle to fulfilling that dream. They also may worry about the future and the suffering their grandchild may have to endure.

They also grieve for their own child. It causes them much pain to see their own child's happiness shattered. They may worry that their new grandchild may become a "burden" throughout the rest of their adult child's life. They may want to protect their adult child from any additional hurt, which they soon find impossible to do. They become confused when their offers for help are not eagerly accepted. They may not understand why their child doesn't want them to "fix it." Or, they may actively deny their grandchild's disability and be very frustrated by their own adult child's attitude regarding the child's problems.

Grandparents may find themselves experiencing emotions and situations they never have encountered before. They may be at a loss about where to seek support for their special concerns. They also may have to re-enter the caretaker role, in order to assist their own adult child in parenting. In order for a grandparent to be a valuable asset in the family, they may need to receive support for their special circumstances. They will need information to understand the disability, an avenue for expressing feelings and concerns and encouragement that they are valued by their adult child and grandchild.



## Siblings

The relationship between siblings is a very powerful one, providing opportunities for sharing, companionship, rivalry, loyalty and the expression of feelings. Together, siblings often support and guide each other through developmental tasks, teach each other social skills and build relationships that will last a lifetime.

When brothers or sisters begin to feel the effect of their sibling's disability, they will voice or demonstrate concerns and feelings that relate to their sibling status. Siblings often experience:



- **Confusion.** What is wrong? How did it happen? Although wanting to know why, children may not be able to understand the reasons or be able to process the information shared.
- **Anger.** Why did this happen to me? Why is my new sister causing so much trouble? In addition, children often react to stress with anger.
- **Anxiety, Guilt.** Did I cause it? How will it change me? They may mistakenly feel that in some way they made the problem happen.
- **Fear.** Will it get worse? Will it happen to me? Siblings may worry that the condition or disability may be contagious and will affect them, also.
- **Jealousy.** Siblings may be jealous of the time their parents spend with their ill sibling or the time the parents may have to spend away from home.
- **Resentment.** They may resent the changes and sacrifices they have had to make as part of the family, as well as the time and money spent on their sibling and not on them.
- **Embarrassment.** Especially for adolescents, the appearance or behavior of their sibling with disabilities may cause acute embarrassment.
- **Ridicule.** Siblings may have to endure ridicule from friends and peers about their "different" sibling.
- **Loneliness, Depression.** Siblings may feel a sense of social isolation for themselves and their family as a result of the disability.
- **Decreased Self-Worth.** Siblings, especially in their adolescent years, may be preoccupied about "being different" because of their sibling's disability. They may be unusually worried about the future.

Certain feelings or crises can be heightened at certain ages; younger siblings who are closer in age to the child with disabilities may focus more on fear, guilt and jealousy. School-aged siblings may experience more resentment, ridicule and embarrassment. Adolescents, many times, must deal with the ridicule of their peer group.

Regardless of age, all siblings have basic needs as part of a family with a child with special needs:

- **Need for Information.** Brothers and sisters need to understand their sibling's disability. Meeting this need may be a difficult task at times. Even though a child may be old enough to be given the information, he or she may be too inexperienced to understand. Explanations need to be age-appropriate and ongoing.

Many children will not ask questions. They may not know what to ask, or they may be afraid of causing further hurt to their already-suffering parents.



Adults may have to initiate information-sharing, often triggered by changes in the behavior, sleeping habits or performance of the child with special needs. Along with information about the disability, siblings need to hear about their family members' feelings and concerns and how the disability may affect each member of the family. Beginning such open and honest communication within the family may require professional guidance.

- **Need for Expression of Feelings.** Siblings need opportunities and permission to express their feelings about their brother or sister. Some children do not know how to express themselves. They often learn how to act through modeling themselves after the significant others around them. When adults and other children are expressing their feelings in a productive way, siblings will be more likely to do the same.
- **Need to be their own person.** Brothers and sisters need to feel valued as both individuals and members of the family. Siblings need to feel that they are treated equally by those around them and that their personal needs will be respected.
- **Need to be involved in the decision-making of the family.** When the siblings participate in discussions about the issues that will affect the whole family, they are more apt to understand and effectively cope with the deci-



sions and their outcomes. Issues such as finances, vacations and changes in household responsibilities are best discussed as a family.

- **Communication.** Communication is essential in all areas of brother and sister support. All family members need to share, listen and acknowledge their crises. Sibling support groups and other outside resources may be helpful, especially on issues relating to their peers.

*-Adapted with permission from the Indiana Parent Information Network, Inc.*

*A family is a unit composed not only of children but of men, women, an occasional animal, and the common cold. ~Ogden Nash*

*The family. We were a strange little band of characters trudging through life sharing diseases and toothpaste, coveting one another's desserts, hiding shampoo, borrowing money, locking each other out of our rooms, inflicting pain and kissing to heal it in the same instant, loving, laughing, defending, and trying to figure out the common thread that bound us all together. ~Erma Bombeck*

Family life is a bit like a runny peach pie - not perfect but who's complaining? ~Robert Brault,  
[www.robertbrault.com](http://www.robertbrault.com)

**The foundation of family-centered care is the partnership between families and professionals. Key to this partnership are the following:**

- Families and professionals work together in the best interest of the child and the family.
- As the child grows, s/he assumes a partnership role.
- There is mutual respect for the skills and expertise each partner brings to the relationship.
- Trust is fundamental.
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.

**Within that framework, ten components of family centered care have been identified. (National Center for Family-Centered Care (1989); Bishop, Woll and Arango (1993)) Family-centered care accomplishes the following:**

1. Acknowledges the family as the constant in a child's life.
2. Builds on family strengths.
3. Supports the child in learning about and participating in his/her care and decision-making.
4. Honors cultural diversity and family traditions.
5. Recognizes the importance of community based services.
6. Promotes an individual and developmental approach.
7. Encourages family-to-family and peer support.
8. Supports youth as they transition to adulthood.
9. Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
10. Celebrates successes.



## Inspiration and Humor



*The following is a collection of inspirational articles. Everyone raising a child with a disability or special health care need will interpret the experience differently. We have selected a variety of articles for your use. You may find that while you may enjoy some articles, you just don't relate to others. Everyone has different tastes.*

# Welcome to Holland

By Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum...Michelangelo's David...the gondolas of Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland".

"HOLLAND?!?" you say. "What do you mean, Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

"But there's been a change of plans," says the stewardess. "They've landed in Holland and there you must stay."

The important thing is that you haven't landed in a horrible, disgusting, filthy place full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around you and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's where I had planned."

And the pain of that will never, ever go away because the loss of that dream was a very significant loss. But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special and lovely things about Holland.

# Celebrating Holland—I'm Home

by Cathy Anthony

(A follow-up to the original "Welcome to Holland" by Emily Perl Kingsley)

I have been in Holland for over a decade now. It has become home. I have had time to catch my breath, to settle and adjust, to accept something different than I had planned.

I reflect back on those years of past when I had first landed in Holland. I remember clearly my shock, my fear, my anger—the pain and uncertainty. In those first years, I tried to get back to Italy as planned, but Holland was where I was to stay. Today, I can say how far I have come on this unexpected journey. I have learned so much more. But this too has been a journey of time.

I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land. I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends.

Some of these fellow travelers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many have encouraged. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring. Holland wasn't so bad.

I think that Holland is used to wayward travelers like me and grew to become the land of hospitality, reaching out to welcome, to assist, and to support newcomers like me in this new land. Over the years, I've wondered what life would have been like if I'd landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

Sure, this journey has been more challenging and at times I would (and still do) stomp my feet and cry out in frustration and protest.

And yes, Holland is a slower paced life than Italy and less flashy than Italy, but this too has been an unexpected gift. I have learned to slow down in ways too and to look closer at things, with a new appreciation for the remarkable beauty of Holland with its tulips, windmills, and Rembrandts.

I have come to love Holland and call it Home.

I have become a world traveler and discovered that it doesn't matter where you land. What's more important is what you make of your journey and how you see and enjoy the very special, the very lovely things that Holland, or any other land has to offer.

Yes, over a decade ago, I landed in a place I hadn't planned. Yet I am thankful, for this destination has been richer than I could have imagined.

# Welcome to Beirut

*by Susan F. Rzucidlo*

There is a work called "Welcome to Holland" that was written by a very talented lady, Emily Perl Kingsley, about her experience in raising a child with a "disorder". Well, she takes a far kinder approach to life than I do and so with apologies to her, I submit, "Welcome to Beirut". My apologies to Beirut as well.

"I am often asked to describe the experience of raising a child with autism—to try and help people who have not shared in that unique experience to understand it, to imagine how it would feel. It's like this..."

There you are, happy in your life, one or two little ones at your feet. Life is complete and good. One of the children is a little different than the other, but of course, he's like your in-laws, and you did marry into the family. It can't be all that bad.

One day someone comes up from behind you and throws a black bag over your head. They start kicking you in the stomach and trying to tear your heart out. You are terrified. Kicking and screaming you struggle to get away, but there are too many of them. They overpower you and stuff you into the trunk of a car. Bruised and dazed, you don't know where you are. What's going to happen to you? Will you live through this? This is the day you get the diagnosis. "YOUR CHILD HAS AUTISM."

There you are in Beirut, dropped in the middle of a war. You don't know the language and you don't know what is going on. Bombs are dropping. "Life long diagnosis"... "Neurologically impaired"... Bullets whiz by. "Refrigerator mother"... "A good smack is all HE needs to straighten up." Your adrenaline races as the clock ticks away your child's chances of a "recovery".

You sure as heck didn't sign up for this and you want out NOW! God has overestimated your abilities. Unfortunately, there is no one to send your resignation to. You've done everything right in your life. Well, you tried. Well, you weren't caught too often. Hey! You've never even heard of autism before. You look around you. Everything looks the same, but different. Your family is the same. Your child is the same, but now he has a label and you have a caseworker assigned to your family. She'll call you soon.

You feel like a lab rat dropped into a maze. Just as you start to get the first one figured out (early intervention) they drop you into a larger more complex one (school). Never to be outdone, there is always the medical intervention maze. That one is almost never completed. There is always some new "miracle" drug out there.



It helps some kids; will it help yours? You will find some of the greatest folks in the world are doing the same maze you are, maybe on another level, but a Special Ed maze just the same.

Tapping into those folks is a great lifeline to help you get through the day. This really sucks, but hey, there are still good times to be had. WARNING! You do develop an odd sense of humor.

Every so often, you get hit by a bullet or a bomb. Not enough to kill you, only enough to leave a gaping wound. Your child regresses for no apparent reason, and it feels like a kick to the stomach. Some bully makes fun of your kid and you heart aches. You're excluded from activities and functions because of your child and you cry. Your other children are embarrassed to be around your disabled child and you sigh. Your insurance company refuses to provide therapies for "chronic lifelong conditions", and your blood pressure goes up. Your arm aches from holding onto the phone while you are on hold with yet another bureaucrat or doctor or therapist who holds the power to improve or destroy the quality of your child's life with the stroke of a pen. You are exhausted because your child doesn't sleep. And yet, hope springs eternal. There ARE new medications. There IS research going on. There ARE interventions that help. Thank God all those who fought so hard before you came along.

Your child will make progress. When he speaks for the first time, maybe not until he is 8 years old, your heart will soar. You will know that you have experienced a miracle and you will rejoice. The smallest improvement will look like a huge leap to you. You will marvel at typical development and realize how amazing it is. You will know sorrow like few others and yet you will know joy above joy. You will meet dirty-faced angels on playgrounds who are kind to your child without being told to be. There will be a few nurses and doctors who treat your child with the respect and caring that any child deserves. There will be people sent into your life who will show you concern and love like few others. Knowing eyes will meet yours in restaurants and malls, they'll understand, they are living through similar times. For those people you will be forever grateful.

Don't get me wrong. This is war and it is awful. There are no discharges and when you are gone someone else will have to fight in your place. But, there are lulls in wars, times when the bullets aren't flying and bombs aren't dropping. Flowers are seen and picked. Lifelong friendships are forged. You share an odd kinship with people from all walks of life. Good times are had, and because we know how bad the bad times are, the good times are even better. Life is good, but your life is never normal again. But, hey, what fun is normal?

# To You, My Sisters (and Brothers)

*By Maureen K. Higgins*

Many of you I have never even met face to face, but I've searched you out every day. I've looked for you on the Internet, on playgrounds and in grocery stores. I've become an expert at identifying you. You are well worn. You are stronger than you ever wanted to be. Your words ring experience, experience you culled with your very heart and soul. You are compassionate beyond the expectations of this world. You are my "sisters."

Yes, you and I, my friend, are sisters in a sorority. A very elite sorority. We are special. Just like any other sorority, we were chosen to be members. Some of us are invited to join immediately, some not for months or even years. Some of us even tried to refuse membership, but to no avail.

We were initiated in neurologist's offices and NICU's, in obstetrician's offices, in emergency rooms, and during ultrasounds. We were initiated with somber telephone calls, consultations, evaluations, blood tests, x-rays, MRI films, and heart surgeries.

All of us have one thing in common. One day, things were fine. We were pregnant, or we had just given birth, or we were nursing our newborn, or we were playing with our toddler. Yes, one minute everything was fine. Then, whether it happened in an instant, as it often does, or over the course of a few weeks or months, our entire lives changed. Something wasn't quite right. Then we found ourselves mothers of children with special needs.

We are united, we sisters, regardless of the diversity of our children's special needs. Some of our children undergo chemotherapy. Some need respirators and ventilators. Some are unable to talk; some are unable to walk. Some eat through feeding tubes. Some live in a different world. We do not discriminate against those mothers whose children's needs are not as "special" as our child's. We have mutual respect and empathy for all the women who walk in our shoes.

We are knowledgeable. We have educated ourselves with whatever materials we could find. We know "the" specialists in the field. We know "the" neurologists, "the" hospitals, "the" wonder drugs, "the" treatments. We know "the" tests that need to be done, we know "the" degenerative and progressive diseases and we hold our breath while our children are tested for them. Without formal education, we could become board certified in neurology, endocrinology, and psychiatry.

We have taken on our insurance companies and school boards to get what our children need to survive, and to flourish. We have prevailed upon the State to include augmentative communication devices in special education classes and mainstream schools for our children

with cerebral palsy. We have labored to prove to insurance companies the medical necessity of gait trainers and other adaptive equipment for our children with spinal cord defects. We have sued municipalities to have our children properly classified so they could receive education and evaluation commensurate with their diagnosis.

We have learned to deal with the rest of the world, even if that means walking away from it. We have tolerated scorn in supermarkets during "tantrums" and gritted our teeth while discipline was advocated by the person behind us in line. We have tolerated inane suggestions and home remedies from well-meaning strangers. We have tolerated mothers of children without special needs complaining about chicken pox and ear infections. We have learned that many of our closest friends can't understand what it's like to be in our sorority, and don't even want to try.

We have our own personal copies of Emily Perl Kingsley's "A Trip to Holland" and Erma Bombeck's "The Special Mother". We keep them by our bedside and read and reread them during our toughest hours.

We have coped with holidays. We have found ways to get our physically handicapped children to the neighbor's front doors on Halloween, and we have found ways to help our deaf children form the words, "trick or treat". We have accepted that our children with sensory dysfunction will never wear velvet or lace on Christmas. We have painted a canvas of lights and blazing Yule log with our words for our blind children. We have pureed turkey on Thanksgiving. We have bought white chocolate bunnies for Easter. And all the while, we have tried to create a festive atmosphere for the rest of our family. We've gotten up every morning since our journey began wondering how we did it.

We've mourned the fact that we never got to relax and sip red wine in Italy. We've mourned the fact that our trip to Holland has required much more baggage than we ever imagined when we first visited the travel agent. And we've mourned because we left for the airport without most of the things we needed for the trip.

But we, sisters, we keep the faith always. We never stop believing. Our love for our special children and our belief in all that they will achieve in life knows no bounds. We dream of them scoring touchdowns and extra points and home runs.

We visualize them running sprints and marathons. We dream of them planting vegetable seeds, riding horses and chopping down trees. We hear their angelic voices singing Christmas carols. We see their palettes smeared with watercolors, and their fingers flying over ivory keys in a concert hall. We are amazed at the grace of their pirouettes. We never, never stop believing in all they will accomplish as they pass through this world.

But in the meantime, my sisters, the most important thing we do, is hold tight to their little hands as together, we special mothers and our special children, reach for the stars.

## As Elizabeth Kubler-Ross has said so movingly:

All the hardships that you face in life, all the tests and tribulations, all the nightmares, and all the losses, most people still view as curses, as punishments by God, as something negative. If you would only know that nothing that comes to you is negative. I mean nothing. All the trials and tribulations, and the biggest losses that you ever experience, things that make you say, "If I had known about this, I would never have been able to make it through, " are gifts to you. It's like somebody had to—what do you call that when you make the hot iron into a tool?—you have to temper the iron. It is an opportunity that you are given to grow. That is the sole purpose of existence on this planet Earth. You will not grow if you sit in a beautiful flower garden, and somebody brings you gorgeous food on a silver platter. But you will grow if you are sick, if you are in pain, if you experience losses, and if you do not put your head in the sand, but take the pain and learn to accept it, not as a curse or a punishment, but as a gift to you with a very, very specific purpose.

# One Mother's Description of Her Child

*Author Unknown*

"My son marches to the beat of a different drummer.  
We can't change the drum that he marches to.  
We can't change the drum that he was given.

However...

We may be able to fine-tune his drum.  
We can spend a lot of time trying to create a drum  
that fits in with all of the other drums in the world,  
but when we've fine-tuned his drum as much as we can...

It still may never be the same  
as all of the other drums.

But...

What would our world be like if all of  
its drums were the same?  
An orchestra has many different types of drums.

And...

Its' music is beautiful because the  
drums all blend together."

*An excerpt from one parent's speech at the  
5th Annual Lexington Family Services Conference.*

# Bill of Rights for Parents

## **1. The Right to Question/To be Informed**

Everyone is told today that it makes good sense to seek a second opinion before having surgery, or before investing money, or before buying a car. It should not be any different for you and your child with a disability whether you are looking for medical care or an educational program. Parents have the right to question, to be informed and to have access to their children's records.

## **2. The Right to Privacy**

Some aspects of your life are simply no one else's business. If you do not want to discuss something, or if you do not want your child's picture taken, it is your right to say "NO".

## **3. The Right to Keep Trying**

Parenting is not easy, but all parents try to do the best job they can. It sometimes becomes harder when well-meaning friends and professionals tell you that you have set goals that your child will never be able to reach. There is nothing wrong with you if you are not willing to give up.

## **4. The Right to Stop Trying**

Well-meaning friends and professionals have also told parents that they do not work often enough or long enough with their child with a disability. You are the one who lives with your child; you are the one who is being asked to do one more thing; you are the one who is somehow expected to accomplish at home what trained teachers have not been able to do at school. If you just cannot do it, it is okay. Do not feel guilty. That is your decision.

## **5. The Right to Set Limits**

There are limits to what one person can do; you shouldn't expect yourself to think about your child all the time. And your child shouldn't expect to be the center of attention. You are not Super Parent.

## **6. The Right to Be a Parent**

You and your child need time to fool around, giggle, tell stories, laugh, and just do nothing. These times are just as much a part of your child's education as the time you spend following the activities in any book. In fact, these times are often more important.



## **7. The Right to Be Unenthusiastic**

Sometimes you feel sad, or you are worried about money or your child, or you feel sick. If other people take that as a sign that you're "not adjusting" or that you're "not accepting your child's disability", that is their problem. You have a right to be "up" sometimes and "down" others.

## **8. The Right to Feel Angry**

Nothing in life prepares anyone for a family member with special health care needs, and when it is your child, it seems all the more unfair. Feel angry if you must, but use your anger to get the best services you can for your child.

## **9. The Right to Be Annoyed With Your Child**

There are days when you like your child and days when you don't, but that does not mean that you don't love him/her. Children with disabilities are just as capable of being ornery as other children, and they should be disciplined.

## **10. The Right to Time Off**

You need time to yourself, time with your spouse or partner and other adult family members, time with your other children, and just plain time without kids. There are many parts to your life, and each deserves as much attention and nurturing, as does your child with disabilities.

## **11. The Right to Be the Expert-In-Charge**

You know your child better than anyone else. Teachers, doctors, nurses, case managers come and go, but you are the expert, you have the right to be in charge of your child's educational, social, and medical decisions—at least until he/she is able to make them for themselves. Parents are the single most important resource that children have.

## **12. The Right to Dignity**

These rights of parents really boil down to the right to be respected and treated as an equal. You expect to be neither pitied nor admired, but you do expect to be listened to and supported in a nonjudgmental way. You expect the truth—from doctors, teachers, social workers, and therapists, who are there to help you; from your friends and neighbors, who owe you a chance to be someone other than a "parent of a disabled child", and from family members.

# *The Ten Commandments*

## **For Parents of Children with Special Needs**

1. Take one day at a time, and take that day positively. You don't have control over the future, over today, or over any other day, and neither does anyone else. Other people just think they do.
2. Never underestimate your child's potential. Allow him, encourage him, and expect him to develop to the best of his abilities.
3. Find and allow positive mentors: parents and professionals who can share with you their experience, advice, and support.
4. Provide and be involved with the most appropriate educational and learning environments for your child from infancy on.
5. Keep in mind the feelings and needs of your spouse and your other children. Remind them that this child does not get more of your love just because he gets more of your time.
6. Answer only to your conscience: then you'll be able to answer to your child. You need not justify your actions to your friends or the public.
7. Be honest with your feelings. You can't be a super-parent 24 hours a day. Allow yourself jealousy, anger, pity, frustration, and depression in small amounts whenever necessary.
8. Be kind to yourself. Don't focus continually on what needs to be done. Remember to look at what you have accomplished.
9. Stop and smell the roses. Take advantage of the fact that you have gained a special appreciation for the little miracles in life that others take for granted.
10. Keep and use a sense of humor. Cracking up with laughter can keep you from cracking up with stress.
11. There is no 11<sup>th</sup>, silly. (See the 10<sup>th</sup>)

From: FEAT

# You Are Not Alone

*by Patty McGill Smith*

If you have recently learned that your child is developmentally delayed or has a handicapping condition, which either is or is not completely defined, this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.



When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a disability, I was devastated--and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a "black sack" being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as "having a knife stuck" in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

Many things can be done to help a parent through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

## ***Common Reactions***

On learning that their child may have a disability, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and with this enormous challenge. One of the first reactions is that of denial--"this cannot be happening to me, to my child, to our family." Denial rapidly merges with anger, which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense

that it touches almost anyone, because it is triggered by feelings of grief and inexplicable loss that one does not know how to explain, nor how to deal with.

**Fear** is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: "What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?". Then other questions arise: "Will he ever learn? Will he ever go to college? Will he or she have the capability of loving and living and laughing and doing all the things that we had planned?"

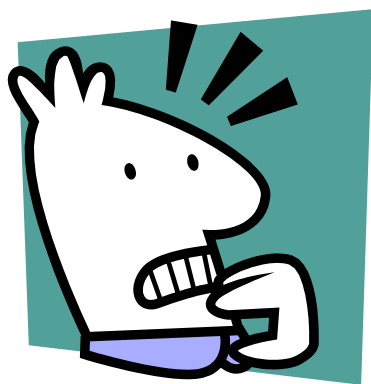
Other unknowns also inspire fear. Parents fear that the child's condition will be the very worst that it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. Memories return of handicapped persons one has known. Sometimes there is guilt over some slight committed years before toward a handicapped person. There is also fear of society's rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers and sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is guilt and concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for having done this? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?" For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertently let her drop and didn't tell me. Much self-reproach and remorse can stem from questioning the causes of the handicap.

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, "Why me?" or "Why my child?", many parents are also saying, "Why has God done this to me?" How often have we raised our eyes to Heaven and asked: "What did I ever do to deserve this?" One young

mother said, "I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship."

Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such a trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's handicap.



Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child is handicapped, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers

with whom no bond of trust has yet been established.

Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person. Rejection is another reaction that parents experience. Rejection can be directed toward the child or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child -- a feeling that many parents report at their deepest points of depression.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through every one of these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise so that they will know that they are not alone. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.



### ***Seek the Assistance of Another Parent***

There was a parent who helped me. Twenty-two hours after my own child's diagnosis, he made a statement that I have never forgotten: "You may not realize it today, but there may come a time in your life when you will find that having a daughter with a handicap is a blessing." I can remember being puzzled by these



words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources. And he was the father of a retarded boy.

My first recommendation is to try to find another parent of a handicapped child, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent- Helping-Parent Programs.

### ***Talk with Your Mate***

Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life -- your best friend, your own parents. For many people, the temptation to close up emotionally is great at this point, but it can be so beneficial to have reliable friends and relatives who can help to carry the emotional burden.

### ***Rely on Positive Sources in Your Life***

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another might be a good friend or a counselor. Go to those who have been a strength before in your life. Find the new sources that you need now. A very fine



counselor once gave me a recipe for living through a crisis: "Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day."

Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is pain in isolation. Sometimes professional counseling is warranted; if you feel that this might help you, do not be reluctant to seek this avenue of assistance.



### ***Take One Day at a Time***

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the "what if's" and "what then's" of the future. Good things continue to happen each day. Take time to "smell the roses."

### ***Learn the Terminology***

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the meaning.

### ***Seek Information***

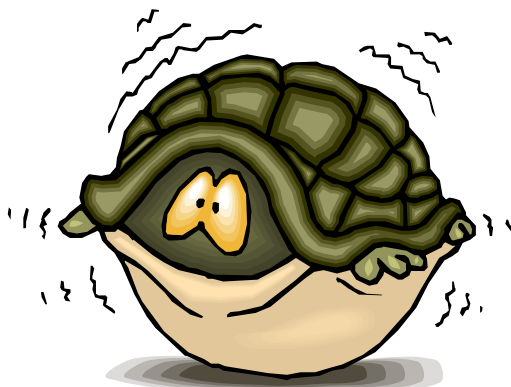
Some parents seek virtually "tons" of information; others are not so persistent. The important thing is that you request accurate information. You should not be afraid to ask questions will be your first step in beginning to understand more about your child. Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions before entering appointments or meetings, and to write down further question as you think of them during the meeting. Get written copies of all documentation from physicians, teachers and therapists regarding your child. It is a good idea to buy a three ring notebook which to save all information that is given to you. In the future, there will be many uses for information that you have recorded and filed; keep it in a safe place. Again, remember always to ask for copies of evaluations, diagnostic reports, and progress reports.

### ***Do Not Be Intimidated***

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is your child, and the situation has a profound effect on your life and on your child's future. Therefore, it is important that you learn as much as you can about your situation.

### ***Do Not Be Afraid to Show Emotion***

So many parents, especially Dads, repress their emotions because they believe it to be a sign of weakness to let people know how badly they are feeling. The strongest fathers of handicapped children whom I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one's strength.



### ***Learn to Deal with Bitterness and Anger***

Ultimately, bitterness and anger will hurt you a great deal more than they will those toward whom the anger is directed. It is very valuable to be able to recognize your anger and then let go of it. It is understandable that parents will be bitter and angry and disappointed to learn that their child has a serious problem. When you realize that these negative responses tend to hurt you and make you less effective with your child, you can decide to do something about them. Life is better when you are feeling positive. You will be better equipped to meet these new challenges when bitter feelings are no longer draining your energies and initiative.

### ***Avoid Pity***

Self-pity, the experience of pity from others, or pity for your child are actually disabling. Pity is not what is needed. Empathy, which is the ability to feel with another person, is the attitude to be encouraged.

### ***Avoid Judgments***

During this period, parents may become judgmental about the way people are reacting toward them or toward their child. Many people's reactions to serious problems are based on a lack of understanding, fear of knowing what to say, or fear of the unknown. Therefore, others may sometimes react inappropriately, but you need not use too much energy in being concerned over those who are not able to respond in ways that you might prefer.

### ***Keep Daily Routines as Normal as Possible***

My mother once told me, "When a problem arises and you don't know what to do, then do whatever it was that you were going to do anyway." Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

### ***Remember That This Is Your Child***

This person is your child, first and foremost. Granted, your child's development may be different from that of other children, but this does not make your child less valuable, less human, less important, or less in need of your love and parenting. Love and enjoy your child. The child comes first; the handicapping condition is second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

### ***Recognize That You Are Not Alone***

The feeling of isolation at the time of diagnosis is almost a universal feeling among parents. In this paper, there are many recommendations to help diminish those feelings of separateness and isolation. You can diminish these feelings by recognizing that they have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.

*For those of us with a sense of humor...*

## **Do you like these IEPs?**

I do not like these IEPs  
I do not like them Jeeze Louise  
We test, we check, we plan, we meet  
But nothing ever seems complete.  
Would you could you like the form?  
I do not like the form I see  
Not page 1, not 2, not 3  
Another change, a brand new box  
I think we all have lost our rocks.  
Could you all meet here or there?  
We could not all meet here or there  
We cannot all fit anywhere  
Not in a room, not in the hall  
There seems to be no space at all.  
Would you could you meet again?  
I cannot meet again next week  
No lunch, no prep PLEASE hear me speak  
No not at dusk, no not at dawn  
At 4 p.m. I should be gone.  
Could you hear while all speak out?  
Would you write the words they spout?  
I could not hear, I would not write  
This does not need to be a fight  
Sign here, date there, mark this, check that  
Beware the student's advocate.  
You do not like them, so you say  
Try again! Try again!  
And you may.  
If you will let me be, I will try again  
You will see.  
Say!  
I almost like these IEPs  
I think I'll write 6003  
And I will practice day and night  
Until they say "You got it right!"

## Mom and Toddler in Grocery Store

*The following is a story from a listserv on the Internet.*

A man observed a woman in the grocery store with a 3-year old girl in her cart. As they passed the cookie section, the little girl asked for cookies and her mother told her no. The little girl immediately began to whine and fuss, and the mother said quietly, "Now Monica, we just have half of the aisles left to go through; don't be upset. It won't be long".

Soon they came to the candy aisle and the little girl began to shout for candy. And when told she couldn't have any, began to cry. The mother said, "There, there, Monica, don't cry. Only two more aisles to go, and then we'll be checking out".

When they got to the checkout stand, the little girl immediately began to clamor for gum and burst into a terrible tantrum upon discovering there'd be no gum purchased. The mother patiently said, "Monica, we'll be out of this check-out stand in five minutes and then you can go home and have a nice nap".

A man followed the woman out to the parking lot and stopped the woman to compliment her. "I couldn't help notice how patient you were with little Monica", he began. Whereupon the mother said, "I'm Monica. My little girl's name is Tammy".

## Your child might have an IEP...If...

- If you have ever attended a meeting at school with 25 professionals...your child might have an IEP.
- If you are the only one wearing jeans...your child might have an IEP.
- If these professionals speak a different language... your child might have an IEP.
- If the meeting room was the size of a closet... your child might have an IEP.
- If you have ever been asked, "Do you think your child is the only one in the district?"... your child might have an IEP.
- If you have ever heard, "We do not have money for that!"... your child might have an IEP.
- If you have ever been called an "overprotective, hysterical parent" or an "uninvolved parent"... your child might have an IEP.
- If you have ever been told your child "will just grow out of it", "is lazy", "slow", "irresponsible", "immature and/or sensitive", etc...etc... your child might have an IEP.
- If you feel you have walked into "Assertiveness Training 101" by accident... your child might have an IEP.
- If you have ever been screamed at by a school official... your child might have an IEP.
- If you have ever been told your child will be lucky to grow up and dig ditches... your child might have an IEP.
- If it has ever been suggested to move to another District... your child might have an IEP.
- If you have ever been invited to home school your child... your child might have an IEP.
- If you have ever called the school and asked for your child and were told "we do not have anyone here by that name..." your child might have an IEP.
- If your family is ever discussed in the teacher's lounge... your child might have an IEP.
- If every time you call the school board office, the person you need to talk to is in a meeting... your child might have an IEP.
- If a meeting with the school has ever been rescheduled more than twice to the time you definitely cannot come... your child might have an IEP.
- If you have ever been patted on the shoulder and called "honey" by the principal... your child might have an IEP.
- If it has ever been suggested that all your child needs is a "good spanking to straighten him/her up... your child might have an IEP.
- If you have been asked by a teacher to "just sign it!"...your child definitely has an IEP.



# Care for the Caregiver

1. Be gentle with yourself!
2. Remind yourself that you are an enabler, not a magician. We cannot change anyone else—we can only change how we relate to them.
3. Find a hermit spot. Use it daily.
4. Give support, encouragement and praise to peers and to management. Learn to accept it in return.
5. Remember that in the light of the pain we see, we are bound to feel helpless at times. Admit it without shame. Caring and being there are sometimes more important than doing.
6. Change your routine often and your tasks when you can.
7. Learn to recognize the difference between complaining that relieves and complaining that reinforces negative stress.
8. On the way home, focus on a good thing that occurred during the day.
9. Be a resource to yourself! Get creative—try new approaches. Be an artist as well as a technician.
10. Use supervision or the buddy system regularly as a source of support, assurance and redirection.
11. Avoid “shop talk” during breaks when socializing with colleagues.
12. Schedule “withdraw” periods during the week—limit interruptions.
13. Say “I choose” rather than “I should, I ought to, or I have to”. Say “I won’t” rather than “I can’t”.
14. If you never say no...what is your “yes” worth?
15. Aloofness and indifference are far more harmful than admitting inability to do more.
16. Laugh and play!

Provided by:

Western New York SIDS Center

200 Fairport Village Landing

Fairport, NY 14450

# Twenty Goals to Grow With

Goals are ideals. They are destination points in our lives that help us to stretch our limits and grow to new definitions of ourselves. These goals reflect the philosophy of this book and may help you to define goals that are uniquely yours.

1. I have a realistic view of my child's abilities and limitations and clearly value my child as a total person.
2. I do not allow myself to live with unrealistic expectations—and therefore repeated disappointments—about what my child cannot do or may never do.
3. I plan what I can for the future, but live a day at a time with a sense of trust that I will handle what happens tomorrow, next year, or in 10 years.
4. I have the knowledge and skills to seek out information and resources in assertive, creative ways.
5. I have hope without expecting miracles.
6. My self-esteem is intact. I do not measure my worth by my child's abilities or limitations.
7. I try to see the world from my child's point of view.
8. I am able to empathize with others, to be sensitive to other viewpoints, while maintaining my own sense of priorities.
9. I have freed myself from unproductive feelings of guilt, anger, shame, blame, and self-criticism.
10. I generally see the glass as half-full instead of half-empty and am able to live each moment to the fullest.
11. I have a sense of perspective about my life, my problems, and my daily hassles.
12. I have a sense of humor and can laugh at myself.
13. I have an understanding of and an appreciation of individual differences.
14. I have maintained a support network of family and friends.
15. I do the best I can within the context of my total family's needs.
16. I realize that I will not be able to do everything, and I will not feel guilty about that.
17. I will not spend every moment trying to teach, stimulate, and cure my child. I will have times with her that are totally for fun.
18. I will not blame myself for any areas in which my child is unable to make progress.
19. I do not need to explain myself and/or my child to everyone.
20. I cannot control what other people think.

***Reprinted from: Nobody's Perfect***

## The Ten Commandments for Stress Reduction

- I. Thou shalt not be perfect, or even try to be.
- II. Thou shalt not try to be all things to all people.
- III. Thou shalt sometimes leave things undone.
- IV. Thou shalt not spread thyself too thin.
- V. Thou shalt learn to say, "no".
- VI. Thou shalt schedule time for thyself and for thy sources of support.
- VII. Thou shalt switch thyself off, and do nothing regularly.
- VIII. Thou shalt not ever feel guilty for doing nothing or for saying "no".
- IX. Thou shalt be boring, untidy, inelegant and unattractive at times.
- X. ESPECIALLY, thou shalt not be thy own worst enemy, but be thou own BEST FRIEND.

## Home from Holland

Sandy Brown

So you've been to Holland, and now you're home. Maybe you planned the return trip, maybe you didn't. It doesn't matter; the end result is that now you are somewhere you really don't want to be. There are many people around you still preparing for the wonderful trip to Italy they plan on taking. There are many more still in Italy. But you are home and have found yourself a foreigner in your own land.

No one wants to hear about your trip to Holland. No one wants to hear about your return home. No one wants to see pictures or hear stories or talk about the sights and sounds and people that were Holland. No one seems to understand that you have left an amazing community behind who knew you as "Little J's mom" or "Little J's dad", who met you at the plane and stayed with you every step of the way until you could travel through Holland on your own. No one calls you by that familiar name any more and you don't know if you will ever see these people again. Family and friends may believe that in not talking, you will forget, move on, and heal. Some of your friends from Holland may stop calling altogether, afraid of having to return home themselves one day. Whatever the reasons, you still want to talk and it's hard to find someone to listen. Your sister tells you to let it go. Your father reminds you that Soandso left Italy after being there for many years. After all, you were only in Holland and you were only there for a brief time. You knew you had to eventually come home; why are you so upset?

Then one day, you bump in to Soandso. They ask about your trip to Holland. They ask about your trip home. They share their own story of their journey to and from Italy. And you find yourself feeling connected to someone for the first time in a long time. Home does not seem like such a strange place any more. Best of all, you learn an important travel tip: you don't need any one's permission to talk about Holland. If your openness makes others uncomfortable, they can choose not to listen. They cannot expect you to be silent. Because Holland is truly a wonderful place to be. Because you had an amazing journey that many others can learn from. Because being in Holland, with all of the experiences you had there, helped shape who you are now. But most of all, because no matter how long you've been away, you will always miss Holland very, very much.

# EARLY CHILDHOOD BULLETIN

*News by and for Parents and Parent Members of State Interagency Coordinating Councils*

Prepared by the Federation for Children with Special Needs  
Parent Component Staff of NECTAS

Spring

1998

## FAMILY EXPERIENCES: Ways to Lead Change Through Telling Your Story

*By Glenn Gabbard*

NECTAS at the Federation for Children with Special Needs, Boston, Massachusetts

I recently attended a conference about model programs serving children with disabilities and their families. After one parent gave a particularly moving account of her family's struggles, the audience took a break. During the break, I overheard a remark from another audience participant. "I don't know if I can listen to any more tear jerking stories," the person complained. "What's the point?"

I was initially startled by the remark, then insulted. How could someone be so callous as to question the experience of a parent? As a parent of two children who receive special education services, I took this comment personally — as if the person were talking about my story — and telling me that it wasn't worth listening to. As I thought more about this situation, however, I realized the problem was not one of insensitivity, but that somehow the story had no impact on some listeners. It did not move them to think and consider using the themes and information as a prompt to change their personal and professional lives.

Whether it be to pediatricians, neighbors, legislators, therapists, conference audiences, teachers, administrators, or peers, parents of children with disabilities are frequently asked to tell all or part of their family's life story.

Parents reveal their stories as a way to under-

stand the past in relation to an imagined future for themselves and their children.

Stories help us connect. Stories also reveal the details, the impact of systems on the daily lives of families and children. They are a powerful way to develop relationships among parents and professionals. These stories are what connect us

to our work and to each other in meaningful ways. They deepen our understanding of individual and shared experiences. Stories often spur change in systems that seem impossible to understand. They can also help clarify disagreements.

Storytelling can also be a huge risk. By sharing a story, you can easily make a point; however, you can also be vulnerable to criticism or misinterpretation. Often, the powerful lessons that these stories reveal are not fully appreciated; often parents grow fatigued with revealing private experiences that are

frequently painful to recall.

This edition of the *Early Childhood Bulletin* will focus on ways parents can shape their stories so that key themes are emphasized and improvements are made within a program or system. We'll cover some of the key issues to consider in preparing and presenting a story. We've also included some additional resources to consider if you wish to pursue this topic.

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***"Stories help  
us connect.  
Stories also reveal  
the details, the  
impact of systems  
on the daily lives  
of families and  
children."***

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# I. PREPARING THE STORY

## WHAT'S THE PURPOSE?

Parents tell their stories in many situations, sometimes when they are invited, others when they discover the opportunity informally. Parents speak in formal settings, including parent training, professional development, keynote speeches or panels for conferences, legislative hearings, school presentations to teachers and students. A group of parents gathered at a recent Part C conference in the Midwest and discussed some of the key purposes for speaking out. They mentioned the importance of using one's own experience to bring change and broaden their experience to apply to others.

- ♦ Turning grief and anger into constructive energy by talking publicly
- ♦ Helping service providers by sharing stories for effective networks to programs
- ♦ Reinforcing values to guide a family's commitment to themselves and their children
- ♦ Influencing public opinion by illustrating how policies affect families
- ♦ Helping yourself and others to feel less alone in efforts to make change
- ♦ Marketing key strengths of early intervention to legislators and other policy makers

- ♦ Entertaining others
- ♦ Sharing information that cannot be easily presented by charts or graphs with others who do not directly experience the problem
- ♦ Raising awareness and promoting sensitivity to the experience and knowledge that grows from these experiences



## Guidelines to consider

The amount of time that you spend on each item on this list may vary depending on what's at stake when you tell the story. There are three major phases to storytelling: (1) preparing what you have to say; (2) actually presenting the story; and (3) following up and assessing the impact of your story.

It's a good idea, however, to spend at least some time on each of the three phases — even if the story that you tell is to a familiar audience, under familiar circumstances.

## Where Do Family Stories Get Told?

"As part of our Parent-to-Parent program, I often meet families who have newly diagnosed children. I find that telling the story of my own children's births helps create an almost immediate bond."

"Managed care has made life for kids with special/health care needs a real nightmare in our area. I told my story to my HMO's board of directors to help them understand how unique my family and others like mine are."



# I. PREPARING THE STORY

## WHO'S THE AUDIENCE?

It is important to think a bit in advance about who will hear your story. A little ground work can help to make the story effective and help you be comfortable in telling it. Who is in the audience can help you to decide which parts to emphasize and, more importantly, why you are telling it. Aspects can change depending on the audience: a story about a wonderful preschool program can emphasize the need for funding with a group of legislators considering the next year's budget; to a group of preschool teachers, it can emphasize the importance of parent/teacher communication and collaboration.

often gives an idea of what can be learned from it — what was the theme or lesson? Sometimes this theme can be stated directly; at other times, it is best to let the listeners draw their own conclusions.



## Some questions to consider:

- ☞ Who is your audience?
- ☞ What is their purpose?
- ☞ What is their education level?
- ☞ How many people are you speaking to?
- ☞ Age?
- ☞ Where are you presenting?
- ☞ Numbers of men and women?
- ☞ Did the audience pay to hear you?
- ☞ Numbers of parents and professionals?

## HOW TO ORGANIZE A STORY

Although most stories have a beginning, middle and an end, they can also vary in length — some are 30 seconds long; others can last over an hour. Engaging stories rely on a beginning that "hooks" the listener who then listens for the details in the middle of the story, and awaits the punch line at the end. The *beginning* sets the stage, identifies the key characters and location, and gets the listener interested. The *middle*— where the plot thickens — adds details, examples, and interesting information to understand the key ideas and people. The *end* usually ties things together and

## The Organization of a Story

### Beginning

- ♦ Where does the story occur?
- ♦ Who are the important people?
- ♦ When did the story take place?



### Middle

- ♦ What happened first, second, third, etc.?
- ♦ What was the major conflict?
- ♦ What were some of the key feelings elicited?



### End

- ♦ What happened to conclude the story?
- ♦ How was the problem resolved?
- ♦ What was the key theme you learned?
- ♦ What is the key theme you want the audience to understand?

## II. PRESENTING THE STORY

### FINDING AND USING YOUR VOICE

The way a story is told is often as important as the story itself. To be an effective storyteller you must have something to tell, someone to tell it to and the ability to make yourself heard. Some suggestions on presenting:

#### RELAX

Before you begin to speak, take a few deep breaths and slowly scan the audience for familiar faces.

#### PROJECT

With large audiences, use a microphone. In smaller groups, project your voice with confidence.

#### PACE

The most frequent problem with nerves is they make us speed up our presentations. Remember to speak calmly and slowly — just a bit slower than normal conversational style. Good listeners require some processing time.

#### EYE CONTACT

It's always helpful to establish clear and frequent eye contact with your audience. Even in small groups, you will find listeners who appear to be attentive; some folks may nod or smile.

It's often useful to consistently look at familiar or sympathetic faces in different parts of the audience. Look around frequently at these groups so that all of the audience feels included.

#### HUMOR

If appropriate, it may be helpful to use a bit of humor. Test any humorous comments with friends or colleagues to see if it works for them. Avoid making any one group (professional or parent) the butt of humorous comments. Teasing and sarcasm are not a good idea — one person's idea of a sarcastic remark might be another's insult.

#### GIVE THE AUDIENCE TIME TO ASK QUESTIONS

- ♦ Allow time the end of your presentation for audience members to ask questions.
- ♦ If someone asks a personal question that hits a raw nerve simply say, "I find that question difficult for me and I would really rather not answer it."
- ♦ Be comfortable saying, "I don't know, but I can find out for you" if you can't answer a question immediately.

## *Where Do Family Stories Get Told?*

"You know, as a preschool director, the connection and empathy I feel with others — parents and professionals alike — is so powerful when I hear stories that connect somehow with my own. I get tired sometimes of hearing broad statements about how important collaboration is in thinking about

family centered services and programs. What really makes a difference for me is when I hear stories about what happened today at the center...what kind of difference we made in the lives of the families we serve."

## II. PRESENTING THE STORY

### WORKING WITH PROPS, OR AUDIO-VISUALS

- ♦ The use of AV materials such as overhead transparencies, slides, videotape selections, photographs, and computer-enhanced presentations can be helpful tools.
- ♦ Know how to work equipment yourself. You cannot depend on someone being there who knows what you need.
- ♦ Be sure the equipment is working.
- ♦ Be sure that your aids are an enhancement of what you are saying and not a distraction.

### WHAT IF I CRY?

For even the most experienced speakers, telling a story that reveals a personal or emotional time can be difficult. Crying is, of course, perfectly acceptable; however, you need to be aware of the audience and their need to understand your emotions and your message. Also, the last audience response you want from telling your story is pity or confusion. Some tips from parent storytellers:

- ♦ If you start to cry, pause long enough to take three or four deep breaths, and then go on. The audience will appreciate your taking the time and being able to hear the rest of your presentation.
- ♦ Sometimes it is useful to explain to the audience that you need to collect yourself and that you really want them as much to understand your what you have to tell them as well as how emotionally difficult it is for you.
- ♦ Mentally focus on something that makes you laugh inside; this sometimes evens out the fear and sadness enough to let you go on.
- ♦ Take a small squeezable rubber toy or some other object that will fit in the palm of your hand. If you start to cry, squeeze the toy to relieve some of the tension.
- ♦ Avoid someone "rescuing" you by interrupting and interpreting what you mean. If you still have a message to convey, take the time to collect yourself and then go on.

## *Where Do Family Stories Get Told?*

"There is so much misinformation in our state about inclusion and natural environments. Recently, I testified at our local school committee meeting and told them how my son was part of his local little league team, even though he uses a wheelchair. A few of the committee people came up later to thank me for showing them some real examples of what we mean by including everyone."

"For the first time in our state, we have to request additional funds for our Part C programs from our legislators. We've set up training in marketing and public awareness for parents and professionals whom we are asking to visit legislators and tell their stories."

## III. FOLLOWING UP

### HOW CAN I GET FEEDBACK?

Understanding how listeners heard your story is as important as preparing and telling it. If possible, ask trusted colleagues or friends to listen to your presentation and to let you know what they thought of it. Prepare focused questions and listen carefully to their responses. This will help you develop the story and emphasize effective features.

Some questions to get feedback:

- ♦ What key phrases and words caught your ear?
- ♦ What was the most successful part of the presentation?
- ♦ What was most difficult to understand?
- ♦ If you knew the story was going to be told again, in what ways could it be different?
- ♦ What were the major themes?
- ♦ How did the audience respond?
- ♦ What about volume? Pace?
- ♦ Did I use humor effectively?
- ♦ Did the story make logical sense?

If there is an evaluation form for the activity in which you were speaking, ask to review it. If you are speaking in an informal setting, ask someone to observe how the audience responds. This can be useful in meetings, training sessions, or even small groups in which stories are told. In some school or hospital settings, families ask a friend to act as an informal advocate; this individual can give you feedback about the interaction if it seems appropriate.



### An Important Reminder

As children grow older and more independent, it's important to consult them about the story details and, sometimes, whether or not the story should be told at all. It's important to remember that as children mature, some will be asked to tell their stories and should understand the importance as well as their right to keep details that they deem private to themselves.

## Where Do Family Stories Get Told?

"When I need to make any big changes in my child's Individualized Education Program (IEP), I know that there may be some resistance. I usually introduce the need for a change with a story about my child that illustrates how the change could

really help. It helps the group to become more child centered rather than focusing on possible conflict between me and them."



## IV. RESOURCES

### ON TELLING YOUR STORIES

University of Wisconsin-Madison, Waisman Center, Early Intervention Program Parent Projects (Producer), & Geier, D. and Thompson, C. (Directors). (1994). *Telling your family story...Parents as presenters* [Videorecording]. Madison, WI: University of Wisconsin-Madison, Waisman Center. 1 Video Cassette plus accompanying video guide. 28 min.

"Telling Your Family Story...Parents as Presenters." Video Cassette. Waisman Center, Early Intervention Parent Projects, University of Wisconsin, Madison. (1994). 28 minutes. Waisman Center.

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"Using Stories as Catalysts for Change." *Parent Leadership Program Training Manual* (March 1996). Lansing MI: Michigan Department of Education. 608 West Allegan Street, Lansing MI 48933 517.373.6335. A useful set of activities designed to foster skill and knowledge building for parent leaders involved in policy making capacities.

### ON PUBLIC SPEAKING

Hoff, Ron and Barrie Maguire (1992). *I Can See You Naked : A New Revised*) New York: Andrews & McMeel.

### STORIES THAT HAVE BEEN TOLD

Simons, Robin (1987). *After the Tears: Parents Talk About Raising a Child With a Disability*. New York: Harcourt Brace. A collection of interviews and stories from parents who share their experience of becoming parents.

Featherstone, Helen (1981). *A Difference in the Family: Living With a Disabled Child*. New York: Viking Press. A classic account of one mother's experiences as a parent and advocate.

Coles, Robert (1990). *The Call of Stories: Teaching and the Moral Imagination*. New York: Houghton Mifflin. The nationally renowned psychiatrist and humanist reflects on the importance of learning from the stories we tell and hear.

Mairs, Nancy (1998). *Waist-High in the World: A Life Among the Nondisabled*. New York: Beacon Press. A recent collection of eloquent essays reflecting on the experience of disability and change.

Thank you to NECTAC for providing this great resource on "Telling Your Story". More great resources can be found at [www.nectac.org](http://www.nectac.org)

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