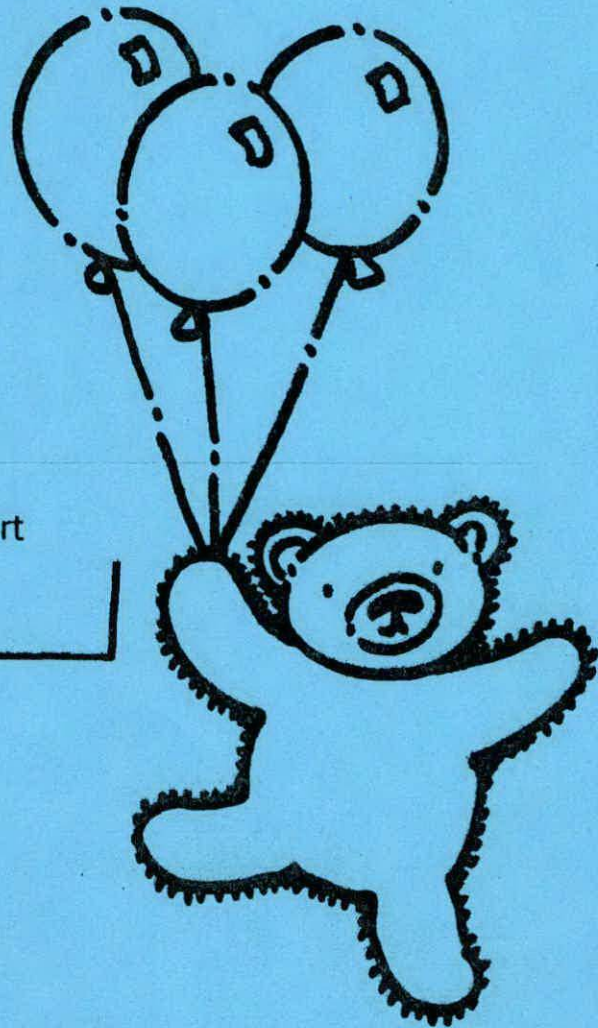


MELD Special Curriculum



Blending Information and Support
for Parents of Children
with Special Needs



MELD Special

Blending Information and Support
for Parents of Children
with Special Needs

MELD Central in Minneapolis, Minnesota is committed
to enhancing and expanding this curriculum
as responses and suggestions are received from
advisors and sites in which
MELD Special programs are operating.
We welcome your input.

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Explanation of Page Coloring System in MELD Special Curriculum

Each chapter of the MELD Special Curriculum is treated as a separate "book" with each cover page as page 1. We hope this system will enable PGF's to easily work with the curriculum so that the topics will fit the special needs of each group and so that PGF's do not feel they must work consecutively through the curriculum. PGF's will know best what their group needs may be and we at MELD do not want to limit the group's progress in any way.

The chart below will help you find the pages you will need in order to plan your group meetings.

<u>Page Color</u>	<u>Explanation</u>
Blue	Cover for each chapter and table of contents.
Gold	Parent Group Facilitator information. Guidelines and ideas to consider when planning group meetings.
Ivory	Content information. The "nuts and bolts" information about specific topics.
White	Learning Activities and Handouts. We printed these in white for ease of duplication. Please feel free to make as many copies of the handouts as your group needs.

We encourage your input on curriculum organization and printing. We want to hear from you about what works well and what could use improvement.

TABLE OF CONTENTS

Chapter 1	Grief	Page
	Introduction for Facilitators	3
	Content for Facilitators	11
	Learning Activities	35

Chapter 2	Parent Relationships	
	Introduction for Facilitators	3
	Content for Facilitators	11
	Learning Activities	41

Chapter 3	Extended Family Relationships	
	Introduction for Facilitators	3
	Content for Facilitators	9
	Learning Activities	43

Chapter 4	Stress	
	Introductions for Facilitators	3
	Content for Facilitators	9
	Learning Activities	41

Chapter 5	Siblings	
	Introductions for Facilitators	3
	Content for Facilitators	9
	Learning Activities	41

Chapter 6	Professional Help	
	Introduction for Facilitators	3
	Content for Facilitators	10
	Learning Activities	51

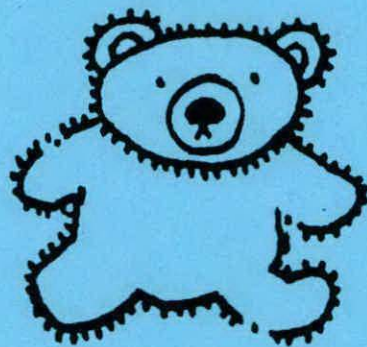
Chapter 7	Play	
	Introduction for Facilitators	3
	Content for Facilitators	11
	Learning Activities	55

Chapter 8	Growth and Development	
	Introduction for Facilitators	3
	Content for Facilitators	11
	Learning Activities	55

Chapter 9	Behavior Guidance	
	Introduction for Facilitators	3
	Content for Facilitators	13
	Learning Activities	55

Chapter 1

**Coping
with Grief**



Coping With Grief

Table of Contents	Pages
I. Introduction For Facilitators	3-10
A. Main Ideas	4
B. MELD Biases	5
C. Facilitator Focus	6
D. Group Issues and Tips	7-10
II. Content For Facilitators	11-30
A. Grief: Our Response to Loss	13
B. Parents Lose Part of Themselves	14-15
C. When A Child's Problem is Identified But There is No Diagnosis	16
D. Stages of Grief	17-19
E. Recycling the Stages of Grief	20-21
F. Chronic Sorrow	22-23
G. Resisting Grief	24-25
H. Coping	26-30
I. Will It Get Better? Can We Survive?	31-32
III. Resources	33-34
IV. Learning Activities	35-47
V. Handouts	a-g
A. Family Reactions To Loss	a
B. The Grieving Process of Parents of Atypical Children	b
C. Grieving/Coping Process of Parents of Handicapped Children ...	c
D. Stages of Loss Experienced by Parents of a Special Needs Child	d
E. Death of a Dream	e
F. Taking the Guilt Out of Parenting	f
G. Ivar's Tale	g

Introduction For Facilitators

Mothers and fathers cite many reasons for joining a MELD Special group. Many don't know anyone else with a disabled or chronically ill child and are interested in meeting people in similar situations. Some want to learn how other parents juggle the multitude of tasks involved in caring for a child with special needs. Others are interested in advice about dealing with medical, educational, and human service professionals. Some parents want to observe other families to find clues about what to expect in the future.

Underlying many of these reasons is another concern: how do other parents learn to accept their child's condition? How do they get over their feelings of loss? How do people live with the emotional and psychological ups and downs of life with a child who is disabled or chronically ill?

Grief is the process of adapting to loss. It is the slow, painful process of "letting go" of someone or something we value. Men and women whose children are disabled or chronically ill suffer a number of losses: the loss of their ideal child, of the kind of parenthood they had hoped for, and of a future free of exceptional anxiety and fear for their child's well being. Depending on the number of demands on parents' energy and time, caring for a child with special needs may also mean giving up valued parts of their own lives as adults.

The stages of grief—shock, denial, anger, guilt, bargaining, depression—are normal, necessary responses to the diagnosis of a child's special needs.

Main Ideas

- There is great variety in the feelings and behaviors with which people respond to grief, and in the pace of their grieving.
- Grief is a process, a series of stages that eventually leads to some degree of acceptance of a loss.
- Parents can develop constructive ways to cope with grief.

MELD Biases

- Grief cannot be resolved until a person is able to acknowledge the feelings caused by loss.
- There is no ideal style of coping with grief. What works for one parent may not work for another.
- Knowing about the stages of grief that typically follow a loss can help parents understand and deal with their experience.
- It is important for partners and other family members to acknowledge differences in their styles of coping, and to be aware that they may often be at different stages in the grieving process.
- The stages of grief—shock, denial, anger, guilt, bargaining, depression—are normal, necessary responses to the diagnosis of a child's special needs.



Facilitator Focus

As you read this chapter and think about facilitating meetings on this topic, consider the following questions:

- What are your feelings about the way you have dealt with your grief over your child's special needs?
- What methods of coping have helped you deal with grief? Did you learn or develop techniques along the way? What were they? How did you learn them?
- What kinds of support from others helped you deal with the range of feelings you experienced, e.g., denial, anger, guilt, sadness or depression?
- Do you feel you went through a series of stages in grieving over your child's special needs? How did your feelings change over time?
- Has your style of grieving been different than your partner's or others you are close to? Have you been able to accept others' styles of grieving, or have they caused misunderstandings and hard feelings?
- How do you recognize when a crisis or event causes you to return to earlier stages of grief, for example anger, depression, even denial? How do you respond to these recycled stages? How do you get through them?
- How will you feel if you believe someone in your MELD Special group is causing himself needless grief? Or if it seems like others are "making the same mistakes" you did in the period following your child's diagnosis? Will you be able to let them get through the stage in their own way without trying to redirect them?

Group Issues And Tips

There are no answers. Much of this chapter addresses the fact that parents of children with special needs are forced to cope with grief, face reality, alter their expectations, and get on with life. Yet while there are general guidelines many find helpful, specific answers about how to come to terms with this kind of situation do not exist. Nevertheless, as these issues come up in group discussions, it is important for facilitators to ask parents to try to describe specific steps they have taken to deal with the emotions of grief:

- How have they overcome their denial of their child's condition?
- How have they found a way to express the blow they experienced with their child's diagnosis?
- How do they contain their anger so that it doesn't become destructive?
- Who and what have helped them deal with sadness and depression?
- When they feel overwhelmed, how do they break a situation down into manageable pieces?

Parents may not have specific answers to your questions (and it will be important to point out that it's natural not to). But simply hearing you ask can help parents become more aware of their coping styles and skills. This awareness may enable them to strengthen those methods that are effective, and to avoid those that create barriers to healing.

This topic relates to all the others your group will discuss. Because special needs require some adaptation in most areas of a child's and family's life, the themes of grief and loss underlie every topic your group discusses.

MELD SPECIAL

Coping With Grief

Acknowledge this frequently, even if you are discussing something that seems unrelated. Be attuned to indications that parents have had to adjust their hopes or give up a way of doing things they value. Ask them how they go about altering their expectations in the area of their lives under discussion, and how they feel about having to do so.

Discussing grief may be threatening for parents. Every group is different in the amount of time it takes members to feel comfortable with each other. When parents develop a sense of trust in each other, they are more willing to speak openly about personal matters. Nevertheless, most groups have some members who prefer not to reveal a great deal about their emotions, and who would probably leave the group if they felt pressured to do so.

Some of the feelings of grief can be difficult to admit, particularly guilt and anger. Once you get to know the people in your group, you and your team mates will learn appropriate ways to approach threatening feelings, and to reassure parents that they are normal and understandable reactions.

Group members may become emotional. You and your team mates may want to plan ways to respond in case group members cry or are overcome by emotion during discussions of grief. Preparing specific words of support helps you remain calm and able to comfort parents. You may want to bring boxes of Kleenex and have your team sit in different parts of the circle so that each of you is close enough to offer support to part of the group.

It is important for other group members to see that facilitators are accepting of emotion, and that it is safe to break down at a meeting. It also gives them the opportunity to learn that other parents have some of the intense or negative emotions they have experienced, and that they may never have had a chance to express.

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Coping With Grief

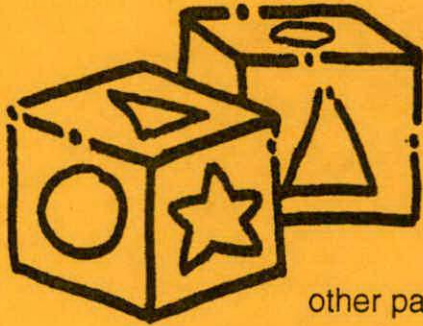
Remember what MELD is and is not. It is important to remember that MELD Special is not a counseling or therapy group. If you sense the issues that emerge in discussions are beyond the scope of this program, talk to your Site Coordinator. Practice ways of redirecting a discussion so that personal concerns are handled responsibly. Some groups invite a psychologist or family therapist to address those issues that are more appropriately handled by a professional.

Prevent group members from imposing their beliefs on one another. Each person finds his own way of making sense out of a loss. It can take many years before some parents find a way to accept their child's condition. The explanations they discover may be derived from:

- spiritual beliefs
- accepting fate, however unfair and arbitrary
- pinpointing a medical, environmental, or even psychological cause of the child's condition.

It is critical that facilitators prevent group members from imposing their personal solutions on one another. Encourage them to acknowledge and respect individual differences in coping with grief. Emphasize the issues they have in common: they all experience loss, unexpected crises, lack of experience with the situation, the need to develop new skills, fear for their children, etc. Return to these themes as often as you sense you need to in order to help parents identify with each other, and to promote group cohesion.

MELD SPECIAL
Coping With Grief



Acknowledge that group members are in different stages of grieving. Encourage parents to support one another as each works through grief at his own pace. This can help those who are beyond the early stages to allow other parents to wrestle with what they have already gone through and may prefer to leave behind.

Convey your concerns to your Site Coordinator. Listen carefully for clues that a parent may not be able to safely come to terms with his child's condition, or with the burdens of caring for him. Listen to your gut and talk to your Site Coordinator if you sense that:

- a parent feels seriously out of control,
- a parent lashes out at the child when angry or frustrated,
- there is emotional distance between the parent and child.

Content for Facilitators

“I felt as if our sorrow would never end, that we would never stop crying.”

—Jane Bernstein

Only mothers and fathers who have lived through the experience can understand the devastation of learning a child has a disability or chronic illness: the shock, panic, desperation, and sense of helplessness that overwhelm parents as they try to absorb the news, and as they struggle to comprehend an avalanche of information about their child's condition at a time when they can barely think straight.

The sudden loss of the healthy child and promising future they had dreamed of is a profound blow for parents, one that can seem to paralyze them. Disbelief alternates with desperate hopes that the diagnosis is wrong or that there is a way to correct it.

As they begin to believe that the child's condition is real and there is no way out, parents are often overwhelmed by anguished questions about how it could have happened and how they will find the strength to handle the situation. They search for clues about ways they could have prevented the disability or chronic illness, even though in most cases the cause is unknown or beyond anyone's control.

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Coping With Grief

It is common for parents to cast blame on themselves and on each other at this stage. Guilt and anger over the unfair and senseless situation into which they, their child, and their entire family have been placed are normal reactions in the early phases of grief.

A MELD Special father reported that he was obsessed by one thought: "How do I find a way to live with this? How can I give it some meaning that makes sense? How do other parents do it? Religion isn't helping. Philosophical and medical answers don't make me feel any better. Why did this happen? Why? Why me? Why my kid? I just read that three percent of kids have some kind of disability and it made me so angry. Why did I have to be one of three percent?" Looking around the circle of parents, he said, "That's why I come to this group. I need to find a way to make sense out of this."

The discussion that followed reflected the fact that each parent struggles to find his own way of coming to terms with a child's special needs. There is no single answer, no ideal form of coping, no formula for acceptance: what works for one parent doesn't work for another.

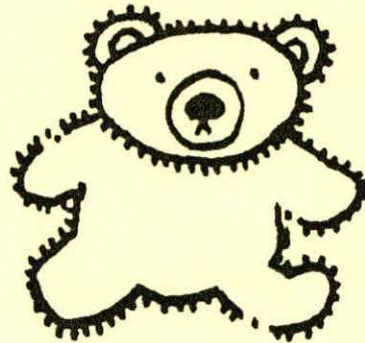
The objectives of this chapter are to help you:

- think about the variety of feelings and behavior with which people respond to grief
- reflect on how you have grieved, and continue to grieve, over your child's disability or chronic illness
- consider the idea that grief is a process, a series of stages that eventually leads to some degree of acceptance
- maintain constructive ways of coping with grief.

Grief: Our Response to Loss

Grieving is the process of adapting to loss. In her book, Necessary Losses, Judith Viorst refers to grief as “a difficult, slow, extremely painful, bit-by-bit inner process of letting go” of something or someone we value. Viorst proposes that because loss is unavoidable, an essential way to understand our lives is to understand how we deal with it. Our response to loss—the way each of us grieves—shapes our lives. “The people we are and the lives that we lead are determined, for better and worse, by our loss experiences.”

A person’s grief is shaped by how he defines what it is that has been lost. The critical factor in a parent’s long term adjustment to a child’s special needs is his perception of the condition—of how severe it is, and how threatening to a meaningful life for the child and family.



Parents Lose Part Of Themselves

Parents grieve not only for their child and his uncertain future, they also mourn the opportunity to be the ideal “ordinary” parent they expected to be. This can be particularly devastating when a child with special needs is the parents’ first born. For it is to their initial venture into parenthood that people bring the cherished images of themselves as mothers and fathers they have constructed over many years, images that will now be tested. Men and women learn a great deal about themselves with their first born; their identity as mothers and fathers is forged in these early interactions, and their long-term confidence often begins with the feelings of competence and satisfaction they develop during this period.

When a child’s special needs make her physical care difficult—for example when feedings are complicated, or when it is hard to soothe, cuddle, play with her, or make her smile—parents may have few opportunities to feel competent about the most basic aspects of parenthood, the aspects by which they typically judge whether or not they are “good” mothers and fathers.

Sometimes a child’s care is so technical that parents feel more like nurses than mothers and fathers. Required routines can be so demanding that there may seem to be no reward for being a parent, only anxiety and exhaustion. And so parents grieve for the opportunity to be the kind of mother or father, and to experience the kind of parent-child activities, they had dreamed of.

MELD SPECIAL

Coping With Grief

Parents grieve as well for other losses sometimes imposed by the child's special needs. These include:

- less time, energy, and emotional reserves for their other children, and for their partners
- the pain the child's special needs causes for relatives and friends, as well as possible changes in parents' relationships with them
- financial difficulties due to medical expenses or to lost income when a parent is forced to give up work to care for the child
- limited job or career opportunities either because there is less time and energy to commit to work, or because a parent must remain at home with the child
- less time for hobbies, friends, social and recreational activities, classes, church, volunteer work, and solitude.



When A Child's Problem Is Identified But There Is No Diagnosis

How do parents grieve when medical or developmental problems have been identified, but doctors are unable to pinpoint their cause? The uncertainty families live with when a diagnosis cannot be made is extremely frustrating. Parents remain confused about what to expect or plan for, what treatments to follow, even about how to think and talk about their child's condition:

- Is it short term or permanent?
- Are there other problems that diagnostic procedures have failed to pick up?
- Is it worth it to repeat tests and examinations, to travel to other medical centers?
- Should they hope for a cure or learn to live with the situation?

Yet even with a diagnosis, many families are left with considerable uncertainty about their child's condition. Approximately half of diagnosed disorders or illnesses have no known cause. Nor does a diagnosis necessarily make it possible to predict what a child will be like in the future. The best course of treatment may be unclear, requiring parents to make difficult decisions about how to proceed with the child's care when there is little concrete information to go on. Unfortunately, at this point medical science understands more about how to diagnose problems than about how to treat them.

Stages Of Grief

“Going through the stages of grief is like climbing a circular staircase—and like learning to climb it after an amputation.”

Many professionals who work with grieving individuals have described the emotional states that typically follow a loss. While these writers have devised different theories and use different terminology, there is considerable consistency among them in the way they describe the grieving process.

In general, grief is referred to as a fairly predictable series of stages, each of which is characterized by a distinct range of behaviors and feelings. While an underlying pattern has been recognized, the precise nature and pace of grieving vary from individual to individual.

Judith Viorst acknowledges that “. . . many of us find it difficult to hear about phases of mourning without bristling, without the sense that some [French chef] of sorrow is trying to provide us with a step-by-step recipe for the perfect grief. But if we can hear about phases not as something that we—or others—must go through, but as something that may illuminate what we—or others—have gone or are going through, perhaps we can come to understand why sorrow . . . turns out to be not a state but a process.”

The course of emotional stages frequently observed in people suffering a loss—including the diagnosis of a child’s disability or chronic illness—can be briefly summarized as follows:

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Coping With Grief

1. **“It’s not possible. I don’t understand. The doctor must be mistaken.”**

Grieving usually begins with shock or denial. Denial is a buffer that temporarily protects an individual from the full impact of a loss until he is emotionally ready to face it. During this stage, a person is often overtaken by a sense of unreality.

2. **“I wanted to go out and hit something. I hated everything and everyone.”**

Anger typically follows the stage of shock and denial. While it is most often directed at the situation, the target of parents’ early anger may be a doctor, each other, others they are close to, or even the child.

3. **“Maybe another doctor will discover it’s not true. Maybe there is actually a cure.”**

Parents may turn next to wishful thinking or bargaining. Some bargain with God for a miracle, promising renewed commitment in return for a change in the child’s condition.

4. **“I don’t want to see anyone. I can’t stop crying.”**

The next stage is one of sadness and depression. There may be preoccupation with the child’s condition, withdrawal from contact with others, and continued crying. People may find themselves questioning their values, beliefs, and faith. Some men find the emotions triggered by this stage particularly difficult to deal with.

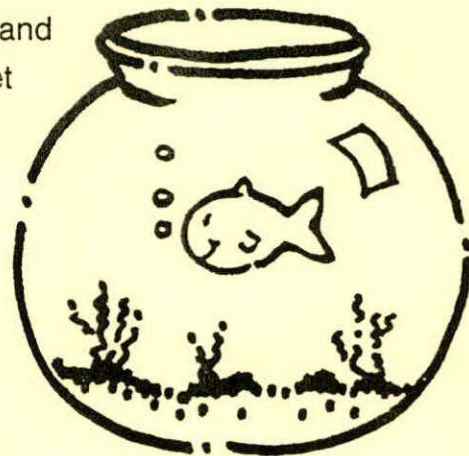
MELD SPECIAL
Coping With Grief

5. "I was no longer completely in the grip of all those ups and downs, drowning in my sadness."

Finally, some degree of acceptance is achieved. Parents become more active in dealing with their family's situation and are better able to make decisions. They release feelings of guilt or blame, and experience the beginning of a sense of resolution, trusting themselves and their judgments. The child's special needs no longer dominate the family's life, and a balance is restored to daily activities.

It is not until this point that some people overcome the stage of denial. It can take this long—a working through of the entire grief process—to accept the fact that their child's condition is a reality and is not going to go away.

Many parents aren't aware of just how or when they enter the stage of acceptance. Sometimes a specific event makes them realize how differently they react to things. Others make a conscious choice to force themselves toward acceptance. A father quoted in Robin Simons' After the Tears said, "You get knocked down by a wave and you can either lie there and drown, or you can get up and move. If you don't keep moving you die." Yet for this man, it took many months before he felt ready to "move."



Recycling The Stages Of Grief

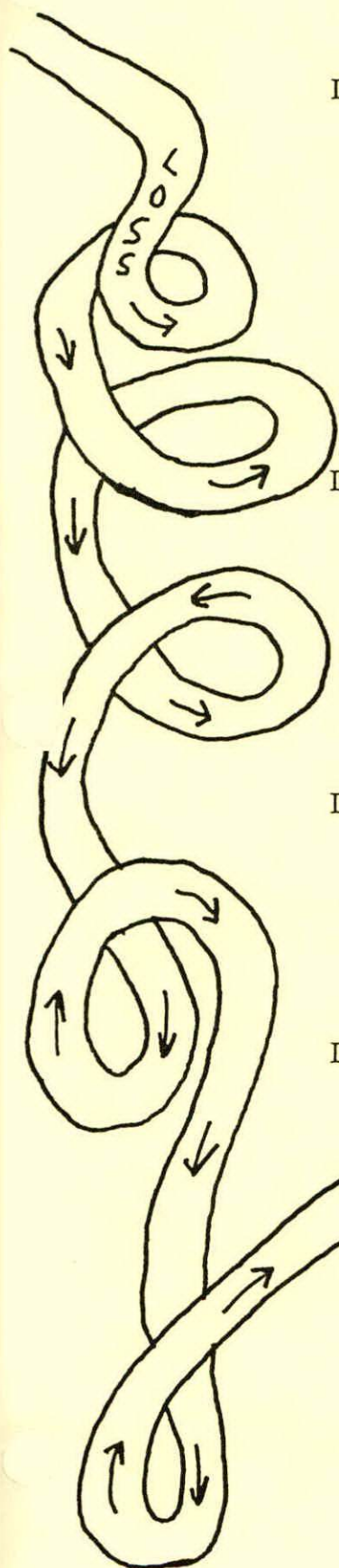
The concept of stages seems to suggest a straight path, an orderly movement forward. Yet most families would describe their grieving as more like a spiral; their progress loops back on itself as they periodically return to earlier stages and then move forward again. Sometimes parents take temporary shortcuts, skipping a stage but returning to it later.

Ardis Kysar uses the image of a garden hose to describe this quality of backtracking during grief. The water running through the hose represents a person's normal daily life. She compares a loss to a kink in the hose; when a person experiences a crisis, normal functioning, like the flow of water, slows considerably or stops altogether.

Kysar's model suggests four stages through which people respond to crisis and loss: denial, disorientation, detachment, and dialogue. She cautions against a rigid use of the framework, however, pointing out that "it is entirely possible for an individual to skip a stage, to be involved with more than one stage at a time, and to experience the stages in a different order. Vast differences in the amount of time spent in a particular stage occur depending on the individual and the loss." Kysar adds that people in our society are typically in a hurry and don't always allow themselves sufficient time to work through the stages of loss.

CRISIS & LOSS KINK THEORY

A Garden Hose Analogy to Understanding Life's Losses



INTERNAL REACTIONS

EXTERNAL SIGNS

DENIAL

Disbelief
Shock

- Cannot admit or refer to loss.
- May appear dazed.
- May appear overly busy.

Anger
Depression

- Physical symptoms such as headaches.
- Easily upset. Agitated.
- Sleep disturbances.
- Erratic eating habits.

DISORIENTATION

Sadness
Despair
Exhausted
Overwhelmed
Feels abandoned
Self absorbed

- Normal functioning is impaired.
- Frequently thinks and talks about loss.
- Unable to reason and plan.
- Cries frequently and easily.
- Needs much sleep.
- Trance-like appearance.

DETACHMENT

Apathy
Withdrawal
Isolation
Self Protection

- Diminished interaction with others.
- Protects self from experiencing similar loss.

DIALOGUE

Recovery

- Life is reorganized.
- Activities and relationships are resumed.

Feels more normal

- Signs from earlier stages may return, triggered by a wide range of events or thoughts.
- Recycling of stages can continue for years.

Adapted from Ardis Kysar and Elizabeth Overstad. Reprinted with permission from:
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Chronic Sorrow

While most parents are eventually able to accept their child's illness or disability, their grieving has no final resolution in the usual sense of the word. In fact, the term "chronic sorrow" has been used to refer to parents' lifelong pain and sadness over a child's special needs. Others have spoken of their feelings as a wound that never completely heals. "You don't just recover and go on," says a father in After the Tears. "It's an ongoing process. You have to continually monitor yourself and your family to keep a handle on how you're all doing."

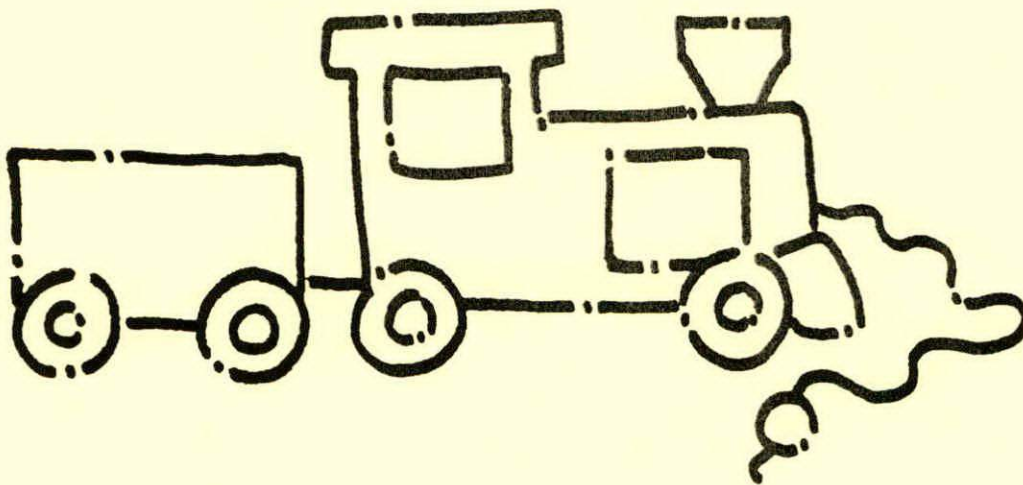
A wide range of experiences may trigger a temporary return of parents' grief. Anger, depression, guilt . . . any of the feelings that followed the child's initial diagnosis can recur over the years, for example when:

- a physical exam or developmental assessment raises new concerns, or squelches hope of improvement
- the child's birthday or other anniversaries cause parents to relive painful experiences
- the child doesn't do the kinds of things other children his age do, for example starting to walk or entering school
- parents must make difficult decisions about alternative treatments, surgery, or schooling
- others respond to the child in an insensitive manner.

MELD SPECIAL
Coping With Grief

Life with a chronic illness or disability is frequently characterized by alternating periods of crisis and stability. Family members experience swings in their outlook as well: confidence followed by pessimism, acceptance by periods of resentment.

"I still vacillate wildly between hope and fear," writes Jane Bernstein. "The images still come upon me without warning, the smallest things plunging me into a despair so intense I cannot breathe—a pretty teenager, a sleep from which [her daughter] can not be roused. When I see her beside another child her age, her head bowed, her hands in fists, I feel as if my heart will break. And yet when she smiles, when I see her squeeze a toy, mouthing every inch of its surface—such normal baby things!—I am filled with hope and happiness."



Resisting Grief

A MELD Special father admitted that for well over a year he spent long hours at work in order to escape close daily involvement with his child's disability, a condition he found very disturbing and threatening. He suspected there were other fathers who did the same. The emotional intensity of raising a chronically ill or disabled child may be particularly overwhelming for men who avoid expressing emotions and who, like this father, describe themselves as preferring to "do something" rather than "deal with feelings."

This father recognized that he had been denying the blow he experienced with the birth of his child. Withdrawing from the situation had seemed the only way to cope with his fears for his son and his loss of self esteem over having a child with problems. He was enormously relieved when he was able to acknowledge that he felt devastated and powerless, and could discuss those feelings with others.

The intense pain of grieving is something people would understandably wish to escape. Some parents need to put their "grief work" on hold until they have the strength to deal with it. They may need to freeze their emotions for a time in order to simply function from day to day. This is a normal coping mechanism in the early stages of grief.

Yet there is general agreement that grief cannot be resolved until a person is able to give in to the feelings caused by loss. Despite its intense pain, grieving has been described as a healing process. It allows a person to become whole again. Not free of pain, but whole.

MELD SPECIAL

Coping With Grief

In Necessary Losses, Judith Viorst suggests what may be happening to the person who resists grief. “. . .if instead of feeling bereaved, we are coping magnificently, shedding no tears and carrying on as if nothing disruptive has happened, we are only deceiving ourselves into thinking we’re ‘taking it very well,’ for, in actual fact, we cannot take it.”

“We may, for instance, unconsciously fear that if once we started weeping, we’d never stop, or that we would have a breakdown or go insane, or that the weight of our grief would crush or drive away those around us, or that all of our earlier losses would swamp us again. . . . We may be tense and short-tempered, or wooden and formal, or forcedly cheerful, or withdrawn, or drawn excessively to booze. We may have physical symptoms, trading in psychic for bodily pain. We also may have insomnia and bad dreams.”

Some people convert repressed grief into anger, becoming furious about things that are unrelated to the child’s disability or illness, and that would not otherwise bother them.

A Twin Cities counselor asks new clients to describe what they have lost and what that loss has meant to them. When they talk about feeling sad, his response is, “Make friends with your sadness because it is right where it should be. It is when we pretend we don’t feel something that we get ourselves into trouble.”

Coping

While parents agree that it is important to cope with grief over a child's special needs, most aren't sure how to begin. No parent is prepared for something like this. As Jane Bernstein suggests, "Nothing teaches us about grief until we grieve, and then it is too late." Especially in the beginning, most parents struggle just to make it from one day to the next.

Many factors influence a parent's style of coping:

- his definition of the child's condition, i.e., how severe he considers it to be, and how threatening to a meaningful life for the child and the entire family
- previous experiences of loss that may have either strengthened or impaired his ability to cope with grief
- temperament/personality
- style of dealing with problems in general
- sources of emotional and practical support
- beliefs and values that either provide a source of emotional and psychological strength, or that generate a pessimistic approach to the situation
- general physical and emotional health
- material resources, e.g., money, equipment, etc.

MELD SPECIAL

Coping With Grief

Factors which influence a parent's style of coping, continued:

- other demands on time and energy
- underlying attitudes about disabilities or illness that promote either hopefulness or despair.

In the period following their child's initial diagnosis, parents are typically overwhelmed by information, intense emotion, physical tasks, and the need to make difficult decisions. They may not even be unaware of exactly what they are feeling. Even later, it can be hard to identify the many reactions they have experienced. People don't or can't always take the time to examine them and they blur.

It may be helpful for parents to actually make a list of the many reactions to their child's special needs they have experienced over time, and to describe how they coped, successfully or unsuccessfully, with each of them. Sometimes the process of writing helps people identify and clarify what they have gone through.

For some people, simply identifying their feelings is an effective way to cope and heal. For others, "getting in touch" with feelings is not enough. For them, true coping means finding the meaning, and even the value, of their experience. After acknowledging what they feel, their questions are:

- What can I do with that response? Where can I go now?
- I don't like what's happened to my child, myself, and my family, but what lies ahead?
- How will I let go of the image of the "ideal" child I hoped for? What are the specific steps I can try to take today? tomorrow? next week?

MELD SPECIAL

Coping With Grief

Questions after acknowledging what they feel, continued:

- I didn't get what I wanted, but what do I want now? How can I break that down into something realistic, something that I can actually achieve?

It is by examining their experience in this way, and developing a reasonable short term plan, that these parents are able to convert pain into something productive and give it some power of healing.

Nevertheless, some children's conditions are so unstable that even a person with effective coping skills can find it extremely difficult to manage day to day life. When a child is in and out of crisis, when his physical care is technical and time consuming, and certainly when his illness is life threatening, it is all a parent can do to simply keep up, physically and emotionally.

The situation can be made more difficult when partners' coping styles are quite different. In general, most parents find it is valuable—although not always easy—to talk to their partner or others they are close to about their different coping styles. The "Parents, You Count Too!" chapter addresses ways parents can approach these differences to reduce misunderstanding and maintain their ability to support one another during tough times. By trying to understand what each needs when feelings of grief erupt, they are better able to anticipate and plan what they will do when the next crisis arises. Each can ask the other:

- What do you think you will need from me? How can I best support you?
- How can I better understand your behavior?
- What is the best way to approach you if I feel we misunderstand each other?

MELD SPECIAL

Coping With Grief

Those who are concerned about being able to communicate during a difficult or emotional period may find it helpful to imagine and practice talking to their partner. By anticipating the words to use to maintain a supportive rather than a defensive atmosphere, partners are more likely to prevent unnecessary hard feelings.

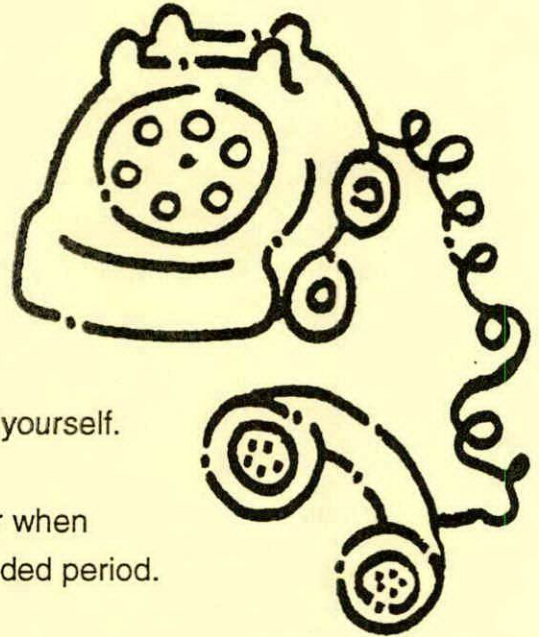
Martha Wingerd Bristor, in "The Birth of a Handicapped Child: A Wholistic Model for Grieving," offers these final suggestions for effective coping:

1. Find people to whom you can tell the story. Events that are important to you must be told before proceeding through the grieving process.
2. Accept your emotions. Feelings of all kinds are strong and common.
3. Express your feelings. Especially find support for expressing anger and sadness. Give yourself the right to cry. Tranquilizers, alcohol, and other drugs cannot do the grief work for you; they only delay the mourning process.
4. If there are other children in the family, include them. Sharing the crisis gives each person an opportunity to develop strength. The way feelings are expressed in a family influences how children accept the situation and whether they develop unnecessary fears. Hug your children when words fail.
5. Maintain friendships and share each others' feelings.

MELD SPECIAL
Coping With Grief

Suggestions for effective coping, continued:

6. Consider joining a support group. Groups offer emotional support and can help parents learn to cope with caring for a child with special needs.
7. Allow time for yourself and for taking care of yourself.
8. Consider talking things over with a counselor when difficulty coping with grief continues for an extended period.



Will It Get Better? Can We Survive?

Once her future obsessed me; my fears of who would love her and what kind of life she would have were so strong that I could not see much else. But nearly four years have passed and it is normal to let go. Time lessens the anxieties, smooths the edges: Time does heal.

—Jane Bernstein

Parents grieving over a child's chronic illness or disability often question their ability to simply make it through the day. It can be impossible for them to think about the future because the future appears to be one overwhelming day after another.

MELD Special group members who have listened to parents of older children describe their state of mind after a few years have wondered, "Will I ever feel that way? Will I ever be able to cope that well?" What experienced parents have told those who are still struggling to stay afloat is this: it gets better. One mother reflected:

"You discover that you can live through it. Somehow you find a way to cope that works for you. It's different for everybody and it's not fun, but you find an inner strength . . . or it finds you. I didn't want to hear about that in the beginning. I resented the fact that I had to deal with this, that I didn't get what I wanted, that my child was going to have a difficult life. I hated hearing people say it was really going to be a growing experience for me; that didn't have anything to do with the way I was feeling for a long, long time. Forget about personal growth . . . how was I going to survive until tomorrow? That's what I wanted to know."

MELD SPECIAL
Coping With Grief

The Chinese character for “crisis” is made up of two symbols: one meaning despair and one meaning opportunity. Perhaps this is a concept that parents of children with special needs can ultimately identify with: grief mixed with hope, pain as part of healing, the opportunity for a meaningful life emerging from despair.

The feelings of grief never go away, “but each time it’s less intense,” says a mother in After the Tears. “It’s not as frightening or overwhelming, and it’s quicker. You don’t believe you ever will at the beginning, but you get stronger . . . You make it.”

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Coping With Grief

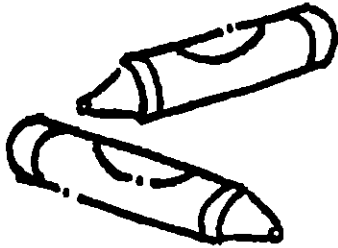
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MELD SPECIAL
Coping With Grief

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Learning Activities

Getting Acquainted Activities

I. Ask each group member to complete this statement: "In general, in spite of my grief over my child's special needs, the thing that keeps me going is"

II. Introduce the idea that a person's past experience with loss can influence how they respond to subsequent losses.

Ask members to briefly describe another loss they experienced at any time during their lives, e.g., death of a relative or friend, parents' divorce, loss of a friend or other important relationship, health problems, unmet career goals, etc. Ask them to describe how these losses may have affected their response to the diagnosis of their child's special needs.

Activities related to the ideas that:

- 1) there is great variety in the feelings and behavior with which people respond to grief, and in the pace of their grieving, and
- 2) grief is a process, a series of stages that eventually leads to some degree of acceptance of a loss.

MELD SPECIAL

Coping With Grief

I. PRESENTATION AND GROUP DISCUSSION

Briefly review the stages of grief. Use the summary beginning on page 17 and/or Kysar's garden hose analogy on page 21. You may want to outline the main points about each stage on a newsprint pad or chalkboard, or distribute them in a handout. Acknowledge the variety of feelings and behavior with which people respond to grief, and the varying lengths of time grieving takes from person to person. Point out that reactions from early stages of grief may continue or recur over many years. You may want to use or read material from the chapter to introduce these ideas.

Use some or all of the following questions in your discussions (this activity can easily take more than one meeting):

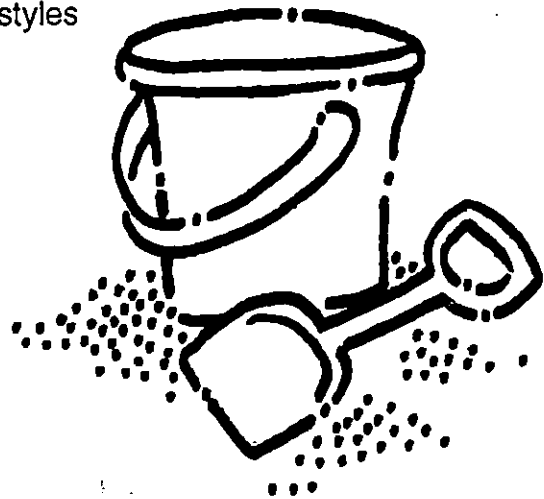
- Does the way grief is described in this model apply to your experience?
- What parts of this model are helpful to you in thinking about your experience? Does it clarify what you have been through?
- What would you change or add to the model to make it fit your experience better?
- Does the model relate to what you have observed other family members going through?
- In thinking about your initial responses to your child's diagnosis, what particular kinds of support or information would have helped you cope with the situation better?

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Coping With Grief

Questions for discussion, continued:

- Does hearing about the stages of grief cause you to re-live some of the emotions of earlier periods? Does it make the emotions of grief stronger? less intense?
- How have your feelings changed over time? What do you think accounts for these changes?
- Have you been aware of periodically recycling the stages of grief over time? What causes a recurrence of the stages of grief, for example anger, guilt, depression?
- Have you found a way of moving ahead when you return to early stages of grief? If so, how? What specific steps do you take?
- How have your reactions and behavior at different stages been different from those of your partner? From those of your relatives and friends?
- What is the impact on relationships between partners and other family members when they are at different stages in the grief process? What is the impact when they have different styles of coping with grief?



II. GROUP DISCUSSION

Have your group members read the following case studies.

Family A

The child of Family A was born with a cleft palate and low birth weight. Although the child's feedings were difficult, doctors told the parents to treat him like a normal baby. His first surgery corrected the cleft palate. Another operation at eight months straightened his eyes and opened a blocked tear duct.

At his 12-month check-up, the child was diagnosed with a severe ear infection, continued low weight, a tight hip joint, developmental delays and an enlarged head suggesting hydrocephalus. The doctor suspected that the child might not walk or talk.

At 15 months, the child had surgery to insert a shunt to relieve the pressure of the hydrocephalus. The procedure was repeated a week later due to shunt malfunction. The surgeon told the parents the child might recover 60 to 100% of his abilities. While he was in the hospital, routine x-rays indicated the child had scoliosis, curvature of the spine.

MELD SPECIAL
Coping With Grief

Family B

In preschool, the child in Family B was evaluated as being delayed in fine motor skills. She frequently became upset over conflicts with peers and teachers, and had difficulty following directions and sitting still. The teachers urged further evaluation. The child's doctor insisted that she would catch up.

In first grade, the child did not learn to read as quickly as the other children. The parents were encouraged to "wait and see." After she fell further behind in second grade, the parents had an evaluation done at a hospital and were told the child had a learning disability. The school instituted special classes. Sometime later she exhibited signs of depression and family therapy was recommended.

The child was mainstreamed into regular classes by the fourth grade and seemed to be succeeding. However, upon entering junior high, she could no longer keep up. The parents were confused when teachers claimed their daughter was lazy. They arranged for another assessment and discovered that vision problems and difficulty sequencing ideas were impairing their daughter's ability to do junior high level work.

(from Deb Ceglowski's Parenting a Special Needs Child)

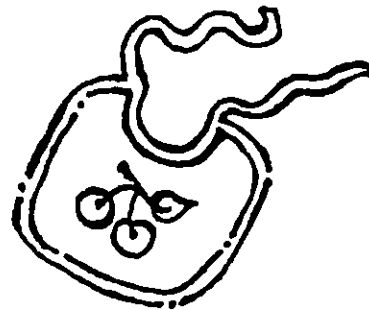
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Coping With Grief

Family C

When my son was born, I was so eager to see him and hold him, but they had him tightly wrapped in blankets. Later, I was told my son had a problem with his left arm, but I didn't see him for several hours. Finally, the pediatrician unwrapped him for me to see. I was stunned! I just knew I would wake up and everything would be alright. No one seemed to understand my feelings. I had many conflicting emotions. I didn't even feel as if this baby was mine. What did this mean? Would surgery help? I just wanted to hold my baby. But it all happened so fast that sometimes I wanted to run away. What had I done wrong?

I finally began to realize that this was my child and I had to cope. Several nurses helped me focus on my baby's beautiful face. I began to accept him. Caring for him became easier. I began to be able to make decisions. I still get angry, but I am able to take care of him. I look forward to going home and learning to help him develop his arm. My husband and I realize we cannot change what has happened, but we can make plans for the best care we can get. We'll make it.

(from Martha Wingerd Bristor's "The Birth of a Handicapped Child— a Wholistic Model for Grieving")



MELD SPECIAL

Coping With Grief

Ask for parents' reactions to these accounts.

- Which situations can they identify with?
- What do they imagine the parents in these three families felt as ongoing problems occurred?

The case studies relate a wide range of circumstances experienced by parents of children with special needs. As an alternative to asking parents for their general reactions to the three accounts, you may want to use the following list to focus discussion on specific situations your group members may have experienced. Ask the group to reflect on 1) how parents might feel when any of the following occurs, and 2) how such situations might be handled:

- physician's impressions of the child's status changes dramatically (e.g., parents told to treat newborn like a normal baby, but by 12 months, severe disabilities are diagnosed)
- delays in seeking or receiving treatment due to conflicting evaluations by professionals
- the child's developmental problems are interpreted by others as personality traits (e.g., learning disability described as laziness)
- information about the child's problems is temporarily withheld from parents

MELD SPECIAL
Coping With Grief

- shock over diagnosis causes parents to feel disconnected from child
- parents wish they could run away from the situation
- parent's response to child's diagnosis is "What did I do wrong?"
- experts unable to predict how severe a child's developmental delays will be
- required treatments place child at risk, e.g., repeated surgeries.

MELD SPECIAL
Coping With Grief

III. SMALL OR LARGE GROUP DISCUSSION OF SELECTED ARTICLES

Distribute photocopies of the articles "Taking the Guilt Out of Parenting" and/or "Ivar's Tale" (See handouts f and g). Ask the group to read one or both of them, either before the meeting or while they are there.

Ask small groups to discuss their reactions to the article(s). How do they relate to their own experiences? Reconvene and ask someone from each small group to briefly summarize some of the thoughts that emerged in their discussion.

IV. WORKSHEET, SMALL AND LARGE GROUP DISCUSSIONS

Ask group members to complete the "Family Reactions to Loss" handout (see handout a). Divide people into small groups or pairs to discuss their answers. Gather again as a large group to discuss some or all of the following questions:

- Do you feel you were taught to grieve and accept loss by your family? What examples were set by your parents or others who influenced you?
- Were there losses you experienced as you were growing up, and in young adulthood, that have affected the way you respond to loss now?
- How have your early "lessons" about dealing with emotions and grief affected your adjustment to your child's disability or chronic illness?
- How do you think you are influencing, or will influence, your child(ren)'s capacity to deal with grief?

MELD SPECIAL
Coping With Grief

V. SMALL OR LARGE GROUP BRAINSTORM AND DISCUSSION

Read or paraphrase the following two paragraphs to introduce a discussion about anger.

Feelings of anger are a predictable part of the grieving process. Many parents of children with special needs find that anger is one of the most frequently recycled emotions. It can be triggered by any number of events, from a relapse of a child's chronic illness or a negative developmental assessment, to a trivial encounter with strangers.

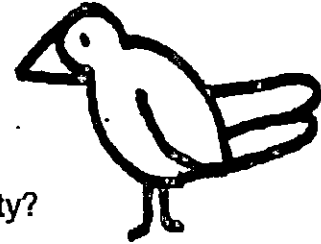
Some parents are surprised that anger is considered a normal part of grieving; some are shaken by its intensity. People are not always encouraged to express this part of their grief. Relatives and friends who are uncomfortable with anger cannot support parents' efforts to cope with it. Unfortunately, repressed anger cannot be resolved.

In small or large groups, ask members to brainstorm the causes of anger for parents of children with special needs. Start with their early reactions to a child's diagnosis and continue with potential sources of anger over time.

MELD SPECIAL

Coping With Grief

You may choose to use the following questions in your discussion:



- Why is anger a normal part of parents' reaction to learning their child has a chronic illness or disability?
- What or who are the targets of parents' early anger?
- Why is it difficult for some parents to acknowledge or admit they are angry?
- What are some effective ways parents can handle anger? Is there a way to channel it into a productive force?
- What can a person do if he feels his anger is becoming destructive to himself or others?
- What might trigger parents' anger as the years go by?

MELD SPECIAL
Coping With Grief

VI. WRITING ACTIVITY

Any of the previous five activities can be done as writing exercises. Depending on the stage of adjustment parents are in, or how willing they are to express themselves in a group, writing can be much less threatening than talking. You may also have some group members who clarify their thoughts best in private; an occasional writing activity will accommodate these individuals. It also lends some variety to your meeting formats.

Select the specific questions or ideas you'd like the group to consider. Distribute writing materials and give people twenty to thirty minutes to put their thoughts on paper. Point out that no one will read what they write unless they choose to share it.

Afterwards, you may or may not choose to have people speak about their general reactions to the exercise, and any insights into their experience it offered them. This could be done in pairs, or in small or large group discussion.

VII. VIDEO

View the videotape "Lost Dreams and Growth," by Ken Moses, a psychologist who works with parents. The 72-minute presentation addresses the grieving process typically experienced by parents of children with special needs. Because of the program's length, you may prefer to devote two meetings to viewing and discussing it.

The video is available for purchase (\$95) from:

Resource Networks
930 Maple Avenue
Evanston, IL 60202
312-864-4522

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Coping With Grief

This activity is related to the idea that parents can develop constructive ways to cope with grief:

SMALL GROUP DISCUSSION

Ask each parent to describe something about his usual coping style when faced with a difficult or threatening situation.

You may want to use the following questions:

- What is your typical reaction to a problem? Do you try to avoid it? Think about it a while and then act? Respond quickly? "Dig in" and problem solve?
With this insight in mind, ask each parent to think about his fears for his child with special needs.
- What are you most worried might happen?
- How would you want to deal with it should it occur? What specific steps or responses would you hope to take? First within yourself, then with your partner or others you are close to, including relatives.
- Would this response be different than your usual way of coping with a difficult situation? If so, how will you go about changing your approach?



Chapter 1

Handouts

**Coping
with Grief**

FAMILY REACTIONS TO LOSS

Complete the following sentences with the first thing that comes to your mind.

1. When I was growing up, people in my family responded to losses by:

2. I knew my father was sad when:

3. I knew my mother was sad when:

4. When I cried, my parents:

5. Now, my family responds to loss by:

6. When someone close to me is sad, I:

7. When my children cry, I:

8. When I found out about my child's disability or illness, I:

(From Deg Ceglowski's Parenting a Special Needs Child)

The Grieving Process Of Parents Of Atypical Children

SPIRO B. MITSOS
Executive Director, The Rehabilitation Center
Evansville, Indiana
Member Agency, UCP Collaborative Infant Project

With no pretensions of research validity, I would like to share some of my clinical impressions and observations about the grieving process as it relates to parents of atypical children. I have not engaged in any systematic collection of data nor any scholarly review of the literature. I am simply looking back on two decades of a variety of experiences and trying to present my impressions with at least a semblance of organization.

Perhaps the simplest approach to discussing the grieving process would be a point of departure involving something that is reasonably well-known. That "well-known" in this case is the grieving process as it relates to terminal illness as described by Elizabeth Kubler-Ross in her book, *On Death and Dying*. Dr. Kubler-Ross' concepts are widely disseminated and reasonably well-known. She describes five basic stages in coming to terms with one's own terminal illness. Stage one is denial, which is basically a buffer, an opportunity to seek corroborating information and buying time to allow the terminally ill patient to come up with some better way of dealing with his imminent death.

The second stage is anger—anger with God, anger with professional helpers, anger with family members, anger with the world in general. This stage involves an outpouring of all of one's life frustrations.

The third stage involves bargaining. This is perhaps less well-known than the others and simply involves an effort to bargain for time to delay the inevitable. The fourth stage is depression. This stage is commonly recognized and obviously mistaken as the grief process, whereas in reality it is only one segment of dealing with the inevitable. The final stage is that of acceptance—acceptance of one's own death. This is not a stage of euphoria. It is not a happy acceptance, but it is a stage of relative peace and calm.

With these five stages as a point of departure, we might now be able to look at parents of atypical children and the experiences they go through as they try to incorporate the fact of having a handicapped child; as they try to organize themselves for living with a youngster who is not normal.

Based on my own experience, a few points seem salient. First and most important, I think all families go through some grief process. Not all go through Dr. Kubler-Ross' five stages; not all go through the stages in the same order. It is impossible to define discrete steps. One rather sees a montage of all five of Dr. Kubler-Ross' stages with each family unit at any given time.

MELD SPECIAL HANDOUT

b-1

The second point is that most families do not go all the way through the process. It seems to be rare, if in fact ever, that a family totally accepts having an atypical youngster, just as a disabled adult rarely accepts his or her disability. They may learn to tolerate it. They may even derive genuine satisfaction from parts of the experience.

My third point is that there is a tremendous difference in coming to terms with terminal illness and impending death, and long-term coexistence with one's own child who, for one reason or another, is not a normal youngster. In the case of terminal illness, there is that discrete end point that can be looked forward to. With a handicapped child there is no finality.

Another general point is equally obvious. The way in which the family, or individuals within the family, deal with the grieving process has tremendous impact on the way they, as individuals, relate to the handicapped child, on the patterns of family interactions with noninvolved members, and on the patterns of social relationships outside the family unit.

As a final point, it seems clear to me that we, as helping individuals dealing with families of atypical infants, can have significant impact on the degree to which they approach some healthy balance of all of these feelings. We are not striving for some naive concept of acceptance of disability, but rather some reasonable balance that allows the family to function as an effective unit, at the same time incorporating a handicapped member and engaging in an essentially normal pattern of relationships that transcends the family unit.

This last point opens up the issue of dealing with family feelings. Again, let me begin by making one essential generalization. This is simply that feelings of the type described by Dr. Kuebler-Ross should not be viewed as pathologic. It seems to me that we in the helping professions easily lapse into interpreting mother's anger, father's denial, everybody's depression, etc., as pathological processes that somehow or another have to be cured or eliminated. These phenomena take on significantly altered perspective when one views them as perfectly normal responses to the horrendous experience of having a handicapped child. Perhaps an analogy is in order. We tend to accept the emotional stages of response to a disaster, be it a shipwreck, tornado, fiery holocaust or what have you, as normal responses to tragedy. All too often, however, these perfectly normal responses are considered abnormal when the disaster is the birth of or development of an atypical youngster. This is obviously an illogical contradiction.

One may ask then, why we have to deal with feelings if we can assume they are normal. The answer is so obvious that it hardly needs elaboration. All of us who have worked with families of handicapped youngsters have seen the impact of maternal depression or guilt on the attachment process. We have seen the inability of parents to provide an environment of relative normalcy, including behavioral limit-setting and discipline. We have seen the devastation of marriages as one spouse devotes his or her life to the handicapped youngster to the exclusion of other family members. We have all seen the impact on other children trying to find identity and security in their relationship with parents when one or both parents are totally absorbed in the life of the one special child.

None of these is pleasant to observe. All too often, however, we seem to be powerless in our attempts to intervene. The family acknowledges that what we are saying is correct and things must change, but nothing seems to happen. All too often the helping people end up rejecting the parents because of their own frustrations over their inability to help the parents "accept" and deal more effectively with their life situation. In rejecting parents, we resort to rationalizations, the most common form of which is "What can I do? They don't accept their handicapped child."

In dealing with parents we must first of all be able to identify what kinds of feelings are paramount and whether or not the feelings are of sufficient intensity to warrant therapeutic involvement. Obviously, some parents go through the process and arrive at a reasonably healthy balance of feelings very early in the game and are able to function as a family unit and engage in activities outside the family unit while at the same time providing a healthy environment for their atypical youngster. The fact that they are periodically able to express their anger and frustration, cry some real tears about their burden and then go on with the job of living and loving is entirely healthy. Perhaps one of the worst things that people do with such parents is to inhibit or stifle the periodic explosions instead of allowing the parent to explode. Too often we tend to ladle out supportive denial, stating that things are not all that bad, pointing out how well they have it compared to other families we know or if all else fails, reaching way back into the bag of tricks and talking about how many great people in the world's history have had the same disability as this family's youngster. All of these approaches are obviously counterproductive. All the family needs at that point is an opportunity to vent and to explode and then get back to work. We, as helping people, should not get any more involved than the parents need.

For many families, the balance is not achieved. In these cases, one or both parents seem to develop a chronic pattern of behavior that detracts from the effective personal satisfaction of family life satisfaction. The three common prototypes are the angry parent, the depressed parent and the denying parent. Keep in mind that prototypes rarely occur in pure form. Anger and denial, for example, are commonly seen in combination. The essential ingredient in the prototype is the pervasiveness and chronicity of the feeling tone. The angry parent is elusive; his anger changes focus frequently. At one moment it may be addressed to the family physician in relation to a specific issue. That issue is resolved only to find him angry with God, and so on and on. There seems to be no resolving of their specific angers by attempting to solve the problem that theoretically brought out the angry reaction. One simply ends up in an endless tailspin of problem solving.

The depressed parent is most easily identified if we can allow our own feelings to flow. If we are relating to a genuinely depressed individual, we feel depressed. The superficial symptoms of depression may or may not connote the depth of depression that generates the feeling in us and arouses our concerns. Depression and guilt are entwined. The depressed parent is perennially sad, commonly needs to expiate guilt by hovering over the handicapped child. These are the parents who are most apt to drive a wedge, isolating themselves from other members of the family unit. The depressed parent has difficulty expressing anger about the handicapped child.

The denying parent is so called in part because he denies his personal feelings. These parents seem to simply refuse to deal with facts like mental retardation, inability to walk, inability to see or hear. They do so largely because accepting the realities would be too difficult for them to deal with emotionally. Denial can take many forms and perhaps a couple of brief anecdotes are in order. I'm reminded of the mother of a youngster with cerebral palsy who was also significantly retarded. The mother had great need to convince the world that her son was a mild case of C.P. One of her convincing maneuvers dealt with toilet training. Obviously, if a youngster at three years was retarded, he would not be bowel trained. What few people out in the world knew was that the mother gave her son an enema every morning of his life. As long as people didn't know that, they could accept the fact that he was toilet trained, the proof being no bowel accidents.

Another anecdote depicts another form of denial—in this case virtual denial of existence. I saw the youngster for evaluation at the mother's request prior to placement in a state residential program for the severely retarded. The youngster showed some residuals of apparent brain damage but was certainly not even mildly mentally retarded. On further exploration, it turned out that I was the fourth or fifth in a chain of attempts to have the youngster institutionalized. Further exploration revealed the fact that this youngster at a very young age was diagnosed as having a malignant brain tumor. Surgery was done, but the mother was informed that there was little likelihood of survival. The child lived. The mother's denial, in a sense, took the form that having once prepared for death, she could no longer emotionally allow this youngster to survive in her world.

For purposes of therapeutic intervention, with full recognition that prototypes do not exist in pure form in most cases and that we do see rather a montage of feelings within the total family unit, we must identify what kinds of feelings tend to be paramount and which feelings are interfering with healthy life processes.

What we do about them depends entirely on where the parents are. There are some reasonably simple rules that seem to apply:

1. Learn to listen.
2. Allow generous amount of time for listening.
3. Respond to feelings.
4. Avoid playing intellectual games.
5. Lead from honesty.

These five rules can be applied in dealing with parents singly or in groups. Whether one prefers working with groups or not is largely a matter of individual comfort on the part of the therapist. Personally, I find it facilitative. Groups, however, do run the risk of other parents playing intellectual games, and the therapist has to be alert to this and intercept with open interpretation. The therapist trying to assist a family working through intense feelings must not be afraid to deal with feelings. An individual who is frightened by anger, by talk of suicide or by morbid fantasies should not try to work with others who are experiencing these feelings.

We must accept feelings freely and be in a position to positively reward and support their healthy expression. Accepting a mother's statement that she would prefer her child dead is clearly different than accepting the fact of murder. One must be careful in facilitating the expression of feeling that one not lose control, as has been the experience in many encounter group situations. The inexperienced, or ill-trained facilitator may have learned how to open people up, only to find that he does not know how to control the feelings once they have been opened up and help the individual reorganize and get himself back together before he leaves the therapeutic arena.

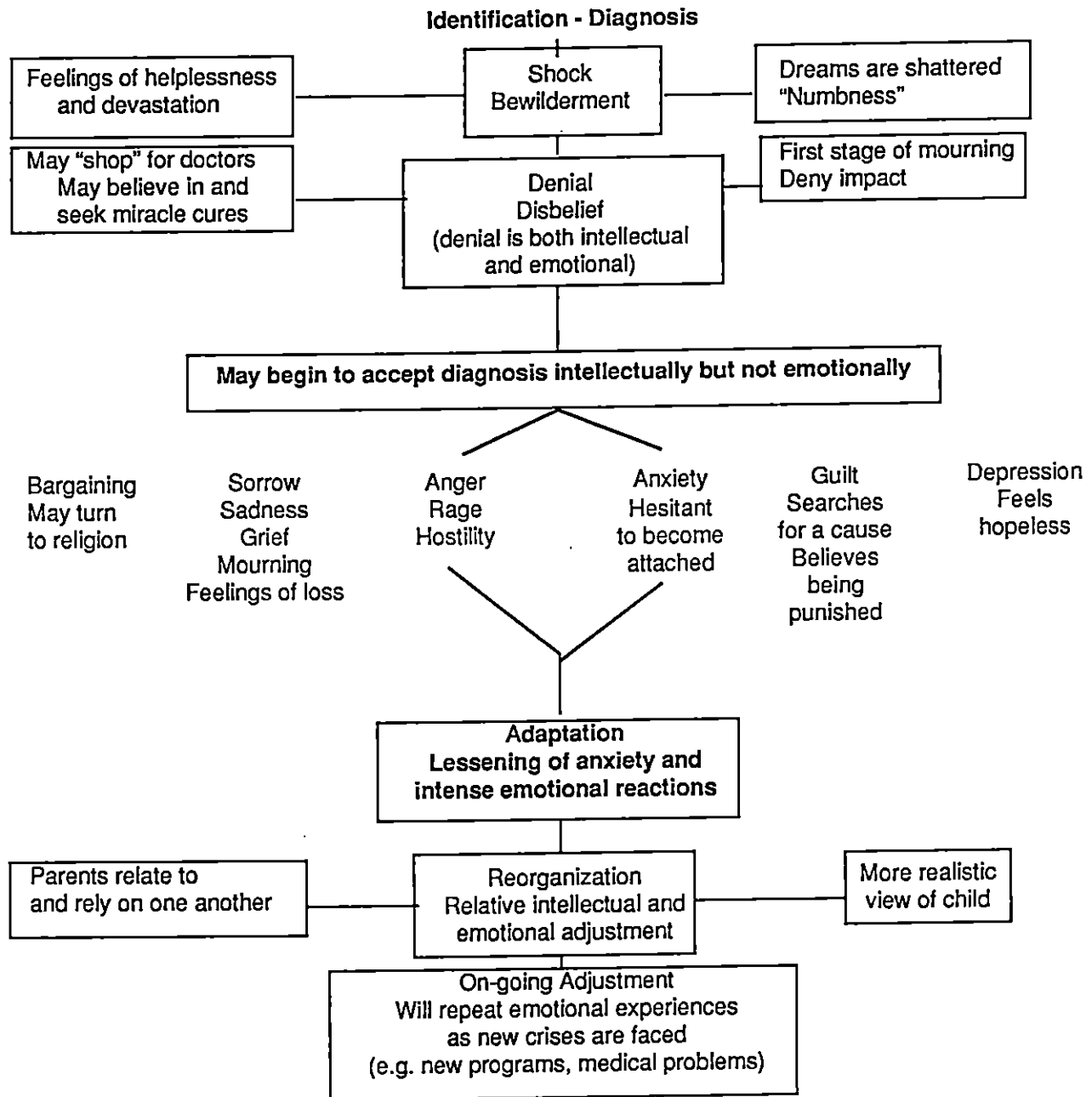
When one is in doubt about what to do, the best course of action is to listen—to listen very actively—but to listen.

My final point is a restatement of a theme that has run throughout this paper: don't expect the unreal. Acceptance is resignation. Acceptance is relative peace. Acceptance is a balance that allows one to go on functioning. Acceptance is not happiness at having been "divinely chosen to be the parent of a handicapped child" or being "blessed with the challenge."

From:

Programming for Atypical Infants and Their Families
Monograph No. 2
United Cerebral Palsy
1976

Grieving/Coping Process of Parents of Handicapped Children



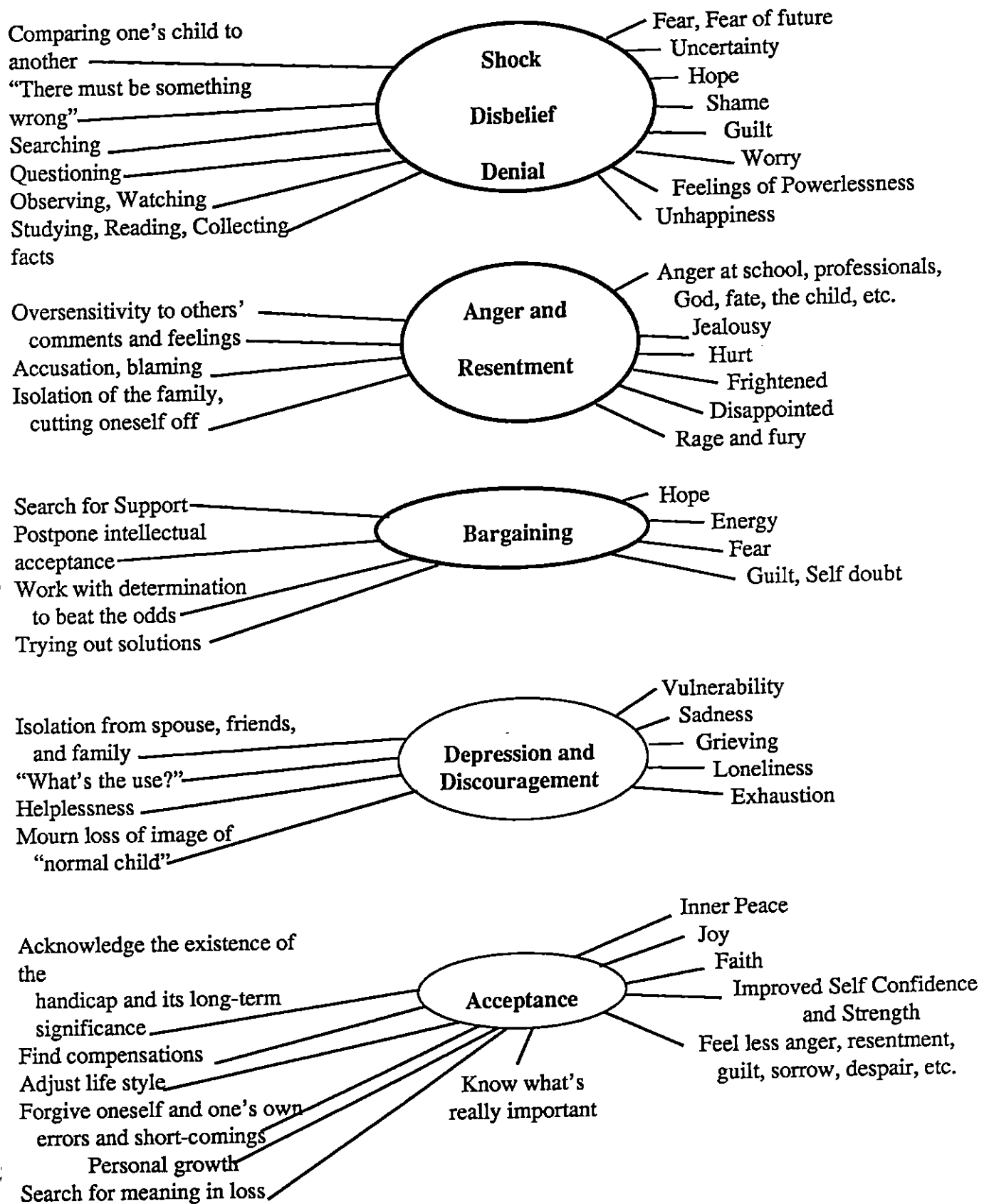
Adapted from: Project RHISE/Outreach
 Children's Developmental Center
 650 North Main Street
 Rockford, Illinois 61103

Stages of Loss Experienced By Parents Of A Special Needs Child

Attitudes/Behavior

Stages

Feelings



Death of a Dream

By Karen Hinderlityer

All parents have to modify the dreams they had for their children before they were born. This is a difficult process when the child has a disability.

Karen Hinderlityer describes how this can be done in a constructive way for family and child.

When a child is conceived, a dream is born. The dream imagines a healthy, strong, and clever child, who with confidence and success, fulfills a desire to bear a child. That vision turns into a nightmare when, upon awakening from childbirth, one hears, "He has some problems." What could *problems* be? Repairable? A minor flaw that surgery or some medicine can cure? "No cure, I'm afraid his condition is severe." The next several days are indistinct. I hear phrases like "multiple congenital anomalies," "never expect him to do much," "institutionalize," etc... Someone please wake me up.

Eleven years ago, I became the mother of a severely, multiply-disabled child. From the beginning I had no illusions that he would develop normally. The dream of him as a basketball star or a college graduate with a wife and two kids quickly faded. I replaced it with another, perhaps more realistic, dream. Then that dream died too.

For years, I made every attempt to fill Brad with opportunities to communicate his needs and feelings, to grow stronger, more independent. I needed to see him use his body and his brain. I read books on infant stimulation. I designed object sorting and picture matching activities that did not interest him. He was not motivated to point to the pictures on the communication board. The mirror we used for speech therapy still hangs on the wall near the floor, unused and collecting dust. The walker and crawligator have been stored away.

We are expected to be good mothers who possess special qualities that enable us to care for our special-needs child. We try another doctor,



MELD SPECIAL HANDOUT

buy the latest gimmicky toy and read another therapy-related book. We invest an incredible amount of time and energy in an effort to rehabilitate our offspring. I agree that it requires patience, endurance, and determination. However, these qualities are inherent in all parenting and child care. I believe there is a period of time unique to each situation when it becomes necessary to let a child be himself, for parents to free themselves to enjoy their less-than-perfect child; to discard the dream.

ACCEPTANCE



The process of accepting that your child is irreparably damaged is marked by periods of guilt, frustration, depression and finally, failure. Grieving is a way to alleviate these negative emotions and can help parents separate from the dream of a normal child. It is difficult to imagine the death of a living child, yet the analogy is astounding and the irony hard to bear.

Last summer I let another part of my relationship with my son die. I grieved over the loss and made mindful funeral arrangements, including my wish to have Brad buried with a new block in his hands. Tearfully, I visualized the scene; reality dictates it is a future one.



I buried the dream, grieving for what he would never be. An eleven-year-old infant remains for me to love, to care for, and to ponder.

The time I spend with Brad is full of hugs, kisses, tickles, and smiles. I know that his favorite forms of entertainment are blocks, books, television, and music boxes. I know what food he likes. His sign language tells me the rest.

MY DREAM, R.I.P.

I can say with comfort, and without tears, that I have a son who does not initiate play with other children. Brad has no friends who call or come to the door asking him to play. He will never scrape his knee, come home with a black eye, or provoke an argument with his sisters.

He will never draw me a picture or make me a present. He will never say, "Mama" or "I love you." Although I am sure he has an understanding of the terms, I still miss the little boy's voice. My son - my dream - may you rest in peace.

from The Exceptional Parent, Jan.-Feb. 1988

Taking The Guilt Out Of Parenting

Margaret Stantler

Guilt again. Not only do we parents of handicapped children carry a load of guilt about our child's disability, but that guilt also makes us over-protective about our child.

It is as if we say to ourselves, unconsciously, "If I leave and something happens, I'll never forgive myself - because look what happened before when I was/wasn't being careful!"

Deep down we still blame ourselves for being in some way neglectful or selfish or just plain bad and we cannot help feeling that this is what made our child handicapped.

Before my third son was born with cerebral palsy, I had two perfectly healthy normal boys. I therefore experienced two vastly different types of motherhood - and two vastly different types of guilt trips over being a working mother and/or leaving my children for a personal break.

Motherhood is synonymous with guilt. Women's magazines and coffee-klatches endlessly analyze the pros and cons of whether mothers should stay home and nurture their children or whether they should have a career and leave some of the childrearing to others.

With my first two children, I juggled these priorities with a fair amount of success. I worked part-time until my second son was born, then stayed home till he was two and his brother was four. Then I found good family daycare and again worked part-time. It was a good arrangement for me. Whatever guilt I had was directed at the condition of my kitchen floor and my children's undisciplined eating habits.

I did not feel I was fundamentally a bad mother. While I may have felt exasperated at times. I did not feel angry or resentful of my kids, nor did I feel the slightest bit of guilt about getting a babysitter for a night out or leaving the boys with grandparents while my husband and I had a weekend away. In short, I felt like most other mothers I knew. I identified with descriptions in articles I read about juggling or conflict in mothering.

All this changed four years ago when our third baby was born.

Not only was he unexpectedly premature, but his development was exceedingly slow. By the time he was diagnosed at eight months of age as having cerebral palsy, my husband and I were drained by fear.

I will not go into the feelings that accompanied my son's diagnosis. The hammerblows to the skull one feels when the doctor pronounces the dreaded verdict I am sure you all know well.

What really surprised me were the feelings of devastated guilt which the diagnosis confirmed.

I analyzed every week of my pregnancy and every day since my baby was born to see if I could blame myself for this disaster. None of this was to any avail. I just could not see how I acted more carelessly than my friends and relatives with their bouncing Gerber babies.

Nevertheless, I punished myself mercilessly. I gave up my job. I manipulated my baby's legs for hours each day in physical therapy. I took him to many different doctors. I found organizations for the handicapped and worked for them diligently. And I did find that the more I did for my baby, the more I loved him. The closer I became to him the happier he was.

It became obvious that my cerebral-palsied child did need me more and for longer than my able-bodied children.

Trapped! I was, and am, truly caught in an emotional bind. I am, like other special needs mothers, stuck in a fly-trap of love."

from The Exceptional Parent, October 1982.

Ivar's Tale

There was once a man from Iceland who was a great poet and singer who won fame in the court of the King of Norway, the court of King Eystein. The King thought much of young Ivar and bestowed many favors upon him and upon his brother, Thorfinn, who also lived in the court of the King.

Now Thorfinn was dissatisfied because of the many favors bestowed upon his brother, and felt that he had been slighted, that his own gifts had gone unnoticed. And so Thorfinn decided to return to his native country of Iceland. Before he left, however, his brother Ivar asked him to bear a message to a young woman called Oddny. Ivar told Thorfinn to tell her not to marry anyone until he returned in the spring.

And so Thorfinn left and had a good journey and arrived in Iceland where he met Oddny. But he himself asked Oddny for her hand in marriage. And so when spring came, Ivar returned to his native land only to discover that his brother had married the woman he loved. And he was filled with sadness and bitterness, and returned to the court of King Eystein a broken and bitter man.

When he returned to the court of the King, all noticed his change, especially the King. The joy in his singing had gone, the enthusiasm of his stories had waned. Ivar was a sad person.

One day, after the main meal had been finished, the King called Ivar to his seat. Ivar approached the King, and the King in a low voice, so that no one else would hear, asked the young Iclander what was the matter. Ivar said, "I am sorry, my Lord, but I am not free to disclose what is troubling me." King Eystein then said, "Well, that is no matter, because I will guess. For I know something bothers you and I will get to the root of this. Tell me, is there someone here in this court whose presence offends you in some way?" And Ivar said, "No."

"Well then, do you think that you are not given sufficient honor?" and once again, Ivar said, "No."

The king thought for a minute, and then added, "Well then, Ivar, is it that there is something in this land that you desire?" And once again, Ivar said, "No." The King pressed him, asking if there were country estates that he wished for. And Ivar sadly said, "No."

Then sensing that perhaps the issue was that of a woman, the King asked, "Is there a woman, perhaps a woman in your own country whom you long for?" Ivar remained silent and the King knew he had asked the crucial question. And Ivar nodded, "Yes."

The King smiled and said, "Ivar, there's no difficulty with that! I am the mightiest king in this part of the world and no one would dare interfere with my wishes. The next boat that leaves for Iceland will have you on board, and you will take a letter from me to her family saying that it is my wish that she become your bride. And certainly no one in Iceland, or anywhere else, would dare to interfere with the wishes of King Eystein."

Ivar said, "It's impossible, my Lord. Not even that." The King stopped and looked at him and said, "Do you mean she's married already?" Ivar nodded, and the King once again fell into silence.

Then after a few moments, the King said, "Well then, Ivar, we must think of something else. The next time I make my rounds of the countryside and visit the villages and towns and the castles, I will take you with me. And as we travel, you will meet many beautiful women, and perhaps your heart will find one of them to satisfy your deepest needs. "Ivar shook his head and said, "No, my Lord, for every time I see a beautiful woman I'm reminded of Oddny, and my grief is deepened."

"Well then, Ivar, I will give you...yes, I will give you lands and estates, large estates, so that you might devote your energies to taking care of the farming, and all other business matters that will keep you preoccupied through the entire year. With your hands filled with the work that has to be done, you will soon forget the woman and happiness will return to you." And Ivar said, "No my Lord. I have no wish, no desire, no ability to do any work."

The King, who cared deeply for Ivar, thought some more and then said, "Ivar, I know! I will give you money, a large sum of money so that you can travel to the farthest corner of Europe. And in your travels you will see many things and experience many adventures. And when all things are accomplished, by then you will have forgotten the woman in Iceland." But once again Ivar refused, saying he had no desire, no wish, no ability to travel anywhere.

The King now thought and thought and thought. And was unable to come up with any suggestion that could help Ivar in his predicament, until finally he said, "Ivar, there is only one possibility, one last thing I can think of. I know that the suggestion is a weak one compared to the others that I've made. Yet, perhaps in some way it might be of some help to you, and so I will make it anyway. Ivar, after the dinner meal is over every night, and once matters of state are taken care of, and after the tables have been cleared, I invite you to stay here with me and to spend as much time as you need to tell me of your feelings, of your love for this woman, Oddny. You may do that for as long as you need, and I will be here." And so Ivar agreed.

And every night when the meal was over, the tables were cleared, and the business matters of state were taken care of, Ivar came to the throne of King Eystein and there he told him his story. He told him his story for days, and weeks and many, many weeks. And every time when he had finished his story, the King never let him leave alone without some sign, some token of care that he had for Ivar. And so at the end of each story, he gave Ivar a small, but meaningful gift.

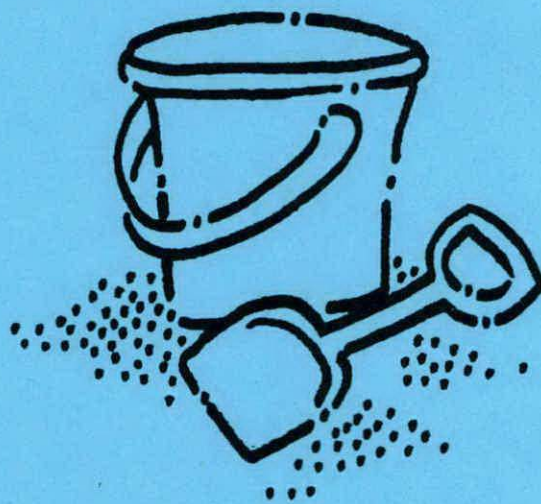
As the weeks turned into months, Ivar found that he had told his story. And when his story was finished, his old joy returned to him. And once again Ivar began to sing, and Ivar began to tell the ancient stories that the Scandinavians loved so dearly. And so he became not only a famous poet and storyteller in the court of the King, but Ivar became a happy man. In the following year, he met a young woman from Norway with whom he fell in love and who loved him.

And so Ivar remained a famous and a happy man spending all the days of his life in the court of the King.

This story is transcribed, with permission, from an audiocassette program entitled "Story-telling for Self-Discovery," by Robert Bela Wilhelm, copyright 1977 National Catholic Reporter Co. Copies are available from StoryFest, 4912 California St., San Francisco, CA 94118.

Chapter 2

Parent Relationships



Parent Relationships

Table of Contents	Pages
I. Introduction For Facilitators	3 -9
A. Main Ideas	4
B. MELD Biases	5
C. Facilitator Focus	6
D. Group Issues and Tips	7-9
II. Content For Facilitators	11-35
A. Parenthood is a Series of Stages	14-16
B. Our Expectations of Ourselves and Our Partners are Influenced by Memories of Childhood Experiences	17
C. How We Decide What Kind of Parents We Will Be	18-19
D. When Parents Have Conflicting Expectations	20
E. Children with Special Needs Affect Adult Relationships	21
F. Single Parents Carry a Double Load	22-23
G. Schedule Time to be Together as Adults, Rather Than as Parents	24
H. Why is it Important to Talk?	25-26
I. Discussing Relationships can be Difficult	27-29
J. What Makes it Easier to Really Talk?	30-31
K. Taking Steps to Examine Your Relationship	32-33
L. Practical Ways to Support Each Other	34
M. Who Does What?	35
N. Conclusion	37
III. Resources	39
IV. Learning Activities	41-54
V. Handouts	a-c
A. Family Function Checklist	a
B. Listen!!	b
C. When I Feel Responsible... ..	c

Introduction for Facilitators

In her book about the first years of life with her visually impaired daughter, Jane Bernstein describes the devastating impact the diagnosis had on her marriage. The couple's state of mind and emotions went "up and down with dizzying speed, despairing, believing, accepting, depressed." During that period, the closeness that had existed between them got "buried in the muck of sadness and fatigue . . . [we] made things worse by losing sight of each other."

It is during this complicated adjustment period that many couples make significant changes in the way they function and relate to each other, changes they may assume are temporary. Sometimes they wait until life "gets back to normal" to address the things they're not satisfied with. Only "normal" never returns and their concerns may never be addressed, but instead become an established part of their lives.

This chapter offers your MELD Special group members the opportunity to assess how their partnerships have changed since their children's special needs were diagnosed. It encourages them to make time for themselves and for these relationships, and to consider ways to maintain a sense of closeness with those who are important to them.

While some sections refer to couples and marriage, this chapter is meant to apply to relationships between both married and unmarried partners. Guiding discussions in a way that is meaningful for both one and two parent families is an important task for facilitators.

Main Ideas

- Parenthood is a series of stages. As children change, mothers and fathers are pulled into changes themselves.
- Our expectations of ourselves and our partners are influenced by memories of childhood experiences. The chapter raises questions for group members to discuss with their partners, particularly regarding the expectations they have of each other as parents.
- The presence of a child with a disability or chronic illness affects our partnerships and other adult relationships.
- Effective communication skills can help parents maintain supportive relationships with partners and other adults. The material addresses barriers to understanding and includes communication skills useful for partners.



MELD Biases

- Families are usually as stable and healthy as the adult relationships within them. Strong, supportive relationships can be particularly challenging to maintain when there are multiple demands on parents' time and energy. Stable and caring adult relationships benefit the entire family and provide valuable role models for children.
- Finding a balance between self, partnerships, and parenting is important to parents' ability to function effectively.
- Relationships with other adults - male and female - offer single parents the support essential to being a healthy individual and effective parent.
- Having unrealistically high expectations for oneself can lead to discouragement, feelings of inadequacy, and too little time for oneself and one's relationships.
- Understanding the patterns they've developed in their relationship helps partners set goals and work out ways to change undesirable situations.
- Children are powerfully influenced by observing how parents spend their time, and how they treat one another and themselves.
- Mothers should not take complete responsibility for the care of children. Men are encouraged to be nurturing, involved fathers, at the same time they are respected for their choice of the style of parenting that fits for them and their family.

Facilitator Focus

As you read this material and plan to facilitate a meeting on this topic, consider these questions:

- Since you became a parent, how have you preserved time for yourself and for the adults you are close to? Are you satisfied with the way things are between you, or are there changes you would like to make?
- Do you feel your expectations of yourself as a parent are realistic? Have you changed your expectations over time? If so, how did you do it?
- Do you think your children have learned from observing you and other grown ups that adulthood brings joys and satisfactions, along with responsibility and commitment?

For many people, answering these questions leaves them with mixed emotions, satisfied with some aspects of their lives and disappointed with others. How will your feelings about these issues in your own life affect your ability to facilitate a group discussion on this topic?

Group Issues And Tips

- The issues that emerge in a meeting on this material can be especially sensitive. Most facilitators find it's best to schedule this topic after the group has been together a while. People will be more willing to discuss personal relationships when they have developed a sense of trust in each other. Each group is different in the length of time this takes.
- Many facilitators find that conducting a meeting about partners' relationships is tricky. As the chapter points out, many couples avoid addressing their relationship. To suddenly be asked to examine or reveal their feelings, even privately, can be threatening.

One way to avoid making people uncomfortable is to make sure it is the group members themselves who select the topics they will discuss from meeting to meeting. Facilitators should determine in advance exactly what aspects of each subject the group wants to address. Spend time at each meeting selecting the topic for the next one, zeroing in on just how the group would like to approach it. In this way, facilitators can be assured of planning a meeting that is appropriate for their group members. This is particularly important for emotionally charged topics like this one.

It has been suggested that a less threatening approach to discussing relationships is to have the group first schedule a meeting or two about members' experiences with extended family and friends. Frustrations and disappointments often occur in these relationships as well, and it can be much less threatening for parents to discuss them than their partnerships. Keep track of the ideas that emerge in these meetings and, if applicable, relate them to later discussions on partners' relationships.

MELD SPECIAL

Relationships Between Partners

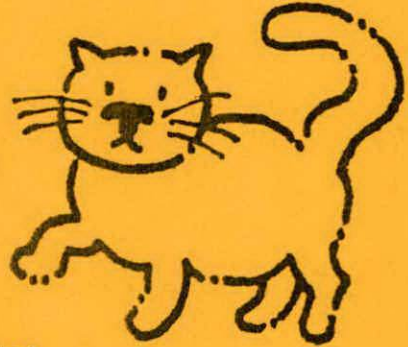
- Facilitators will need to be sensitive to what, and how much, each member feels comfortable disclosing in the group. It is important that people don't feel pressured to discuss things they would prefer remain private.
- There is an abundance of material here. You may wish to address this topic during two or more sessions. Consider the interests and style of your group members as you select material and activities for your meetings. Especially for parents who are struggling with painful feelings, the material may be quite threatening and take a long time to work with.
- It is important to remember that MELD Special is not a counseling or therapy group. If you sense that the issues that emerge in discussion are beyond the realm of this program, talk to your Site Coordinator. Practice ways of redirecting a discussion so that personal concerns are handled responsibly. Some groups invite a psychologist or family therapist to address those issues that are more appropriately handled by a professional.
- It is important for facilitators to be continually sensitive to the needs and concerns of the single parents in their group, but particularly with regard to this topic. It addresses relationships between adults, specifically partners in parenting, while many people, especially women, are going it alone.

Some of the single parents in your group may have supportive people close by: relatives, friends, roommates. The ideas in this chapter can be applied to those individuals as well as to the single parent's relationship with the child's other parent. When planning a meeting, it is essential to develop questions or activities that will promote a meaningful exchange of ideas for both single and paired parents.

MELD SPECIAL

Relationships Between Partners

- Many parents of disabled or chronically ill children give priority to everything except their own personal needs. Lack of time, energy, the belief that doing something for themselves is selfish are among the reasons parents neglect themselves and their relationships. An important point for facilitators to emphasize is that taking care of themselves and their adult relationships is not selfish, it is not a luxury, it is critical to the well being of their children and the entire family.



It will be important for you and your team mates to encourage group members about this in a manner that is sensitive to their individual situations and personal styles, as well as to their stage in adjusting to their child's condition.

If parents have never taken much time for themselves, the thought of a whole evening out of the house may seem impossible to them, much less a weekend. If they are ready to make a change, and they may not be, they may need to take small steps toward focusing on themselves.

Depending on the number of demands facing them at the time, encouraging parents to take care of themselves and their relationship may sound to them like yet one more thing they should be doing and aren't, yet another failure to feel discouraged about. Present these ideas as a long term goal to work toward at their own pace. Encourage them to take their time and do what feels manageable.

Content for Facilitators

“We all came to our marriages full of confidence and expectations about how life in our families would be; we had ideas about who would do the dishes, what we could talk about and how we would bring up children. Although we might not have discussed our expectations concretely, we established our family patterns with our daily reactions, choices, and discussions. In order to meet the daily demands of young children and young working lives, many couples put aside some basic issues and wait for the children to grow up. For a great many of us, however, putting aside our needs as individuals or as a couple took a toll on our relationship as partners. We sometimes miss seeing that a crucial part of providing security for our children is keeping the couple relationship alive.”

Carolyn Pape Cowan, “How A Couple Becomes a Family”

Most people—couples and singles—experience enormous change when they become parents for the first time. Routines change. Work changes. Parents’ self images change. Spontaneity is a thing of the past because now there is a child to consider.

Family relationships are restructured after the birth of each subsequent child as well. With the addition of a new family member, each person takes on not only a new relationship, but a new role in the family. Some of the changes are welcome, some are difficult. Family members vary in the issues

MELD SPECIAL

Relationships Between Partners

that are important to them as they adapt to this restructuring, and in the time they need to deal with them.

New babies make great demands on a family's emotional and physical resources. When a child has a disability or chronic illness, this disruption takes on extraordinary intensity as the family struggles to cope with the impact of the diagnosis.

It is during this transition that some couples make significant changes in the way they function and relate to each other, changes that may become long lasting. This is not a problem as long as the new patterns are acceptable to both of them. Unfortunately when one or both parents are dissatisfied with their altered relationship, they sometimes wait until life "settles down" to address their concerns . . . only life doesn't settle down and their concerns may never be addressed, quietly becoming part of their way of life.

"[My husband and I] made things worse by losing sight of each other," recalls Jane Bernstein in her book about the first four years of life with her visually impaired and developmentally delayed daughter. She describes the devastating impact her daughter's diagnosis had on the couple, their state of mind and emotions going "up and down with dizzying speed, despairing, believing, accepting, depressed." During that period, the closeness that had existed in their marriage got "buried in the muck of sadness and fatigue."

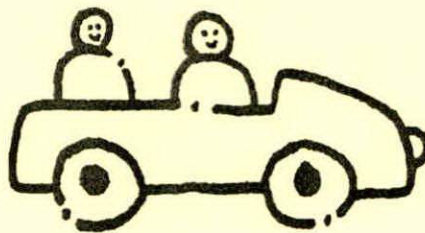
It's also easy to postpone dealing with personal issues when simply keeping up with the basics of daily life is so demanding. Finding the time and energy to focus on adult relationships can seem impossible. When both parents in a two parent family work, when a single mother works or does not live with another adult she is close to, when there is more than one child in the family, when a child has a disability or chronic illness, it is particularly likely that concerns about the parents' relationship will be placed on the "back burner."

MELD SPECIAL

Relationships Between Partners

This chapter offers your MELD Special group the opportunity to examine how your partnerships have changed since your children's special needs were diagnosed. It encourages you to make time for yourselves and for these relationships, and to consider ways to maintain a sense of closeness with those who are important to you. This is essential for your own happiness, but also because strengthening the adult relationships in a family strengthens the family itself; it is in everyone's best interest.

The chapter addresses both one and two parent families. While some sections refer to couples and marriage, the material is meant to apply to relationships between both married and unmarried partners. Some of it may relate to the single person's relationship with the child's other parent, who may or may not be involved in raising the child. It is hoped that group members will use this material in whatever way it can be helpful to the relationships they consider important in their lives.



Parenthood Is A Series Of Stages

Just as each of us proceeds through stages of development in our lives as individuals, parenthood has been described as a cycle of stages as well. In her book The Six Stages of Parenthood, Ellen Galinsky describes the developmental steps of mothers and fathers.

The first phase takes place during pregnancy, when mothers and fathers form images of what lies ahead: of what their child, and parenthood itself, will be like. During this “image-making stage,” parents prepare for changes in themselves and in their adult relationships.

The “nurturing stage” begins with the child’s birth. “Parents compare their images of birth, of their child, and of themselves as parents with their actual experience. They become attached to the baby, and in that attachment, in learning how much and when to give, their conceptions of themselves become blurred and changed, often leading to identity questions: What are my priorities? How much time should I give to the baby and how much to the other aspects of my life?”

Galinsky labels the third phase of parenthood the “authority stage.” It begins when the child exhibits early signs of independence, signs which force parents to consider what kind of authority they want to be and how they will set limits for the child.

The Six Stages of Parenthood continues with descriptions of subsequent phases in the development of mothers and fathers: the “interpretative stage” when the child begins to spend more time “out in the world” and parents become interpreters for what they discover there; the “interdependent stage” during the child’s adolescence; and the “departure stage” when children begin to leave home.

Relationships Between Partners

It is the child who pulls his parents through each stage and into the next. Parents change as their children change. And when there is more than one child in the family, parents find themselves in the position of working through more than one stage at a time.

Reporting on her interviews with men and women, Galinsky recalls that “whenever parents describe a new event in the life of their family (an event as large as the birth of a child or as small as their child’s reaction to a new toy), they used the words ‘should’ or ‘supposed to’ or ‘expected.’ I realized that parents had pictures in their minds of the way things were supposed to go, and of the way that they as parents and their children were supposed to act. I came to think of these pictures as images—because they were often fleeting, not fully conscious.”

Parents use these images to measure their success or failure as mothers and fathers. “If an image has not been achieved in reality, it is seen as a loss and can cause anger and depression. If an image is realized, it brings joy.”

Galinsky describes how writing the book changed her as a parent, and particularly the way she handles emotions. “When I find myself caught in a bind, everything seeming to cave in on me, I look for an underlying image. I ask myself, ‘What am I expecting that’s not coming true?’ Then, when I uncover the image, I ask myself if it is a realistic one. If I decide it is, I look for constructive ways to achieve it; if it’s not realistic, I try to replace it with a goal that’s more workable.”

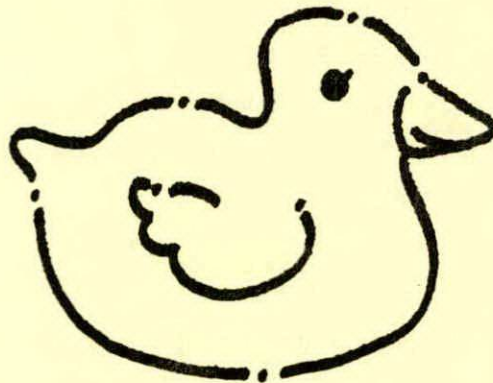
Holding on to unrealistic expectations means living with disappointment and discouragement. Growth comes when we are able to adjust our images to fit reality . . . a simple way of describing something that is extremely difficult to do.

MELD SPECIAL

Relationships Between Partners

The concept of “images” is one that comes up again and again in parents’ lives, and that has great significance for families of children with special needs. For much of parents’ adjustment to a child’s disability or chronic illness has to do with giving up or reforming an ideal image of their child and their own lives as mothers and fathers. In Raising a Handicapped Child, Charlotte Thompson refers to the actual “death” of an image, and the birth of another:

“Your child’s birth, accident, or illness - whatever suddenly made you the parent of a handicapped child - may have felt like a death to you. In a real sense it was. Our lives from physical birth to physical death include many lesser deaths, times when we lose a cherished hope or something we treasure. We grieve at such times, just as we do when someone we love has died. The other side of these deaths-in-life is the possibility of birth and rebirth. New strengths we didn’t know we had can be born of our need and desperation. New interests and skills can spring up from the very burial place of a long-cherished dream. This is a testament to the basic goodness and creativity of human beings. We are able to renew and rekindle our love of life again and again.”



**Our Expectations Of Ourselves And
Our Partners Are Influenced
By Memories Of Childhood
Experiences**

Our expectations of our partners and others we look to for support are influenced by our memories of childhood experiences, by the relationships we had and observed in our families. By observing our mothers and fathers over the years, we developed our earliest understanding of what it means to be an adult, a partner, and a parent. Our parents' example has a powerful influence on our idea of what it means to be a "good" father or mother. As adults, we may feel this influence is positive or negative, something we want to repeat or would prefer to change in our own families.

As a way of thinking about these relationships, list four ways that your parents influenced your attitudes about family life and personal relationships. What kind of examples did they set in these two areas?

How We Decide What Kind Of Parents We Will Be

Reflecting on parenthood brings to mind all kinds of generalizations and “shoulds.” Some of us may have been raised in homes in which mothers “should” be wise, organized, keep peace in the family, and say, “Don’t put your elbows on the table,” while fathers “should” be strict, work a lot, teach kids about physical tasks like riding bikes, and be able to fix anything.

“Shoulds” are also imposed according to standards set by society, and by the examples and attitudes of friends and acquaintances. You may have established other “shoulds” for yourself, even without realizing it. We often struggle with these influences as we work on developing our own styles as parents, styles that may be very different from those of our mothers and fathers, or from those around us.

A child’s disability or chronic illness can limit parents’ ability to do the things they feel are important to being a mother or father:

- When a man feels it is essential for a father to be the protector of his family, what can happen to his self image when his child has significant medical or developmental problems beyond his control? He may feel he has failed in an essential role from the moment his child is born with a special need.
- When he believes a man should be a good provider for his family, what happens to a father’s self esteem when his child requires expensive therapies, medications, surgeries, equipment, or nursing care that the family’s income and insurance cannot entirely cover?

Relationships Between Partners

- When he has expected to be the primary decision maker for the family, what are the effects of having to depend on physicians and other professionals to determine much of what the child and family must do from day to day to maintain the child's optimum health and development?
- When a woman feels a good mother is able to soothe her child when he is troubled or in pain, what happens to her self confidence when she cannot reduce the difficulty the child's special needs creates for him, or the anxiety or pain caused by medical treatments?
- When she believes a mother is responsible for maintaining a child's health and creating an environment in which the child learns and develops, how does she adjust to recurrent medical complications beyond her control, or the limited developmental progress that is inevitable in some special needs conditions?

The expectations they have for themselves as protectors, providers, decision makers, soothers, teachers and physical caregivers are among the most fundamental aspects of parents' sense of identity. To be denied the opportunity to fulfill these hopes is a profound loss for any man or woman, a loss that is often grieved and accomodated over a lifetime.



When Parents Have Conflicting Expectations

In two-parent homes, there are almost inevitably some different and even conflicting expectations of the roles each adult will assume in the family. Perhaps one person imagined only the playful, tender roles that come with parenthood . . . so who will comfort the crying child, accompany him to the doctor, and carry out prescribed treatment plans? Perhaps one parent imagined no time away from the child for months and months, while the other looked forward to an evening out or a vacation away from everything.

How do parents compromise these expectations? Discussing their hopes and concerns about “who does what” can minimize misunderstanding and help them negotiate those roles about which they might disagree.

Children With Special Needs Affect Adult Relationships

Regardless of how secure, close-knit, and happy a family may be, life changes dramatically with the birth of a child with special needs. Some changes are irreversible:

- decisions and activities must be planned around the child's needs
- parents' individual freedom decreases, as does time spent alone and with other adults
- household and childrearing tasks multiply; roles need to be renegotiated
- parents' self image may be radically altered and self esteem may suffer
- parents live with continual fear about their child's well being and future
- the financial burden imposed by the child's condition can be extraordinary
- parents are required to make difficult decisions about their child's treatment and care at the same time they are trying to educate themselves about the condition.

In fact, if "crisis" is defined as "a time of losing what you are without having an idea of what you will be," parents may seem to be in a never-ending crisis. Each parent reacts to a child's disability or chronic illness in a highly individual way. When they are preoccupied by their own feelings and needs, partners may be unable to respond to each others'. A sense of distance or isolation can develop in what may have been a very close relationship.

Single Parents Carry a Double Load

Our consultants report that the concerns of single parents of children with special needs are basically the same as those of dual parents. The primary difference, of course, is that single parents are “doing it all alone.” When there isn’t another person to share day to day responsibilities, and when there is only one source of income, the reality for single parents is less time, energy, companionship and money.

Single MELD Special parents report that having to “be everything” is the most difficult part of their lives. One mother said, “Sometimes I feel so pulled apart. I have to change hats and it’s hard for me to change hats quickly. I’m trying to balance all the aspects of a complicated life: financial needs, career planning, parenthood, advocacy, making medical decisions, and trying to take care of my personal needs. Very few things get done the way I want them done. I really fear being inadequate. I’m behind on things, even sending out

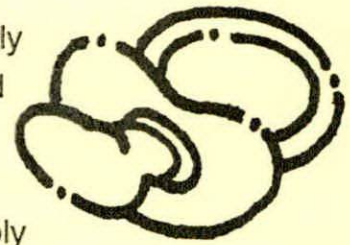


complaints! I’m jealous of mothers who can stay home with their child and be an advocate whenever it’s necessary. It would be nice to focus and do things really well. My life feels like a teeter-totter, going up and down with constantly changing priorities. I try to remind myself that having one good parent is better than having two parents in a relationship that’s not working.”

MELD SPECIAL

Relationships Between Partners

The demands of raising a child with special needs typically causes families to become more isolated than they would otherwise be. For single parents, this situation can be even more marked. Keeping up with “the basics” of day to day life can be so demanding that a single parent simply doesn’t have the time and energy needed to maintain close, supportive relationships.



Isolation makes raising children, especially special needs children, much more difficult. When a single parent does not have a built-in and reliable support system, it is extremely important to find a way to maintain friendships and other adult relationships. Support is not a luxury: it is critical to the well being of both parent and child. Unfortunately, in order to do this, single parents are forced to be very resourceful, and the extra effort requires energy they may not have.

Schedule Time To Be Together As Adults, Rather Than As Parents

A relationship can be compared to a garden. It takes planning and work to create and sustain it. If no one spends time caring for it, weeds choke out flowers and new growth. In order to maintain the sense of being true partners, adults need time together, away from their children. Yet finding time can be particularly difficult for parents of children with special needs.

It can also be very difficult to leave a child. Competent sitters for a child who requires special physical care are usually extremely difficult to find. (Child care for disabled and chronically ill children is a difficult and complicated issue, beyond the scope of this chapter.) Yet even when a good sitter is available, it can take a long time for parents to feel comfortable leaving. Breaking away from the intense one-to-one care that makes up daily life with the child, and breaking away from worries about the child's well being, can be very hard. Each parent needs to do this in a way and at a pace that is right for him.

Then there's money . . . yet time together need not be an expensive evening or a long vacation. MELD Special parents report that the most meaningful times are often the "little" ones: sharing coffee, taking a walk, or browsing in a shop together.

Why Is It Important To Talk?

Some parents feel it is too difficult to reach out to others when they are under stress. Or they may believe that mature people are able to handle emotional turmoil on their own. They often wait to find support until they're less anxious or a crisis has passed.

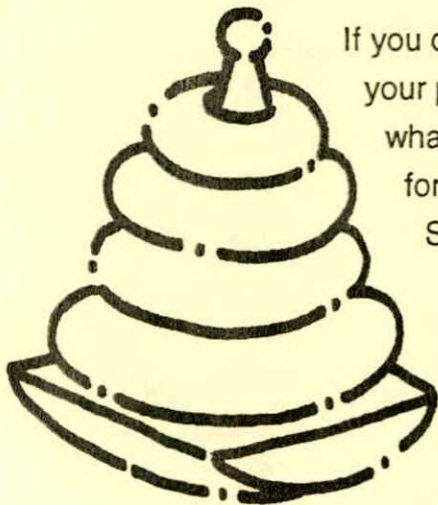
Yet it is precisely when a person feels most alone and overwhelmed that it is important to find some way to "connect" with others. Far from indicating weakness, seeking support from others is a sign of strength and of a person's commitment to having a healthy family.

Sharing your feelings during very stressful periods or when adapting to a new experience can be particularly helpful because:

- You can release anxiety and tension that decrease your ability to deal with problems.
- By understanding what you are going through and what you need, others are better able to support you.
- You may gain insight into what you are experiencing by putting it into words.
- You may receive information that relieves your fears.
- Relationships may deepen as you confide in others and develop trust.

MELD SPECIAL

Relationships Between Partners



If you don't feel ready or able to talk things over with your partner or a friend, it might help to write about what's happening to you in a journal or in the form of a letter you don't actually intend to send. Some people find that a professional counselor can help them "get used to" expressing themselves, and enable them to eventually turn to others.

It can be easy to let things slide and not talk about problems and fears when you believe things will eventually settle down or "get back to normal." The risk is that by overlooking problems or distance between you and your partner now, you may create even greater distance in the months and years ahead.

The suggestions offered above are not easy; in fact, they can be very threatening. Consider only those ideas that sound right for you, or adapt them so that any steps you take will suit your needs and your style. Take your time. Observing how others in your MELD Special group handle closeness may be helpful as well.

Discussing Relationships Can Be Difficult

There are many reasons why it can be difficult to discuss the things you wish were different about your relationship and the way you function at home:

- The intense and complicated emotions involved in parenting a child with special needs can be hard to put into words. Sometimes it's difficult to understand what you're feeling and why.
- Parents may be in such different states of mind from day to day, or week to week, that it may seem impossible to talk and try to understand each other. One may be "up" and feeling hopeful while the other may be anxious and pessimistic.
- Each parent may be at a different stage in grieving or in accepting their child's disability or illness. This can make it difficult to sympathize with each other's point of view.
- Single parents may not live with another adult they feel close to. Arranging time to talk things over with others who are involved in their child's care can be extremely difficult.
- It can be threatening to talk about negative feelings, especially when they are related to a partner's behavior. Many people avoid confronting each other when feelings of guilt and blame are involved.
- There are times when one person simply may not have the energy or emotional reserves to deal with the other's concerns. It's not a matter of "not caring," it's that on that day, or during that stressful period, it's just too much to take on the other person's feelings. If parents can

MELD SPECIAL

Relationships Between Partners

communicate this, feelings of rejection may be avoided and they can try to find a time to get back to the issue later.

- Even though negative feelings between partners are universal, it's common to believe other people manage better than you do in both emotional and practical ways, or that having negative feelings and emotional turmoil indicates that you are a weak or ineffective person. When parents are unable to accept their negative feelings as reasonable or legitimate, it's hard to have confidence about discussing and resolving them.
- Some people fear that talking about negative or threatening feelings makes them come true, or that putting feelings into words will open an emotional dam that will never close.

In Raising a Handicapped Child, Charlotte Thompson quotes the mother of a boy with congenital muscular dystrophy:

"What is that stuff that I'm holding back? What kind of things am I not letting come through? Am I afraid that I will go out of my mind if I let down my guard? Am I just tired? Am I not accepting reality? We can cry on the surface, but to really open up our hearts and let it out, we don't. And why don't we? I'm so scared that if I start I'm never going to stop. I don't know if I'm going to go out of my mind. It's this huge vessel that is so full of so much emotion. I know psychologically it's not good to hold it in, and I should go through the pain and let it out, adjust to it."

Differences in individual coping styles can create problems as well. In some families, one parent is more communicative and needs to discuss things frequently in order to cope with stress and worry. Yet the other parent may feel that talking only makes the situation worse; for this person, the ability to function under stress requires carrying the burden in silence.

MELD SPECIAL

Relationships Between Partners

function under stress requires carrying the burden in silence.

The more communicative or expressive parent can feel abandoned - needing to talk but unable to approach the withdrawn partner - while the silent parent feels defensive and pressured to change.

A compromise can be hard to achieve. It can help if partners are at least able to explain why they react the way they do. Understanding why one person needs to talk and why discussion heightens another's anxiety may minimize feelings of hurt and rejection.

The intense emotions that are part of raising a child with special needs can create an atmosphere that actually triggers conflict between partners. Anxiety, fatigue, or frustration about the child or the nature of day to day life may be transferred to other issues. The real source of these conflicts can be confused, and confusing.

"In the beginning Paul and I used all our energy just to stay afloat, and all of our promises to each other and all of our fights had Rachel's blindness behind them," recalls Jane Bernstein in Loving Rachel: A Family's Journey from Grief. "That night we quarreled over his grocery shopping, and I ended up in tears because of the overblown cucumbers he brought home. Later, when I figured out why I had gotten so upset he would not hear what I had to say, and I went to sleep realizing that we are still torn apart by this. . . Rachel's sickness was like a great storm that had blown us apart, and it took time for Paul and me to pick ourselves up and put our lives in order . . . I did not see this failure as a failure of love—who knew that our way of grieving would be so different? What was there to prepare us?"

MELD SPECIAL
Relationships Between Partners

**What Makes It Easier
To Really Talk?**

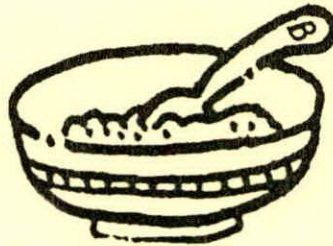
The following guidelines can be helpful in maintaining effective communication between adults.

- Don't tell your partner what she should or shouldn't feel. Acknowledge and accept the way she sees things without trying to change it.
- Let the other person "think out loud." In other words, just listen, acknowledge what he is thinking or feeling, and don't feel like you have to try to "fix" things for him.
- Don't offer advice unless you verify that the other person wants it.
- Don't assume you know what the other is thinking or feeling, or how he will react to what you have to say. Check it out.
- Practice restating what you hear the other person say to be sure you understand. Ask questions to clarify what you've heard or to help the other person think further.
- Discuss one issue at a time. Don't change the subject.
- Don't do the dishes, fold the laundry, watch TV, or read the newspaper while you are "listening."
- Allow for silence. It can be companionable and provide time to think.
- Stay in the present. Grievances should be dealt with at the earliest possible moment. Don't save them up to use as weapons.

MELD SPECIAL

Relationships Between Partners

- Be open to compromise.
- Brainstorm possible solutions and explore alternatives. Select one or more options together.
- Try to come to a conclusion; reach a point of understanding or develop a plan about how you will proceed.
- Sometimes partners need to say to each other, "Please hold me." This can communicate a sense of belonging and security that reassures both people.



Taking Steps To Examine Your Relationship

Perhaps some of the material you have read so far has already sparked discussion between you and your partner. The following questions offer another way to think and exchange ideas about your relationship.

If you decide to respond to these questions, remember that only you know what you want and need from relationships, and what your capacities are as partners. Try not to dwell on the “ideal” but on what’s right for you. Then discuss your answers with your partner. Include what is good about the way things are and what each of you would like to change.

- 1** Do you talk together about a variety of things happening in your lives or do you find yourselves invariably dwelling on your children?
- 2** What enjoyable, relaxing things have you done together in the last month or two? What would you like to do in the next few months?
- 3** How can you show your partner that you care about him/her and value what s/he is and does? How frequently is this communicated?
- 4** Do you sometimes feel you get angry with each other instead of with the situation? In what ways does anger “bounce” from its starting point and affect others who aren’t the source of the anger? Is it possible to talk about this?
- 5** What are the consequences of investing all your love, attention, and energy in a child? What are the pitfalls for the child? For the parent(s)?

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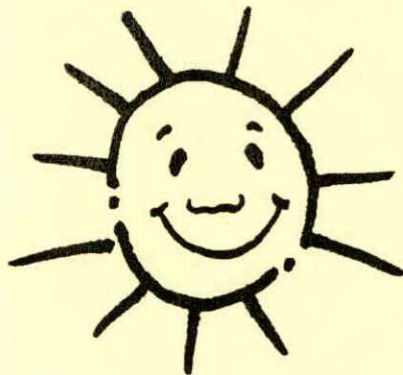
Relationships Between Partners

- 6** Does your community have marriage enrichment programs?
Is this something that might interest you?
- 7** Describe the unique and positive qualities of your relationship.
- 8** Describe the ups and downs in your relationship that seem to be related to the stage of life each of you may be in, and to your child(ren)'s stage of development.

Practical Ways To Support Each Other

You may want to set aside some time to think about what would ease some of the burdens in your life. Make lists of what you can do for your partner and what you would like your partner to do for you. Sometimes a very simple act is the most helpful of all. For example, many MELD Special parents report that they would be grateful for fifteen minutes of solitude for a hot bath, to read without interruptions, or to work on a project.

Sometimes people aren't sure what they need. Parents of children with special needs may go through periods when they feel overwhelmed and can't think clearly about this. Furthermore, needs can change from day to day, and even hour to hour. Acknowledging this is a step toward being able to ask for and receive what you need at the time, however changeable and confusing that may be. If it helps, consider the arrangements you make with your partner to be temporary so you can be open to new situations and feelings. So you can change your mind. This kind of flexibility can help you stay afloat.



Who Does What?

In some two parent families, one person may be—or may appear to be—better able to handle pressure or function in stressful situations. If that parent takes on most of the tasks involved in caring for their special needs child, he or she may become angry or resentful about bearing an unequal share of the responsibility. The other partner may become anxious and fearful about feeling dependent. Or one of them may be satisfied with the arrangement while the other is frustrated. Perhaps both parents would prefer to be involved in the child's care, but one of them somehow becomes the primary caretaker. This can make it difficult for the other parent to have more than a very limited role in the child's life.

In After the Tears, Robin Simons quotes a mother who reported, "I was doing four therapies a day, 30 minutes each, plus washing, cooking, cleaning, and taking care of two other kids. I was going crazy. Finally, I said, 'Look, I can't do all this myself. You have to help.'"

Some families arrange to rotate tasks. You might select the jobs each of you actually likes doing and then divide and rotate the less desirable ones. Child care activities, such as getting up at night or taking the child to appointments, can be traded as well. It may help to talk about what really needs to be done—can some tasks be simplified or even eliminated?—and what is truly important to each of you. Many parents automatically do things the way their mothers and fathers did, or simply out of habit, when in fact they'd be willing to change. You might also work out a system for trading time with each other or with friends so that one of you can carry the parenting load for a while to give the other some time off.

Relationships Between Partners

Conclusion

Raising children is always a highly emotional undertaking; raising a child who is disabled or chronically ill intensifies this quality. The feelings involved are not only powerful and complicated, they are always changing. Maintaining a sense of equilibrium as individuals, as partners, and as a family is a tremendous and difficult challenge for parents.

Understanding the expectations you have of yourself and your close relationships, and deciding whether those standards are realistic at this point in your lives, may help you live in a manner that takes your needs, your temperaments, and your values into account.

This is a difficult, lifelong process. When you feel your expectations aren't realistic or appropriate for you, or when your day-to-day family patterns no longer "fit," it's one thing to say "Change them." It's another to know how to go about doing so. Reports from other parents about what worked for them recommend that you:

- take your time
- be patient and kind to yourselves
- give yourself credit for tackling something that's extremely difficult
- give it a try and, if something doesn't work, take the time you need to find another way
- talk to others you feel are supportive, non-judgemental, and who understand what you're going through and how difficult it is.

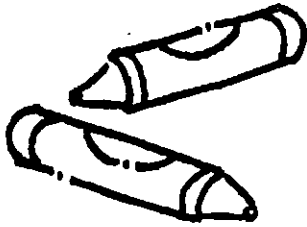
Discussing this topic in your MELD Special group can be an opportunity to identify your strengths as individuals and as partners. Exchanging ideas may help you discover ways to remove some of the barriers to a sense of stability and hope in your daily lives and close relationships. And it may reinforce the idea that taking care of yourselves is one of the most important things you can do . . . for yourselves, and for your children.

MELD SPECIAL
Relationships Between Partners

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MELD SPECIAL
Relationships Between Partners



Learning Activities

I. Activities related to the idea that our expectations of ourselves, our partners, and others we are close to are influenced by memories of our childhood experiences.

LARGE GROUP DISCUSSION

Introduce the idea that we grow up observing the way our parents live their lives, and slowly, by watching their examples, we develop our first understanding of what it's like to be an adult. If you like, select material from the chapter to help you introduce this concept and to elaborate or clarify ideas that emerge during discussion.

Ask your group members to describe what they learned about either of the following from observing their own mothers and fathers over the years (members can substitute adults other than their parents if they wish—anyone they consider a strong positive or negative example or role model from their childhood, e.g., grandparents or other relatives, family friends, other people's parents, etc.):

- 1) what it's like to be a parent
- 2) adult relationships (between partners, relatives, friends, etc.)

What is it about these examples they would like to repeat in their own lives, and what would they like to do differently?

-AND/OR-

MELD SPECIAL

Relationships Between Partners

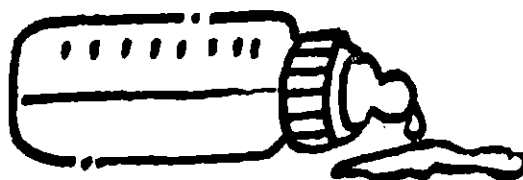
Ask members to describe “ways I am like my parents that I didn’t plan to be.”

You might want to include the following information, or something like it, as background for parents’ reflections:

Understanding our childhood experiences is also a way of understanding and dealing with the inevitable differences of opinion that arise in two parent families. When we learn how our partners’ past influences their attitudes about family life and childrearing, we can appreciate or accept some of the reasons they feel strongly about particular ways of doing things.

Understanding childhood experiences also offers some insight into the struggle that exists for many parents when they find themselves unconsciously repeating the kind of parenting they experienced, even when they would prefer to raise their children differently.

As you remember your childhood, you’re bound to come upon some feelings and memories that are uncomfortable or painful. We’re not suggesting you uncover these memories to be confrontive, angry or blaming, but to promote a clearer understanding and choice about your own actions as parents.



MELD SPECIAL

Relationships Between Partners

SMALL GROUP DISCUSSION

Ask each group member to take ten minutes to generate a list of characteristics a good mother "should" have, and a good father "should" have. Divide members into small groups to exchange their ideas.

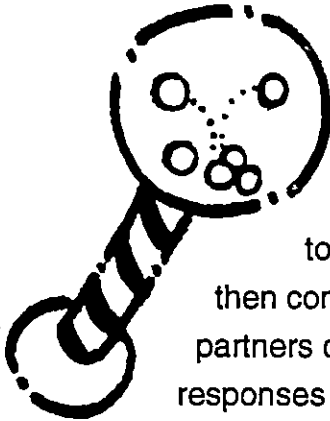
As they do this, single parents might relate their list of "shoulds" for the opposite sex parent to other adults in their lives, and consider who could offer their child the experience of those qualities.

Ask parents to answer the following questions during their discussion:

1. How might your list of shoulds have been influenced by your memories of your parents?
2. How does your list of shoulds compare to that of your partner?
3. How do your shoulds for yourself differ from what you think others expect of you?
4. Which shoulds do you wish you could get rid of?
5. Do you feel your expectations of yourself and others are realistic?
6. How have your shoulds been affected by the presence of a child with special needs? Which qualities or behaviors have you felt unable to fulfill because of the situation? What is that like for you?
7. Do you carry out the same roles in your family that you think you would have if you hadn't had a child with special needs?

MELD SPECIAL

Relationships Between Partners



WORKSHEET

Distribute copies of the "Family Function Checklist" (see handout a) and ask parents to take about fifteen minutes to complete it. You might have people do this individually and then compare and discuss their answers with their partners. Or partners can complete the checklist together, discussing their responses as they work.

Single parents, or people who attend without their partners, might gather in a small group to discuss the amount of responsibility they carry alone, and how they might increase others' involvement in family and household tasks.

Point out that one goal of this activity is to heighten people's awareness of how much they juggle, and to give themselves credit for doing so. Parents typically don't receive recognition for their efforts and they often lose sight of just how much they do to maintain their home and family life. A parent group can play a valuable role in helping its members appreciate this . . .and themselves.

Obviously another goal of the checklist is to serve as a tool for evaluating the division of household responsibility, and to encourage partners to maintain an equitable or acceptable system of operating together.

MELD SPECIAL

Relationships Between Partners

II. Activities related to the idea that the presence of a child with disabilities or chronic illness affects adult relationships.

SMALL GROUP DISCUSSION

Distribute a photocopy of the following list of quotes to each group member. Explain that they are taken from Helen Featherstone's A Difference in the Family, a book about raising a child with special needs.

Tell the group the discussion is intended to give them a chance to reflect on feelings expressed by others in similar situations, and to think about whether or not they can identify with them.

Divide people into small groups with facilitators sitting in different groups. Have someone in each group read one quote at a time and ask participants to discuss their reactions.

Write the following questions on a newsprint pad or chalkboard and ask the group to refer to them to guide their discussion of each quote.

- What is it about raising a child with a disability or chronic illness that could lead a parent to feel this way?
- How might someone resolve the struggle suggested in the quote?

When the group reconvenes, ask a representative of each group to comment generally on some of the thoughts that were raised. Facilitators should take notes and conclude the activity by summarizing the themes or issues that are reported.

MELD SPECIAL

Relationships Between Partners

From Helen Featherstone's A Difference in the Family:

1. Many people believe that a child's disability will strengthen a good marriage rather than weaken it.
2. If a handicap constricts a couple's life at every point, the marriage becomes a prison.
3. Fear divides parents even before they know what is wrong. . .when you are frightened yourself, it can be particularly upsetting to hear your fears articulated.
4. Some parents find that the natural irritation they feel with their disabled child—and often they have successfully disguised it from themselves as well as their families—contaminates their relationship with one another.
5. Sometimes mothers and fathers of exceptional children face particular difficulties because they are divided internally as well as between themselves.

MELD SPECIAL

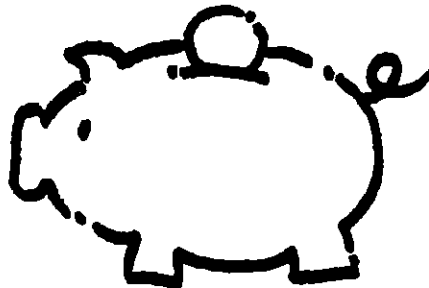
Relationships Between Partners

LARGE OR SMALL GROUP DISCUSSION

Ask the group to respond to the following questions.

- Describe an experience or incident you were involved in during the last few days that made you feel GOOD about adult relationships?
- Describe an experience or incident you were involved in during the last few days that made you feel BAD about adult relationships?
- What would you have to do or change to get more “feeling good” experiences?
- What are some approaches partners might use to maintain a supportive relationship?

Facilitators should keep track of the ideas that emerge during the discussion (if you break into small groups, ask for a brief, general report from each after members reconvene). Conclude the activity by summarizing the general themes.



MELD SPECIAL

Relationships Between Partners

WRITING AN IMAGINARY LETTER

Give parents about 20 minutes to write a letter to their partner or another adult they are close to.

In this letter, describe:

- how you feel about your life with your special needs child
- how you think this has affected your relationship with the person
- how you think the other person feels about this.

There are a number of ways facilitators might choose to conduct the rest of the meeting:

- Depending on the people in your group, this exercise may be most effective if you suggest the letter be an imaginary one that will never be seen by the person it's supposedly written to. In this case, introduce the activity as an opportunity for each group member to privately explore his feelings in the areas listed. Have each person work on the letter and leave it at that. Encourage group members to do whatever they want with their letters, or any new awareness they might have gained from working on them.
- Again depending on your assessment of the individuals in your group, you might choose to continue the meeting by asking partners to pair off and exchange and/or discuss their letters.
- Divide people into small groups made up of two or three sets of partners or single parents. Ask them to discuss in general terms the things that came to mind while writing their letters. Emphasize that people are not expected to talk about things they would prefer remain private.

MELD SPECIAL

Relationships Between Partners

- Have people divide into small groups that don't include their partners to discuss the thoughts and feelings that emerged while writing the letter. Some groups feel this is a less threatening way to express their feelings than turning immediately to their partners. However, some people might object to being asked to reveal their feelings when partners are not there to hear them.

If you choose to break into small groups, ask someone from each one to give a general report on some of the issues that were discussed, e.g., "Some of us have felt that . . ." and "Other people said . . ." not "Mary feels John has become withdrawn . . ." Facilitators need to emphasize this general style of summarizing discussion.

MELD SPECIAL

Relationships Between Partners

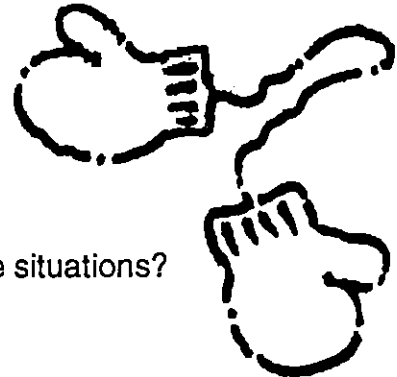
III. Activities related to the idea that effective communication skills can help parents express feelings and maintain supportive relationships with partners and other adults.

BRAINSTORM AND DISCUSSION

As a group, generate a list of situations or feelings that can be difficult for adults to talk about regarding their relationships and life with a special needs child. Have group members speak generally rather than asking them to divulge specific information about how they operate in their relationships.

Ask them to consider the following:

- Why might this be so?
- What are some ways people might defuse these situations?



Summarize and conclude with the hope that the discussion has generated some new insights members can use as they respond to issues that come up in their daily lives.

MELD SPECIAL

Relationships Between Partners

DISCUSSION/PRESENTATION

Introduce the topic of communication and your plan to address both what can make it easy or comfortable for people to talk things over, and what can stand in the way of effective communication.

Prepare for the meeting by generating a list of barriers to communication taken from the material in the chapter and your own ideas. Develop a second list of guidelines or hints for effective communication.

First ask the group to suggest or describe some barriers to effective communication: habits, behaviors, verbal responses that make it hard to talk and be open. You may want to write their comments on a newsprint pad or take notes to read back to the group. After the group has generated ideas, add any from your prepared list that haven't been mentioned. Summarize the main themes of this part of the discussion.

Next ask the group to describe what helps people talk to each other, i.e., what qualities, behaviors, and responses in a listener help them express themselves. Again, have your prepared list of guidelines ready but see how many of them you can elicit from the group before wrapping up with any that haven't been mentioned.



MELD SPECIAL

Relationships Between Partners

Summarize the discussion and conclude with any main ideas you feel might help the group use this information. These might include the following:

- Problems in communication are often simply habits that have developed over time, habits that can be slowly changed. We all have the ability to master these skills.
- Sometimes long lists of effective communication techniques can be defeating; they look like too much to take on. You might want to point this out and suggest that people choose one or two techniques they'd like to practice or establish in the coming months. Good communication is a lifelong skill, mastered gradually over time.
- These are techniques parents model and teach their children. Maintaining an atmosphere of openness and trust about expressing feelings helps children in their own close relationships throughout life.

SKITS

If your group does the brainstorm activity described above, select one or more of the situations suggested during the discussion and develop a skit of 3 to 5 minutes based on each one. Develop a "dialogue" that demonstrates positive methods of communication. Present the skits to the whole group. Ask for comments about the content of each situation presented.

MELD SPECIAL

Relationships Between Partners

DISCUSSION

Considering the individual members and style of your group, choose from the following questions to generate discussion between partners or in small groups of two or three:

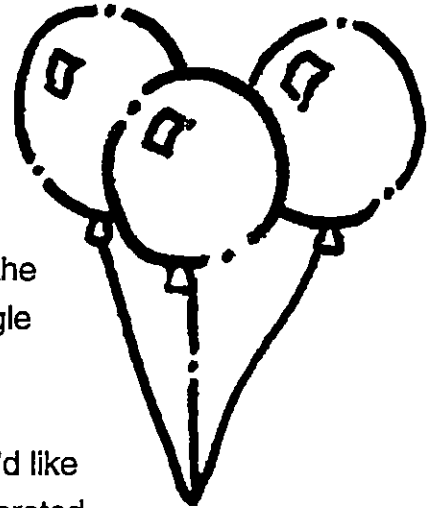
- What feelings about life with a special needs child and its effects on your relationship are difficult for you to deal with?
- How do you think things look from your partner's point of view?
- What are some things you feel your partner is finding difficult to face now?
- What are the signals your partner gives that are clues that s/he is bothered by something?
- Do you and your partner have a way of checking in with each other? How do you ask "Are you ok?" or "Can I help?"
- What are some things you are finding difficult to maintain in your relationship?
- What concerns do you have about the time you spend together?
- What are some ways you have found to adjust to being the parent of a child with disabilities or chronic illness while still meeting your own needs?
- When your confidence and self-esteem are low, what do you do to try to feel better?

You might write selected questions on a newsprint pad or chalkboard, or distribute copies to each group member to refer to. You may also want to ask for brief, general reports on some of the ideas generated during the discussion, or you may choose to simply encourage parents to take whatever helpful hints they can from the meeting.

MELD SPECIAL
Relationships Between Partners

PANEL

Invite four or more parents of older children with special needs to speak to the group about their experience, particularly the changes that occurred in their relationships as a result of their situation or the feelings engendered by it. Include couples and single parents if possible.



Send each panelist a list of questions or issues you'd like them to address at the meeting. These can be generated from questions in the various learning activities or from material in the chapter. Even better, ask your group members to suggest specific issues they'd like the panelists to address.

Tell panelists in advance how much time each person will have to speak, and how much will be allotted to a general question and answer session following the panel. This will help you guarantee that everyone has an accurate expectation of how the meeting will be conducted and their role in it.

Chapter 2

Handouts

**Parent
Relationships**

FAMILY FUNCTION CHECKLIST

Identify who performs each of the tasks listed under the nine family functions. If more than one person is involved in an activity, rate the degree of involvement of each individual as follows:

- 1 = almost never performs the task
- 2 = sometimes
- 3 = almost always

Mark "NA" if no one in your family performs the task.

	Family Member A	Family Member B
<p>FINANCIAL TASKS</p> <ul style="list-style-type: none"> generates income pays bills does banking handles investments oversees insurance and benefit programs budgets family income makes purchases 		
<p>SELF-DEFINITION TASKS</p> <ul style="list-style-type: none"> praises family members for accomplishments supports family members in difficulties and celebrations plans whole family activities accepts differences in family members helps family members recognize family members' strengths maintains a sense of humor and perspective 		
<p>AFFECTION</p> <ul style="list-style-type: none"> hugs and kisses family members encourages emotional expression spends time with family initiates intimacy and sex with partner comforts hurt or sick family members listens to family members 		

	Family Member A	Family Member B
<p>GUIDANCE</p> <p>teaches children to play cooperatively provides constructive feedback about behavior helps family members solve problems sets and enforces bedtime disciplines children assigns chores supervises chores takes family to church attends church makes suggestions for use of time and helps in time management planning</p>		
<p>PHYSICAL TASKS</p> <p>does grocery shopping cooks meals buys and sews clothes washes, folds, puts away clothes takes children to doctor does yard work monitors home safety transports children bathes and dresses children fills car with gas cleans bathroom washes dishes changes bed linens replaces toilet paper fills ice cube trays takes care of pet takes garbage out washes car dusts, vacuums washes floors</p>		

Adapted from Deb Ceglowski et al. Parenting a Special Needs Child. Winona, MN: Winona County Maternal Child Health Task Force, 1987.

	Family Member A	Family Member B
<p>REST AND RECUPERATION TASKS</p> <p>plans vacations goes out without children arranges for sitter or respite engages in hobbies watches television takes children out engages in sports helps children with hobbies/sports</p>		
<p>SOCIAL TASKS</p> <p>helps children be involved in group activities engages in community activities decides when to visit relatives entertains children's friends entertains adult friends talks to friends on phone spends time with friends spends time with partner's friend writes relatives</p>		
<p>EDUCATION</p> <p>helps children with homework attends parent-teacher conferences reads books to children listens to child reading listens to child's report of school initiates discussion of politics/religion, cultural events, sports, and feelings encourages curiosity and wonder monitors TV viewing takes children to museum, library encourages spouse's development</p>		
<p>VOCATIONAL TASKS</p> <p>listens to partner's job interests helps partner select job allows partner to help in job selection considers family needs in job selection</p>		

Listen!!

When I ask you to listen to me and you start giving advice,
you have not done what I asked.

When I ask you to listen to me, and you begin
to tell me why I should not feel that way,
you are trampling on my feelings.

When I ask you to listen to me and you feel
you have to do something to solve my problems,
you have failed me,
strange as that may seem.

Listen!!, All I asked was to listen to me—
not talk or do—just hear me, please.

Advice is cheap—Seventy five cents can get you
both “Dear Abby and Billy Graham” in the same newspaper.

And I can do for myself, I am not helpless.
Maybe discouraged and faltering, but not helpless.

When you do something for me that I can do
and need to do for myself,
you contribute to my fear and inadequacy.

But when you accept as a simple fact that I do feel what I feel,
no matter how irrational, then I can quit trying to convince you
and get about this business of understanding what is behind
this irrational feeling.

When that’s clear—the answers are obvious and I don’t need advice.
Irrational feelings make sense when we understand what’s behind them.

So, please listen and hear me,
and if you want to talk,
wait a minute for your turn—
I will listen to you.

Excerpts from “Listen” by Ray Houghton.

When I feel responsible for others

I... fix
protect
rescue
control
carry their feelings
don't listen

I feel... tired
anxious
fearful
liable

I am concerned with:
the solution
answers
circumstances
being right
details
performance

I expect the person to live up to my expectations.

When I feel responsible to others

I... show empathy
encourage
share
confront
am sensitive
listen

I feel... relaxed
free
aware
confident

I am concerned with:
the person
feelings

I believe if I just share myself,
the other person has enough to make it.

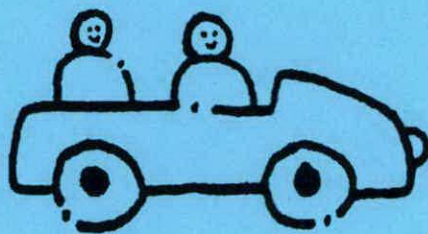
I am a helper, a guide.

I expect the person to be responsible for himself
and his own actions.

I can trust and let go.

Chapter 3

Family Relationships



MELD SPECIAL
Family Relationships

Family Relationships

Table of Contents	Pages
I. Introduction for Facilitators	3-8
A. Main Ideas.....	6
B. MELD Biases	7
C. Facilitator Focus	8
II. Content for Facilitators	9-37
A. Grandparents: Double Grief	11-13
B. Some Common Behaviors Among Relatives	14-16
C. Changes in Friendships	17-18
D. Others Have Questions About the Child's Condition	19-20
E. Attitudes Behind Others' Behavior	21-23
F. Anticipating and Dealing With Others' Reactions	24-26
G. Responding to Advice	27-28
H. Family Gatherings	29-31
I. When Do You Confront People About Behavior That Troubles You?	32-33
J. What kinds of Support Can Others Offer?	34
L. Conclusion	39
III. Resources	41-42
IV. Learning Activities	43-58
V. Handouts	a-d
A. Five Types of Social Support	a
B. A Fully Human Life	b
C. When Children Tease.....	c
D. Ideas for Support From Family and Friends for Families of Children With Disabilities and Illnesses	d

Introduction for Facilitators

What comes to mind when you think of relatives, your own or in general? At their best, members of our extended family* care more for us and have a greater personal investment in us than anyone else. Not only are relatives potentially our most dependable source of support and help, they can have an enormously rich supply of love and attention to give our children.

This endorsement does not mean that relatives won't have differences of opinion about the best way to raise a child. Even in the best circumstances, sensitivity to and conflict with parents or in-laws may be heightened when a child is born. The individuals in an extended family represent different traditions, values, biases, knowledge and experience. Their attitudes may or may not be compatible. Relatives' advice about childrearing may be abundant and conflicting, and no one's point of view is necessarily right or wrong.

Advice and differences of opinion are particularly difficult to cope with when parents are feeling vulnerable from the circumstances of raising a child with special needs. Uncertainty, worry, and fatigue make it difficult to maintain confidence about your effectiveness as a parent—about whether you are doing what's best for your child, and about how competently you are handling the difficult decisions you are forced to make about his care. What mothers and fathers usually need most is

*Extended family refers to a person's network of relatives and can include people who aren't literally relatives but who are considered part of the family.

MELD SPECIAL

Family Relationships

sympathy, encouragement, and lots of credit for the job they are doing. A chronic illness or disability is rarely a "black and white" situation. A parent who is already struggling with the doubt inevitable in caring for a child with special needs can be overwhelmed when others try to impose their point of view or way of doing things.

While this chapter approaches relatives as a potentially valuable source of support, it is likely that some of your MELD Special group members won't think of their families in this way. If it is possible for relatives to put aside their differing points of view and join forces on behalf of the child and the family, there is much to be gained. But parents who feel undermined by relatives may need encouragement to be assertive or to look for support outside their families. Those whose families live far away or are otherwise unavailable will need to do this as well. Parents in particularly negative situations may want to consider whether the best course might be to back away from unsupportive relationships.

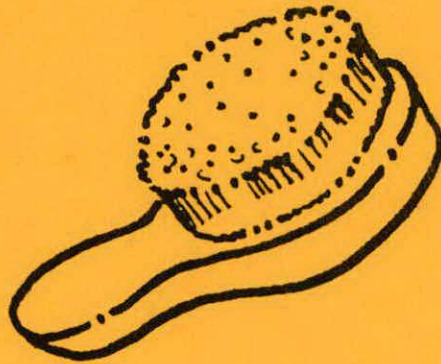
In addition to extended family, friends are a valuable source of support and love. Yet parents frequently report a change in friendships after their child's special needs are diagnosed. This chapter examines some of the reasons relationships change, as well as ways to maintain strong ties.

Finally, this chapter addresses the reactions of strangers to special needs children, and ways parents can respond to awkward or painful incidents in public. Outings with children who are disabled or chronically ill inevitably elicit puzzled looks, comments or questions from others. MELD Special parents have benefitted from the opportunity to exchange ideas about how they handle these incidents in a way that protects their child's self esteem and their own.

MELD SPECIAL

Family Relationships

Because their special needs children are very young, your group members may not yet have a great deal of experience with family gatherings, get-togethers with friends, or encounters with strangers. Group discussions will enable them to share those experiences they have had, as well as concerns about what might happen in the future. Exchanging ideas with those in similar situations can help parents develop realistic expectations of others' behavior, anticipate awkward situations, and plan ways to deal with them.



Main Ideas

- Families of children with special needs have relatives and friends who can be counted on for support and those who drain their energy and confidence.
- Parents can develop realistic expectations of their child's and their own interactions with extended family and others.
- Parents can generate a plan for handling awkward situations with extended family and others.
- Parents can develop comfortable and appropriate ways to explain their child's condition to others, or to avoid explaining it when they prefer.

MELD Biases

- Parents have the right to determine their own style of family life and childrearing.
- Relatives and friends often give advice out of a need to confirm the value of their own ideas and experience, as well as out of a desire to help parents.
- Expectations between parents and relatives often need to be discussed and clarified.
- Supportive relatives can be as great a natural resource as one can find. It's worth the time and energy to work things out if at all possible.



Facilitator Focus

As you read this material, consider the following:

- During the period following your child's diagnosis, what were your concerns about the effect the situation would have on your relationships with relatives, friends and others?
- Did any of your relationships with family members or friends change—positively or negatively—during that period? How? How did you react to or deal with those changes?
- What do you know now about relationships with family and friends that you wish you had known before?
- How have you been able to maintain supportive relationships with members of your extended family, friends and others? With whom do you feel safe, valued and respected?
- How have you been able to prevent unsupportive relatives and friends from undermining your confidence and your ability to function effectively as a parent?
- How have you dealt with conflicting or unwanted advice? Has it been difficult for you to see it as other than personal criticism?
- Have you found ways to offer advice givers information that enables them to better understand you, your child and your situation?
- If your own experience with relatives and friends has been negative, how will you detach yourself from your feelings about it so that you can listen objectively to the concerns of your group members?

“I’M ONLY TRYING TO HELP!”

Content for Facilitators

“Handling the handicap of our little boy is not nearly as difficult as handling the handicap of our friends, and of a society that still has a long way to come concerning disabilities. Our Matthew is not the end of our world—he is only the beginning of a deeper world—one that is more sensitive and more loving. We don’t love him less because he is not perfect; we probably love him even more. Life is not one success after another. It is one challenge after another. There are mountains to climb and valleys to conquer. And strange streets to travel. I smile at Matthew as I cradle and rock him after his late night feeding. I always did love to cross the streets.”

JoAnn Samuells

JoAnn Samuells’ perspective may or may not reflect your feelings about the nature of raising a child with special needs. But virtually every family in this situation can identify with her sentiments regarding negative social attitudes toward the disabled. When a child’s special needs are diagnosed, parents struggle to cope not only with their own reactions and those of their other children, they also find themselves worrying about whether other people—relatives, friends, other children, the public—will accept their child and their family’s situation.

MELD SPECIAL

Family Relationships

The diagnosis of a child's disability or chronic illness can dramatically alter parents' relationships with extended family members and friends. Relatives and friends experience many of the same reactions that parents do: shock, denial, anger, sadness and depression. Yet each person grieves in a different way, at a different pace.

Over time, relatives and friends are often at different stages in adjusting to the child's diagnosis than the parents themselves are. They may also differ in their attitudes about the condition, how severe they consider it to be, and what effect they think it will have on the child's quality of life. People also vary in the way they deal with difficulties in general.

These different attitudes and coping styles may be compatible, or they may create misunderstanding and hard feelings between parents and others. While relatives and friends can be a tremendous source of support, unfortunately this is not always the case.

This chapter is intended to help you:

- Examine your current support network and identify other possible sources of support.
- Assess your expectations of the way you, your child, your family, and other interact.
- Consider how your feelings and behavior can influence the way other approach your child.
- Develop strategies for handling difficult situations such as stressful family gatherings, insensitive comments, and unhelpful advice.
- Acknowledge who and what you can and cannot change.

Grandparents: Double Grief

The "Parents, You Count Too!" chapter describes the images men and women bring to family life: their hopes about what their children and parenthood will be like. Grandparents have images as well, awaiting the arrival of each new family member with specific expectations. When a child is disabled or chronically ill, grandparents must reconcile this unexpected "reality" with the one they had imagined.

"Grandparents worry about the effect the child will have on his or her parents," writes Patricia Vadasy. "The hopes that grandparents held for their own child's future must be adjusted, and [they] often experience a double grief, for both their grandchild and their child."

In Marion Rasmussen's "Disability in the Family," a grandmother reflects "The pain of Andrew's disability has not left me. I live with the pain of seeing my daughter and her husband coping with the problems they face: 24-hour nursing care for Andrew; his tracheostomy; his being respirator-dependent; coordinating schedules; both parents working full-time; no privacy; their incessant fatigue. I know when something is wrong by the hard edge of brittleness in my daughter's voice, the hint of despair."

Some grandparents are overwhelmed by grief and are unable to maintain the emotional reserves necessary to support their children. One mother commented, "My parents are really in pain about this. I wish we knew some way they could get the support they need because my husband and I just can't do it for them . . . we need it too badly ourselves." While people may feel anxious or guilty about alarming their parents with bad news about their child, they can also feel hurt when they are deprived of the support they need from them.

MELD SPECIAL
Family Relationships

Especially when they live out of town, many grandparents are unclear about the real nature of the child's condition and prognosis. They can't observe her abilities and limitations first hand. Visits and phone calls may not provide all the information grandparents need to accurately understand the situation, and misunderstandings can develop.

Grandparents' questions and comments may imply that the child's condition is better or worse than it really is, or that the parents aren't handling the situation capably. They may question the professional care or treatments the child is receiving, and suggest parents try something else. In their concern for the family, their conversation may focus on the child's difficulties, neglecting the things about him that are going well and that the family takes pleasure and pride in.

Grandparents who live at a distance may feel:

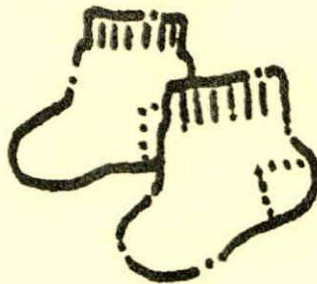
- Guilty because they aren't near enough to help.
- Sad because they cannot be with those they love.
- Left out because they are isolated from problems and decisions.
- Relieved because they avoid hospital and therapy visits, and the daily pain of a difficult situation.
- Unusually fearful because they have too little contact to "get used to" the situation over time.

MELD SPECIAL

Family Relationships

Some grandparents feel less attached to the child with special needs than they might otherwise be, or than they are to other grandchildren; most of their energy and emotion go into dealing with the fact of the disability or illness instead of into developing a relationship with the child. While over time parents come to see the child before the disability, it can be extremely difficult for grandparents and others to stop seeing the disability before the child.

Grandparents' ability or failure to be supportive and accepting of a child's special needs can have a significant effect on how other relatives, and even the child's parents, handle the situation. When they are unable to move beyond shock or denial and fail to accept the diagnosis, grandparents' feelings can be transferred to others and influence their behavior toward the child. On the other hand, when they are involved with the child and family in positive, supportive ways, it may encourage others to do the same.



Some Common Behaviors Among Relatives

The meaning a person gives to a situation determines how he deals with it. Relatives often differ in how they define the implications of a disability or illness, and the degree of loss it represents. Some of these perceptions might be paraphrased as follows:

- “This is the worst thing in the world. The family will never recover. What kind of life can the child possible have?”
- “We’ve got to do everything we can to try to make this condition go away.”
- “We’ll learn to accept it. The child won’t have an easy time but we’ll love him and give him as full a life as possible.”
- “There’s no sense worrying. She’ll get better. She’ll grow out of it.”

You may be able to describe other ways people perceive a special needs condition.

When parents and relatives define the situation differently, it can be hard to sympathize with each others’ point of view and feelings. And it can make it difficult for parents to receive the kind of support they need. For what parents often want most is simply to be listened to, to have their emotions and struggles acknowledged and understood, to feel that their perceptions aren’t crazy. Some parents report that others spend a lot of time trying to “fix” their situation, to make everything all right again, when all they really want is a sympathetic ear and presence.

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Family Relationships

In describing the wide range of responses among relative, parents of children with special needs report there are those who:

- need long or repeated explanations in order to understand the child's disability or illness
- require tremendous support from the child's parents in order to overcome their own fear and grief
- appear uncomfortable talking or hearing about the child's condition
- deny a problem even exists
- embrace the child with special needs as a favorite
- do not talk to or about the child
- convey their concern through incessant advice giving
- feel anxious or embarrassed about telling others that someone in their family is chronically ill or disabled.



Some relatives find ways to support parents and to be close to the child: they phone, visit, babysit, plan get-togethers, and most of all do a lot of listening. Others may withdraw or appear to subtly reject the family. Yet failure to help isn't necessarily rejection. When family members seem distant or unsupportive, they may be trying not to interfere, or they may not understand how to help and how welcome their support would be. Anxieties or problems in other areas of their lives may also prevent them from being more involved.

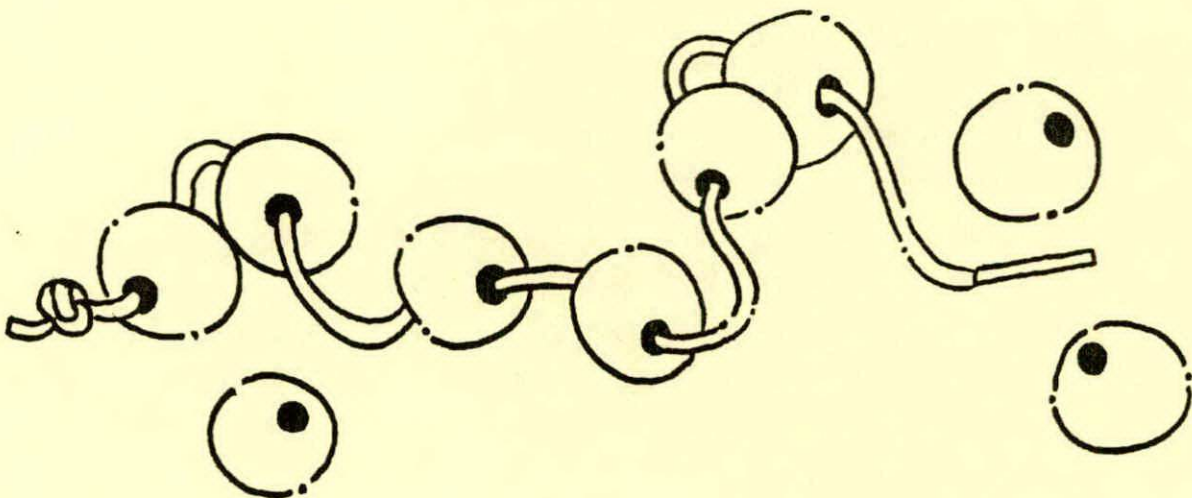
MELD SPECIAL

Family Relationships

The situation can be complicated when long standing personal issues such as sibling rivalry, conflicts over separation and independence, or hurt feelings from the past resurface as relatives discuss the child's needs. Attempts to be helpful may be rejected because of parents' feelings about the person trying to be involved.

Sometimes others convey double messages: while they express their sympathy, parents feel they actually avoid listening to them and dealing with their feelings. A sense of distance develops. One MELD Special mother discovered that even though people typically ask how her daughter is doing, some don't actually want to hear the details. "I've learned to sense when someone doesn't want an answer to 'How's it going?' so I just say 'Fine,' no matter what. It's humiliating to confide in someone who's not listening."

While a family functions most effectively when its members communicate their feelings, some parents report there are times when they cope best by avoiding those relatives who react negatively or somehow make the situation worse.



Changes in Friendships

Most families experience changes in—or even a loss of—friendships after a child's special needs are diagnosed. There can be many reasons for this:

- You and your friends may suddenly feel you live in different worlds and not know how to bridge the gap. You have a whole new set of concerns your friends don't have to deal with. If you lose sight of the fact that you still have things in common, your feelings of closeness subside. If, however, you no longer believe you do have enough in common, the basis of your friendship may in fact have slipped away.
- Friends sometimes feel awkward when their worn children are not disabled or chronically ill. They may wonder how you perceive them and whether you are comfortable being around them.
- When your schedule is consumed by childrearing and household tasks, appointments, therapies, and special treatments, it can be difficult if not impossible to find the time or energy to get together.
- Friends may not be able to overcome their discomfort about your child's disability or illness and what it has done to your way of life.
- Seeing you in pain can make friends feel helpless. Not knowing how to be involved or support you, and not knowing "the right way" to ask, they withdraw.
- The intensity and complicated nature of your day-to-day life can overwhelm some people. Friends may have difficulty sustaining their ability to support you when your family experiences frequent crises.

MELD SPECIAL

Family Relationships

More reasons for changes in friendships:

- People may feel your child's special needs prevent them from being involved in his life.
- Friends may be hurt or resentful that you are no longer able to give as much to the relationship. Or they may simply be confused about what to expect from it. One parent reported that "Many of my friends tell me it's hard to be my friend now. I'm preoccupied with my child and our family situation."
- Others may feel taken advantage of if the only time you see them is when you need to ask for their help with the many tasks you juggle.

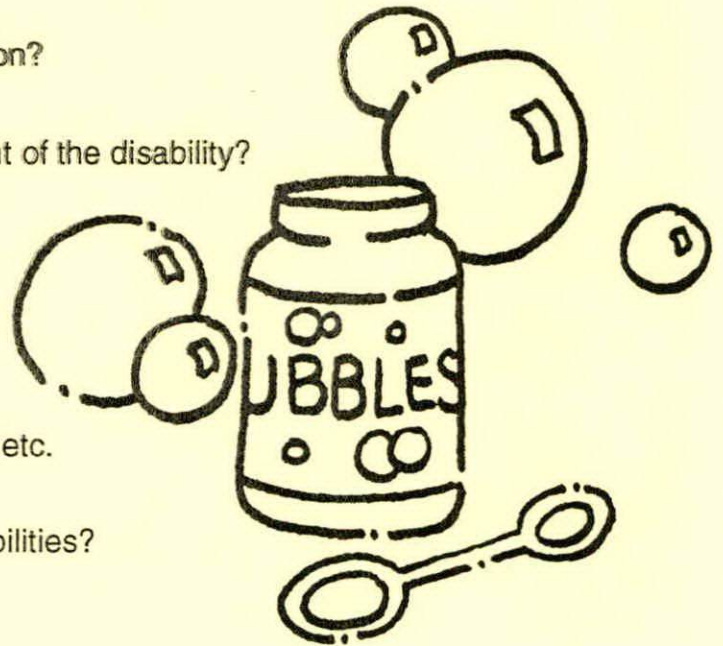
Ken Moses, a psychologist who works with parents of special needs children, denies the common wisdom that you really find out who your friends are when your child turns out to have this kind of problem. "They're all still your friends," he says, "you just find out who's able to cope, and who isn't."

Others Have Questions About The Child's Condition

Family and friends typically want information about the nature and implications of the child's disability or chronic illness. In fact, some awkward comments and behavior are simply a sign of people's need for such information.

There are many questions family and friends may have:

- How was the diagnosis made?
- How do they know for sure this is what the problem is?
- How much is known about this disability/illness?
- Is there a medical or surgical solution?
- Is there a way to evaluate the extent of the disability?
- What is the child's full potential?
- What is her level of intelligence?
- Will the child be able to walk? talk? etc.
- What can be done to develop his abilities?
- How will therapy help?
- What kinds of programs are most effective?



MELD SPECIAL

Family Relationships

More questions family and friends may have:

- What would be most helpful to the child's parents?
- When do you get over the sadness?
- How can you avoid sheltering the child too much?
- Will the child be able to go to school? play with other kids?
- Will future grandchildren be affected?
- What will happen when she grows up?
- How can I relate to the child?
- How can I ask questions without being intrusive or insensitive?
- What can I do to feel at ease with the child and the family, to maintain our feelings of closeness?

Attitudes Behind Others's Behavior

In Loving Rachel: A Family's Journey from Grief, Jane Bernstein describes people's reactions when she and her husband attend a party some time after the diagnosis of her daughter's visual impairment:

“ . . . some of the guests cannot bring themselves to talk to us, and others rush over to tell us how well we look. What a discomfort our presence arouses among those we know! We are no longer two people who have come to a gathering with our interests and opinions ready for whoever wants them. We are The Parents of a Blind Child, and the guests who stand beside us at the banquet table, or sit on the adjoining cushion of a living room couch, vibrate with unspoken questions. I have been on the other side and, confronted with someone else's hardship, wondered: Should I say something, is better to avoid the subject altogether? Is it insensitive to speak of other things, or would it be a relief? In truth, it's a no-win situation, for when nothing at all is mentioned, the unspoken words overpower all that is said, and Rachel's blindness clouds the air around us, and when we are asked to relay our tale . . . I watch the curious edge toward us, I feel as if we have become our story and nothing more.”

There are many reasons people react awkwardly or insensitively when they encounter a disabled or chronically ill person:

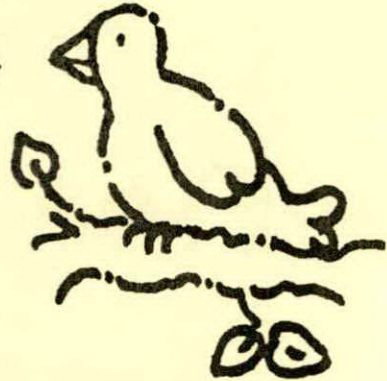
- The unfamiliar is often unsettling or frightening.
- They are concerned about hurting the child's or parent's feelings by saying the wrong thing.

MELD SPECIAL

Family Relationships

More reasons people react awkwardly or insensitively:

- They lack information about a specific disability or how to interact with a person who has it.
- They fear becoming disabled themselves.
- They are simply tactless and/or insensitive.



Many of the misunderstandings and barriers encountered by parents of children with disabilities and chronic illnesses are the result of what has been called "handicappism." According to Joyce Pelzer, handicappism is similar to any other "ism" such as racism or sexism. It is a form of discrimination defined as attitudes and practices that lead to unequal or unjust treatment of people with disabilities or chronic illnesses.

Many beliefs are based on stereotypes that label the disabled as individuals of limited capability who must be pitied and constantly helped. People typically focus almost entirely on what a person with special needs can't do rather than what he can. The general lack of understanding about the true nature of special needs conditions creates an atmosphere in which the disabled can become almost invisible members of society, prevented from achieving their potential in all areas of their lives.

As parents encounter handicappism, they may be able to help others replace the myths about special needs with the facts:

Myth: All disabled people are handicapped and/or crippled.

Fact: A disability means that a person may do something differently than a person without disabilities, but perhaps with the same result and with equal participation.

MELD SPECIAL

Family Relationships

Myth: Disability is a constantly frustrating tragedy.

Fact: Disability is an inconvenience. Each individual with special needs accommodates her situation differently.

Myth: People with disabilities have different goals than people without disabilities.

Fact: Like everyone else, people with disabilities vary in background, experience, education, temperament and values. It is impossible to differentiate people with and without disabilities in terms of their goals.

Myth: People with disabilities are happier being with "their own kind."

Fact: People with disabilities enjoy being integrated in all areas of public life, including schools, transportation, employment and social situations.



Anticipating and Dealing With Others' Reactions



Some parents report they more or less get used to people's reactions; others find it actually gets harder over time.

Sometimes it simply depends on the day or the situation.

A hurtful comment can throw parents off balance and make them feel as upset as they did during the period just after the child's condition was diagnosed. Feelings of anger, hurt, disappointment, isolation, and rejection may be recycled many times over the years.

If they have the energy, parents can try to reach out to people who appear uncomfortable around their child. Volunteering information is helpful. Parents almost inevitably become educators explaining the child's condition and needs to others. They may find they set the example or tone for how others interact and communicate with their child; people often find a way to be comfortable by observing and imitating the parents.

Many mothers and fathers report that the effort to educate family and friends is worth it. A man quoted in Robin Simons' After the Tears said, "My father . . . took it hard at first. But we talked a lot and he spent a lot of time with my son. Now his attitude is accepting and he is helpful and understanding." A mother describes herself as ". . . an ambassador for my kids. I need to teach other people about handicaps so they won't be ignorant, fearful and prejudiced. I need to do this with everybody because everybody needs to learn. But I especially need to do it with my friends and relatives because I need them on my side." Another mother believes "If I can educate others, it will eventually be helpful to me."

MELD SPECIAL

Family Relationships

Yet parents also report that there are times when dealing with awkward reactions is just too much of a hassle. They resent having to always be the ones who try to make others comfortable, having the burden of maintaining relationships rest with them and their child, especially when they are feeling vulnerable.

No parent should feel obligated to explain a child's condition simply because someone asks about it. However, if you're willing to respond, it can help to develop some automatic responses—very brief, simple ways to describe your child's condition—that won't depend on your emotions and energy level at the same time.

Sometimes just your presence and manner will be enlightening. For example, a mother described her disabled son's pleasure wheeling up and down the supermarket aisles in his wheelchair one day. An acquaintance kept spotting them as they shopped and she finally commented, "Wow, he's having a ball!" The boy's mother simply replied, "Sure!" and felt that perhaps the other woman's understanding had been deepened. When people make pitying or pessimistic comments about her child, another mother responds by automatically pointing out something positive, e.g., "Yes, but the doctors are really pleased about how she . . ."

While parents' actions can influence the way people perceive their child, this should not be interpreted to mean that they are responsible for others' behavior and attitudes; these are very much beyond parents' control.

MELD SPECIAL

Family Relationships

The following responses have helped some parents deal with encounters with strangers:

- When people stare, just smile in a friendly fashion without comment, or say "Hi."
- When someone comments on your child's limitations or difficulties, mention his abilities and strengths, for example, "He has a great smile, doesn't he?" or "He really loves reading and games."
- When a stranger asks a question, use general terms such as developmental delay, birth defect, or body chemistry.
- Turn strangers' questions aside by saying something like "I prefer not to discuss my children with people we don't know," or "I really don't feel comfortable talking about personal matters like this."
- Compose three to five statements you'd be willing to provide about the essential points of your child's condition. Write them down, practice with your family or friends, or repeat them to yourself until they become automatic.
- A "look" can be very effective. Practice a facial expression that conveys what you'd often like to say in particular situations, for example, "I'm simply not going to talk about this" or "Are you kidding? I'm not here to respond to you and your rudeness!"

Responding to Advice

Imagine what life would be like if no one gave advice unless they were asked to do so . . .

Advice is particularly difficult to cope with when parents are feeling vulnerable from the circumstances of raising a child with special needs. A chronic illness or disability is rarely a "black and white" situation. Uncertainty, worry and fatigue can make it difficult to maintain your confidence about whether you are doing what is best for your child. A parent who is already struggling with the doubt and tough decisions that are part of caring for a child with special needs can be overwhelmed when others try to impose their point of view or way of doing things. What mothers and fathers need and deserve is sympathy, encouragement, and a lot of credit for the job they are doing.

Advice can be acceptable or intolerable depending on who gives it. While it often seems to be a form of criticism, it can help to think of it in other ways. The need of advice givers is most often to confirm the value of their own experience and ideas. Suggestions have less to do with your actions than with the advice giver's need for affirmation and a desire to contribute something. Many people find that reminding themselves of this helps them maintain some detachment when they receive unwanted, unhelpful advice.

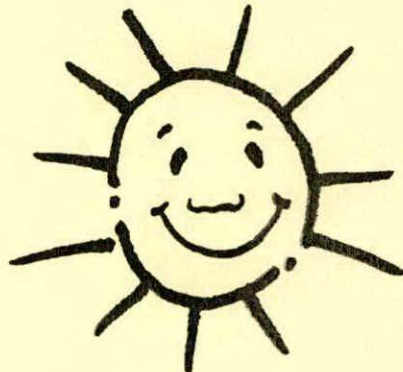
If you can, try to sift valuable suggestions from those you plan to discard. If you automatically reject everything, you might lose a "pearl." Remember that you are constantly receiving suggestions you choose not to use, for example from magazines, TV and books (including this one). Accept what fits for you and discard the rest.

MELD SPECIAL

Family Relationships

When they receive unwanted advice, some parents find it's worth trying to explain that while they need and appreciate the person's love and support, it is important for them to be in charge of their family.

When something is said that is helpful to you, give credit to the person. Being appreciative occasionally may allow people to forget the advice you didn't take. You may want to ask family members and friends for their opinions now and then. Invite an interested relative or friend to go with you to the doctor or school conference. Four ears are better than two, and you will have an informed companion to talk to.



MELD SPECIAL
Family Relationships

Family Gatherings

Even in the best circumstances, family gatherings can be a “mixed bag.” They can create a sense of connectedness, tradition, protection and renewal. There are special foods, family jokes, reminiscing, play, hugs and gifts. Family members usually know the very best about each other. But they can also know the worst, and family gatherings can uncover old conflicts and hurts as easily as they can old satisfactions and pride. What our parents, in-laws, and other relatives think can matter more to us than the opinions of other people, so it’s easy to be sensitive to what’s said or done at a family get-together.

The beginning of this chapter pointed out that people’s attitudes about a child’s disability or chronic illness determine their behavior. An extended family’s ability to draw the child with special needs into its activities, as well as to nurture his parents and siblings, will depend on who’s present at each gathering and how those individuals feel about the condition.

Some parents find get-togethers a haven for themselves and an opportunity for their child to feel unconditionally loved. Others approach them with dread, having experienced the awkwardness and anxiety their child’s presence arouses in relatives. As a way of protecting yourself and your child, you may want to ask yourself:

- Which people help me feel healthy, confident, and energized as a parent? Those are the ones I want to spend time with.

- What kinds of family contacts or occasions are comfortable, enjoyable, and least likely to generate problems? How can more of these be planned?

MELD SPECIAL

Family Relationships

Some awkward situations are probably inevitable. It can help to plan ways to respond in case one occurs at a family gathering. Considering the possibilities and preparing for them helps parents feel more in control. You may want to develop your “strategy” by imagining the scenes that concern you. Ask yourself:

- What’s the worst thing that could happen during this event?
- What can I do in advance to prevent it from happening?
- How can I handle things while we’re there to prevent it from happening?
- What can I be prepared to say or do if the situation gets uncomfortable, if “the worst” occurs?

Parents can help by explaining procedures or behaviors that appear to make others uneasy, such as respiratory difficulties, suctioning, eating routines, seizures, or the child’s method of moving or speaking. Many people panic and freeze when a problem occurs, for example when a child suddenly vomits or needs to be suctioned. It may never cross their minds that they could be of help as they sit by, desperate for the child’s mother or father to do something. Parents may want to ask relatives if they’d be willing to pitch in the next time something similar occurs; many people feel less distressed about a situation when they understand what is happening and learn ways to help.

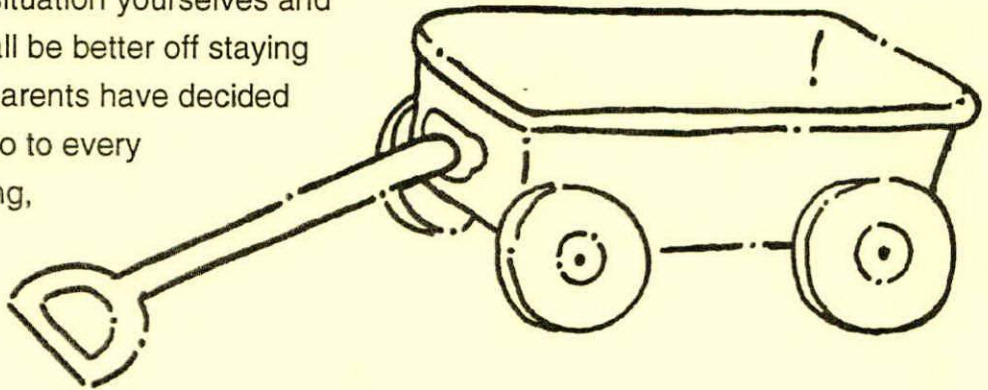
It may also help to suggest specific ways relatives can interact with your child. For example, suggesting a game she enjoys or demonstrating how to exercise her can give people ideas about how to spend time together comfortably.

MELD SPECIAL

Family Relationships

Every child should feel he is a valued member of his extended family. Even when relatives are uncomfortable about a special needs condition, or about particular aspects of the child's routine care or behavior, it's important that the child isn't removed or excluded from events that include children.

On the other hand, there may be times when you feel, for whatever reason, it's inappropriate or undesirable for your child to attend a family get-together. She may be having a bad day, be overtired, or seem uncomfortable about going out. Or you may simply not have the energy to deal with the situation yourselves and realize you'd all be better off staying home. Many parents have decided they needn't go to every family gathering, or that it's okay to get a babysitter.



When Do You Confront People About Behavior That Troubles You?

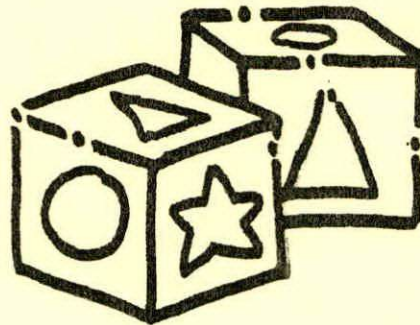
When parents feel angry or hurt about others' responses to their child, they may or may not feel comfortable confronting them about it. It's natural to let a fair amount of time go by before deciding to talk to someone about what's bothering you. Yet waiting can make a troubling situation worse; letting tension grow makes it harder to talk about a concern in a way that won't backfire.

There are many reasons parents avoid confronting this kind of problem:

- The person whose behavior concerns parents may be difficult to talk to, for example, defensive, sarcastic, patronizing, or generally unsympathetic.
- Confronting people risks hurting their feelings and many parents are reluctant to take this chance.
- They may be worried about sounding too aggressive or feeling out of control if they try to explain their feelings about a sensitive or emotional issue.
- They may fear the person they confront will turn against them.
- Talking about negative feelings is discouraged in some families. Hurt feelings are habitually nursed in silence. Emotional outbursts may be taboo. This kind of "family tradition" can make it threatening for anyone who considers trying to talk things over.

MELD SPECIAL
Family Relationships

Each individual must decide whether it's worth the risks involved in trying to change things in a relationship. When not confronting a problem means possibly giving up on the relationship and losing ties to someone important to you or your child, it can push you to take a chance. The guidelines for effective communication included in the "Parents, You Count Too!" chapter may be useful for thinking ways to approach family or friends about your concerns.



What Kinds of Support Can Others Offer?

Ask a roomful of people what support means to them and you'll no doubt receive a wide range of answers. In order to give and receive meaningful support, it's important to identify what it means to you and to those you care for.

Research by Betty Cooke and her colleagues summarizes five kinds of support parents reported receiving or wanting:

- **Emotional support** conveys the sense of being cared for and loved just as you are, however you may be feeling.
- **Esteem support** offers the feeling of being valued and respected for who and what you are, and what you do.
- **Network support** provides a sense of trust and security through belonging to a group to which you also have obligations.
- **Appraisal support** provides feedback about your actions, and suggestions for resolving difficulties.
- **Altruistic support** conveys the belief that you are worthwhile because of what you have done with and for others.

Any or all of these forms of support can be provided by extended family members, friends, or anyone who willingly extends himself to be involved in your life. If you are not receiving a form of support that is important to you, consider who you might turn to for it.

What Else Can Others Provide?

Raising children alone is extremely difficult. Raising children who are disabled or chronically ill alone is probably impossible. Most of all it's unnecessary. Every parent deserves and can benefit from the support and assistance of others. Yet it can be hard to accept help, and even harder to ask for it. It may help to remember that letting others support you is good for your child, and it is rewarding for the people who get involved.

While there are many things others can do to support your family, sometimes it's hard to know what to ask for. The following list was adapted from material by Reverend Gary Bodin who suggests ways others can strengthen parents' ability to cope and live in a healthy manner. When someone says, "Just let me know what I can do to help," you may want to share this list with them. It may give you both some ideas and help clarify their expectations and your own.

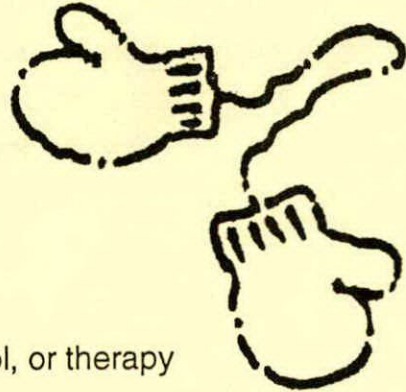
Consider whether it would be helpful for someone to:

- Provide a place and/or time for you to get away and be taken care of yourself for a while.
- Be a day brightener, a person who can make you feel better when life has gotten you down.
- Provide special treats or occasions.
- Babysit: any time, when parents work, for vacations, or for emergencies.
- Be companions to the children, sharing in their fun.

MELD SPECIAL
Family Relationships

Consider whether it would be helpful for someone to: (continued)

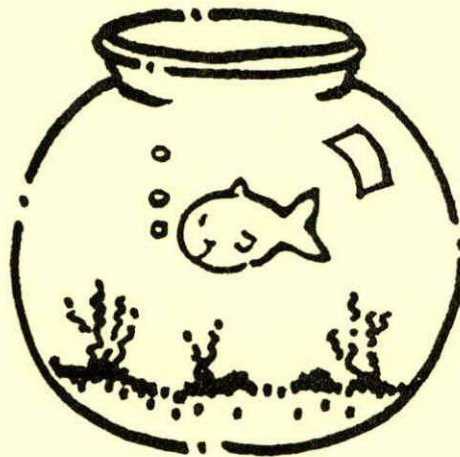
- Serve as emergency back-up when any kind of arrangement falls through.
- Become a source of wisdom about being a parent.
- Teach children skills: cooking, fishing, sewing, etc.
- Take vacation time to be with you and the children, or just the children.
- Provide food.
- Help with housecleaning and errands.
- Make and fix things for the children.
- Arrange family get-togethers.
- Provide rides to doctor appointments, school, or therapy
- Be a rocker, soother, comforter.
- Read children's stories.
- Help children discover nature.



MELD SPECIAL
Family Relationships

It may help others to hear you suggest:

- Be yourself. If you don't know what to say, say "I don't know what to say."
- Be silent. You needn't be a cheerleader. Just listening is often best.
- Show that you care with your time, your presence, a smile.
- Be warm. Don't be afraid of touch. Shake hands or hug.
- Be aware of the emotions that are stirred up during subsequent pregnancies. Talk together about fears and needs.
- Reminisce. Share memories of good times together.
- Be positive. Focus on what the child can do, the child's lovely qualities.



MELD SPECIAL
Family Relationships

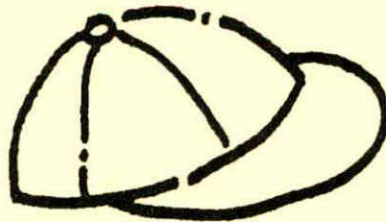
Conclusion

Relationships with family and friends can be simple and natural, or complicated and strained. This chapter addresses very personal issues and may not really get at what the situation is like for you and those you are close to. Carrying out the recommendations that have been included is not easy. Suggestions that sound simple or logical enough can actually be very difficult and even threatening to put into action.

You might try to change things about your relationships and feel your efforts are unsuccessful. You may develop a plan and then be too tired or occupied to carry it out. Based on past experience, you may feel these approaches aren't worth it, or that it's too late. Some parents find that certain relationships with family and friends simply can't be maintained or recovered.

Yet because the support of family and friends is hard to replace, most MELD Special parents report it's worth the time and effort to deal with problems in order to preserve their self confidence as well as the relationships they value.

While all families have ups and downs in their efforts to get along, a recommendation from Marilyn Segal's book, In Time and with Love, may suggest the wisest course toward the long term goal of maintaining strong ties: Give it all time . . . Children usually have a knack for winning friends.



MELD SPECIAL

Family Relationships

Resources:

Bierbauer, Elaine. "When Children Tease," The Exceptional Parent, May, 1987.

Ceglowski, Deb, et al. Parenting a Special Needs Child. Winona, MN: Winona County Maternal Child Health Task Force, 1987.

Clarke, Jean Illsley. Self-Esteem: A Family Affair. Minneapolis, MN: Winston Press, Inc., 1978.

Cooke, Betty D., Marilyn Martin Rossmann, Hamilton I. McCubbin, and Joan M. Patterson, "Examining the Definition and Assessment of Social Support: A Resource for Individuals and Families," Family Relations, 1988.

Downey, Pat. New Directions for Exceptional Parenting. Washington D.C.: Association for the Care of Children's Health.

Gilkerson, Linda. "A Fully Human Life," Family Resource Coalition Report, No. 2, 1988.

Kelso, Jill. "Nurturing a Special Child," The Exceptional Parent, November-December 1987, Vol. 17, No. 8.

Linn, Erin. I Know Just How You Feel: Avoiding the Clichés of Grief. Cary, IL: The Publisher's Mark, 1985.

Rasmussen, Marion. "Disability in the Family," Meeting Ground, November-December 1987. Golden Valley, MN: Courage Center.

Samuells, JoAnn. "Handling a Handicap," Baby Talk, February, 1985.

Segal, Marilyn. In Time and With Love.

Vadasy, Patricia F. "Grandparents of Children with Special Needs: Supports Especially for Grandparents," Children's Health Care, Summer 1987, Vol. 16, No. 1.

MELD SPECIAL
Family Relationships

Resources for Families:

Especially Grandparents newsletter, Advocates for Retarded Children of King County, 2230 Eighth Avenue, Seattle, WA 98121. \$8.00 per year.

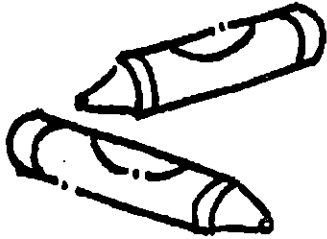
Grandparent Workshops, University of Washington Press, P.O. Box 50096, Seattle, WA 98145-0096. \$18.95 + \$1.50 postage/handling. Call toll-free, 1-800-441-4115.

“Let’s Play to Grow” kit of physical play activities for the child with special needs and his/her family. Joseph P. Kennedy, Jr. Foundation, 1701 K Street NW, Washington D.C. 20006.

Ilse, Sherokee. “What Family and Friends Can Do . . . after miscarriage, stillbirth or infant death.” Pregnancy and Infant Loss Center, 1415 E. Wayzata Blvd., Suite 22, Wayzata, MN 55391. Useful for adapting to help family and friends be supportive.

Ilse, Sherokee. “Grieving Grandparents . . . after miscarriage, stillbirth or infant death.” Pregnancy and Infant Loss Center, 1415 E. Wayzata Blvd., Suite 22, Wayzata, MN 55391. Useful for adapting to help family and friends be supportive.

MELD SPECIAL
Family Relationships



Learning Activities

You may want to set the tone for the meeting by having group members bring scrapbooks, pictures or posters of extended families. Display them as people arrive and encourage everyone to examine them before the meeting begins.

GETTING ACQUAINTED ACTIVITIES

I. Ask each parent to use one or two words to describe the relationship with their relatives they remember having as a child. Have them take a few minutes to explain.

II. Ask each parent to describe the strengths of his extended family.

ACTIVITIES related to the idea that families of children with special needs have relatives and friends who can be counted on for support, and those who drain their energy and confidence.

I. Individual writing and group discussion

Give everyone writing materials and ask them to make a list of their extended family members, grouping them into those who are supportive and helpful, and those who aren't. Have them take about ten minutes to identify and write what they think makes the difference. Then ask group members to discuss their conclusions.

MELD SPECIAL
Family Relationships

You might want to include the following questions in a follow up discussion:

- Have your relationships with family and friends changed since your child's special needs were diagnosed? Why might this be the case?
- Whose advice is welcome? Why?
- Whose advice is intolerable? Why?
- Is it harder for single parents to fend off unwanted advice? If so, why?
- How do/can we get support instead of unwanted advice?
- Are there times you withhold information from relatives? Why?

II. Discussions about support in general

A. Brainstorm what group members think of when they consider the word "support." What does it mean to them? What do they look for when they want support? Make a list of their answers on newsprint or a chalkboard.

Summarize people's comments and the general categories of support represented on the list, adding any thoughts of your own.

Emphasize the following points in a follow-up discussion:

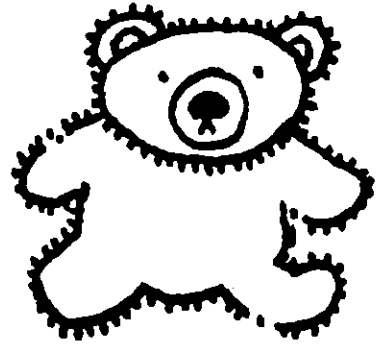
- Support means very different things to people.
- Whether or not a person considers something supportive is influenced by his temperament and experience.
- Being aware of our preferred style of receiving support can help us ask for what we need; understanding the preferred style of others can help us give appropriate support to others.
- It is important to avoid making assumptions about the kind of support others need, and to try instead to observe or ask about what they prefer.

MELD SPECIAL

Family Relationships

Use the following questions to generate discussion:

- How might you apply these ideas to your relationships with relatives and friends?
- How have you and your extended family and friends supported each other in the past? What do you wish was different about this? How might you go about making these changes?
- How can people find out how others like to receive support? How can they tell others what they themselves would like to receive?



B. Using handout (a) "Five Types of Social Support," ask group members to identify the kinds of support they receive from various extended family members or friends. Include the following questions in a follow up discussion:

- If there are specific types of support you would like but do not receive, who might you turn to?
- How can someone ask for support? What do you actually say to someone?
- How can MELD Special group members support each other? What kinds of support are you hoping the group will provide? How can we make sure we're aware of each others' need for support over time?

MELD SPECIAL
Family Relationships

C. As individuals or in small groups, have members write an answer to the following "letter" from a grandparent of a child with special needs:

Dear Ken and Sue:

Your Dad and I have talked of little else but our visit with you since our return. It was so good of you to have us. I hope it's not so long between visits next time.

We're wondering if you've thought of getting more special help for Timmy. He's such a handful for you. Do you ever think of switching doctors? I was reading in a magazine that medication can sometimes help kids with Timmy's condition. Maybe another doctor there is familiar with that kind of treatment.

I must admit we've been awake many nights worrying about Steven's attitude toward school. And his appearance, Sue! I know about kids and their fads, but do you think there's anything you could do about his hair? It's embarrassing sometimes, isn't it?

We don't mean to interfere. It's just that we're so concerned, and we're sure it's hard for you to keep up with everything. Remember to call us Sunday evening.

Love to you all,

Mother

MELD SPECIAL

Family Relationships

Activities related to the ideas that parents can develop:

- 1) realistic expectations of their child's and their own interactions with extended family and others,
- 2) comfortable and appropriate ways to explain their child's condition to others, or to avoid explaining it if they prefer.

I. Ask the group to recall comments others have made about their child's special needs. What have people said to them that has been helpful and unhelpful? Use a newsprint pad or chalkboard to record comments in two lists. The lists might include, or you might want to add, some of the following:

Helpful comments:

Tell me about it.

What was/is that like for you? for your child? for your family?

What did the doctor say?

How did your child react?

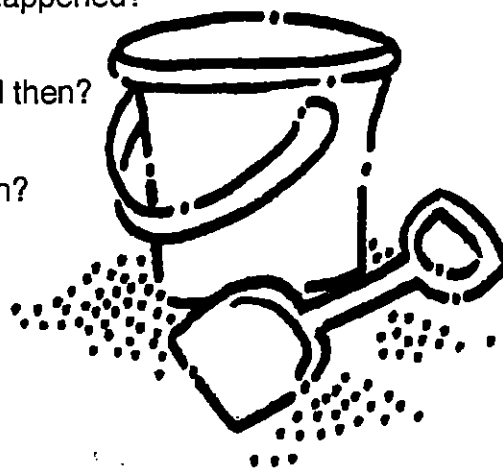
What did you think/how did you feel when that happened?

How can I/we help?

Would it help if I took care of your child now and then?

Would it help if I went with you to the doctor?

Would it help if I came over to visit now and then?



MELD SPECIAL
Family Relationships

Not helpful:

What happened to your child!?

It must be God's plan.

I know how you feel.

The baby of a friend of mine had an even worse problem.

Don't feel guilty.

It could be worse.

You'll have other healthy children.

Good heavens! How could this happen to a person like you?

You must be very special to have a child like this.

But she's such a good looking child, how could she possibly have a problem like that?

I just don't know how you manage!

I'm sure things will get better/turn out all right.

I feel so sorry for you and your family.

Ask members to describe how parents feel when they hear these comments. Have them suggest effective ways to respond to annoying or hurtful comments. (They may also want to discuss the responses they sometimes wish they had the nerve to give!)

MELD SPECIAL
Family Relationships

II. Ask group members to generate lists of behaviors they have found helpful and unhelpful. This is similar to the preceding activity except instead of comments, you are asking for things people have done, the ways they have approached the situation. Supportive behaviors might include:

- Asking parents how they feel, rather than presuming they know.
- Accepting parents' feelings and point of view rather than telling them how they should feel.
- Keeping in touch; being available.
- Not offering advice unless they've been asked for it.
- Just listening.
- Including the child with special needs in events and discussions.
- Conveying pleasure in the special needs child.
- Sending the child gifts, cards, and all the things received by children without disabilities.
- Celebrating the small and often delayed victories in development made by the child.

III. Small group discussion. Ask the group to exchange ideas about how parents might respond when relatives react to a child with special needs in the manner represented by the following quotes:

"I suffered for him — for what he might have been. I resented what his birth had done to my lovely daughter."

"We go to visit our relatives, and they don't talk to my retarded child. They'll talk to the rest of us, but they don't talk to her. We'll get in the car to go home, and she'll cry and ask, 'Why don't they ever talk to me?'"

"We were so thrilled this week when Jamie started sitting up. He's four years old and has been working on holding himself up for a long time. We immediately called my parents and their response was 'When is he going to start walking?'"

MELD SPECIAL
Family Relationships

IV. Large or small group discussion based on some or all of the following questions:

- What do I want from my relationships with family and friends?
- What are some of the disappointments or frustrations in these relationships?
- What can I say or do to help family and friends understand our situation and be supportive? What do I hope to accomplish by telling them how I feel?
- What's possible to change? How could I go about changing things? How do I feel about what can't be changed? Do I believe it's my fault?
- What do I say when I just don't feel like explaining my child's or my family's situation but I don't want to be rude?
- How can I help my children, both those with and without disabilities, learn to respond to insensitive questions and comments, and awkward situations?

V. Have group members compose a "birth announcement" that would describe:

- their child's situation, including problems, delays and strengths
- the family's needs
- requests for helpful interventions on the part of family and friends.

Have group members exchange their birth announcements. Encourage comments or questions about them.

MELD SPECIAL

Family Relationships

A follow-up discussion might include the following:

- Would these details still be useful for relatives and friends?
- Do you think your family and friends are aware of the things you included in your "birth announcement"?
- How have you conveyed this kind of information in the past?
- How might you do so now?

VI. Plan a family evening. Invite MELD Special members to bring relatives to a potluck supper or dessert. If families do not live nearby, or some group members prefer not to invite them, encourage people to invite friends.

You might plan an activity to help people get acquainted. For example, each person could bring a baby picture of himself. Put them up on a bulletin board and have people guess who's who. Or each family could create a poster or banner representing something about it.

VII. Panel discussion: Invite three or four parents of older children with disabilities or chronic illness to discuss their experiences dealing with relatives and friends. Include couples and single parents if possible.

Send each panelist a list of questions or issues you'd like them to address at the meeting. These can be generated from questions in the various learning activities or from material in the chapter. Even better, ask your group members to suggest specific issues they would like panelists to address.

Tell panelists in advance how much time each person will have to speak, and how much will be allotted to a question and answer session following the panel. This will help you guarantee that everyone has an accurate expectation of how the meeting will be conducted and their role in it.

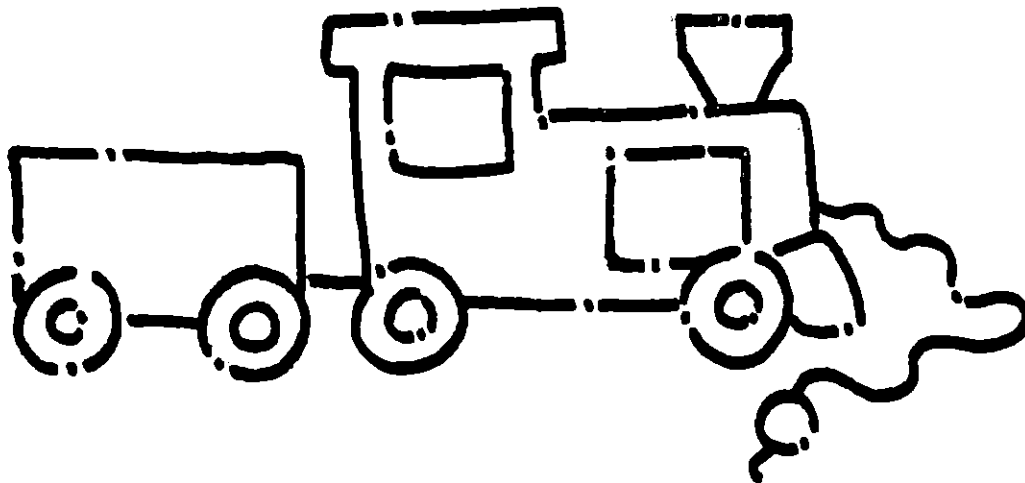
MELD SPECIAL
Family Relationships

VII. Your public library may be have one or more of the following films. Preview any you choose to use and develop questions or an activity to stimulate discussion of group members' reactions to the ideas presented.

"It's Harder for Patrick" Films, Inc., 733 Green Bay Road, Wilmette, IL 60901.

"James Is Our Brother," 1975. Time/Life Multimedia, 1271 Avenue of the Americas, New York, NY 10020.

"I'll Find a Way," National Film Board of Canada, 1977. Film Board of Canada, 16th floor, 1251 Avenue of the Americas, New York, NY 10020.



MELD SPECIAL

Family Relationships

Activities related to the idea that parents can generate a plan for handling awkward situations with extended family and others.

I. Large group discussion

A MELD Special mother realized that there are some disabilities she has difficulty dealing with, that make her uneasy. Acknowledging this helped her develop insight into others' reactions to her child's condition.

Ask group members to consider their feelings about disabilities or illnesses other than that of their child. Are there some conditions that make them feel particularly uneasy?

You may want to ask group members to find, read, and bring to this meeting a newspaper or magazine article, brochure, or other material on a disability or chronic illness other than their child's. Part of the discussion could address each person's impressions about the information, new insights, etc.

The point to raise with the group about this is that we all lack knowledge and have misconceptions about some conditions. This lack of understanding influences our reactions to individuals with these special needs. One role of MELD Special is to make us all more aware of and sensitive to the needs of people with disabilities and chronic illnesses. While the group focuses on the specific conditions of members' children, occasionally addressing others forces us to stand back a bit, and can give us deeper insight into our own situations.

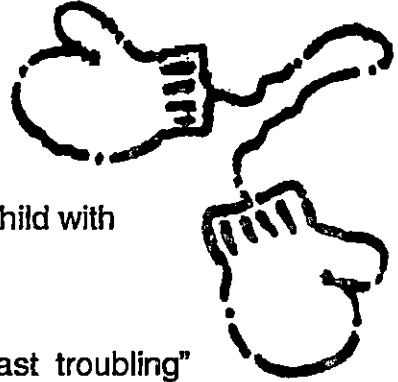
You might choose to use the following questions:

- What were your attitudes about special needs when you were growing up—in grade school, adolescence, young adulthood?

MELD SPECIAL
Family Relationships

Questions (continued):

- Did your attitudes change over time? If so, how?
- How have your attitudes changed since having a child with special needs?
- What do you consider the “most troubling” and “least troubling” disabilities or chronic illnesses? Why?
- What would be the most comfortable way for you to receive information about someone else’s disability?



II. Large group discussions

A. Ask parents to describe experiences that have been awkward or painful because of relatives' or friends' reactions to their child with special needs. Have the group exchange ideas about effective ways to respond to such incidents.

B. Ask each person to identify the positive characteristics they have observed in the individual children in the group. Discuss ways parents can point out these qualities when answering people's questions about their child—rather than focusing on the limitations imposed by the disability or chronic illness.

C. Ask each parent to give one general statement they could use to explain their child's situation. Then have them list two or three essential points about their child's condition they would include in a somewhat longer explanation to a friend. Set up simulated encounters with people and ask group members to practice offering the explanations they have devised.

MELD SPECIAL
Family Relationships

III. Discuss the following scenarios, or have small groups role play ways to handle these incidents.

A dozen people are gathered around the dinner table at a get-together of family and/or friends. One of the children begins to do the following, which is characteristic of her special needs condition:

1) unusual physical or verbal behavior that is very noticeable but not destructive (you may want to specify what this is),

OR

2) vomiting or lack of control over some secretions.

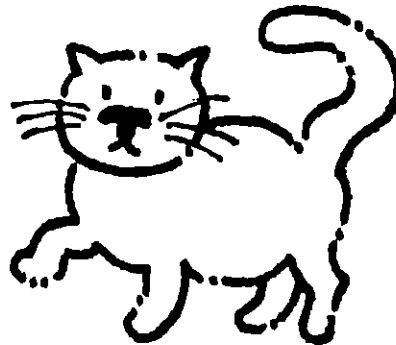
- What is your family's or friends' response?
- What is your response?

Your child has a facial disfigurement due to a cleft lip and palate. While in the grocery store, a four-year-old in the next line says in a loud voice, "Mommy, look at that girl. She looks so weird."

- What do you say?
- What does the other mother say?

When your child was born, only your parents visited you in the hospital. In addition to not visiting, few of your friends called. Feeling hurt, you decide to call a friend and ask her why.

- What do you say?
- What is her response?



MELD SPECIAL
Family Relationships

For each of the previous situations, discuss:

- How the parents might feel
- What the child's reactions might be (you may want to specify the child's age)
- Effective ways to plan and organize gatherings including children with special needs
- Ways to help children with special needs feel truly included in the family
- The kind of advice parents typically receive in such a situation. What kind of advice is welcome and from whom? How can unwanted advice be handled?

IV. Large or small group discussion and role plays

Ask group members to generate ideas about how to respond to the following situations.

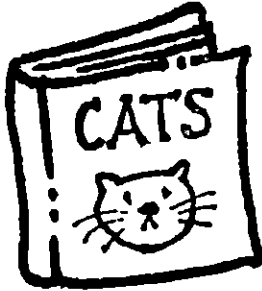
- Grandparents offer advice that conflicts with your sense of what is right for your child and family.
- A friendly babysitter insists your child eat foods you know or suspect are not good for him.
- Relatives have gradually disappeared from your life. They have not written or called in many months.
- At a family reunion, an aunt pays attention to only one of your children—the non-disabled child—and acts as if he is the only child in the family.
- A neighbor says, "Your son isn't talking because you don't talk to him enough. Leave him with me for a week and I'll have him talking."

The group might set up "skits" based on these or other situations, giving whoever is willing the chance to practice responding.

MELD SPECIAL

Family Relationships

Activities that encourage developing a strong sense of family tradition.



I. Family traditions, rituals, and shared interests are important to maintaining a sense of cohesiveness. Traditions need not be limited to elaborate holiday events. Simple daily routines can become traditions, e.g., baking on weekends, bedtime rituals, a way of celebrating a change of seasons, weekly visits with relatives, a few minutes of cuddling and reviewing the day when a parent comes home from work, words or phrases that become part of a family's "secret language." These informal rituals have tremendous meaning for children, nurturing a sense of continuity and closeness in the family.

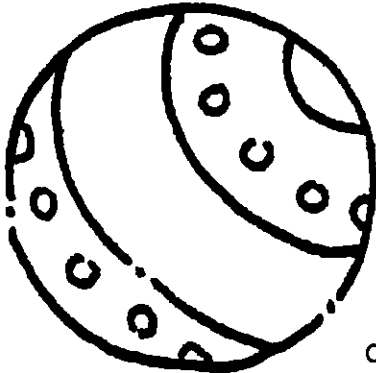
Allow a few minutes for each group member to make a list of activities, rituals, and traditions they enjoy(ed) in their own family and with relatives. Then ask each parent to describe one of these. Encourage group members to borrow the ideas others describe.

Where applicable, discuss how holiday or everyday traditions might be adapted for a child's special needs condition. For example, parents of a blind child emphasize Christmas traditions that appeal to senses other than sight: decorating the house with quantities of evergreen and bells, burning scented candles, cuddling on the couch with a fuzzy "Christmas blanket," and special foods and beverages.

MELD SPECIAL
Family Relationships

II. Activities for parents to do at home (you may or may not choose to relate this to a group meeting).

A. Set aside a time with your family to create family or individual scrapbooks. If possible, gather at least one year's worth of mementos for an album depicting the year: tickets, programs, school papers, balloons, photographs, clippings, drawings, notes, letters, etc.



B. As part of a family gathering, ask each person to bring something from or representing a day s/he will long remember. Ask everyone to talk about the object and what that day meant to them. The memento might be a newspaper clipping, phone message, photograph, household item or decorative object, piece of clothing, etc.

Chapter 3

Handouts

**Family
Relationships**

FIVE TYPES OF SOCIAL SUPPORT

Emotional Support: you are cared for and loved as a person.

“She tells me she loves me and appreciates me and the things that I do for her . . .she just loves me for being me.”

Esteem Support: you are valued for who and what you are and what you do.

“I overhear his comments to others, and out of our conversations together I definitely get the feeling he feels I do a good job as a mother.”

Network Support: you receive a sense of trust for belonging to a group to which you also have obligations.

“There is a lot of give and take here because we can all share our feelings and concerns. What I contribute is important.”

Appraisal Support: you get feedback about your actions and suggestions for resolving difficulties.

“It’s nice to go outside to a greater circle of people and test your feelings and methods and values and learn from that. You get reinforcement for what you’re doing right.”

Altruistic Support: you believe you are worthwhile because of what you have done with and for others.

“I like to repay some of the kindness they’ve shown me. It will make me feel good to be able to do that.”

—from Betty Cooke, et al. “Examining the Definition and Assessment of Social Support: A Resource for Individuals and Families”

A Fully Human Life



by Linda Gilkerson

Recently, I came across a newspaper article about Steven Hawking, the well-known astrophysicist who has ALS, or Lou Gehrig's disease. He is severely disabled. Physically, that is. He commented that he was lucky to have chosen a career that is primarily mental work, that he had a wonderfully supportive wife and family, and that his colleagues have been unfailingly helpful. "Fortunately," he said, "my disability hasn't been a serious handicap."

My guess is that, at some point in our lives, each of us has wondered about what it means to be disabled. Maybe we have a friend who had polio, or a neighbor who has a child with a hearing loss, or a high school classmate who was injured in Vietnam, or a cousin who has cerebral palsy, or an officemate whose new baby was born with spina bifida.

Perhaps we have noticed the feelings that come up for us when we are with someone with a disability - when we walk past a woman putting her wheelchair in the backseat of her car, when we enter an elevator where several deaf adults are involved in a sign-language conversation, when we watch the Special Olympics on TV, or when we check out at the corner market and the owner's son who has Down's Syndrome carries out our bags.

Because we live in a society that has rigid standards for appearance and performance and that places a high value on independence, it is hard for us to imagine that the lives of persons with disabilities can be full and satisfying. In fact, in the literature on family adjustment to a child with disabilities, the most common framework for disability is that of a tragic event. Is it possible that there are other ways to think about what a disability means to an individual, to his or her family, and to society at large?

Let's start by considering the difference in meaning between the words disability and handicap. Traditionally, disability refers to actual diagnosed medical condition, while handicap refers to the extent to which it impairs someone's functioning.

The degree to which a disability handicaps an individual depends on many factors. Hill (1949) provides a way to understand a crisis that is very helpful in explaining how the same disability can affect people in such different ways. He calls the model the ABCX Model. In this framework, A is the stressor event, B is the resources that an individual/family have to bring to bear on the crisis, C is the personal meaning that the individual/family gives to the event, and X is the resulting level of crisis. Let's use Steven Hawking's experience to see how this model applies.

A, the stressor, event is ALS disease. Among the resources (B) he has to bring to bear on the situation are strong support from his family and his colleagues, the type of work he does, and his previous accomplishments and stature in the field. The personal meaning he gives the event (C) is, to paraphrase his wife, "Steven doesn't give in to his disability and we don't give in to him." In other words, his interpretation of his condition is that it is one that can be handled. The resulting

level of crisis (X) for this individual with ALS disease is mediated by the considerable resources he has, and by the personal meaning that he attributes to the disease ("I can handle this"). Another individual with the same condition who has fewer resources and/or who views the disability in a different way would have a very different outcome.

It is surprising for us to realize how influential the meaning that an individual gives to their disability is to their ultimate functioning in the world. In fact, the rehabilitation literature suggests that the personal meaning assigned is the most powerful predictor of long-term adjustment to disability, more powerful even than the type of disability one has or the severity of the condition. Thus, how an individual feels about him/herself is one of the most important aspects in his/her adjustment to disability.

In looking at our own beliefs about disability, what has been our contact with persons who have physical or mental differences? What feelings do these experiences evoke in us? Can we learn to separate how we feel about a disability from the individual who has the condition? Are we willing to re-evaluate our views in the light of what persons with disabilities have to teach us?

"The deaf are not ready yet to function in the hearing world" are words that forever changed Gallaudet College and caused a whole nation to re-examine its beliefs about persons with hearing impairments. Intuitively, all of us -lay persons and professionals in the field- understood the depth of the students' feelings and the correctness of their position. Perhaps it is the hearing world that has not been ready to live with persons who are different from ourselves. Are we ready to listen?

Adults with disabilities often say it is the attitudinal, rather than the architectural barriers that are the the hardest to overcome. Now that P.L. 99-457 greatly expands the possibility of services for young disabled children and their families, it's time to take the next step: to re-examine our views of disability, to tackle the attitudinal barriers, and to develop a framework that empowers families to love their children unconditionally, and enables their children to reach their fullest potential.

Children can learn to live with a disability. But they cannot live well without the conviction that their parents find them utterly loveable.... If the parents, knowing about his (the child's) defect love him now, he can believe that others will love him in the

future. With this conviction, he can live well today and have faith about the years to come.

(Bettelheim, 1972)

What framework would empower children and families to have the conviction Bettelheim speaks of? I posed this question to my friend Marsha Saxton, a counselor of persons with disabilities, an author (1987) about women's issues and disability, and an adult with a physical handicap. She said that such a new view would acknowledge that disability involves a loss of some capacity, that it is usually accompanied by some objective hardships, and that it is an equally valid, fully human lifestyle.

We know that a child's self-esteem develops both from within -the child's own sense of competence- and from without -the approval he receives from others. Because cultural beliefs affect how families feel, and how families feel affects children, we are compelled to look again at society's beliefs about disability -to look again within ourselves.

Gilkerson, Linda. "A Fully Human Life", Family Resource Coalition Report, 1988 No. 2, pg. 3.

When Children Tease

Children with disabilities can be confronted with thoughtless attitudes and remarks. The author describes how to help the child deal with these situations as well as how to help change the attitudes of the neighborhood.

by Elaine Bierbauer

As I was getting dinner late one Sunday afternoon, my twenty-year-old son, Gary, who has a severe learning disability, approached me.

"When I was riding my bike this afternoon, those little kids on the next block said, 'There goes that retarded kid,' " he said.

"That was cruel, Gary, but they're only children," I said. "They don't know any better. Besides, you aren't retarded. You know that. If you know where they live, why don't you go and talk to their parents?"

He walked out of the kitchen only to return a short while later. "I'm still angry about what those kids said. I'd like to go up there and beat them."

"I don't blame you for being angry. I'm angry too, but beating them up would only get you into trouble. Why don't you go out in the garage and punch your punching bag for awhile? Make believe it's those kids you're punching, and yell at them. Tell them off. That may make you feel better, and it won't do anyone any harm." He left again, without taking my advice.

Soon he was back. "I sorta feel like crying at what they said."

Parents must learn to ...
protect their disabled
children from thoughtless
cruelty and discrimination

"Go ahead and cry if you want to," I said, knowing that he probably wouldn't. He seldom does. "I feel like crying, too. It makes me so mad."

"Now I feel like I don't want to go out anymore."

My reply came hard. "Because you think people are going to look at you and think you're retarded?"

He nodded.

I ignored the hurt and bewilderment in his beautiful, hazel eyes. "Listen, son," I said. "There are always going to be people out there who will say cruel things to hurt you. You know that you aren't retarded, but even if you were, it wouldn't make any difference. Some people just can't cope with the fact that other people look or act or think differently from the way they do. Why do you think that some white kids say cruel things to Black or Chicano kids? It's because they think these kids are different somehow, and they're scared of anyone whom they see as different from them. These kids think you're different because you have a disability.

"You're lucky, Gary. You have a family and friends who love you. We don't see you as different, and even if we did, we wouldn't care. We'd still love you because you're you."

Maintaining a Balance

When he was younger, I would have grabbed my coat, tore out of the house, rounded up those kids and marched them home to their parents. I would have wept, raved and ranted, then tried to soft pedal the whole incident in an effort to alleviate my son's hurt and anger. But Gary is older now, and he's certain to be faced with similar situations from time to time. My job is to help him learn how to deal with them safely and realistically. I, too, am older. I won't always be around to shield him from the hurts and to protect him from the consequences of unrestrained anger on his part.

Parents must learn to maintain an excruciatingly fine balance in their efforts to protect their disabled children from thoughtless cruelty and discrimination, while at the same time trying to teach their children to deal with them safely and effectively. Overprotection and overreaction, while understandable, only compound the child's problems and solve nothing.

I know that he's different, and he knows it, too. I cannot deny the fact to myself or to him. Neither can I permit him to deny it to himself. We both must face it, accept it, deal with it, and live with it. When I'm occasionally forced to remind him that he does have a disability, he says, "But I don't have one now."

"Yes you do, Gary," I gently insist. "You know that." Saying it doesn't come easy, but it has to be said.

Practical Suggestions

Parents, teachers and youth leaders who have a disabled child on their block, in their classroom or in their youth activity group can help foster understanding, tolerance and compassion by being open



Elaine Bierbauer and her son Gary

about the nature of the disability. Adults need to be alert to cruel words and deeds directed at the disabled child, and to act promptly to put an end to them. By the same token, inappropriate behavior or acts of cruelty perpetrated by a disabled child should not be tolerated either.

Parents of disabled children need to talk to the parents of children on their block once their disabled child is old enough to play outside. Most adults have little experience in living with children with disabilities. They may need help in telling their own children what behavior is appropriate.

Parents of children with disabilities should give other parents, and older children as well, information about their child's disability and the way in which he functions, especially in relation to other children. They should encourage other parents to come to them if confronted with a problem and assure them they will try to deal with it calmly and rationally. They should make it clear that this is how they intend to act and that they hope to be treated in the same fashion in return.

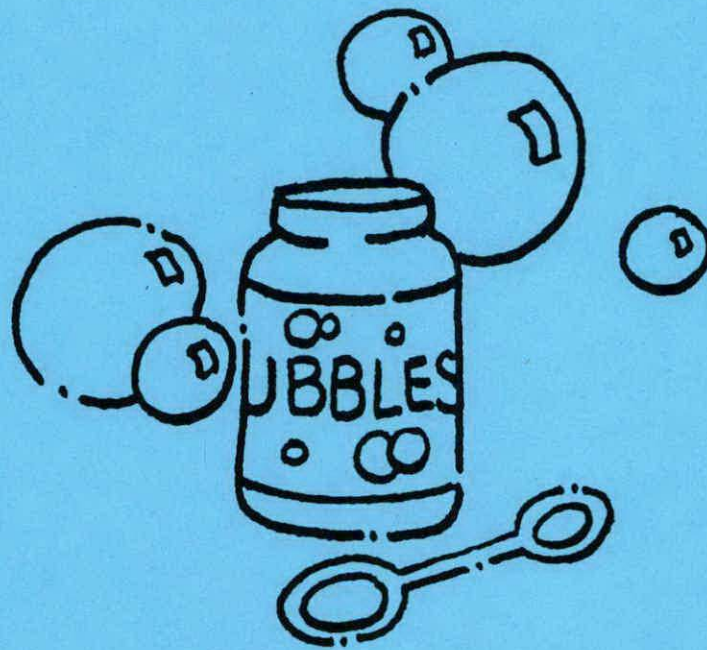
Simply teaching one's children not to stare at or laugh at a child who is "different" and not to call another person retarded (whether he is or isn't) would make life less painful for the disabled child and his family.

Ideas for Support From Family and Friends for Families of Children With Disabilities and Illnesses

1. Provide a place/time for you to go to get away and be taken care of for awhile.
2. Be a day brightener, a person who can make you feel better when family life has gotten you down.
3. Provide special treats, often or occasionally.
4. Babysit, anytime, for vacations, only for emergencies, or never.
5. Act as companions to children, sharing in their fun.
6. Be substitute parents, when parents work or when they're away.
7. Offer to be emergency back-up, occasionally or frequently.
8. Become a source of wisdom about being a parent.
9. Teach children skills (e.g. cooking, fishing, etc.)
10. Take their vacation time to be with you and the children, or just the children.
11. Be a cook, baker of nourishing and healthy treats.
12. Provide a source of financial help.
13. Make and fix things for children.
14. Arrange family get-togethers.
15. Provide a ride to a doctor's appointment, school, or therapy.
16. Be a rocker, soother, comforter.
17. Read stories to children.
18. Help children discover nature.
19. Be yourself. If you don't know what to say, say "I don't know what to say."
20. Be silent. You need not be a cheerleader. Sometimes just listening is the best.
21. Be supportive. Understand and show that you care with your time, with a hug, with a smile.
22. Be warm. Don't be afraid of touch. Shake hands or hug.
23. Bring over a casserole.
24. Clean the house.
25. Be aware of subsequent pregnancies. Talk together about fears and needs.
26. Be reminiscent. Share memories of good times together.
27. Be positive. Focus on what the child can do! Comment: What a nice smile!

Chapter 4

Stress



MELD SPECIAL

Stress

Stress

Table of Contents	Pages
I. Introduction For Facilitators	3-8
A. Main Ideas	4
B. MELD Biases	5
C. Facilitator Focus	6
D. Group Issues and Tips	7-8
II. Content For Facilitators.....	9-37
A. Some Sources of Stress	11-12
B. What Influences the Way We Cope	13
C. Coping: How to Begin	14-15
D. The Importance of a Support Network	16-17
E. Ineffective Coping Techniques	18
F. Specific Strategies for Reducing Stress	19-31
G. Family Members Cope With Stress Differently	32-33
H. Conclusion: Viewing Life Through Crisis-Colored Glasses?	35-37
III. Resources	39-40
IV. Learning Activities	41-56
V. Handouts	a-d
A. Sometimes I'm Tired	a
B. Are You Burning Out?	b
C. Meeting Parental Needs A Never-Ending Dilemma	c
D. "You Will Grow Because of This"	d

Introduction for Facilitators

Stress is a topic that comes up again and again in MELD Special groups. Discussions vary in focus and intensity depending on which of the many sources of stress parents identify, e.g., recurring feelings of grief, negotiating an educational plan with an understaffed school system, too many phone calls to the doctor, too few hours in a day . . . stress turns up as part of many topics.



This chapter is designed to help parents identify sources of stress in their lives and maintain effective ways to cope with them. It suggests coping techniques that are effective in a wide range of situations. Its goal is to equip parents with a process for dealing with whatever difficulties they face, now and in the future. Because the information in this chapter can supplement facilitators' preparation for meetings on many other topics, they may find themselves returning to it frequently over time.

Main Ideas

- Chronic stress can jeopardize parents' health and well being, as well as that of their family.
- Much of the stress experienced by parents of children with special needs is due to a sense of not having sufficient control over their lives.
- An event may not necessarily be stressful in and of itself. It is generally how a person interprets a situation that determines whether it is stressful.
- Individuals differ in what they consider stressful and in the way they cope with difficulty.
- People do not always recognize when they are experiencing excessive levels of stress.
- Effective coping techniques can be learned.
- An adequate support network is a critical factor in a person's ability to cope with stress.
- When individual differences in coping styles are misunderstood, they can strain personal relationships.

MELD Biases

- Parents have a responsibility to maintain or learn ways to effectively manage stress.
- There is no one right way to cope with stress.
- Having a supportive atmosphere in which to discuss stress can help prevent some of its negative effects.

Facilitator Focus

As you read this material, consider the following questions.

- What creates stress for you?
- How do you deal with stress?
- How has the way you cope with stressful situations changed over time, particularly since your child's special needs were diagnosed? What accounts for these changes?
- What situations are still difficult for you to cope with? What do you feel might help you handle them more effectively?
- If you feel group members are "making the same mistakes" you once did, how will you resist the temptation to offer advice and try to rescue them?
- How will you support parents who are struggling with issues you feel they shouldn't be so concerned about? Or people who accept things you believe they should try to change?
- How will you encourage group members to accept and support the very different ways parents perceive things, for example the fact that what one person finds extremely stressful is no more than annoying to another?

Group Issues and Tips

All stress is created equal. Some MELD Special parents report they are sometimes reluctant to discuss their problems if they don't seem as severe as those of other group members. It is important for facilitators to reinforce the fact that everyone's stress is legitimate and understandable. Each MELD Special family is dealing with a unique set of issues: their children have diverse conditions of varying severity, individuals differ in what they consider stressful, and each parent is in a different stage in adjusting to their child's special needs.



It is important for facilitators to draw out all members' concerns and to acknowledge what each is going through. Everyone's troubles are real; no one has to earn sympathy.

Because MELD Special participants represent a wide range of special needs situations, a critical task for facilitators is to continually point out what group members have in common. Emphasize the general issues that apply to everyone: that every parent experiences difficulty and there are usually steps that can improve or resolve stressful situations. By acknowledging that everyone is dealing with similar basic issues, facilitators encourage a supportive group atmosphere in which parents identify with each other despite their differences.

MELD SPECIAL

Coping With Stress

Prevent group members from offering unsolicited advice. As parents describe situations that create stress for them, it is important for facilitators to prevent group members from trying to solve each others' problems by offering unasked-for advice. One family's solutions may not work for another. While people mean well in these situations, advice should only be offered if a parent requests it. A primary goal of these discussions is to encourage the use of problem solving skills that enable parents to discover the coping techniques that are appropriate for them.

Use facts to get at feelings. Facilitators report that group members sometimes have difficulty identifying or describing their reactions to stress. It may help to focus discussions first on the practical or concrete aspects of a situation, and slowly move to how those circumstances make parents feel. For example, if parents are concerned about their child's growth and a considerable amount of their attention is given to maintaining a high calorie intake, first discuss the facts of the situation: ask the parent to describe how they handle it and how things are going. Then move to asking about the emotions that accompany this stressful process, e.g., "How does it feel for you when your daughter gains only two ounces in a month?" or "What is it like to go in for your son's check-up when you know there's been very little weight gain?"

Convey your concerns to your Site Coordinator. Listen carefully for clues that a parent may be unable to safely come to terms with his child's condition or the demands of caring for him. Listen to your gut and talk to your Site Coordinator if you sense that:

- A parent feels out of control.
- A parent lashes out at the child when under stress.
- There is emotional distance between the parent and child.

Content For Facilitators

Few parents reach an emotional promised land; most have good days and bad days. They solve one set of problems only to uncover another. Insight comes without blotting out confusion and regret.

Helen Featherstone

No one lives a stress free existence, yet the level of stress experienced by families with chronically ill or disabled children is certainly higher than average. In order to meet the extraordinary demands on their time, energy, and emotions, mothers and fathers of children with special needs must be able to cope with the strain that is an inevitable part of their parenthood. Their sense of well being is essential not only for themselves, but for their entire family.

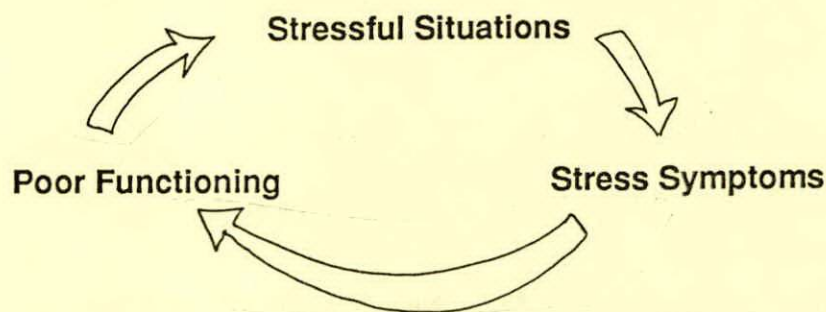
Some stress can be constructive, motivating a person to solve problems and make changes for the better. But stress can also be destructive, causing a person to feel overwhelmed and unable to see a way out of a difficult situation.

Other chapters address many of the sources of stress for parents, among them the chronic sorrow of having a child with special needs, negative social attitudes toward illness and disability, and strain on marriages and other close relationships. When these factors are combined with the demands of everyday life and a child's special care, it is easy to understand why many parents have difficulty turning their attention inward and giving priority to their own well being.

Unfortunately, chronically high levels of stress can create a cycle that is difficult to break. Discouragement and physical symptoms like headaches and lack of energy create even more stress by impairing parents' ability to function.

MELD SPECIAL

Coping With Stress



Parents of children with special needs have a responsibility to cope with and reduce stress, to solve problems, and to slowly—sometimes painfully slowly—bring pleasure back into their lives. While parents cannot avoid grief and anxiety, children need mothers and fathers who do not feel continually overwhelmed. The cost of being consumed by stress is too great for the entire family.

A MELD Special father described how a pediatrician's comment transformed his outlook. While discussing his feelings about life with his chronically ill child, the father said, "The worst thing that could happen would be if my daughter died." The pediatrician responded, "No, the worst thing would be if you, her parents, died emotionally and psychologically, and if your marriage died." This thought motivated him to begin to come to terms with his fears, and to cope in constructive ways with the stress caused by his daughter's condition.

As Helen Featherstone suggests in the quote above, stressful circumstances are never eliminated in families with special needs children. And yet again and again, parents discover effective ways to handle problems and to maintain healthy family lives in spite of recurrent difficulties.

This chapter is intended to help you:

- identify sources of stress in your life
- recognize how you respond to stress, and
- maintain positive ways to cope with it.

Some Sources of Stress

Many MELD Special parents feel much of their stress is due to not having sufficient control over their lives. The need to be continually “on call” to their child’s special needs can make parents feel passive and unable to plan on a daily or long term basis. While parents eventually discover the things over which they have some control, a child’s special needs inevitably impose limits on the family’s activities. Accepting their powerlessness to change things is an ongoing struggle for many mothers and fathers.

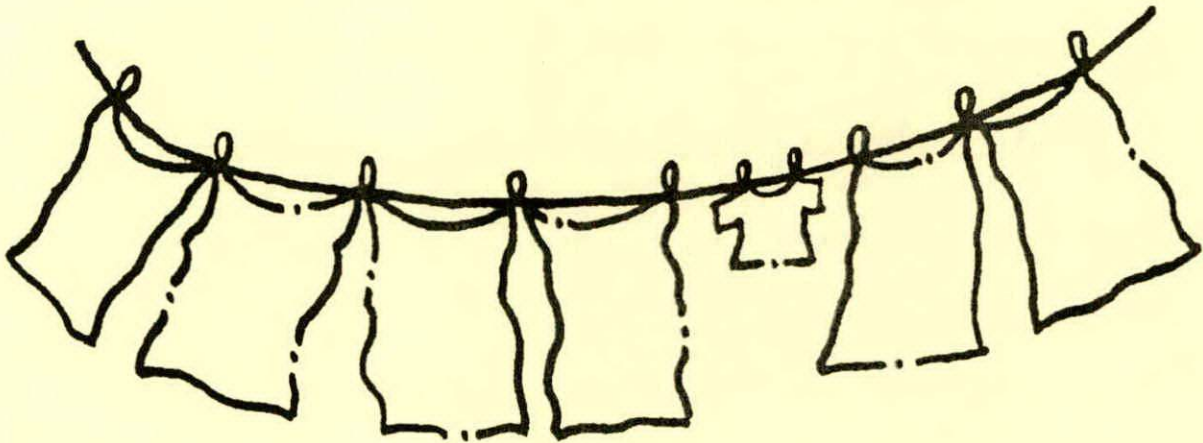
In addition to a lack of control, other sources of stress for parents include:

- ongoing feelings of grief over their child’s condition
- fear for the child’s short and long term well being, the unpredictability of the child’s condition
- demanding physical care and supervision of child
- complications of child’s condition, lack of progress in growth and development
- juggling household and family responsibilities with jobs and other outside commitments
- lack of time for marriage and other relationships, and for self
- financial burdens
- others’ insensitive reactions to child’s special needs

MELD SPECIAL
Coping With Stress

Other sources of stress for parents include (continued):

- complicated or unresponsive social service, health care, or educational systems
- intrusion of professionals in family life causing a sense of lost authority as a parent, of being dependent on professionals in order to manage
- problems in other areas of their lives that make the situation worse.

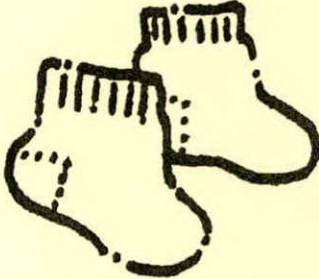


What Influences the Way We Cope?

An event may not necessarily be stressful *in and of itself*; it is generally how a person interprets a situation that determines whether it is troubling. Individuals differ in what they consider stressful and in the way they approach difficult situations. A parent's reactions and coping behavior are influenced by many factors:

- temperament
- stage of grieving or adjustment to child's condition
- prior experiences with stress and the coping skills developed in those situations
- beliefs and values that influence reactions to stressful events
- degree of family closeness
- adequacy of support systems providing information, understanding, encouragement, and help
- problem solving skills
- level of knowledge about the child's illness or disability
- existence of other problems
- parent's physical and mental health

Recognizing the role these factors play in their response to stress can help parents understand their behavior, and perhaps that of those around them. Knowing what impairs their ability to cope may help parents avoid those obstacles that are within their control.



Coping: How To Begin

Grant me the courage to change what I can,
the serenity to accept what I can't, and the
wisdom to know the difference.

Recognizing when you need to reduce feelings of stress is a key survival skill. Once you have acknowledged that stress is getting the better of you, consider ways to improve the situation and select the approach that seems best at the time.

Many factors determine which coping techniques are appropriate for you, among them your stage of adjustment to your child's condition, the other things going on in your life, and how you are feeling physically and emotionally. Only you can decide if an approach fits for you. Other people may suggest ways to cope, yet techniques that help one person don't necessarily work for another. Advice may or may not be suited to what you are ready, able, and willing to do at the time.

MELD SPECIAL

Coping With Stress

In her book, Loving Rachel: A Family's Journey from Grief, Jane Bernstein describes the pressure she felt when others tried to influence the way she coped with her daughter's disabilities:

"Why am I being so negative, my mother asks. Why won't I look at the good side? The exam showed no deficits, [my husband] says. Can't I believe that instead? Take one day at a time, [my friend] tells me. My mothers says, Take one day at a time. Look, you've just got to take one day at a time, says [my husband]. An acquaintance I meet in town pats my shoulder and offers her sage advice. Take one day at a time. Thank you. I appreciate your concern. I promise I'll let you know if there's anything you can do . . . WAIT! — I've just thought of something. You take one goddamn day because I simply cannot do it. . . . it's my baby, her life, her future. . . . stop telling me to take one goddamn day at a time."

In thinking about ways to relieve stress, consider how you've coped with problems in the past. While no other situation is comparable to having a chronically ill or disabled child, past experience may offer clues about ways to deal with the difficulties facing you now. You have strengths that have worked in other situations; you can call on those strengths now.

Recall difficult experiences that occurred at any time in your life. Which do you feel you handled effectively? What coping techniques worked well for you? How might you draw on those methods now, even though the circumstances are very different? Keep these techniques in mind along with the successful approaches you are already using to deal with your child's special needs. As you face difficult situations, even those that seem to be getting the better of you, remind yourself that you have managed stress in the past and draw on that experience.

The Importance of a Support Network

Perhaps the most critical influence on a person's coping ability is the level of support available to him, support in the form of sympathetic listeners, companionship, practical assistance, and information. Chapter 3, "I'm Only Trying to Help!" addresses the range of support others can offer, as well as ways parents might ask for it.

As you consider the way you handle stress, ask yourself:

- Who do I currently turn to for support?
- What kinds of things do I receive it for?
- What other forms of support would I like to have? Who could I turn to for these?
- Do I feel it is okay to need support and actively seek it, or does it make me feel needy and incompetent?
- Do I believe others are willing to support me?

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Coping With Stress

Many parents report they don't have a single source of support, but one that is made up of many *individuals and resources*, each offering something different. In addition to *family and friends*, a good support system can include health care and social service *professionals*, and the staff at a child's school or day program. If any of these individuals is, or seems to be, sympathetic and easy to talk to, you might turn to them for support on a regular basis. Many professionals welcome the opportunity to offer this kind of assistance and consider it one of the most valuable and rewarding aspects of their work. If no one comes to mind, you might ask others to recommend people with the qualities or experience you are looking for.

It can take time and persistence to find truly supportive people. Sometimes they appear where you least expect them. One mother said she learned that "You get support where you get support. If someone is helpful and can listen, I'll go back to that person again and again when I need encouragement."

Ineffective Coping Techniques

People sometimes try to cope with stress in ways that ultimately prove to be ineffective or even destructive. Unsuccessful methods include:

- trying to put worries out of your mind or doing other things to distract yourself
- blaming someone or something else for problems
- withdrawing from others
- doing something—anything—even if it is impulsive, inappropriate, or impractical
- letting or asking others to make decisions for you, even at the expense of what you feel comfortable doing
- reducing tension with alcohol or drugs

People don't always recognize when coping techniques are ineffective or are damaging their well being. Taking time to evaluate their behavior can help parents identify what might be working against them.

Specific Strategies For Reducing Stress

Having several coping techniques “up your sleeve” provides you with options for handling stress. Different situations may require different approaches, and some work only temporarily. Monitoring the way you deal with stress and reminding yourself of alternatives can enhance your ability to meet multiple demands.

Eight specific approaches to dealing with stress are summarized below. While the list is not exhaustive, these methods are among those most often described as helpful by parents. You will likely recognize things you are already doing or have tried in the past.

I. Assess how you are functioning on a given day:

Each day, set aside a brief period to very deliberately observe how you are doing. Take some time to ask yourself:

- How am I feeling today?
- What have I been doing?
- Am I using my time effectively?
- How do I feel about myself?
- What can I do to help myself feel good?
- What could I do to make the rest of the day go better?
- Would it help to have support or assistance with what I am facing?
Who could I turn to for it?

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Coping With Stress

Depending on the kind of day you are having, ask yourself, Why am I coping well today? or Why am I not coping well today? Identifying what makes things go smoothly can help you build more of those elements into the days ahead; recognizing what turns a day sour may help you prevent at least those stressors that are under your control.

II. Assess your overall functioning and that of your family:

The following questions are a tool for evaluating your overall functioning. This is a more comprehensive review than the questions above. It is intended to increase your awareness of those aspects of your life that might be changed to enhance your well being and your ability to cope with stress. Base your answers on the way things have been going for you in the last few months.

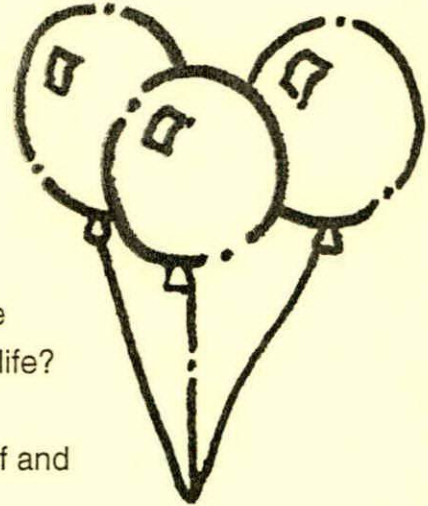
Assess your outlook:

- What are my emotions usually like from day to day? Are these a clue about the level of stress I'm experiencing and the way I handle it?
- Who and what create stress for me? How can I avoid them?
- Who and what make me feel relaxed and confident? How I can see or do more of them?
- Do I take responsibility for lowering the stress in my life? Do I believe I am capable of doing so?
- Do I express my feelings or do I bottle them up?

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Coping With Stress

Assess your outlook (continued):

- Is there a balance in my life between work, play, and rest?
- Do I laugh very often? Who and what make me laugh? How can I build more of these into my life?
- Do I set unrealistically high standards for myself and others?
- Do I accept what I cannot change?
- Am I continuing to learn, or is my mind stagnating?



Assess your physical condition:

- Is my body giving me signals that I'm operating with too much stress? If so, what are they?
- Do I:
 - get enough sleep?
 - exercise at least three times a week for 20 minutes or more?
 - maintain a balanced diet?
 - maintain a weight that is healthy and feels comfortable for me?
 - avoid alcohol, non-prescription drugs and cigarettes?
 - believe I have control over these things?
- Does taking care of my body seem like a hopeless undertaking? Do I believe it will make a difference in how I handle stress?

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Coping With Stress

Assess the well being of your family:

- Are the members of my family aware of each other's concerns?
- Do we communicate about the stress each of us is feeling?
- Would it help to schedule regular family meetings to discuss these issues?
- Do we schedule enough enjoyable family activities each week?
- Do I regularly spend time with each child?
- Do we set goals as a family and work toward them?
- Are we able to compromise in order to work together?
- Do our physical surroundings add to our stress? What can we do to create a more comfortable, quiet, and peaceful home atmosphere?
- Hugs reduce stress . . . do we touch each other enough every day?

(Adapted from material by Nancy Kristensen, Director, Early Childhood Family Education, Winona, Minnesota)

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Coping With Stress

III. Approach a difficult situation by using a problem solving procedure

What's referred to as the "problem solving process" is simply a series of steps used more or less naturally by everyone. People are not usually aware of using the process, or they may skip important steps and forfeit some of its benefits. Problem solving is a simple formula that can be applied to any situation. It is a useful tool for systematically examining a problem and planning ways to resolve it.

Try the following five steps in tackling an issue that has you feeling "stuck."

1. Define the problem. Try to be very specific about what is bothering you or not going well. Some people find that doing this in writing clarifies their thoughts best. Or it may help to talk to someone; an objective listener is sometimes better able to identify the underlying issue. As part of defining the problem, state what it is that you want to happen, i.e., what is your goal?
2. Generate a list of possible solutions. Think of as many ways of solving the problem as you can, even if they seem impractical or impossible. At this stage, the most important thing is to develop lots of ideas, to generate as long a list as you can, and to resist thinking about how each idea would or wouldn't work. (You may continue adding to this list as you work and reflect on the problem.)
3. Select a plan of action. Consider the implications of each alternative. Narrow the list down to the approaches that seem most promising and feasible. Then select one to try.

MELD SPECIAL

Coping With Stress

4. Try it. This is the hard part, the part you may have to push yourself into. At this point, try not to worry about results; you'll evaluate things later. Just put your energy into carrying out your plan for a designated length of time. Adopting an attitude of "Let's just give this a try and see what happens" can help you avoid feeling defeated if the idea doesn't work, and it will allow you to remain open to trying other alternatives.
5. Evaluate how it worked. After testing the approach, assess whether you feel you are making progress. Even if the problem hasn't yet been solved, do you feel you are moving in the right direction, however slowly? If you believe this isn't the best method to help you achieve your goal, return to your list of possible solutions and select another. Repeat steps 4 and 5.

As you proceed, be open to changing your method, your timeline, and perhaps even your specific goal. Some problems are difficult to resolve, some won't budge, and some prove to be beyond anyone's control. Remaining flexible about how quickly things will improve and how much change is possible can help you avoid some of the discouragement that naturally accompanies difficult problem solving.

Parents report that using this process increases their sense of control and confidence. Many keep the written guidelines on hand to remind them of the steps, and to encourage using them before problems get out of hand. Problem solving reminds parents that a difficult situation can often be broken down into manageable parts, and that they have choices. One mother said she functions better since she began reminding herself, "Refuse to become a victim. Concentrate on the issues over which you actually have some control and explore every single alternative. Tackle problems even when you feel extremely discouraged. You really will feel better—even if that's hard to believe."

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Coping With Stress

IV. Getting a break: time away from the child

One mother describes raising a child with special needs as a marathon rather than a sprint. Time away from the child is essential to parents' ability to finish the marathon, she says. Breaks in responsibility can help parents maintain a sense of balance in their lives—provided they have reached the point of feeling comfortable leaving their child; parents vary in how long it takes them to reach this point.

Respite and child care for children with special needs are complicated issues beyond the scope of this chapter. But in order to get away, parents must obviously find a competent sitter, a difficult task for many families. Arranging childcare, planning, and juggling schedules can require so much effort that parents may feel getting away is too much bother and turn down opportunities to relax and renew their energy.

Fathers typically spend more time away from home than mothers. Not surprisingly, women tend to feel more isolated than their partners. Some mothers report that part-time jobs or other outside activities give them a needed break from family demands, provide meaningful activity and new relationships, and enable them to cope better when they are home.

For many people, breaks or periods of solitude while at home are as important to their well being as getting away. Time alone in the house can help parents maintain their perspective and avoid feeling physically and mentally overwhelmed. Frequent short breaks, even a few minutes here and there as a release from daily demands, can be surprisingly helpful.

MELD SPECIAL

Coping With Stress

One MELD Special mother emphasizes the need to make every break count. She calls it “mind space” when she can savor the moment. While her son is concentrating on a toy or the television, she takes a minute to just breathe, look out the window, make a phone call, or read a page or two. It may seem more important to use such moments to catch up on household tasks, but the energy gained from mini-breaks pays off for parents in many ways. Taking care of themselves is not a luxury. If it's hard to justify doing these things on their own behalf, it may help to remember that a child needs a parent who is as peaceful and rested as possible.

V. Evaluate the way you use your time

An effort to reorganize their use of time helps some parents restore a sense of balance in their lives. Real control over time is probably impossible; life with a chronically ill or disabled child—not to mention family life in general—is often unpredictable. Yet most people can identify areas of their lives that would benefit from selected time management techniques. Parents have offered the following suggestions as ways to begin evaluating or restructuring the use of time.

- Set priorities. Begin by identifying all the tasks you feel you must do: big and small, mundane and urgent. As you consider each one, ask yourself, “Would anything terrible happen if I didn't do this?” If the answer is “no,” eliminate it from your list (unless you really enjoy it). Then rank the remaining tasks according to their importance or necessity. Tackle your “To Do” list in that order so that you focus your efforts on the things that are most important to you.

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Coping With Stress

One way to determine your priorities is to consider the things you'd most like to happen for yourself and your family. These goals suggest what's most worth spending your time on. Consider how each task on your list is related to your goals and give priority to those that are most likely to help you achieve them.

While unexpected events force parents to be flexible, train yourself to work your way down your "To Do" list without skipping things. Trust your judgment about what's important and, in general, stick to your priorities in spite of difficulties.

- Consolidate tasks. Handle things in bunches when possible: do a number errands at one time, pay all the bills at once, prepare more than one meal as long as you're cooking anyway.
- Get help and delegate tasks. Search out organizations and individuals who can help you get things done. It is extremely difficult, if not impossible, to raise children and maintain a household without help.
- Fight procrastination. Tackle unpleasant tasks first, when you're feeling "up," and then turn to the activities you enjoy or don't mind doing. Confront yourself about why you might be avoiding certain tasks. Feeling organized promotes a sense of coping; letting things slide doesn't.
- Schedule time for yourself and your relationships. As often as possible, try to allot some time each day for yourself, your partner or friends, and for each of your children.

MELD SPECIAL

Coping With Stress

- Consider saying "no." It may help to cut down on the number of your obligations or commitments, even if only temporarily. Consider whether this might free enough time to help you get reorganized.
- Be realistic. Even the most organized plans and schedules go awry. Children get sick, cars won't start, and babysitters cancel. Give time management techniques a try and then be flexible. Don't waste time regretting the things you didn't get done. Concentrate on moving toward your goals at a pace that's reasonable in your circumstances, and give yourself credit for what you accomplish.

VI. Redefine or reframe stressful situations

Many parents find it easier to cope with a stressful situation when they redefine or "reframe" it. Reframing is deliberately thinking about a problem in a new way in order to identify something positive or acceptable about it.

One mother "reframed" her struggle to find competent child care for her disabled son, a search that had caused her frustration and anger for many months. She forced herself to stop thinking of it as an endless series of dead ends and discouraging encounters with social service staff, and redefined it as a slow but successful battle that would eventually pay off in good, affordable care for her son and other children with special needs. Thinking of the situation in a positive way gave her the energy and optimism she needed to persist. Reframing also allowed her to recognize the valuable skills she had developed in the process. These included the ability to:

- negotiate a large bureaucracy

MELD SPECIAL

Coping With Stress

- effectively communicate in person and in writing with a variety of professionals
- generate alternatives for how services might be provided and subsidized, and
- master the emotions that had previously impaired her ability to persist in difficult circumstances.

There may be times when parents question the fulfillment that is possible from raising a child with special needs. Reframing can help them recognize the contributions a child with disabilities makes to family life and to their own development as adults. Many families with a disabled or chronically ill child report that while the experience is difficult, frightening, and not something to be wished for, it changes family values for the better, renews their sense of what is important, and gives greater meaning to life.

VII. Identify your strengths

It can be easy to emphasize the difficult aspects of raising a child with special needs. In stressful circumstances, parents often focus on their shortcomings, on what they fail to do to improve things. Worry and multiple responsibilities leave mothers and fathers with little energy or inclination to acknowledge what they do well.

One mother wrote, “. . . the job of juggling responsibilities leaves us very little time to evaluate our remarkable performance. Each day we try to meet as many demands as possible. We never get to the bottom of the list of things to do. We seldom feel a sense of accomplishment for a job well done because our duties are repetitious and tedious.”

MELD SPECIAL

Coping With Stress

Parents deserve to recognize their strengths and give themselves credit for the job they are doing. Yet this kind of confidence is foreign to many mothers and fathers. Ask yourself, "What am I good at doing with my kid(s)? What qualities do I bring to parenting that contribute to being an effective mother or father? What do my children seem to enjoy about me? What do I enjoy about being a parent?" Acknowledging these things promotes feelings of satisfaction and pride which can balance the inevitable stress of raising a child with special needs.

It is also important to recognize that you continue to function from day to day even when you feel overwhelmed, that you keep moving on what may be an incredibly bumpy path. Especially when you are feeling ineffective, uncertain, or critical of yourself, it is reassuring to acknowledge your ability to simply function under stress.

VIII. Keep a Journal

It can be hard to recognize improvement in a difficult situation when you're immersed in it from day to day. Stress can be the result of feeling you're not making any progress, and getting discouraged undermines a person's ability to cope. A journal or diary helps you remember things and provides a record of improvement you might not otherwise be able to keep track of.

Using a notebook just for this purpose, keep notes about how a situation is going. Write about events as they happen, recording your thoughts, feelings, observations and concerns. Document every success, no matter how small. Photographs and charts also demonstrate improvement.

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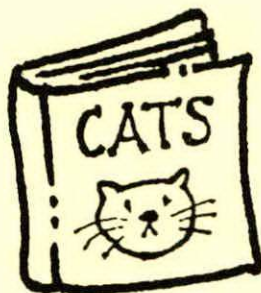
Coping With Stress

Some parents make notes daily, others less often. Some write a lot, some a little. Be as detailed or as general as you like, whatever makes the notebook helpful and easy to use. Some parents name their journals for the situations they are working on, e.g., John's Educational Plan Notebook or the Things Are Going to Get Better Book.

A journal can be used to document problems as well as progress. By recording their concerns—for example when a problem begins and how it develops—parents have a reliable record with which to consult professionals should it become necessary.

The act of writing helps many people clarify their thoughts and develop a better perspective on a situation. A journal also offers a safe place to express feelings or try out new ideas.

Many people shy away from starting a journal because they lack confidence in their writing skills. Yet the notebook is meant only for personal use and should be written in whatever style an individual chooses—as if he were thinking or talking to himself, but in writing. Perfect sentence structure or punctuation have no bearing on the value of a journal. Concern about writing skills only gets in the way.



Family Members Cope With Stress Differently

Family members' reactions to a given event often differ because each interprets the situation differently. One person may suffer considerable stress over something another finds merely annoying. Even when people find the same things stressful, their coping styles may conflict.

Unfortunately, when people perceive or respond to things differently, it can be hard to sympathize with and support each other. Misunderstandings between partners and relatives can make stressful situations even worse.

It is important for family members to understand the things that create stress for each other, and why they respond the way they do. Chapter 2, "Parents, You Count Too!" addresses ways to avoid misunderstanding and conflict during tough times. In general, most parents find it is valuable—although not always easy—to talk to those they are close to about their different coping styles. By understanding each other's behavior and needs, parents are better prepared to support each other when a crisis occurs. Each person can ask the other:

- What do you think you will need from me? How can I best support you?
- How can I better understand your behavior?
- What is the best way to approach you if I feel we misunderstand each other?

MELD SPECIAL
Coping With Stress

The things individual family members find stressful can change over time and new coping techniques may need to be adopted. All families must renegotiate these issues as circumstances change and as parents and children enter new stages in their lives. A habit of discussing problems and a sense of working on them as a family helps everyone remain flexible and willing to discard coping behavior that no longer works.

Reflecting on her family's adjustment to their child's special needs, a MELD Special mother said "In the beginning, a lot of the stress was due to the newness of the whole situation. But you learn how your family functions over time. It takes time, but you learn how to make it work for your family."

Conclusion: Viewing Life Through Crisis-Colored Glasses?

A MELD Special father said he'd gotten in the habit of thinking that just about every problem in his family was somehow due to having a child with special needs. "After a while, it occurred to me that a lot of those things would probably have happened anyway, that they probably had more to do with the kind of person I am, or my wife is, or the way we handle things in general, or what the other kids need, or just because those are the kinds of things that happen in life. I'm so used to focusing on my son's disability that I think I lose sight of the fact that a lot of what happens to us is normal life stuff, the stuff that happens to everybody."

In Meeting the Challenge of Disability and Chronic Illness: A Family Guide, the authors point out that "some problems are caused by an illness or disability, and other problems are complicated by it. Still other problems have nothing to do with the special need at all." Events and changes that are not related to the child's condition explain as much about the way a family functions as the special needs and their management. The ability to distinguish disability-related from non-disability-related issues is important to a parent's ability to solve problems.

The authors continue: "Disability and chronic illness can appear to be all-encompassing circumstances that complicate and blacken all aspects of your life. And sometimes a disability or illness can be experienced as a tragedy that leaves your family without hope, power, or resource. These feelings are very real and deeply valid. Yet the question remains: What can we do about these feelings and circumstances? Plenty."

MELD SPECIAL
Coping With Stress

Jane Bernstein documents the slow return of a more normal family life following the birth of her disabled daughter. “. . . you want so badly to . . . have back in your life all the ordinary, unspectacular moments that your family had before the diagnosis. You want to enjoy a snowstorm, a bath with your older daughter, a walk downtown to have bagels for breakfast, a day where nothing much happens, but with such tranquility and good spirit. It occurs to you that these things have not vanished; they are a part of everyday life, and when you are in good spirits they are life’s pleasures, and when you are not they are its burdens. . . . You decide that . . . you will grab on to these moments, stay with them, wring pleasures from them.”

One mother wrote that part of the answer is looking beyond the negatives, acknowledging but not dwelling on them. “We constantly try to distinguish the positive elements in our parenting experiences from the negative ones. We invest our emotions in the positive things we see in our children—the things they do, the qualities they have, their personality traits. . . . We respond to these. . . . The more we do so the better we feel. Our children’s pluses give us a feeling of confidence and competence. They reaffirm our beliefs in ourselves and what we are doing.”

These attitudes no doubt help reduce stress, yet it can take a long time before the mother or father of a chronically ill or disabled child is ready to see things this way. Individuals heal and restore their sense of balance at different paces. Nevertheless, each parent is eventually able to ask himself, “Are my fears about my child’s future robbing our family of the present? Am I able to take advantage of the small pleasures in life, and to help my children do so as well?”

MELD SPECIAL

Coping With Stress

Families reach an important landmark when a child's special needs cease to be the central issue in their lives. "Our problems are serious, yet we still can relax and enjoy each other. Our homes should be a haven . . . yet our homes are often incubators of problems which infect our families," writes one mother. We need to protect the quality of the time we have with our children, to give them the chance to live in an atmosphere of love and of all the happiness we can muster along with our pain and uncertainty.

When parents feel discouraged about their ability to cope and improve their situation, it may help to remember what they offer their children simply by loving them. That love is what children need most. It is what they can feel in their parents' presence even during times of fear and stress. The belief in a parent's love is basic to a child's sense of security and ability to overcome difficulty. Its power cannot be overestimated.

MELD SPECIAL

Coping With Stress

Resources:

Bernstein, Jane. Loving Rachel: A Family's Journey From Grief. Boston: Little, Brown and Co., 1988.

Curran, Delores. Stress and the Healthy Family. Minneapolis: Winston Press, 1985.

Featherstone, Helen. A Difference in the Family: Living with a Disabled Child. New York: Penguin Books, 1980.

Goldfarb, Lori, Mary Jane Brotherson, Jean Ann Summers, Ann P. Turnbull. Meeting the Challenge of Disability or Chronic Illness: A Family Guide. Baltimore: Paul H. Brookes, 1986.

Gordon, Sol. A Survival Guide for People Who Have Handicaps. Syracuse, NY: Institute for Family Research and Education.

Horton, Maureen. "Sometimes I'm Tired," Meeting Ground. Golden Valley: MN.

Kanat, Jolie. Bittersweet Baby: A Family Meets the Challenge of a Child with Disabilities. Minneapolis: CompCare Publishers, 1987.

Lerner, Helene. Stress Breakers. Minneapolis: CompCare Publications, 1985.

McCubbin, Hamilton, et al. CHIP: Coping Health Inventory for Parents. Madison, WI: University of Wisconsin, 1983. [Available from the Family Stress, Coping and Health Project, 1300 Linden Drive, University of Wisconsin, Madison, Wisconsin 53706. Designed to assess parents' perceptions of behaviors they are currently using to manage family life when they have a seriously ill or chronically ill child. CHIP is a self-report instrument with a checklist of 45 specific behaviors. Parents are asked to record how helpful each coping behavior is in their situation.]

_____. Family Stress, Coping and Social Support. Springfield, IL: Thomas, 1982.

Mills, James Willard. Coping with Stress: A Guide to Living. New York: John Wiley and Sons, 1982.

Pulver, Robin. "You Will Grow Because of This," The Exceptional Parent.

MELD SPECIAL
Coping With Stress

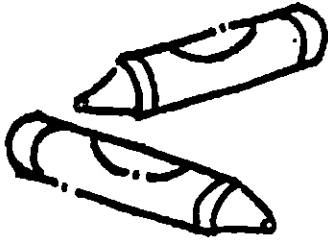
Resources (continued):

Simon, S. B. Meeting Yourself Halfway: 31 Value Clarification Strategies for Daily Living. Miles Argus Communications, 1974.

Tubesing, D. A. Kicking Your Stress Habit: A Do-it-Yourself Guide for Coping with Stress. New York: Signet.

Weatherly, Judith. "Meeting Parental Needs: A Never-Ending Dilemma" in The Disabled Child and the Family: An Exceptional Parent Reader, M.J. Schleifer and S.D. Klein, ed. Boston: The Exceptional Parent Press, 1985.

Weisman, Avery. Coping with Cancer. New York: McGraw-Hill, 1979.



Learning Activities

Getting Acquainted Activities:

- I. Ask each group member to complete the following statement:

"In general, in spite of stress, the thing that keeps me going is . . ."

This exercise is also very effective at the conclusion of a meeting, especially after a discussion that has focused on parents' difficulties and negative feelings.

- II. Briefly describe something that causes stress for you as a parent, other than the fact of your child's special needs.
- III. What thoughts about coping with the stresses of raising a child with special needs would you share with parents who are just "starting out?"
- IV. In what ways do you feel you have become stronger as a result of coping with the stresses of raising a child with special needs?

MELD SPECIAL
Coping With Stress

Activity related to the idea that chronic stress can jeopardize parents' health and well being, as well as that of their family.

Distribute copies of handout (a), "Sometimes I'm Tired" and give parents several minutes to read and think about it. The following questions can be used to elicit the group's responses to the poem:

- What were your reactions as you read the poem?
- Which feelings expressed in the poem have you experienced?
- The poem expresses a mother's deep discouragement. Why are some parents reluctant to admit such feelings?
- If such feelings continue over time, how might they affect a parent's ability to cope with daily demands and stresses?
- What would you say to Maureen Horton if she confided these feelings to you over a cup of coffee?

MELD SPECIAL

Coping With Stress

Activity related to the idea that much of the stress experienced by parents of children with special needs is due to a sense of not having sufficient control over their lives.

Large or Small Group Discussion

In large or small groups, ask parents to describe their reactions to the following statements from Helen Featherstone's A Difference in the Family. You may want to write the statements on newsprint or a chalkboard, or distribute them as handouts.

- Fatigue perpetuates itself by preventing people from energetically seeking or imagining a different way of life. Solving problems requires change, and change requires effort. To a truly tired person, most "solutions" look like new problems.
- Like so much of the rest of life, part of the trick is separating problems into manageable pieces instead of fusing all issues into one giant wax ball of misery.

Activities related to the idea that individuals differ in what they consider stressful and in the way they cope with difficulty.

I. Construct collages

Provide a variety of craft materials such as newsprint, freezer or construction paper, scissors, tape, markers, and magazines. Ask each parent to create a collage depicting sources of stress for families of children with special needs.

MELD SPECIAL

Coping With Stress

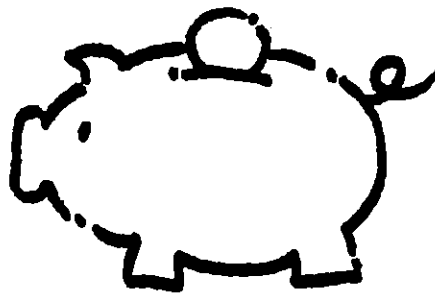
Have parents discuss the collages in small groups. Ask them to consider the following questions:

- Which stressors might be decreased or eliminated?
- Which cannot be changed?
- How can parents cope with the things that are beyond their control?

II. Small Group Discussion

In small groups or pairs, ask parents to:

- develop a definition of stress
- describe things that make a day go well
- describe things that make a day go badly
- suggest ways to prevent the things that make a day go sour and are under parents' control
- suggest ways to cope with the things that make a day go sour but are not under parents' control



Reconvene and ask a representative of each small group to briefly summarize its discussion. Take notes on the general ideas that are presented and conclude by summarizing them and the ways parents might apply them.

MELD SPECIAL

Coping With Stress

Activity related to the idea that people do not always recognize when they are experiencing excessive levels of stress.

Worksheet and Discussion

Have each parent take the "Are You Burning Out?" quiz included as handout (b) in this chapter. Then ask members to discuss the following questions in small groups:

- What are your reactions to the burnout quiz?
- What does the idea of burnout mean to you?
- How do you or can you recognize burnout in yourself?
- How do you or can you get over it? prevent it?
- What can you do if you feel someone close to you is burning out?

Activities related to the idea that effective coping techniques can be learned.

I. Handouts and Discussion

Read handouts (c) and (d), "Meeting Parental Needs" and "You Will Grow Because of This." Use one or both as the basis of a group discussion. Distribute copies for group members to read ahead of time at home, or schedule time to read at the meeting.

MELD SPECIAL
Coping With Stress

Ask parents to discuss their reactions to the handout(s). You may want to use the following questions:

- Which feelings expressed by these parents have you experienced?
- How have you dealt with similar circumstances?
- How do you think Robin Pulver and/or Judith Weatherly were able to reach the point of recognizing the positive aspects of life with a disabled child and its contribution to their own development as adults?
- People's judgement of how well they are managing depends on what they expect of themselves. Judith Weatherly writes that she measured her performance as a mother against an ideal role model and kept falling short. Do you feel your expectations of yourself are realistic?

II. Small Group Discussion

Have each parent describe something about his typical coping behavior when faced with a stressful situation or problem. You may want to ask the group to consider the following questions.

- When faced with a stressful situation, do I try to avoid it? Act quickly? Think about it a while and then act? Problem-solve?
- Would I like to change the way I react to stress? If so, how?
- How can people learn new ways to cope when what they're doing doesn't work?
- How did I cope with stress before my child's special needs were diagnosed?

MELD SPECIAL
Coping With Stress

III. Skits

Divide into two or three small groups. Give each group 15-20 minutes to prepare a skit about a specific problem or the feelings of stress that are part of raising a child with special needs. Each group can choose the situation it wants to portray. The "plot" must include an example of either the problem solving process, or a specific technique for coping with stress.

After each skit is performed, ask the "audience" to identify the problem solving or coping behaviors that were represented. Record them on newsprint or a chalkboard. Discuss each coping technique in terms of style, suitability for different kinds of individuals, and how to develop it.

An alternative to the skits is to divide into small groups and have one or more parents volunteer to describe a real problem or stressful situation they are dealing with. Ask the group to apply the initial steps of the problem solving process to each concern, i.e., define the problem, generate alternatives, evaluate alternatives, and select an approach.

MELD SPECIAL
Coping With Stress

IV. Presentation and Discussion

Introduce the idea that a person's ability to cope with stress and multiple demands is lower when he feels disorganized. By examining their use of time, parents may be able to identify ways to be more efficient, and to maintain their energy and morale.

Give your group the following directions:

Many time management experts begin by asking their clients to describe a typical day. Most parents would answer, "Are you kidding? There is no such thing!" Nevertheless, as a way of evaluating your use of time,

1. List the activities that go into most of your days. Write down everything you do on a more or less regular basis, including household tasks, appointments, activities with children and others, job, errands, etc. Consolidate related activities into categories if you like. Then estimate the amount or percentage of time you spend on each on a daily or weekly basis.

How much of your time do you spend on enjoyable activities with your family? On work? Personal time? Household responsibilities? Taking care of your child?

2. Draw a circle representing a "time pie" of your typical day. Divide the pie into wedges of appropriate sizes to indicate each category on your activity list. Then draw another time pie that represents how you would like your typical day to be spent.

Ask parents to suggest the steps they would need to take to move from their current time pies to the ones they would prefer.

MELD SPECIAL
Coping With Stress

Following this exercise, briefly review some or all of the time management strategies suggested in this chapter. You may want to focus the discussion by distributing photocopies of the material or by listing main ideas on a newsprint pad or chalkboard. Use the following questions to elicit parents' reactions to the techniques:

- Which time management techniques sound helpful for you and your circumstances? Which would you actually consider trying? What steps would you have to take to implement them?
- Would you say you have realistic expectations of how much you can accomplish in a day?

V. Small or Large Group Discusison

It can be natural to focus on the hardships of life with a chronically ill or disabled child. The following exercise offers a break from thinking about stress and a chance to celebrate the child.

Distribute writing materials and ask each parent to take 10 minutes to complete the following sentences:

- My child likes to . . .
- My child is really good at . . .
- My child has made progress in the area of . . .
- Something that really pleases me about my child is . . .

Ask parents to share one or more of their answers with the group. Conclude the exercise by summarizing parents' thoughts about their children and acknowledging their joy and pride.

MELD SPECIAL
Coping With Stress

VI. Small Group Discussion and Creative Activity

Divide into three groups and assign one of the following to each:

- 1) Discuss the ways you incorporate your child's treatments or therapies into the family's daily routine. How does your family remember medications, decide who does what, and share responsibilities? Develop a creative way to convey these ideas to the rest of the group. You might present a skit or pantomime, design a poster or brochure, conduct an interview, or write new words to a familiar melody.

- 2) Brainstorm enjoyable family activities that might enhance a pleasant home atmosphere. Your list might include taking a walk, riding bikes, popping corn, going for ice cream cones, playing a game together. Develop a creative way to convey your ideas to the rest of the group. You might present a skit or pantomime, design a poster or brochure, conduct an interview, or write new words to a familiar melody.

- 3) Exchange ideas about ways to calm down when stress is so intense you feel like exploding. Your list might include counting to ten (or ten thousand?), relaxation techniques such as visual imagery or deep breathing, taking a bath, going for a walk, listening to music, baking a cake, eating the whole cake. Develop a creative way to convey your ideas to the rest of the group. You might present a skit or pantomime, design a poster or brochure, conduct an interview, or write new words to a familiar melody.

Reconvene and have each small group make its presentation. Give the "audience" time to respond to each activity, and to suggest additional ideas regarding each of the three problem areas.

MELD SPECIAL

Coping With Stress

VII. Homework

Encourage families to try the "A Matter of Pride" exercise at home. This is an opportunity for each person to acknowledge feelings of pride and to have them affirmed by other family members.

Each person is asked to think about things he has done that made him feel good about himself. Family members then take turns completing the sentence, "I am proud that . . ."

Some families use the following list to jog their memories about things they are proud of that might not occur to them during the activity.

- something I am able to do on my own
- praise I received for a special achievement
- a new skill I have learned
- something I did to help someone
- something I did that was creative
- a situation in which I was open and honest
- my positive thinking about the world and people
- something I did that demonstrated love
- a special friendship I have made
- something I did to keep healthy
- something I recently made as a gift for someone
- a conversation during which I listened carefully to what someone else had to say.

(adapted from S. B. Simon's Meeting Yourself Halfway: 31 Value Clarification Strategies for Daily Living)

MELD SPECIAL
Coping With Stress

Activities related to the idea that an adequate support network is a critical factor in a person's ability to cope with stress.

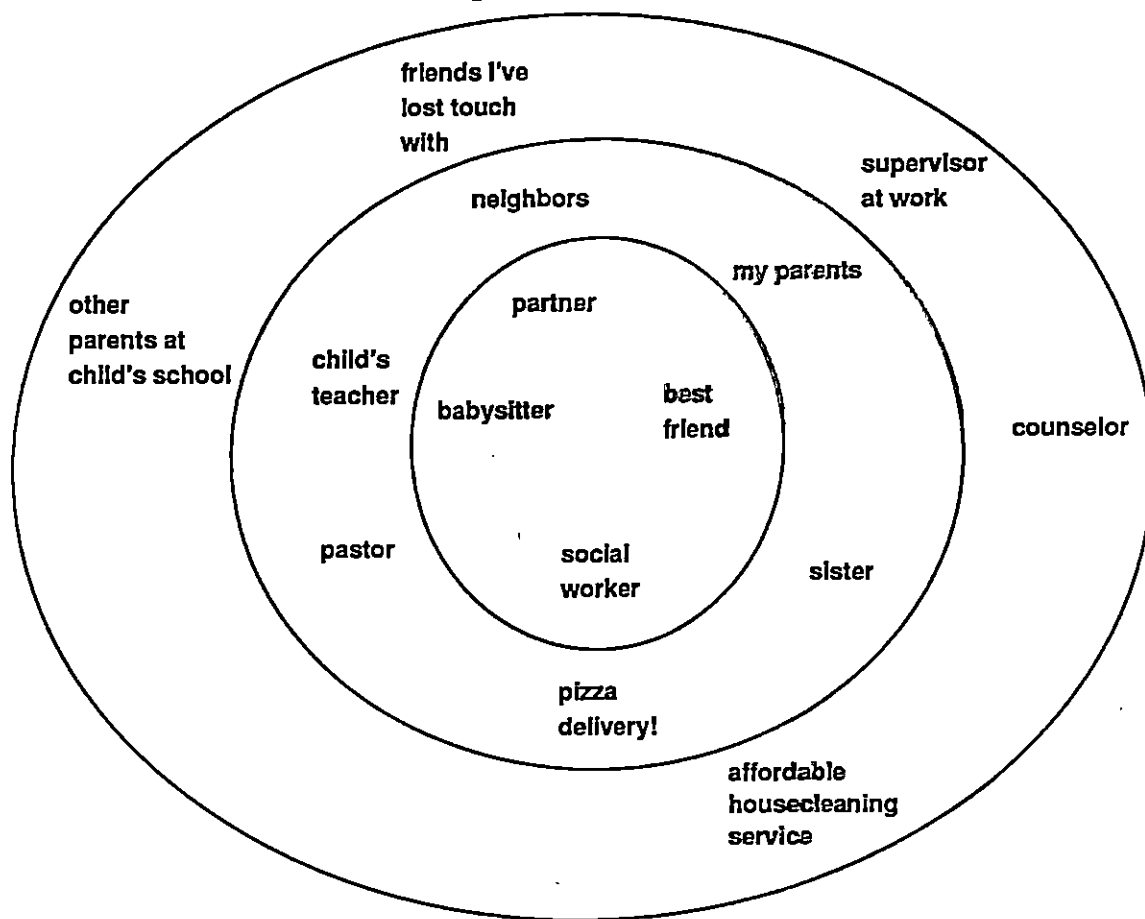
I. Worksheet and Discussion

Distribute a pencil and two or more sheets of paper to each group member. Give them the following instructions:

- 1) Take ten minutes to list the people and resources that make up your support network, i.e., the individuals, services, and things that "keep you going."
- 2) On another sheet of paper, draw three concentric circles and write the names of your most valued and consistent sources of support in the inner circle.
- 3) In the middle circle, write the sources of support that are important to you but are not among those you consider most critical or reliable. All the names from your list should now be in either the inner or middle circle.
- 4) Use the outer circle to list people or resources that are not currently sources of support but who you could consider turning to.

MELD SPECIAL

Coping With Stress



Support Network

Ask group members to describe their reactions to the exercise. You may want to use the following questions:

- Were you surprised by where you placed certain people in your diagram?
- How would you evaluate your support network after seeing it laid out in this way?
- What are some specific ways to reach out for support?

MELD SPECIAL
Coping With Stress

Questions to use in reaction to the support network exercise (continued):

- What stands in the way of seeking new sources of support?
- Do you feel it is okay to need support and to actively seek it, or does it make you feel needy or incompetent?
- Do you believe others are willing to support you?

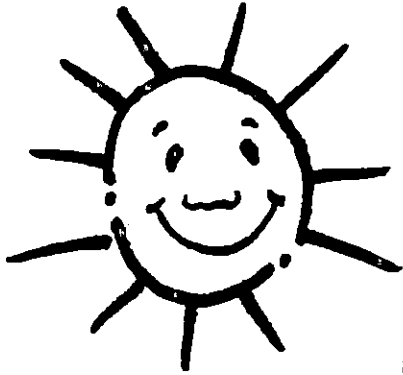
II. Brainstorm and Creative Project

Facilitate a brainstorm of the kinds of support parents need to raise children with disabilities or chronic illness. Encourage the group to include every kind of personal contact, service, or practical assistance that benefits parents. The list might include:

friends, neighbors, acquaintances
health care professionals
social workers
counselors
churches
parent groups
organizations representing specific conditions, e.g., ARC
foster grandparents
respite care programs
babysitting cooperatives
public health departments
teachers
other parents
libraries
hospital child life personnel
camps
hotlines
legal services
transportation services
businesses
civic groups

MELD SPECIAL

Coping With Stress



Have the group construct a table top sculpture symbolizing the forms of support they have listed, or a realistic model of the resources actually available in their community. Provide a variety of supplies such as markers, paper, craft supplies, dolls, toy cars and buildings, small related objects, pictures, and magazines.

Conclude with a discussion of the ideas that occurred to parents while constructing the sculpture or model. You may want to ask parents the following questions:

- What new ideas about obtaining support for your family occurred to you while building the model?
- How does a family match its individual needs with the sources of support available in its community?
- In general, what are the steps parents take once they have identified something they or their child need?

(adapted from the Association for the Care of Children's Health's "Seasons of Caring")

MELD SPECIAL

Coping With Stress

III. Discussion

Introduce this activity by pointing out that the goal of the MELD Special program is to provide information and support for parents. Convey the hope that your group can be a valuable part of its members' support network.

Have the group brainstorm ways the MELD Special group could support a member who is going through a tough time. The list might include:

- listen
- empathize with each other because of their similar circumstances
- provide a sense of belonging
- be a sounding board
- answer questions
- ask questions to encourage deeper thinking
- check back over time to see how the situation is going
- validate each others' efforts to be good parents

Ask parents to suggest ways members might ask the group for support. How can they help each other feel comfortable doing so?

IV. Homework

Suggest that parents submit a description of a problem to the The Exceptional Parent magazine's "Reader's Forum." The magazine prints readers' submissions and invites parents in similar situations to correspond with them. ("Reader's Forum," The Exceptional Parent, 605 Commonwealth Avenue, Boston, MA 02215)



Chapter 4

Handouts

Stress

SOMETIMES I'M TIRED

Sometimes I get really tired of being the mother of Michael.

I get tired of dragging 3 kids to Rehab for his therapy appointments twice a week.

I get tired of watching how he walks and talks and writes so I can answer questions for the doctors and therapists and teachers.

I get tired of pushing him to do things that are hard for him to do.

I get tired of forcing him to struggle into his own shoes and socks and shirts and pants.

I get tired of reminding him to use his right hand.

I get tired of modeling and correcting his speech.

I get tired of watching for his bus everyday.

I get tired of school conferences and IEP's.

I get tired of exercises.

I get tired of being his advocate.

I get tired of this lifestyle.

-Maureen Horton

From Meeting Ground, The Newsletter of Courage Center,
Golden Valley, MN.

Are You Burning Out?

Think back over the last six months. Have you been noticing changes in yourself or the world around you? Think of your family . . . your office . . . social situations. Allowing about 30 seconds for each item, answer the following questions. Assign a number from 1 (for no or little change) to 5 (for a great deal of change) to designate the degree of increased difficulty you have experienced.

1. Do you tire more easily? Feel fatigued rather than energetic?
2. Do people annoy you by telling you "You don't look so good lately?"
3. Are you working harder and harder and accomplishing less and less?
4. Are you increasingly cynical and pessimistic?
5. Are you often overtaken by a sadness you cannot explain?
6. Are you forgetting things (appointments, deadlines, personal possessions)?
7. Are you increasingly irritable? short tempered? disappointed in the people around you?
8. Are you seeing close friends and family members less frequently?
9. Are you too busy to do even routine things like make phone calls, read reports, or send out Christmas cards?
10. Do you suffer from chronic physical complaints, e.g., stomach or headaches, a lingering cold?

11. Do you feel disoriented when the activity of the day comes to a halt?

12. Are you unable to laugh at a joke about yourself?

13. Does sex seem like more trouble than it's worth?

14. Do you have very little to say to people?

Very roughly now, place yourself on the burnout scale. If your score is:

0 — 25	You're doing fine
26 — 35	There are things you should be watching
36 — 50	You're a candidate for burnout
51 — 65	You are burning out
over 65	You're in pretty deep water and you're not doing your physical or mental well being any favors.

Keep in mind that this is merely an approximation of the level of stress you are experiencing, useful as a guide to a more satisfying life. Don't let a high score alarm you, but pay attention to it. Burnout is reversible, no matter how far advanced it is. A high score simply indicates that the sooner you start being kinder to yourself, the better.

Meeting Parental Needs: A Never-ending Dilemma

Judith Weatherly

New parents are often advised that remembering to attend to their own needs as well as their newborn's is a vital ingredient for healthy family life. This advice is often forgotten or neglected when a child is born with a disability. Judith Weatherly describes her efforts to solve the never ending problem of finding the balance between meeting her needs and those of her chronically ill son.

My nine year old son was born with serious kidney problems and has been on dialysis for most of the last six years. Sometimes people ask me, "How do you do it?" This question annoys me. For one thing, I have never been too sure what "it" is. But I have finally come up with an answer. I do "it" by being selfish. In fact, I have decided that selfishness is a highly desirable—perhaps essential—personality trait for the mother of a chronically ill child.

Not a "Saintly" Mother

When we found that our son had a chronic illness which meant that he would require extra care, I assumed that as his mother, I would cheerfully provide that care. I measured myself against the stereotype of a devoted, saintly mother, living night and day in service to her stricken child. And, inevitably, I found myself falling far short of my imagined role model. I got tired, yelled at my child, and occasionally wished for the peace of a deserted island.

Society now recognizes feelings of anger, resentment, and isolation as a part of normal motherhood. Parenting books and counselors urge getting away, maintaining outside activities and friendships, and reserving time for the marital relationship. But too often, this understanding attitude is reserved for "normal" families. I felt that our family should be immune to all negative feelings about this child.

“Normal” Feelings

The more I read and the more I talked to other parents of children with disabilities and normal children, the more I found that feelings and emotions about children are very much the same in all families. The accident of illness or disability serves only to intensify feelings and emotions, not to change them.

Both positive and negative feelings may be magnified by a child's chronic illness. Love may be stronger, but so may be resentment. Overwhelming joy over the child's accomplishments may be offset by depression caused by self-imposed isolation. Mothers or fathers who feel that life must be devoted to the afflicted child may find themselves overcome by physical exhaustion, frustration and depression.

The isolation common to many mothers of young children is intensified by the feeling that “no one understands” and no one can help. I found that my excessive attention to my son's needs led to a loss of perspective. For a time, I almost stopped seeing him as a child, a separate person, and saw only a disease, a handicap, a collection of symptoms. Most of my life was lived through my child; his successes and failures became my own. Neither of us could succeed or fail on our own merits. In many ways, I was more dependent on my son than he was on me.

The Problem of Interdependence

Almost accidentally, I began to realize that our relationship was not a healthy one. When my son was two, I took a temporary job for just a few hours a day. Gradually, I noticed how much more we seemed to be enjoying each other and how much more rapidly he seemed to be developing. Perhaps we both needed a change.

Our interdependence was caused partly by my own inability to let go of my child's care and was partly a natural extension and effect of society's expectations of the roles of disabled child and mother.

The problem has no easy solutions. Seven years later, I am still struggling with the issues of his independence and mine. Like that of many disabled children, his care requires extra time and attention. But a dose of selfishness (not necessarily guilt free) has sometimes been a catalyst in finding some solutions and alternatives. And surprisingly often, what is good for me turns out to be good for him as well.

Similar advice comes from others who have come to terms with their own special needs and those of their children. Mary Lou Weisman, the mother of a son with muscular dystrophy was advised, "It's hard enough for determined women to have lives outside of their children's. It's going to be especially difficult for you." (Mary Lou Weisman, *Intensive Care*, New York: Random House, 1982, p. 152.)

Suzanne Massey found one way to cope with the anxiety produced by the uncertainty of living with hemophilia. "Sometimes after Bobby's cerebral bleeding, as the pressure grows more intense, I realized that to keep my mind intact, to keep from turning around in my cage like a panic-stricken animal, I had to do something hard, something mentally challenging. It had to be something so difficult that it would, by its own force, wrench my mind away from the unresolvable mysteries that tormented me everyday." (Robert and Suzanne Massey, *Journey*, New York: Warner Books, Inc., 1975, p.204.)

Helping Myself

Self-help solutions for mothers abound in today's feminist influenced culture. And just as the problems of normal and exceptional parents are remarkably similar, so are the positive steps to alleviate them. At different times over the years I have started a regular exercise program, returned to school, worked part time, and become active in church and volunteer work. Sometimes, the solution itself has not been as important as the fact that I have done something that I wanted to do and from which I benefited.

It is still very hard for me to let go of the idea that I am the only one qualified to take care of my child. Maybe no one can do it better, but surely someone else can do it well part of the time. And I may do it better when I am not on duty twenty-four hours a day.

There have been many times when things have gone wrong. Guilt is quick to overwhelm me—why wasn't I there when he needed me? The temptation to do it all myself, to be sure it is done right, not to give up control, is often strong. But when I give in to it, I am soon tired and resentful and things really do not go any better or more smoothly. Any home with children moves from crisis to crisis; ours may just be a little more frequent and unusual.

Lisa Cronin Wohl has written, "In a book that I read before my daughter was born, one mother said, 'I never gave up anything for my child.' At the time that woman sounded selfish to me. Now, in the wake of experience, I think I know what she meant. Of course a mother gives up a lot for her child: blood, sleep, tears, not to mention time, money and peace of mind. But a mother must not feel obliged to give up herself. Not unless she wants to raise a motherless child." (Lisa Cronin Wohl, Book Review, Ms., April 1982).

I believe that in the long run, my selfishness will benefit the whole family. When I am not available or willing to do everything for him, my child finds that he can do more for himself than either of us imagined. When I feel that I am achieving something on my own, and am enjoying my life, my special child becomes more of a special joy instead of a special burden. Our son's problems will always be a part of our family, but they are no longer its focus.

from The Disabled Child and the Family: An Exceptional Parent Reader. M.J. Schleifer and S.D. Klein, ed. Boston: The Exceptional Parent Press, 1985.

"You will grow because of this"

Robin Pulver

The words I recall most clearly from the numbing meeting at which my husband and I learned the results of long months of testing of our toddler son are, "You will grow because of this." The doctor who said we would grow had moments before informed us that David, our picture-perfect, difficult boy with the mischievous gleam in his eyes was not just a late bloomer. He was mentally retarded.

No, I thought. I'm all for growing, but not at the cost of my child's well-being. Let me choose another way instead.

But even now, two years later, "You will grow because of this," are the words that sound in my head each day. Now I thank that doctor for his gentle, forthright manner and for giving me something I must do for myself, not just for my son.

Our daughter Nina was three when her brother was born. Like all siblings of newborns, she asked again and again, "When will David be able to play with me?" I urged patience.

Then, soon after David turned three, I had to tell her what I had just learned myself: that although we had given David a cake with three candles, her brother was more like a year-and-a-half old baby. He would always be slow and never catch up.

Recently, she spoke of her sadness at seeing her friends' siblings in kindergarten at her school. That is where her brother should be now.

I told her, "When I walk by those kindergarten rooms and see all the drawings on the wall, my heart hurts, too. Sometimes I wish there were a pill we could give him to make his brain all better."

"Me too," said my daughter, "but then I'd probably miss my good old brother."

The doctor said, too, that our daughter would quite likely grow up to be sensitive and insightful.

GROWING

David has opened up the world of people with disabilities to me. He has made it accessible, and I have learned - how I have learned - from the children and their parents who provide me with examples of good sense, humor, courage and survival. Without my son, I would never have known them. They are my heroes. They are the yardsticks against which I measure my growth. I strain to catch up.

Sometimes, I experience the "imposter syndrome." I attend meetings for parents of special children and support groups. I apply for respite care. I know we need these things, yet I feel like a faker. For thirty-five years I cruised in the mainstream. My son has yanked me with him into the backwaters. Yet I am like a fat person, suddenly thin, who still feels fat. I am like a person with an inferiority complex who does not believe in her new success. Sometimes I feel I am only posing as the mother of a child with a disability.

Most days are all too real. The frustrations - days spent trying to teach David a simple skill most of us take for granted - last on and on. There is no telling myself that I will soon wish for these childhood days again. These days endure. The usual things that people say now strike horror in my heart:

**"They grow up so fast."
Some do not.**

**"I wish I could keep him/her at this age forever."
No, you don't.**

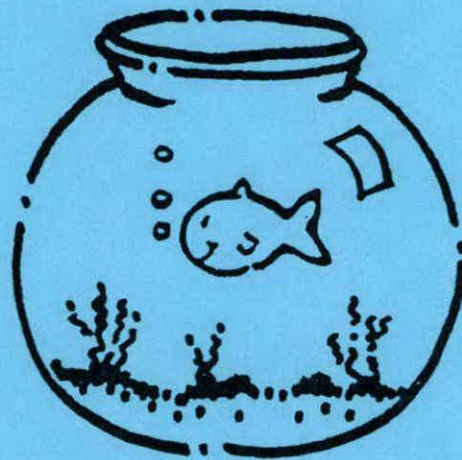
I will not reap the normal rewards of parenting a son. Chances are there will be no reflected glory at graduation or wedding ceremonies. There will be none of the sweet, sad poignancy of seeing him go off to college.

But I do feel intense pride in his achievements - his recent hard-won struggles to put on too-big socks and turn doorknobs. I adore his sense of humor and mischievous eyes. I love him, and the miracle of that love calms me at the core. I do not always feel the calm, but I have learned I can count on its return.

At our house, we listen to a tape by Raffi, the children's folk singer. One song begins, "I wonder if I'm growing. I wonder if I'm growing. My mom says, yes, I'm growing, but it's hard for me to see." We sing along, and I know that this is not just for my children. It is a song for me.

Chapter 5

Siblings



MELD SPECIAL

Siblings

Siblings

Table of Contents	Pages
I. Introduction For Facilitators	3-7
A. Main Ideas	4
B. MELD Biases	5
C. Facilitator Focus	6
D. Group Issues and Tips	7
II. Content For Facilitators	9-34
A. What is it Like for Siblings?	11-14
B. Finding a Place in the Family	15
C. Parents' Emotional Health and Availability: The Keys to Siblings' Ability to Cope	16
D. Influences on Sibling Relationships	17-18
E. How Parents May Reinforce Sibling Rivalry	19-20
F. Ways to Help Children Cope	21-29
G. When Should Parents Worry?	30-31
H. Finally, What Do Siblings Recommend?	32-34
III. Resources	35-39
V. Learning Activities	41-54
VI. Handouts	a-b
A. Dear Aunt Blabby	a
B. The Stories of Melissa, Jerome, Vanessa and Allen	b

Introduction for Facilitators

Who has it best? Who has it worst? One of the keys to the outcome of relationships between siblings is parents' recognition of the special pressures that might weigh on brothers or sisters in their particular place in the family. As each growing child's belief in her or his unique capacities is fostered, the fear that he or she might just become a mere shadow of an older brother or sister, or suffer a compensating and compelling need to overshadow that sibling, is overcome by the happier and more lasting experiences of friendliness, mutual pride, and love.

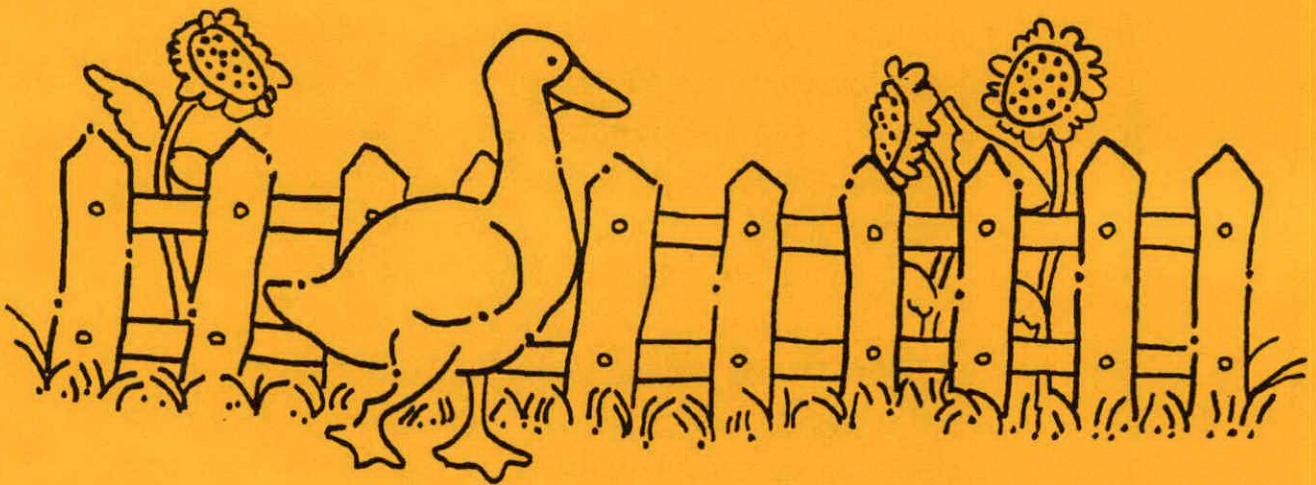
Helen Arnstein

If you grew up with brothers or sisters, or have more than one child yourself, you've had first hand experience with sibling relationships and appreciate their complexity. Being able to get along with others involves skills that come only with age, for example, the ability to share, take turns, compromise, and understand other points of view. But age and stage of development are only part of what influences a child's ability to thrive as one among others. Temperament, experiences outside the home, parents' attitudes and behavior, a disabled or chronically ill sibling: these are among the many factors that shape a child's relationships.

This chapter is designed to help parents in your MELD Special group examine sibling relationships — in general, as well as when one child has special needs. Its goals are to increase group members' understanding of what it's like to have a disabled or chronically ill brother or sister, and to identify ways that parents can promote family harmony.

Main Ideas

- Relationships between children with special needs and their siblings are more like than they are unlike other sibling relationships.
- Children are affected in both positive and negative ways by having a brother or sister with special needs.
- Parents can promote a positive self image for each child and enhance relationships between siblings.
- Siblings can develop skills to cope with difficulties caused by having a brother or sister with special needs.



MELD's Biases

- Sibling relationships are important and should be nurtured.
- Although sibling relationships might not appear problematic when children are very young, it is important for parents to understand what might be ahead for their family.
- It is important that a child's special needs are not continually the focus of the family.



Facilitator Focus:

As you read this material and plan a meeting on this topic, consider these questions about your experience:

If you have brothers or sisters:

- What were your relationships like as children?
- How did your parents treat you and your siblings while you were growing up? Did they foster competition or cooperation? Did they support and praise each child?
- How have your parents continued to treat you and your siblings as adults?

If you have more than one child:

- What kind of relationship seems to be developing between them?
- What pleases you about your children's relationship? What do you wish was different about it?
- How have you dealt with rivalry or competition between your children?
- Do you feel your own experience as a brother or sister influences the way you respond to each of your children? For example, are you aware of sympathizing more with one child because his circumstances remind you of your own when you were young?
- What have you learned about sibling relationships from being a brother or sister yourself, or from having more than one child?

Group Issues and Tips

- Group members with only one child might feel this topic doesn't apply to them. Point out that some of the information may relate to their child's relationships with friends or relatives. It may also be of interest to those parents who consider having more children.
- Parents may not be interested in this topic if their non-disabled children are very young and do not appear to experience problems from having a sibling with special needs. Point out that by becoming familiar with typical concerns of siblings, parents may be able to anticipate and prevent unnecessary conflicts.

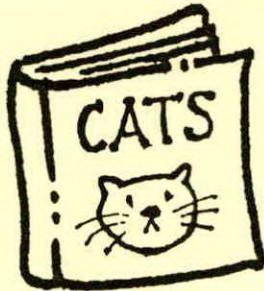
Content for Facilitators

All my life I've seen people stare at my sister and now I realize how glad I am not to be like one of those people. . . . before I was two, I didn't think of her as handicapped—she was just another one of my sisters—but I always knew there was something different. . . . As time moved on, I pretended I wasn't embarrassed by Jennifer. But I really was when my friends were around. By the time I was 14 or 15 though, I realized my good friends loved her, too. I hadn't realized that before. I hadn't given her a chance.

— from Betty Binkard's Brothers and Sisters Talk to PACER

Parents with more than one child often wonder how their non-disabled children will be affected by growing up with a brother or sister with special needs. Many factors influence siblings besides the presence of a chronic illness or disability. This chapter examines some of those influences, as well as ways parents can help each of their children feel loved and secure. It explores why siblings react the way they do, and offers ideas for preventing or resolving difficulties.

MELD SPECIAL
Siblings



In her book, After the Tears: Parents Talk about Raising a Child with a Disability, Robin Simons points out that “siblings are caught between two worlds: the outside world and the world at home. These worlds place very different demands on them, and they want to do well and be loved in both. Outside the home, a premium is placed on normalcy. All children, through their adolescent years, want to be as much like other children as possible. They want their families to be as much like other families, too. Within the family, children want almost the opposite. They want to stand out—to feel special in their parents’ eyes. Having to compete with a brother or sister who really is “special” is difficult. It makes then understandably jealous and resentful.”

Because they are so involved in the care of their child with special needs, or because their children don’t express themselves directly, parents are not always aware when siblings experience difficulty. By closely observing even very young children, parents can remain alert to siblings’ concerns and help prevent them from becoming serious problems.

What is it Like for Siblings?

Siblings' perceptions are determined in part by their age and stage of development. For example, very young children are often unaware that a disability or chronic illness is exceptional. Until they approach school age, children are not particularly attuned to or influenced by others' reactions and often do not notice that a person with special needs may be considered unusual.

One mother reported that her little girl took a long time to realize her older brother with cerebral palsy was not an ordinary child. It wasn't until her daughter was five and walking through a shopping center that she noticed people staring and asked, "Why is everyone looking at Bobby?" In Betty Binkard's Brothers and Sisters Talk to PACER, a boy "recalls first sensing that something was wrong with the way his sister behaved when he visited friends' homes and noticed that their brothers and sisters acted very differently from his."

Siblings are often affected by negative social attitudes toward particular special needs. Because the more visible or obvious conditions attract more attention and are often the most stigmatized, children may, for example, be teased about having a brother or sister who is mentally retarded, but not one with cystic fibrosis.

MELD SPECIAL

Siblings

One of the most critical factors in siblings' functioning is the way they interpret their parents' attitude toward the child with special needs. Mothers' and fathers' examples are a powerful influence on the way children cope. There are also responses that appear to be common to family members of all ages:

“Sadness, anger, guilt, embarrassment: siblings of a handicapped child experience almost all the same feelings their parents do,” writes Robin Simons. “And like them, they encounter these feelings over and over again each time a new hurdle arises. In the same way that parents sometimes wish for a non-handicapped child, siblings sometimes wish for a ‘real’ brother or sister, one with whom they could better share their time and feelings. And one who wouldn’t make so many problems for them.”

Among those problems, siblings may:

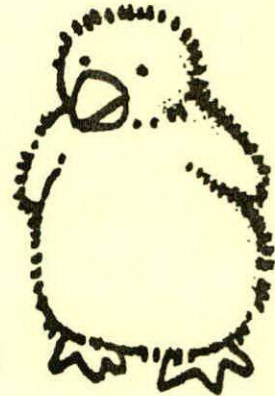
- resent the amount of time parents spend with their brother or sister
- feel their needs are sometimes or often neglected
- be ashamed or embarrassed by their brother’s or sister’s special needs
- feel frustrated that their brother or sister cannot play like other kids
- fear “catching” the disability or chronic illness
- fear they may have caused the condition

MELD SPECIAL

Siblings

Among those problems, siblings may, continued:

- feel their sibling interferes with their privacy or activities with friends
- feel angry that the sibling with special needs “gets away with” misbehavior
- have difficulty dealing with friends regarding their sibling’s special needs
- be hurt by insensitive questions, snubs, or teasing about their sibling’s disability or illness
- become withdrawn or irritable when unable to cope with their concerns
- try to overachieve for their parents’ benefit to compensate for the sibling’s limitations
- underachieve due to guilt about not having special needs, or as a reaction to pressure to excel
- worry about their sibling’s health, inability to do things “normally,” and lack of friends
- worry about the future, for example, whether they will have to take care of their brother or sister.



MELD SPECIAL

Siblings

Despite their difficulties, siblings often report they also gain something from having a chronically ill or disabled brother or sister. In A Difference in the Family, Helen Featherstone suggests that the situation offers children not only unusual problems, but unusual opportunities. For example, siblings frequently:

- learn to accept and appreciate differences in others
- develop compassion
- feel a sense of accomplishment from meeting challenges as a family member
- feel very close to the members of their family
- develop a stronger sense of responsibility than other children their age
- appreciate the importance of good health and normal development.

If you have more than one child, how do you think these lists of problems and benefits represent your children's experience? If they are old enough, you may want to ask your children to evaluate the lists. Do they agree with them? What would they add or delete?

Finding a Place in the Family

A young child's sense of security and self worth are largely derived from the belief that his parents love and appreciate him. It is therefore essential that mothers and fathers find ways to convey to each child that he is a valued member of the family.

In Brothers and Sisters Talk to PACER, a boy urges parents to "find ways not to let the child who's handicapped dominate all of the family's worlds." When an illness or disability is the focus of a family, siblings may conclude that their parents will only pay attention to things that are related to it. If they are unable to claim an important place in the family based on their individuality, siblings often try — usually unconsciously — to develop an identity or role related to the special needs. There are a number of ways children do this. They may:

- Become over-protective and over-responsible caretakers for their brother or sister.
- Develop "special needs" of their own to gain parents' attention and sympathy, for example, complaining, clinging, or developing symptoms.
- Strive to be perfect to receive praise for their achievements and for not adding to their parents' burden.
- "Act out," i.e., behave in negative ways for attention or to express troubled feelings.

These strategies are unnecessary when a child's need for his parents' recognition is satisfied, when he receives attention for the right reasons: as an individual.

Parents' Emotional Health and Availability: The Keys to Siblings' Ability to Cope

It's not easy for mothers and fathers to give their children sufficient support and attention when they are under considerable stress themselves.

Because so much time and energy go into keeping up with daily life and the demands of a child's disability or illness, parents often put their own needs and well being on the "back burner." Many parents report chronic anxiety, fatigue, and a feeling of being fragmented.

Every child needs a parent who is emotionally available to him. One factor affecting parents' availability is the degree to which they have resolved their feelings about a child's special needs. This is a difficult task; coming to terms with the situation often takes years, perhaps a lifetime. Yet in order to give each of their children the attention he needs, parents must find ways to deal with their grief and the other demands on their physical and emotional energy. Mothers and fathers who are overwhelmed do not have the reserves to respond to their children's needs. Taking care of themselves is not a luxury for mothers and fathers: it is essential for their entire family's well being. The chapters on grief, stress, and relationships

suggest a variety of ways parents can maintain their equilibrium.

Influences on Sibling Relationships

While their circumstances are unique in many ways, the relationships between children with special needs and their siblings are more like than they are unlike those in other families. Sibling rivalry is often considered a normal part of growing up, but several factors affect how intense or disruptive it is:

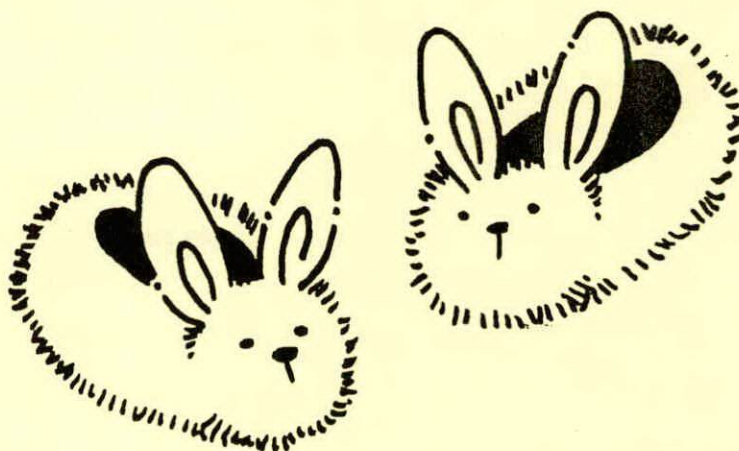
- Siblings' **temperaments** or personalities affect their compatibility, but not always in predictable ways. For example, friction may develop when one child is physically active, outgoing and adaptable while another is cautious, shy, and prefers quiet activities. On the other hand, the principle of "opposites attract" can operate as well: two very different children may thrive on each other's qualities.
- There is some evidence that a child's **birth order** may affect his relationships with siblings. First-born children often wonder why parents would ever have another child. Second-borns may feel they will never measure up to an older brother or sister. Middle children can feel lost in the crowd and strive hardest to gain attention. And the youngest may feel forever babied and overshadowed.
- The **spacing of children's births** can affect how much time and energy parents have to give each child, especially when they are very young. Siblings who are close in age may both need so much from parents that intense competition is built in from the start.

MELD SPECIAL

Siblings

Factors which affect how intense or disruptive sibling rivalry is, continued:

- Many of the skills needed to get along with others are only acquired with age. The developmental level of very young children does not enable them to willingly accept compromise, delayed gratification, or other points of view. And until their language ability is well developed, children express their feelings primarily through behavior, often disruptive behavior.
- Gender jealousy occurs when children of one sex don't feel as valued or encouraged by one or both parents as children of the other. Sibling relationships are also affected when children prefer playing with kids of their own sex.
- The way children are treated by people outside the family can have a positive or negative impact on sibling relationships. For example, a child whose self confidence suffers because he is picked on at school may have less ability to cooperate with siblings.



How Parents May Reinforce Sibling Rivalry

A child's perceptions of how his parents feel about him and his siblings are a critical influence on his ability to get along in the family. Conflict arises when children compete for parents' attention and admiration, or when they believe others have privileges they are denied.

Normal sibling rivalry is intensified by a child's feeling of being without a special place in the family -- a self doubt that is typically not expressed and is often unconscious in the child. So while mothers and fathers may know they don't love one child more than the another, it's how their children interpret their feelings that counts. By examining their behavior, parents may be able to determine if they are unintentionally fostering rivalry in their children, in particular through favoritism, comparisons, or competition.

- **Favoritism** is a parent's preference for one child. It can be conveyed directly by giving more time, attention, or things to one child, or indirectly, for example by not recognizing one child's attributes or achievements. Children may be concerned about favoritism even when it does not exist. The constant care required by a chronically ill or disabled child sometimes gives siblings the impression that he is favored. The term "special needs" may in fact contribute to this interpretation.

It may be impossible to literally treat children equally. But parents can deal with them fairly, as individuals, understanding and responding to each child's unique needs. And they can only hope that their children understand and accept their actions. In Brothers and Sisters Talk with PACER, the eighteen year old sister of a disabled girl reflected, "My parents treated us equally — but to be equal, Jennifer had to have more direct attention from our parents. We never felt shut out because of her needs, though. Our whole family always got attention."

MELD SPECIAL

Siblings

- **Comparisons and Competition --**

Sometimes parents develop a habit of describing their children by identifying how they resemble or differ from one another. When they routinely compare them, for example by using labels like “the dependable one,” “the sensitive one,” or “the troublemaker,” parents run the risk of gradually noticing only certain kinds of behavior and reinforcing only part of a child’s nature. Children quickly grasp that they cannot expect to receive recognition for their own qualities and abilities, but for how they measure up to their siblings.

It is easy to say that one child is expressive, imaginative, curious, or easily hurt without pointing out that he is more or less so than his siblings. And it is easy to describe the strengths of a child with special needs so he is not labeled slow or weak.

Parents typically praise and reinforce the behavior and characteristics they value most, for example, obedience, academic excellence, athletic ability, or an outgoing nature. If they compare their children, it is often regarding how each demonstrates these favored qualities. Parents may believe that comparing children is an effective way to motivate them. Yet in the long run, when children believe they must compete for their parents’ admiration, develop qualities that don’t come naturally, or deny those that do, their self confidence is undermined. Children thrive when parents cherish them for “being themselves,” when they are praised for following their own interests and natural abilities.

Ways to Help Children Cope

Parents are a child's most important *source of guidance* in learning to cope with problems. The critical first step for parents in *helping* children cope is to maintain their own physical and emotional health. This preserves the energy they need to monitor and respond to their children's behavior.

Parents' own actions are also a powerful example. The way mothers and fathers cope influences the way their children do. By modeling and teaching coping skills, parents offer sons and daughters essential lifelong tools. Some of the techniques described in the "Coping with Stress" chapter can be adapted and taught to children.

How can a parent tell when a child is struggling and needs help? Many siblings are too fearful or too young to be able to ask questions and express their feelings about a brother's or sister's special needs. Some are simply confused and don't know how to approach their parents. It can be easy to believe children are free from worry. By closely observing siblings and providing opportunities to talk, parents promote an atmosphere in which children feel secure about confiding in them and seeking their help.

Parents enhance sibling's ability to cope when they:

- provide information about the special needs condition
- encourage siblings to express their feelings
- model and teach effective communication techniques
- model and teach problem solving skills.

- **Provide Information About the Special Needs Condition**

“I love my brother but I’d like to understand more about his handicap. I don’t really know why he acts the way he does.”

Parents can help by encouraging siblings to ask questions about what they want to know, and by explaining the disability or illness in a way that can be understood at their level of development. (Some parents have benefitted from professional advice about what a child can comprehend at a certain age.) Nevertheless, children often absorb facts slowly and even developmentally appropriate information may need to be repeated frequently over time as siblings’ maturity and ability to understand grow.

In Brothers and Sisters Talk to PACER, a boy reflects that he can’t remember precisely when he became aware of what his brother’s special needs were. “I think my understanding of his disorders came in a step-by-step fashion. As actual situations occurred, my mom would talk about how there were some things Tom couldn’t help or control. She always told me about the things going on in his life that were significant.”

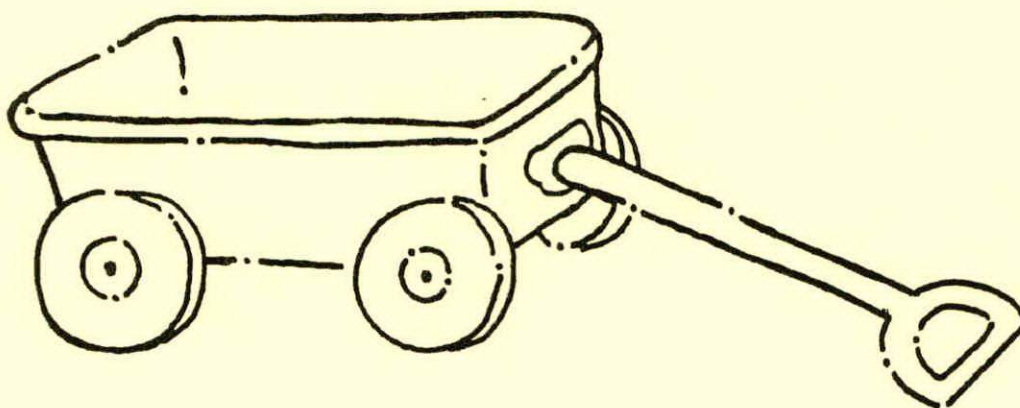
Children also benefit from learning and practicing specific ways to explain a brother or sister’s special needs to others. Equipped with a ready response to questions, siblings feel more in control of potentially uncomfortable social situations. Children also learn by listening to their parents respond to the reactions — including the insensitive remarks — of others.

MELD SPECIAL

Siblings

A child's understanding of a sibling's special needs is also deepened by the opportunity to participate in his care. In After the Tears, Robin Simons suggests that giving children tasks to help a disabled sibling can also defuse resentment over the extra attention he receives. One mother says, "In our house everybody has a task in relation to David. Julie (age 11) makes his lunch every morning. Mark (12) helps him get dressed. We try to keep their jobs short so they don't resent the time they have to help him. The trick is to enable siblings to feel involved and useful without feeling so responsible that they become mini-parents."

"Involving other children in his routines helps the handicapped child too, making him feel like an integral member of the family. He needs to feel that his role is secure and equal to everyone else's. This means being treated the same way, being taken on the same outings and following the same rules as all family members." Another mother said, "We want our other kids to see Jamie as just another—very important—kid in our family. She's not a handicapped child: she's a child with a handicap. That's a big difference."



- **Encourage Siblings to Express Their Feelings**

Helping siblings discuss their feelings may or may not be easy. Parents can encourage them by setting an example: by talking about their own feelings. But a lot depends on how expressive a child is to begin with, and on the way family members are used to communicating with each other. A lot also depends on how willing parents are to hear negative things, and on the way they respond to what their children have to say. Siblings may avoid talking about their feelings because they're afraid of getting into trouble, hurting their parents, or adding to their burden.

"I think parents will have to create communication opportunities between themselves and their children," said one sibling. They "will probably have to ask some leading questions, too, because kids won't initiate telling their folks about some of the bad things they feel. Their feelings can include a lot of guilt and shame — not the kind of things that children feel very proud of themselves for feeling. . . . parents will probably need to draw out their kids. Maybe they won't even get a response at first, but the door should be opened."

It is important that children feel free to express their true feelings rather than what they think their mothers or fathers want to hear. And yet it can be hard for parents to accept negative feelings in their non-disabled children. When parents are doing the best they can in complicated and demanding circumstances, a sibling's perceptions may seem inaccurate, selfish, or unfair. One way to maintain a balanced perspective is to consider each child's stage of development, to be familiar with how any child of that age perceives things, and to avoid wishing he were "more mature."

MELD SPECIAL

Siblings

The first step in encouraging children to talk is to provide unhurried time alone with you. While it may take some work to get them started, once children begin to talk, the best response is simple listening — attentive silence, eye-to-eye contact, and short encouraging comments, such as:

- “I’m listening. Please tell me more.”
- “Would it help to talk about it?”
- “How does that feel?”
- “How did that happen?”
- “What is that like for you?”
- “Do you have some ideas about how to handle this?”
- “Is this uncomfortable? Would you rather talk later?”

Other approaches that may help your children feel secure about confiding in you include the following:

- Convey that you understand what your child is saying with occasional comments like “Oh. . . Uh huh . . . Mmm. . . I see. . .”
- Acknowledge emotions by naming them, e.g., “That sounds frustrating!” This lets your child know you understand what he is saying. Labeling also helps children learn to identify their feelings — the first step in dealing with them. Mothers and fathers play a critical role in providing children with a vocabulary of emotions.

MELD SPECIAL

Siblings

Other approaches that may help your children feel secure about confiding in you, continued:

- Acknowledge what you understand your child wishes would happen, perhaps by giving him his wish in fantasy, for example, "I wish I could make it easier for you to be alone with your friends right now!"
- Talk about specific behavior you've observed and wondered about in your child, for example, "I've noticed you've started to leave the house whenever I do Eric's therapy." This conveys your concern and may break the ice by giving him something specific to discuss.
- Reassure your child that strong and negative emotions are normal in everyone. Tell him it's important to you to know when he's angry or upset, and that he's not going to get in trouble for having negative feelings.
- Suggest an emotion you suspect your child has, for example, "Tom, I bet you feel really mad sometimes because of all the time and attention Angie's treatments take." It's a huge relief to a child to simply feel understood. Putting feelings into words can help children diffuse and deal with them.

In Equals in Partnership: Parents of Disabled and At-Risk Infants and Toddlers Speak to Professionals, a mother says, "I remember one time Zach was home for a visit — this was after he was placed — and he had just gotten a new wheelchair which was very spiffy looking, and kids came from around the block because they wanted to walk him in his new wheelchair. My daughter must have been six or seven then, and she came in the house really angry, and she said, 'No one wants to play with me, they just came over to see Zach.' And something went off in me — I was in a rage. I thought, 'You can walk! You can talk! You're a healthy child!' But I didn't say that because I read the right child psychology books, and I said, 'Sounds to me as if you're very angry.' And she said, 'Yes, I am!' And I said, 'It's hard having a cute handicapped brother in a new wheelchair.' And she said, 'Yes, it is.' And that's all she wanted. She wanted to be able to be legitimately pissed off and jealous."

- **Model and Teach Effective Communication Techniques:
"I" Messages**

Parents can help children recognize and express feelings by suggesting specific ways to put them into words. By teaching and modeling communication techniques, parents offer children valuable tools for maintaining healthy relationships.

"I" messages are one technique for expressing feelings constructively. Because they are not only effective but simple to learn and use, many parents find "I" messages contribute a great deal to their family's ability to communicate. Very young children may not yet have the understanding and language ability to construct "I" messages, but by modeling the technique, parents prepare them to adopt it as they become ready.

MELD SPECIAL

Siblings

An "I" message is so named because it focuses on how the person who's talking feels or perceives things rather than on the rotten things he thinks someone else has done. The statement has two parts:

- 1) how I feel, and
- 2) why I feel that way.

For example:

- "I feel very angry when you mess up my toys because they could break or get lost!"
- "When you rip my homework, I get mad because I have to do it all over again!"

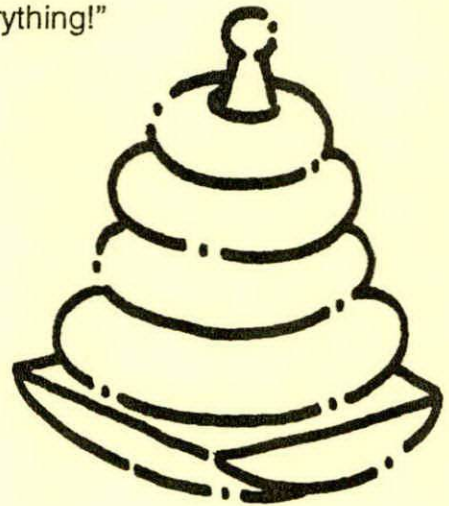
"I" messages are worded to avoid accusing, blaming, and demeaning others. Because they are stated in fairly neutral terms, "I" messages can actually promote understanding during conflict. They are a relatively non-threatening way to let off steam and negotiate with others. And because they focus on specific behavior, "I" messages clarify what others can do differently to avoid future conflicts. When people don't feel attacked or defensive, they may be more willing to be accomodating.

MELD SPECIAL

Siblings

Practice converting the following complaints into “I” messages. If your children are old enough, they might enjoy doing it with you.

- “Cut it out, you creep, you’re wrecking everything!”
- “Stay out of my closet, slob!”
- “Turn your radio down right now!”
- “Get out of here and don’t come back!”
- “Don’t ever play with my toys again!”



- **Model and Teach Problem Solving Skills**

The problem solving process suggested for parents in the “Coping with Stress” chapter is useful for children as well. Problem solving skills promote a sense of mastery, an important factor in an individual’s sense of well being. Siblings who have developed ways to approach and resolve problems are less likely to become discouraged.

Children respond enthusiastically to the structured steps of problem solving. By reviewing the process and helping their children plan and practice ways to implement it — and by using it together to resolve problems affecting the whole family — parents provide children with a powerful tool for their entire lives.

When Should Parents Worry?

When a sibling exhibits troubling behavior that may or may not be a reaction to having a brother or sister with special needs, parents may be confused about its meaning or about the best way to respond. Changed or disruptive behavior can be a normal temporary sign of a child's efforts to cope with a transition or stressful event. However, when the behavior persists in an extreme form over many weeks; when it interferes with the child's development, safety, or normal activities; or when it significantly disrupts family life, parents should be concerned. Professional advice can help parents understand and improve the situation.

Behavior that warrants intervention includes:

- lack of interest or avoidance of other people
- extreme fearfulness, aggression, or conflict with other children
- excessive anxiety, worry, tension, or nervousness that may be vague or may be associated with particular situations
- continual sadness, boredom, lack of energy, or sense of hopelessness
- emotional flatness or lack of responsiveness, extreme passivity
- marked change from usual patterns of behavior, e.g., a quiet child becomes wild
- inability to adjust to routines, rules, and limits set by parents and other caring adults

MELD SPECIAL

Siblings

Behavior that warrants intervention includes, continued:

- inability to recover from episodes of frustration, loss of control, or emotional upset
- disturbances in eating, sleep, bowel and bladder control and other routines
- problems with attention, concentration, or organization in play and activities
- child suddenly becomes accident-prone or continually takes risks
- persistence of self-comforting habits or mannerisms (e.g., rocking, thumbsucking, masturbating, eating, or sleeping) to an extent that interferes with other activities.

(from Susan Erbaugh's "Mental Health Needs in Early Childhood")

Finally, What Do Siblings Recommend?

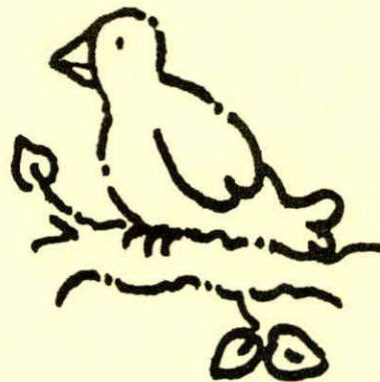
In an effort to understand siblings' experiences, several authors have wisely consulted the key source: children themselves. In their book, Brothers and Sisters: A Special Part of Exceptional Families, Thomas Powell and Peggy Ogle report the suggestions for parents made by a panel of siblings. They recommend that mothers and fathers:

- accept their child's disability or chronic illness in order to help others do the same
- express their own thoughts and feelings to the whole family
- regularly spend time alone with each child
- listen to siblings and allow them to express negative feelings
- tell each child what they admire about him and acknowledge his contribution to the family
- obtain children's books or other resources about special needs
- involve siblings in decision making and care of the child with special needs while maintaining appropriate limits on how much they are expected to do
- allow the child with special needs to do as much as she can for herself
- use respite care and other support services

MELD SPECIAL
Siblings

Siblings recommend that mothers and fathers, continued:

- be fair
- teach siblings positive ways to interact
- let siblings settle their own differences
- welcome other children and friends into the home
- recognize situations that are stressful for siblings and plan ahead to minimize negative effects
- encourage “normal” family life and activities
- join or promote the development of sibling programs and support groups
- when appropriate, consult professionals to help siblings cope with stress
- don't expect siblings to be saints.



MELD SPECIAL

Siblings

In his article, "Sibling Rivalry," Ronald Pitzer also suggests that parents:

- allow the child without special needs to have his way at least half the time. To protect their disabled or chronically ill children, parents sometimes tip the scales in their favor.
- emphasize family unity and permanence. When children "tattle," remind them that no matter how unpleasant the sibling's behavior may be, he is still "one of us."
- listen to their children to help them understand the others. Siblings often have valuable insights about what a brother or sister is struggling with, thinking about, or trying to express.

If you find yourself thinking that a parent would have to be just about perfect to achieve family cooperation, remember this: it takes years to create serious, uncorrectable problems. Even in the most healthy, well functioning families, life is something like a balancing act or teeter-totter: some days, some seasons, some years are better than others.



MELD SPECIAL

Siblings

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MELD SPECIAL

Siblings

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MELD SPECIAL

Siblings

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- Wright, Betty R. My Sister Is Different. Wisconsin: Raintree Children's Books, 1981.

MELD SPECIAL

Siblings

Organizations:

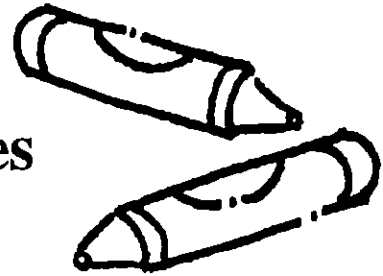
The Sibling Information Network
University of Connecticut
Box U-64, School of Education
249 Glenbrook Road
Storrs, Connecticut 06268
1-203-486-4031
Newsletter available.

A Sibling Program
ARC-Fresno Children's Center
5755 E. Fountain Way
Fresno, CA 93727
1-209-291-0611

The National Sibling Network
P.O. Box 300040
Minneapolis, MN 55405
1-612-872-1565
Addresses the needs of siblings and adult children
of persons with mental illness. Newsletter available.

Siblings for Significant Change
105 E. 22nd St.
New York, NY 10010
1-212-420-0430.

Learning Activities



GETTING ACQUAINTED ACTIVITIES

I. Have group members briefly describe their childhood relationships with their siblings, using specific incidents as examples. You might also ask if and how these relationships have changed over time. Ask those group members who are “only” children to comment on that experience or to describe their childhood relationships with close friends or cousins.

II. Ask group members to describe one thing they really like about each of their children and how they observe those characteristics enhancing their sibling relationships. If members have only one child, ask them to describe the positive qualities he brings to his relationships with playmates.

MELD SPECIAL

Siblings

Activities related to the idea that relationships between children with special needs and their siblings are more like than unlike other sibling relationships.

I. Large Group Discussion

Ask parents for their views on the advantages and disadvantages of being the firstborn, the second, middle, or youngest child in a family. You may choose to use the following questions in a follow up discussion:

- If you grew up in a family with more than one child, how did the factors we've discussed affect you and your siblings?
- If you have more than one child, which of these factors do you observe in them?
- Are there ways to minimize the disadvantages of a child's position in the family's birth order?
- How might characteristics of birth order be affected by a child's disability or chronic illness — for the child with special needs himself and for his siblings?

MELD SPECIAL

Siblings

II. Small or Large Group Discussion

Review the factors summarized in the chapter as influences on sibling relationships, e.g., temperament, spacing, gender, outside influences, etc. You may want to actually read the section to introduce this discussion.

Ask group members to evaluate the importance of each factor — in general, in their own childhoods, and among their children. You may want to include the following questions in a follow-up discussion.

- What effect might a special needs condition have on these factors?
- If you have more than one child, which of these factors seem to affect your children's relationships?

III. Large Group Discussion

Read the following to your group:

Psychologists Brian Sutton-Smith and B. G. Rosenberg asked the following questions of several large groups of fifth and sixth grade students from two-children families:

- "How do you go about getting your brother or sister to do what you want him or her to do?"
- "How does your sibling get you to do what she or he wants you to do?"

MELD SPECIAL

Siblings

The following list includes the many strategies children reported:

Beat up, belt, hit, scratch, punch, pull hair, bite, promise, boss (say, "Do it, Shut up"), bribe, blackmail, ask, tickle, flatter, ask to do something because I'm older, get angry (shout, scream, yell, get mad), play tricks, complain to parent, cry, pout, sulk, take turns, tell tales, attack things (hide toys, spoil bed), explain, reason, persuade, ask other children for help, break things (toys, let air out of tires), do something for the person, ask for sympathy, take things (ride bicycle, steal toys), make feel guilty, bother them (turn off radio, change TV channel), pretend to be sick, pray, tease (name calling, pester, nag), threaten to tell, make a wish about it, stop from using phone or bathroom, spook them, exclude (can't play, can't go with, lock out of room), give things (candy, money, toys), give them their choice (watch TV, play), be nice, sweet talk.

"Mind boggling," the authors write.

Ask parents to consider the following:

- Why do siblings feel they have to use so much power and coercion to get what they want?
- Are such struggles inevitable between brothers and sisters, or are there ways to remedy the situation?

MELD SPECIAL

Siblings

Activities related to the idea that children are affected in both positive and negative ways by having a brother or sister with special needs.

I. Handout, Small and Large Group Discussion

Divide into three groups and give each of them one of the following letters to "Aunt Blabby." (A copy of these letters is also found in Handout a.) Have parents read the letter and discuss the questions below. You may want to write the questions on a newsprint pad or easel. Have each group compose a letter in response to the child. Ask someone in each group to take notes in order to summarize its discussion when the large group reconvenes.

- How would you state the problem from the letter writer's point of view?
- What are the child's feelings?
- What might the parents' feelings and motivation be?
- What could parents do to improve the situation for the letter writer?

MELD SPECIAL

Siblings

Dear Aunt Blabby,

Sometimes I feel like the invisible man. My brother has Down Syndrome and needs a lot of things that seem to take up all my parents' time. It seems that the only time they pay attention to me is when I get into trouble, and that's no good. How do I let them know they have two kids instead of one?

Signed, The Invisible Man

Dear Aunt Blabby,

I have a problem that maybe you can help me with. Just because my brother has a chronic illness and I don't, my parents expect me to be some sort of "Superkid." Does that seem fair to you? What can I do?

Signed, Not a Superkid

Dear Aunt Blabby,

My brother is autistic and when I get mad at him, my parents yell at me and tell me that I shouldn't get angry with him because of his problem. Then I feel bad. But it doesn't seem fair. I thought we were supposed to treat him like everybody else.

Signed, I Don't Get It

(from Sibshops: A Handbook for Implementing Workshops for Siblings of Children with Special Needs by Donald Meyer, et al.)

MELD SPECIAL

Siblings

II. Panel Discussion

Invite three or more siblings of children with special needs to talk to your group. Select older school age children or young adults, and try to recruit boys and girls whose siblings have different disabilities or chronic illnesses. Ideally, the panel should be composed of children who are not related or known to your group members. This is a non-threatening opportunity for parents to learn how some siblings feel about their circumstances, information that might give them insight into their own children's behavior.

Begin the meeting by having panelists introduce themselves and identify their brother or sister's special needs. Ask parents to introduce themselves and briefly describe their children.

MELD SPECIAL

Siblings

Tell panel members in advance how much time they will have (e.g., 5-10 minutes each), how many others will be on the panel, and that you plan a question and answer session after they have spoken. You may want to mail the panelists a short list of questions you'd like them to answer, for example:

As you think about your family and what it is like when one child has a disability or chronic illness,

- What has been difficult for you about having a brother or sister with special needs?
- How do you feel you have benefitted from the experience?
- What have your parents done especially well in raising you and your brother(s) or sister(s)?
- What do you wish they had done differently?
- What advice would you give other kids who have a brother or sister with a disability or chronic illness?

MELD SPECIAL

Siblings

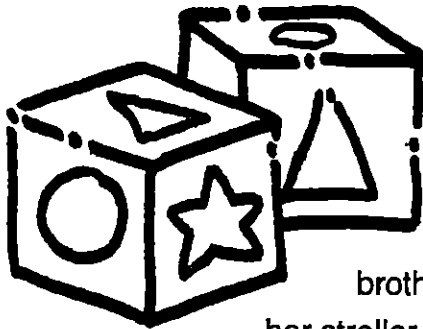
III. Handout and Group Discussion

In small groups of three to five, ask parents to read the following stories about siblings of children with special needs and answer the discussion questions for each. (These stories can also be found in Handout b.)

Melissa's story

Melissa hates to bring her girlfriends home. Kelly, her older sister, uses a wheelchair and doesn't have any friends in the neighborhood. So whenever Melissa brings friends home to play, Kelly barges in. She always wants Melissa's friends to play with her "stupid" little dolls. Melissa's friends are usually polite to Kelly, although a few of them will look at each other and snicker when Kelly starts up. Then Melissa gets red in the face and sometimes wishes Kelly would go visit someone else and not come back.

- List all the feelings Melissa might have about her situation.
- Why does Kelly bother Melissa when she has company?
- What could Melissa do to prevent Kelly from bothering her and her friends?
- How would you respond?
- Do your children have problems when friends come over?



Jerome's story

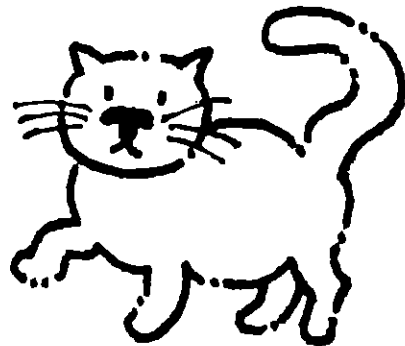
Even though she's severely retarded and can't see, Bonita's a lucky little girl. She has an older brother, Jerome, who is crazy about her. He puts her in her stroller and takes her out for walks, and sometimes sings her songs which make her smile and laugh. More than once, he's even changed her dirty diapers. Some of Jerome's friends wonder why he spends time helping a sister who can't see or walk or play games. One of his friends actually asked him why he did it. Jerome replied, "Because I know if I was retarded and Bonita wasn't, she'd do the same thing for me."

- Why is Bonita so lucky?
- What are some ways in which your children are unselfish to their special sibling?
- How would you respond if you were Jerome's and Bonita's parent?

Vanessa's story

"Dear Diary," wrote Vanessa. "I have a terrible secret that I have never shared with anyone. Before my brother, Christopher, was born, I was the youngest in our family. I got a lot of attention from my folks and my brothers and sisters. When I was four, my mom told me we were going to have a new baby in the family. I wasn't too happy about that news. Just before Christopher was born, I had a temper tantrum and my mom got real upset with me. Two days later, my mom had Christopher. I remember that he couldn't come home from the hospital right away because something was wrong. Chris is now eight years old. He acts very strange. He can't read and the few words he can say usually don't make sense. Dear diary, my terrible secret is that I think Chris's problems are all my fault because I made my mom so upset."

- List all the feelings Vanessa might have about her situation.
- How can parents find out that a child has this kind of troubling secret?
- What could her parents do or say to help Vanessa feel less guilty?



MELD SPECIAL

Siblings

Allen's story

Last month, Allen's parents told him the bad news: Allen's little brother has Down Syndrome. "He'll be just like us in almost every way," his mother told Allen, "except it will take him longer to learn. The doctor said that he'll probably be mentally retarded."

This year, Allen has been having a terrible time in math and he almost flunked his last two tests. Today, when he had difficulty with another test, Allen wondered, "Am I retarded, too?"

- List all the feelings Allen might have about his situation.
- Why did Allen wonder if he was retarded?
- How can parents find out that a child has this kind of worry?
- What could Allen's parents do or say to help Allen worry less?

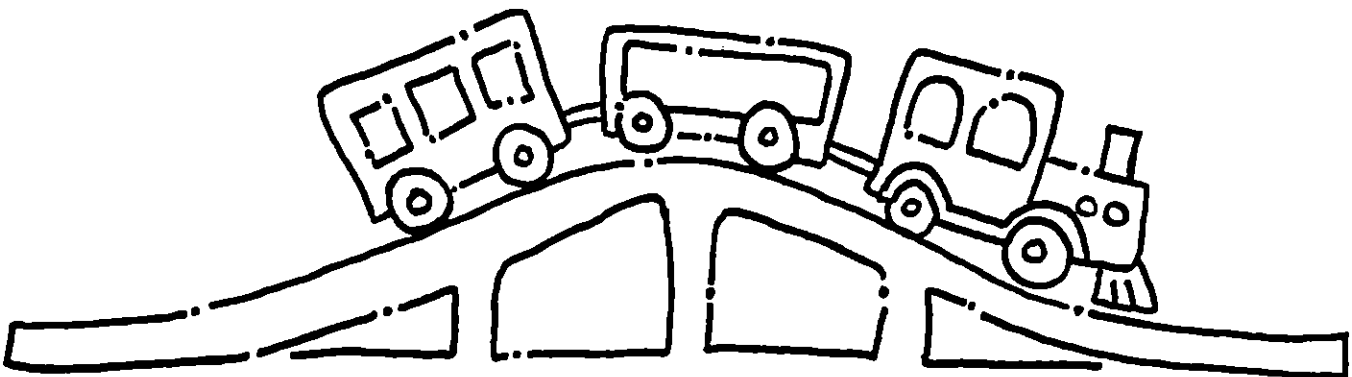
(adapted from Living with a Brother or Sister with Special Needs: A Book for Sibs by Donald Meyer et al.)

MELD SPECIAL
Siblings

Activity related to the idea that parents can promote a positive self image for each child and enhance relationships between siblings.

WORKSHEET AND DISCUSSION

Ask parents to list their children and write the positive, special qualities each child brings to the family. Then have each group member briefly describe these attributes to the group. Ask parents if they think their children are aware that they appreciate these qualities in them. As a group, generate ways parents can reinforce positive traits so that each child feels he has a valued place in the family.



MELD SPECIAL

Siblings

Activity related to the idea that siblings can develop skills to cope with difficulties caused by having a brother or sister with special needs.

SMALL GROUP BRAINSTORM AND WRITING ACTIVITY

An important part of encouraging children to express themselves is teaching them to identify their feelings. By discussing children's reactions to different experiences with them, parents can help them understand their feelings and provide them with a vocabulary for discussing emotions.

Have parents break into small groups to develop lists of words that identify feelings, e.g., angry, afraid, sad, lonely, happy, excited. Then ask them to generate words describing the range or degree of each emotion on their list. For example, anger can range from annoyance to rage, fear from uneasiness to terror.

Finally, have parents develop examples of "I" messages that include some of these feelings. You may want to review or read the information on "I" messages from the chapter (pp. 27-29) to prepare them for this part of the exercise. Ask parents to comment on how "I" messages are likely to be received compared to a more accusing way of saying the same thing.

Chapter 5

Handouts

Siblings

Dear Aunt Blabby,

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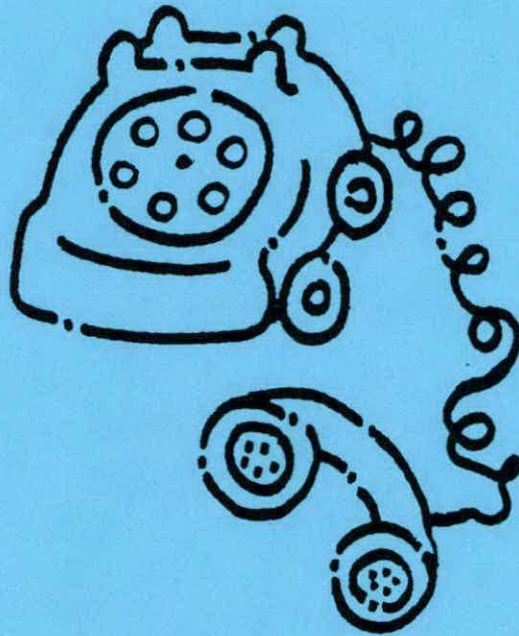
- List all the feelings Allen might have about his situation.
- Why did Allen wonder if he was retarded?
- How can parents find out that a child has this kind of worry?
- What could Allen's parents do or say to help Allen worry less?

(adapted from Living with a Brother or Sister with Special Needs: A Book for Sibs by Donald Meyer et al)

MELD SPECIAL HANDOUT

Chapter 6

Working with Professionals



MELD SPECIAL
Working with Professionals

Working with Professionals

Table of Contents	Pages
I. Introduction For Facilitators	3-10
A. Main Ideas	5
B. MELD's Biases	6
C. Facilitator Focus	7
D. Group Issues and Tips	8-10
II. Content For Facilitators	11-45
A. Parents as Advocates and Case Managers	12-13
B. Parent Roles and Skills	14-16
C. Keeping Records	17-21
D. Researching Resources	22-24
E. Building A Team	25-32
F. Making Decisions	33-35
G. Advocacy	36-38
H. Assertiveness	39-45
III. Resources and Chapter References	47-50
V. Learning Activities	51-62
VI. Handouts	a-e
A. Problem Solving	a
B. Where to Get Help and Services	b
C. Assertiveness Quiz	c
D. Current Source of Information, Support and Services	d
E. Expected Role of Parent and Doctor	e

Introduction for Facilitators

It isn't easy for parents of special needs children to assume active roles in getting the professional care and services their children need. Encouragement and knowledge can help parents take on these challenging roles.

Parents encounter varying degrees of difficulty in managing their children's care. Most parents do not initially have all the skills they need to care for their special needs children. If a child's disability or chronic illness is severe or rare, the parents may have great trouble finding help. Other parents may find that services are available, but not for a child of their child's age. Or a family's financial situation may make the help their child needs nearly impossible to obtain. In addition, small community service systems may not have enough professionals or suitable services available, and large service systems may be confusing. Either way, bureaucracies and paperwork can be intimidating and parents can be overwhelmed by official procedures and language.

Even when parents find the services they need, they may discover that the professionals take over the care for their children instead of working with them to provide that care. When doctors and other care-givers have been in practice for many years without meeting parents who are actively involved in their children's care, they may not know how to respond to parents' assertiveness about their children's needs. Others work under such enormous time pressure that they feel they can't stretch themselves further to respond to parental concerns. Some feel they have legitimate concerns about what they consider inappropriate actions by unknowing parents. And some professionals feel that their authority is threatened by the parents' efforts and knowledge, or they may simply not want parents involved.

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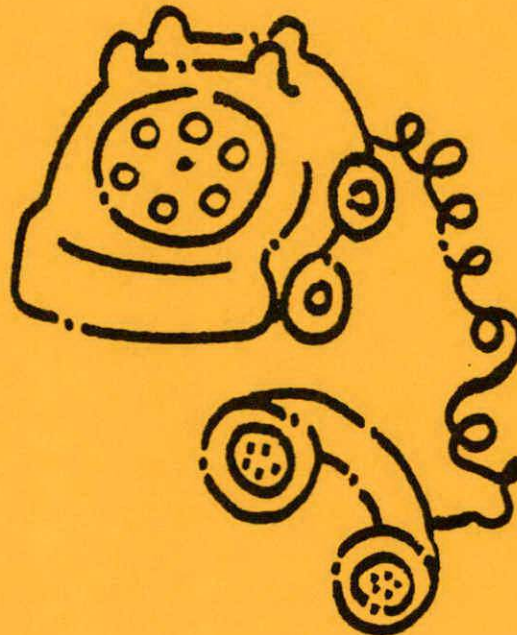
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Whatever the reasons, professionals who are not supportive of parents' involvement make the parents' jobs as advocates for their children even more difficult. The actions and attitudes of such professionals may intimidate the parents. The parents may worry about offending the professionals. . . and that the professionals might retaliate against their children. Parents need to learn what they can expect from a parent-professional relationship; they need to develop confidence in their knowledge of their options and in their ability to work effectively with the professionals.

This chapter helps your MELD Special group identify and discuss the skills and qualities they need to become effective advocates for their children. It teaches them how to build a community resource team: first by sharing information about resources for screening, diagnosis, financial help, support, child care, respite care, equipment, supplies, and other needs; then by learning and practicing one or more decision-making strategies; and finally by practicing assertiveness in asking questions, defining and resolving problems, collecting resources, making decisions, and letting professionals know what they, their families, and their children need. The chapter will also encourage them to develop steps for resolving unsatisfying relationships with professionals involved in their children's health care or education.

Main Ideas

- Parents of children with special needs can be parents *and* advocates or case managers for their children.
- Parents of children with special needs can build a resource team of professionals, friends, and others in order to help their children develop to their full potential.
- Assertiveness skills will help parents of children with special needs let professionals know what they, their families, and their children need.



Meld's Biases

- First, and most importantly, a parent of a child with special needs is a parent of a child.
- Parents may not feel they have all the skills and qualities of an advocate, but most skills can be learned and developed. The important thing is to get started.
- There are many choices to make for a child with special needs, and parents have the right to make those choices.
- There are many benefits to taking a team approach for serving young children with special needs.

Facilitator Focus

As you read this material and think about facilitating meetings on this topic, consider the following questions:

- To what degree have you chosen to be involved in the decisions and the direct care for your child?
- What are your primary sources of information, support, and service?
- What skills have helped you become an advocate for your child?
- How have you learned to trust your own judgment in finding services that "fit" your child and your family?

Group Issues and Tips

The discussions this chapter encourages may stir up current, or even very old, anger in parents. Some of the anger will seem justified and will be easy for other group members to sympathize with. However, at other times a parent may be angry for what seems to be no reason at all. Consider the possible roots of such anger.

- Some of it may arise out of fear and anxiety. The group may be able to help those parents express their fears directly or to suffer through their grief.
- Other anger may develop in parents who are tired, preoccupied, or restless. Most of the parents in your group will be tired at some times, especially after lots of testing and conferences, and that tiredness can cause them to become angry more quickly than usual.
- Parents may have unresolved issues from their own childhoods that get activated again when they are dealing with professionals regarding their children. They may be able to recognize that some of their anger belongs to the past; some parents may want to deal with those issues through private counseling.

MELD SPECIAL

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Some parents will have children who have not been clearly diagnosed; they may feel very frustrated because they can't get professionals to give them a clear picture of their children's conditions and futures. Other group members need to talk about their feelings for these parents. They may be afraid to give emotional support or they may not know what kinds of support to offer. When they listen to the parents talk about how it feels to be uncertain about their children's diagnoses, they may feel greater fears about their own children and their parenting skills. Allow all the parents in your group to talk about the feelings these discussions create in them and to discuss the types of support that are most helpful.

The specific cultures that families are part of will influence how they can set up their support networks. You will need to consider how you can help parents improve their parenting skills within their own cultures. Some cultures do not favor assertive roles for parents. Native American or Southeast Asian groups may expect that heads of households or tribal and clan leaders (who may not be the child's parents) should be the ones to make decisions about which special services to use or about whether to use special services at all. You may think the parents should make those decisions, but for the parents it may work better to agree with the decision of their traditional leader than to lose the support of their culture.

Single parents face special problems in dealing with community professionals. They may be socially isolated, and they may have very little money and very little time. Consider how you will guide discussions to be sensitive to the issues they face.

MELD SPECIAL

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Fathers in your MELD Special group may have special problems dealing with professionals. They may struggle with the feeling that they have lost control of their family's future and that they should have that control. If you can help these fathers express their feelings, they will find out that they are not alone.

You will probably need to make special preparations for the discussions in this chapter.

- If you want to have speakers or panel discussions, contact the people you would like to invite several weeks or even months before the date you need them. Give your guests some general information about your MELD Special group and share your questions and goals for the session with them.
- If you are going to have hand-outs, remember to prepare enough of them ahead of time.
- If you can, hand out lists of local organizations and professionals who would be helpful to parents of children with special needs.
- Collect examples of record-keeping methods and ways that people organize their paperwork about their children. These could help others sort out the information they need to keep.

Content for Facilitators

Sometimes I feel overwhelmed. How can I evaluate this program? How do I know this is best? Then I remember that it's a team approach. I'm not in it alone. It's just my job to get the specialists I trust to talk to each other about it. I remind myself that they know programs, and I know my child.

— MELD Special Parent

Gradually, I learned to speak out and take control. I started to say 'no' to doctors if too many tests or appointments were scheduled at the same time. I made lists of questions before each visit and brought another person with me with the same set of questions, so that if I skipped one, the other person would ask it. The two of us could later compare our perceptions of what was said and intended. I had thought of bringing a tape recorder or at least taking notes so that I wouldn't miss any of the details. Instead, I've contented myself by reading Ryan's medical records. Not many details are missed in medical communications. It just seemed that the more I could understand, the better off I would be.

— Maureen Sage,
Exceptional Parent Magazine, December, 1979.

Parents as Advocates and Case Managers

Parents of children with special needs sometimes discover that they need to be parents, advocates, *and* case managers for their children. Many parents coordinate and monitor all the tasks that get the services for their children. Without the hard work and determination of their parents, many special needs children wouldn't get what they need.

An "advocate" is someone who speaks for the rights and needs of another person and tries to make sure those rights and needs are met. Parents love their children and are committed to them. They know their children better than anyone else, so they are probably the best people to advocate for their children.

One mother said, "Thinking of myself as my child's 'case manager' makes it easier for me to ask for the things that he needs. Sometimes I think I can't ask for one more thing for my child because other people will say, 'She's a pushy mother.' Then I remember, 'I'm the manager; it's my job to ask.'"

"Case manager" is a professional term that refers to the person who coordinates the care and services that are provided for another person. A special needs child's case manager may be a county social worker, a public health nurse, a physician, a third party funding source—or a parent. The case manager should help the child get the services he or she needs, so the case manager ought to have extensive knowledge about services and complete information about the child.

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For a parent to be both an advocate and a case manager—as well as a parent—is very hard work. The parent may feel anger, grief, and frustration at being required to fill so many roles. These feelings creep up at each new stage of the child's life: when the child enters a prekindergarten program, meets a new physician, or starts a new therapy program.

Many parents may appreciate having a professional act as case manager for their child. To receive case management services, the family usually must ask the county that has financial responsibility for their child to assign a case manager. That county is usually the county where the child lives. Sometimes it is difficult to convince the county to assign a case manager, however.

Parents can be good case managers and advocates themselves for their children. They can figure out what their children need and which of those needs are not being met. Some parents find it helpful to have a friend attend conferences with them to take notes and discuss the conference with them when it is over. Single parents, especially, may want to ask for such companionship. As a matter of courtesy, the professional staff people should be told ahead of time who is coming to the meeting and what their roles will be.

The tasks that parents can take on as they become advocates or case managers are outlined in this chapter. Parents will have to decide how much they want take on. Most decisions relating to their children can be theirs to make, if they want to. However, some decisions, for instance, about who is eligible for certain services, belong to professional service providers.

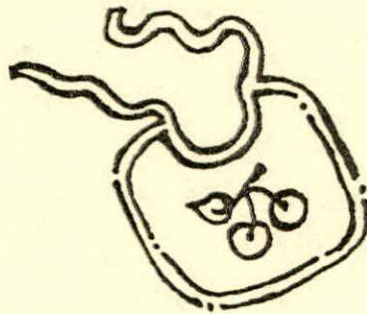
Parents may eventually become advocates for whole groups of children or parents. Many parents of children with disabilities or chronic illnesses have tremendously influenced laws, how much money is available for programs, and on local policies.

Parent Roles and Skills

Parents are in a unique position to serve as advocates and case managers for their children. They are the people with the most consistent relationships with their children; they **know their children** better than anyone else does. They are usually also the people most knowledgeable about their children's medical records and disabilities. Who can do better at insuring that children are provided with the most helpful resources than the people who care for them most and know them the best?

Starting with their knowledge of and concern for their children, parents can develop some other skills that will help them take on effective roles in getting their children's needs met. This chapter will devote one section to each of the following skills:

- **Keeping Records**
- **Researching Resources**
- **Building Teams**
- **Making Decisions**
- **Advocacy**
- **Assertiveness**



As parents develop these skills, they will feel more confident dealing with professionals and providing for their children. Most parents won't think they have good skills in all of these areas; some will be afraid they can't even develop the skills. But parents who have been in MELD Special groups in the past emphasize that the important thing is to get started. Most parents can learn these skills and get better at them as they practice.

MELD SPECIAL

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A few other skills are worth mentioning. Parents will find themselves developing these over time. In some cases, they may want to get special support to encourage these skills.

Communication skills. Parents of special needs children end up talking with a lot of people. They talk in person, they talk over the phone, and they talk through letters. The better they are at communicating, the better they will meet their own and their children's needs. Some parents may want to take special communication courses or practice exercises from the assertiveness section to improve these skills.

Patience. The parents in a MELD Special group probably all know that they need patience. They need patience with their children, with professionals, with bureaucracies, with each other, and with themselves. Some of the parents may be able to explain to others how they gradually came to be less impatient.

Stress Management. Parents need the sense to take time out when they are tired or burned out. They won't achieve much when they are forcing themselves to work too much or too long. It may help them to review the MELD Special chapter on coping with stress.

Introspection. Parents who can sit back and take a look at themselves will be able to notice if they are burned out, or if they are being over-protective of their children, or if they are angry for reasons other than the things they thought they were angry about. The MELD Special group can help many parents begin to look at themselves and their behaviors in a non-threatening way.

MELD SPECIAL

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Humor. People can retain their energy and enjoyment of life much better when they learn to laugh at the delays, foul-ups, and messes of life as well as about its joys. Experience gives many parents this grace.

Emotional Acceptance. Parents who can accept and then channel their negative feelings—anger, disappointment, grief—into constructive activity, find their emotions to be a source of energy instead of an emotional drain. They need also to develop the ability to let go and realize their own limitations; no one can do everything. Parents who want help with this may want to find group or individual counseling.

Transportation Resources. Having a car is not exactly a skill—but the ability to get transportation services is. All parents need to discover the best ways to get themselves and their children around. Some need to learn to drive; others need to get a bus schedule.

Entertainment. Any parent who has waited with a child in a doctor's office knows that keeping the child happy while waiting is a great skill. It may call for creative planning (wrapping up small gifts like raisins or toy cars for the child to unwrap while waiting) or refusal to be ashamed (perhaps by a child who is in pain and crying or by other people who stare). Parents can share tips on how to survive these ordeals as easily as possible.

Keeping Records

Parents are usually the people who know the most about their children's medical records and disabilities. If the parents don't remember what has happened or don't keep clear and complete records, then nobody will know very much about what is going on with the children.

Parents are also the people whom children have to depend on to follow through with their treatment plans until the children can take on responsibility for their own care. Parents are the ones who usually must work with the child on at-home enrichment, stimulation, and remedial activities. The parents are the ones who need to learn to handle the equipment and medications that their children's conditions may demand. The parents are the ones who must remember appointments, prepare for them, and get to them. Parents are the people who let doctors and other professionals know what is working for their children and what is not. Parents who don't keep good records are not able to carry out the services that their children need.

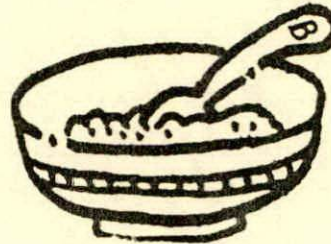
Parents need to learn to be keen observers. They need to notice what is going on with their children. They need to learn to keep accurate, complete records. And they need to find efficient ways of organizing the records they keep so that they can find information when they need it.

MELD SPECIAL

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In order to be better observers, parents learn to take notes. First they can list things they want to watch for, such as:

- Their children's behavior at home
- Behavior guidance techniques they have tried and their children's reactions
- Their concerns
- Their children's allergic reactions
- Their children's schedules
- Their children's likes and dislikes
- Their own priorities for change
- The operation and reliability of equipment they must use for their children.



Parents should be encouraged to develop their own lists of things to observe about their children at home. The lists may include only the items above or many that are specific to a particular child and family.

Parents also need to keep records of their interactions with the professionals who serve their children. Sometimes to do that they need to learn the terminology used by those professionals. They can start by keeping lists of special terms and then asking the professionals they work with or other people they trust to define them. Gradually they will be comfortable using those terms themselves.

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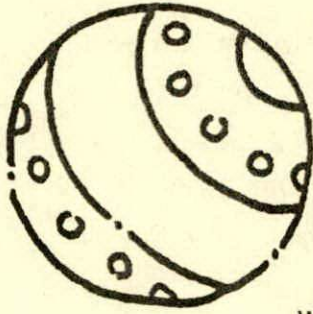
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When the parents are dealing with professionals they should write nearly everything down at first. They have to process much information in a short time and under a great deal of pressure, so it isn't possible to remember it all or even respond to it all when it comes. If the parents have written down the information they are given, they can read it calmly later and figure out exactly what it means and what they think about it. Then they can transfer the things they need to their calendars or to other specific files of information they might keep.

They should keep records about growth, about immunizations, about types of therapy and educational services their children receive, about surgeries, about hospitalizations, and about other services. They need to keep complete written records about program decisions and plans and about the next steps that are going to be taken and who will take those steps. Each type of record could be kept in a separate file. Every time the parents write something into the files, they should date the entry and include information about the date the immunization or service took place, about where the thing they are writing about happened, and about who provided the service. They should keep copies of treatment plans, medical and dental records, evaluation reports, test results, and letters professionals send them regarding their children. They need to write down addresses and phone numbers, even if they don't think they'll need those addresses or phone numbers again. They need to keep the notes they make before, during, and after any meetings, phone conversations, or informal discussions they have with professionals. As part of the treatment records they keep, parents should write down whether particular services, treatments, and prescriptions seemed to help or not.

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Working With Community Resource Personnel



Keeping track of all this information is not easy. Some of it could be put on an appointments' calendar that the parents keep even after the year is over because it serves as an excellent reminder of when things happened. Growth and achievements could also be recorded on a calendar. Other kinds of information will need special files and plenty of paper. Parents will have to each develop systems of organizing the information that make sense to themselves.

Parents who keep this kind of information, organize it so they can find the bits that they need, and take their records with them when they talk with professionals, are parents who will be listened to by the professionals. Instead of saying, "I think something is wrong with my son," these parents will be able to say, "Since you prescribed medication X to my son, he has not slept more than two hours at a time." Whenever parents can use specific details when talking with professionals, they are more likely to get the services they need.

MELD SPECIAL

Working With Community Resource Personnel

Often it is wise for parents to write letters to professionals after a meeting telling the professionals what the parents think was discussed and decided at the meeting. A parent might write, "From our discussion on November 6, I understand that my child will be receiving the following services. . . ." That way if the parent is wrong, the professional is likely to contact them and clear up the misunderstanding. If the professional has a tendency to forget what he or she has agreed to do, the letter will give them a forceful reminder.

Parents of special needs children are probably the people who know those children best. One parent said, "I am still learning what it all means. And much of what I think I know is constantly subject to change." Sometimes parents will feel that they don't know much at all, but they still probably know the most. Other people have only brief interactions with the children, so the parents are the ones who can speak up for them the best. The work it takes to observe what is going on with a child and keep records will pay off.



Researching Resources

Learning about what resources are available to special needs children and their families is a huge task. But it is not quite so huge for parents who keep good records. Those parents are able to figure out from their children's specific needs and histories what kind of services they need. They don't have to know everything—they only have to know where to get the specific services they or their children need. These parents don't ask the vague question, "Where can I get help for my child?" Instead they are able to ask specifically, "Where can my child get help with this particular problem?" or "Where can I find a physical therapist?"

Parents who decide to learn about the resources available for their children will have to become comfortable asking questions. They need to know when to ask and whom to ask. Sharing ideas in the MELD Special group and practicing asking the questions can help many parents become comfortable with this role.

The MELD Special group is also an excellent source of information about what services are available. Parents who come to know other parents who have children with similar needs can get information about sources of help from those parents. Parents can also get information about services from professionals they already know or have received help from. They can call their county social services, look in the yellow pages, or call the resources listed in this chapter. The important thing, once again, is for the parents to get started. Once they learn a little bit about the service network, it will be easier for them to learn more.

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Parents may need special help in finding financial resources. They need to know about what kinds of financial assistance are available to them, what sources that assistance comes from, and how to apply for it. They also need to know about insurance and tax laws in order to get the money that may be available to them from those sources.

Parents may at first be especially intimidated by laws. It is worth their while, however, to take the time to find out about laws that relate to their children and to them. Both federal and state laws set down the ground-rules for the services that are provided for children with special needs. Laws that parents will want to look into include:

- Section 504 of the Rehabilitation Act
- The 1963 Mental Retardation Facilities and Community Mental Health Centers Construction Act;
- The Social Security Amendments for Intermediate Care Facilities for the Mentally Retarded, 1965 and 1971;
- Title XVI of the Social Security Act, 1972;
- The Vocational Rehabilitation Act Amendments, 1965 and 1973;
- The Education of All Handicapped Children Act, Public Law 94-142;
- The Family Rights and Privacy Act;
- The Developmental Disabilities Act, Public Law 100-146;
- The amendments to the Education of the Handicapped Act, Public Law 99-457 (These authorize preschool programs for three- to five-year-olds and early intervention for infants and toddlers with disabilities.)

MELD SPECIAL

Working With Community Resource Personnel

The details of these laws are not included in this chapter because how they are interpreted and used constantly changes. What a law means in one state or school district may not be what it means in another. To get copies of any legislation, parents can contact their state senator's office. To know how the law is used in their area, they will need to talk with other parents or professionals. They could contact the local Association for Retarded Citizens, their state-level office of services for the handicapped, or Legal Aid. The groups listed at the end of this chapter might be helpful.

Parents need to know what a law requires. (The term "mandates" might be used in the law for "required.") If the law says that certain services are mandated, but if they are not being provided, parents can quote the law to whomever ought to be providing the services. Showing that they are informed may help parents get the services their children need and have a right to. On the other hand, sometimes service providers get uncomfortable and defensive when they recognize that parents know what they ought to be doing—parents will have to evaluate the situation to determine what is the most effective method of getting their goals met.

Building a Team

A resource team is like a net that supports and nurtures a special needs child. The parents are the most important strands in that net, but they cannot support their child well all by themselves. Parents do well to build a resource team of professionals, friends, and others in order to help their child develop to his or her full potential. Together all the people in the team can make a net that adequately supports the child.

A team approach to meeting the needs of special needs children has many benefits. It is better for the children, better for the parents, better for the friends and informal support people, and better for the professionals involved.

- Children benefit when they receive services from a team of people who cooperate and share information. They see adults working together; they are given a variety of influential parental role models; they are able to understand what to expect from different adults. They benefit because their parents are less stressed by having to do everything themselves. They learn that they can have some control over their care and that they can participate in decisions. They tend to come to know themselves better, get higher self-esteem, and learn self-advocacy skills more quickly than do children who have contact and receive care from fewer cooperating adults.

MELD SPECIAL

Working With Community Resource Personnel

- Parents benefit from not having to provide all the services themselves. They can relax with the knowledge that other people will be available to support their children, even when they themselves are burned-out. In addition, the parents can feel secure that they have a legitimate partnership role with professionals—that their decision-making roles and parental power are not being taken over by others. They have a chance to contribute to program plans, they are included in the passing of information about their children, they are given structured opportunities to provide feedback and to discuss related issues. As they grow more comfortable with the team, they will feel themselves growing personally and their belief in their own competence increasing. They will gain an overall sense of how the service systems work, so they will be able to find other assistance more easily when their children need it.
- Friends and informal support people benefit from being included in the team. Too often their support and importance is not acknowledged. And too often they are not asked to provide the services that they could provide and that would benefit the children. Grandparents, neighbors, friends from support groups and churches—all are people who could be asked to go with the parents to conferences, to provide extra tutoring for children or to give the parents a break from childcare. They will take their responsibilities more seriously if they are included in some discussions about the children's needs and if their support is verbally recognized.

MELD SPECIAL

Working With Community Resource Personnel

- Professionals benefit when there is a treatment team. They are given more complete information because it comes from a variety of sources. They can come up with and select from a greater number of ideas for treatment planning when several informed people contribute to the process. They can do better planning and provide better services when they know what else is being done to support the children. They can trust that the treatment plans they devise will be carried out if all the people involved in providing that service (the parents, grandparents, social workers) have agreed to it. Professionals who are working as part of a team can act more human; they don't need to be all-knowing and solely responsible. They can receive feedback from parents and others and they can contribute their comments on other aspects of service.

Usually, the parents are the ones who coordinate the service teams for their children. It's not unusual for MELD Special parents to work with up to twenty professionals who are involved in their children's care. Many of the people on the team will never even talk directly with one another. Instead, the parents are the carriers of information among the various other service providers. The parents can set up meetings between some of the service providers or ask them to discuss an issue with one another, but often the parents are the only ones who have most of the information and know all of the providers. Sometimes, other service professionals disagree with one another. Then the parents need to be strong advocates for their children's needs. (Parents need negotiation skills not only for working with professionals; often they need them to work with the team at home, for instance, to address frustrations among their children about the special attention and time given to the child with special needs.) Beyond managing the team, the parents are also the ones who can best evaluate what works and why and decide how to proceed.

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It is often helpful for parents to invite a variety of people to participate in decision-making. They can consider asking a daycare provider or teacher or therapist, any of whom can add another viewpoint about their children's need and capabilities. Involving others in decision-making and service provision can be time-consuming and physically exhausting, so parents will need to plan ahead for the effort involved and set priorities for what they want to concentrate on.

Parents could consider these suggestions when setting priorities about whom to include in the service team, what problems to focus on, and what steps to take next.

- Identify and rely on professionals they feel they can trust.
- Distinguish between short-range and long-term issues and concerns.
- Balance the costs and benefits of each part of the plan for their children.
- Sequence the options logically. For example, they might say, "If _____ doesn't work, then we can still _____."
- Consult other parents who have followed similar courses of action.
- Compare all ideas to see if they fit with their personal style and with what their common sense tells them.

That first point is very important. To support their children, parents need to develop positive working relationships with professionals they trust. They are the only ones who can decide how much they trust any one professional. If they become uncomfortable with one service provider, they can try to substitute that professional with another whom they feel more at ease.

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Sometimes parents feel that a service provider is lying to them. Most professionals do not intentionally or consciously deceive, exclude, or manipulate. They intend to be there to help parents help their children. It is useful if parents remember that professionals are often overworked, underpaid, and working with limited resources. Sometimes a professional needs the support and understanding of the team in order to feel refreshed enough to do his or her job well.

If parents feel frustrated with the vagueness of a professional, it might help them to remember that sometimes professionals cannot be exact because medicine and behavioral sciences are not exact. Some problems can be described in more than one way; others are very hard to describe even though everyone can tell they exist. Sometimes professionals just don't know what's wrong.

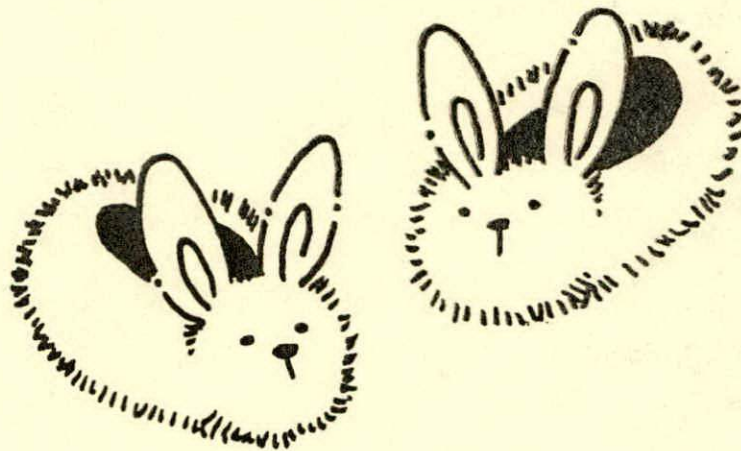
On the other hand, professionals may try to deny problems. Sometimes they provide incomplete and vague information. Sometimes they deny or gloss over a problem. They have expectations for the children with whom they work, just like parents do, and they might not want to face their disappointments directly. Other professionals might avoid giving bad news because they can't deal with parents' pain or anger toward them or because they don't know what to do about it. Unfortunately, some teachers or professionals begin to avoid families who have a large number of problems. Parents need to remember that professionals are people too and have some common human failings. It may help for them to voice their frustrations to the professionals without attacking them directly.

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The two most common things for parents to complain about regarding the ways professionals treat them are that they don't always get listened to and that they are not always treated as individuals. One mother said, "I get tired of being treated as a 'case.' I want to be more than a 2:00 appointment." When professionals don't take enough time to listen to the parents, when they undermine the parents' sense of what's best for their children, and when they focus on the weak points of the children instead of the improvements, the parents need to speak up for themselves and indicate what it is they need from the professionals. If they continue to feel they are not listened to or treated as individuals, they may want to find a new professional to replace the one they are dissatisfied with.

Finally, at times a family feels that all the professionals, therapists, and home visitors are intruding into their family life. It is worth noting that although this team of helpers is necessary to the family, it sometimes feels like the family has totally lost its privacy.



Fostering Teamwork

There are many things that parents can do to foster teamwork with professionals so that they become allies in serving the children. They can:

- Develop positive communication skills: be assertive but not aggressive, listen, act rationally.
- Find professionals they can talk to. Realize that it's okay to shop around. When they find one professional they can communicate with, they can ask that person to help them work with others. This will reduce the number of separate contacts necessary and also the resulting stress. If professionals use medical "jargon," parents can ask them to explain again in words that they'll understand.
- Tell professionals what they know about their children's home environments, daily schedules, strengths, and weaknesses. They are the experts about their own children.
- Be prepared. Read about their children's conditions. Make lists of questions before they go to appointments. Keep a log of their observations.
- Stick to the topic. State their concerns at the beginning of the appointment. Make future appointments to bring up unanswered concerns.

MELD SPECIAL

Working With Community Resource Personnel

To foster teamwork with professionals, parents can (continued):

- Speak up . . . nicely. If they have a problem, a question, an alternative idea, or a complication, they should say so. They can ask the same question of several professionals to see differences of opinion, more sides of the problem, or different interpretations of the situation.
- If they wish to ask particularly sensitive questions and their child or someone else is present, they can ask to speak to the professional in private.
- Say "no" to doing the therapy . . . occasionally. Parents can choose to be a parent or simply a person for some time rather than constantly being their child's case manager.
- Form a partnership with the professionals in their lives. Professionals are people, too, with good days and bad days. If parents want them to be genuinely open, the parents must acknowledge that professionals have frustrations, needs, and fatigue as well. Parents can let them know when they have been particularly helpful and appreciated.

(from Simons, Robin. After the Tears: Parents Talk About Raising a Child with a Disability. New York: Harcourt Brace Jovanovich Publishers, 1987.)

Making Decisions

One of the never-ending difficulties of parenting children with disabilities or chronic illness is that parents have to make thousands of practical decisions. They must figure out whether to send their children to day activity centers and which ones, whether to use nursery schools and which ones, how to get special equipment, which of two surgeries to accept, how to find help, what kind of individualized education plans to support, whether to appoint a guardianship and whom to appoint. . . the list could go on and on.

Some parents are afraid of making decisions so they let someone else make the choices for them. These parents end up giving up a lot of their power. They need help to understand that it is usually best for their children and for themselves if they have some control over the decisions that affect them. They need help learning how to make decisions. Sometimes a child's disability is so severe that the parents must give up most of the decision-making power. Other times a parent's lack of interest or energy mean that someone else has to make the decisions. But most of the time, parents can learn to make the decisions they need to with some outside help.

MELD SPECIAL

Working With Community Resource Personnel

Parents can make decisions more easily if they follow a problem-solving method like this one. (A copy of this can also be found in Handout (a).)

Problem Solving

1. **Problem Definition.** Ask yourself—
What's the problem? What is my concern? What else can I say about this? How do I feel when this problem happens?
2. **Problem Sharing.** Ask—
Who else has a similar problem? What happened for other people?
3. **Problem Causes.** Ask yourself—
Why does this problem exist? What are the underlying issues?
Why do think this problem happens?
4. **Problem Solutions.** Ask yourself—
What solutions have I tried? What varieties of strategies have other parents tried? What have I done when the problem arises?
5. **Solution Evaluation.** Ask yourself—
How did the solutions work? How did other strategies work? What happened after each solution was tried?
6. **Brainstorming.** Ask yourself and others—
What are some other ways of solving this problem? Can anyone think of any other ways of solving this problem before it happens?

MELD SPECIAL

Working With Community Resource Personnel

Once parents have gone through a process like this about a decision they have to make, it is usually much easier for them to determine what they think is best to do. This process is especially helpful when parents are working with professionals who disagree with each other about what is the best thing to do.

When parents face the extreme difficulty of working with disagreeing professionals, it may help them to keep some tips in mind.

- They must remember that they are the ones with the power to determine what is best for their children and their families.
- They always have the option of getting an opinion from or changing to a third professional. They could ask a diagnostic center at a university, a nearby teaching hospital, a clinic, or the local health department to suggest someone else they could consult with.
- They could get the disagreeing professionals to talk to each other in person or on the telephone. Maybe they can come to some agreement.
- They could decide to accept one opinion for awhile and then judge the results. Does it work? Does the child accept the treatment? How does the treatment affect the family's life? After trying the first method for awhile, they can decide to keep using it or they can switch to the other method.

The parents will find life moves with the greatest possible ease if they build up a healthy working relationship between the professional and the team members they select and if they retain their power to make decisions. Gradually they will come to have confidence in their own intuitive judgements and know that they have probably made the right decisions even when they begin to have doubts.

Advocacy

Parents are probably the only life-long advocates their children have. As advocates, they are the ones who look out for their children's best interests, who see that their children's needs are met, who speak up for their children when their children can't speak up for themselves. Children learn to speak up for themselves and defend themselves by watching the examples set by their parents. If they see their parents advocating effectively for them, they will learn to advocate for themselves.

Sometimes parents need a professional advocate to help them fill this role. For example, because parents care more than anyone else about their children, they are sometimes emotional in discussions about their children's care. When their emotions make them unable to speak effectively for their children, they may need a professional advocate to assist them. Parents can ask a school teacher or the local Association for Retarded Citizens to recommend an advocate. Professional advocates might be able to keep their cool better, be more objective, and perhaps bring more knowledge about the rules and laws to the discussion.

But parents don't always need to get professional advocates to support them. They can ask a friend or a relative to come with them to conferences and meetings. Having a supporter along can help the parents feel less outnumbered by professionals and the other person may be able to listen and speak more objectively than the parents can.

MELD SPECIAL

Working With Community Resource Personnel

Parents can get a lot of help in being advocates for their children if they work with a group of other parents who have children with special needs. The group can be a support system, an information source, and an action group. As an action group, the group can advocate for the needs of a number of children with a similar disability. Together, a group of parents can have more impact than one family.

It is best to solve problems informally by talking them out with the professionals and resource people involved. However, if informal talk does not work, parents have more forceful legal options they can use. Public Law 94-142 guarantees that families of children with special need have the right to due process. That means that if public officials, like school personnel, make decisions that the parents think are wrong for their children, the parents can use four different procedures.

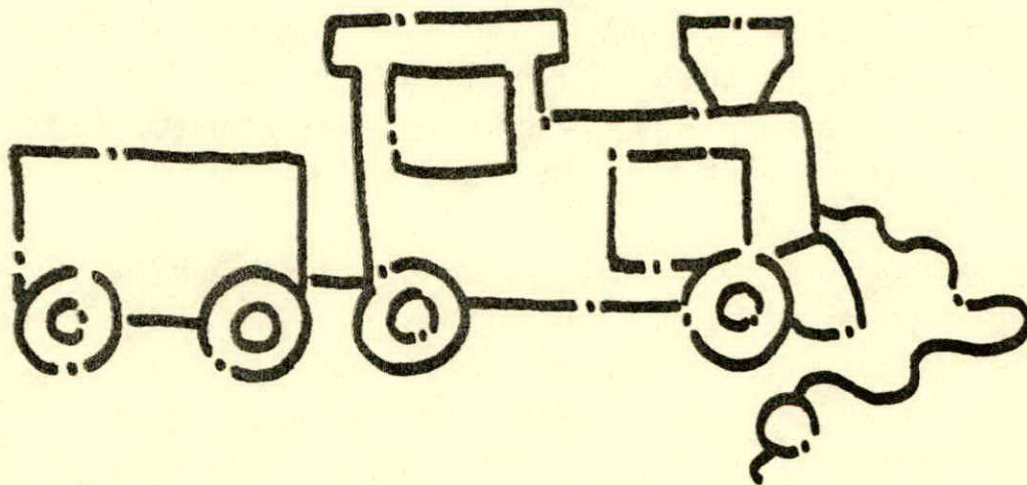
1. Parents can get an independent evaluation or consultation; they do not have to rely on the evaluation of the public official who made the decision.
2. Parents can ask for a "due process" hearing with a neutral hearing officer who will listen to both sides of the disagreement and make a decision.
3. Parents can file an administrative complaint or appeal to an authority who is in charge of the laws that they think were violated; perhaps that person would be the State Commissioner of Education or the State Office of Civil Rights.
4. Parents can file a lawsuit and let the courts determine what is the correct action.

MELD SPECIAL

Working With Community Resource Personnel

Already the courts have decided that a school, for example, cannot deny services to a child with disabilities just because they don't have enough resources to provide those services. They have to get the resources. Any services that are called for by an individualized educational plan must, by law, be provided, even if the services have to be bought by the school.

Just the same, parents need to think carefully before beginning any due process actions. Sometimes the difficulties of the process are more harmful than the benefits of the end results. Other times the process is very much worth any difficulty it causes. Usually informal talks produce the needed results.



MELD SPECIAL

Working With Community Resource Personnel

Assertiveness

For parents to be effective advocates for their children, they must act assertively. Being assertive means not letting other people walk all over you. It also means not walking all over other people. People who are assertive can stand up for their own rights and express their ideas in direct, honest, and appropriate ways, and at the same time they can keep on respecting the rights and opinions of others. Assertive people learn to make compromises instead of having confrontations.

Instead of acting assertively, parents can act either passively or aggressively. Passive behavior is just giving up. Parents who are passive often feel intimidated and overwhelmed by professionals. They are sometimes afraid to disagree. Parents who act aggressively tend to make enemies. They yell and blame and refuse to listen to others. Parents who act aggressively also often feel overwhelmed by the service systems. They become rageful because they don't believe they really have any power. Both kind of behavior—passive and aggressive—make parents feel helpless and out of control.

Parents who have learned how to act assertively, on the other hand, are able to get results for their actions. They begin to recognize that they do have power. In addition, acting assertively increases their self-respect and their self-confidence and it makes others respect them more. The authors of Parents Are to Be Seen AND Heard wrote that "In a large, complex society like ours, assertiveness is often a necessary element of survival and for parents of handicapped children, assertiveness is absolutely necessary in order to serve as an effective advocate for the child."

MELD SPECIAL

Working With Community Resource Personnel

Assertive parents get what they need for their children. And they have better relationships with others because they use open and honest communication.

One family that had learned to act assertively realized that their special needs child needed an aide to ride the bus with him in case he suffered seizures between home and school. They insisted that the school's individualized educational plan be appropriate for his needs and not limited because of how much an aide would cost. Finally, the school district staff agreed with them and provided the aide.

Another family of a child with special needs worked through long, complicated, and difficult negotiations with their public school district. They wanted the school to provide services that were needed and that were also required by the laws of the state. The officials at the school felt they they did not have the right equipment to provide the services, they knew they did not have enough staff people, and they knew they did not have enough money. They told the parents that they just could not provide the services that the parents felt were necessary for their child. The parents said to them again and again, "We're not interested in making this a win-lose situation. Let's just see how far we can try to take this." And they kept meeting and meeting and meeting with the school staff people. The parents admitted that the school had difficulties in providing the services. Still, they kept on saying, "Our daughter really needs these services." They wrote a letter to everyone involved after each meeting. In the letters, they listed their primary points as well as the issues or conclusions that had come up during the meetings. In the end, the parents were able to get every service that their daughter needed.

Assertive language like these parents used does not blame the other people but tries to communicate in an acceptable way. Assertive language tries to keep the dialogue open to reach mutually agreed-upon solutions. Therefore, it tries to keep the focus on resolving the problems.

In "Unlocking Doors: A Guide to Effective Communication" Betty Binkard describes several levels of assertive language that parents can use.

1. Basic assertive language—honestly standing up for your own beliefs and feelings. Parents could say, "I think the test shows an improvement, but I still have some other concerns."
2. Empathetic assertive language—mentioning the feelings of the people you are talking with. Parents can say, "I understand that it's impossible to predict exactly what will happen with this new treatment: however, I'd like to hear more about your opinion as to the most likely results."
3. Escalative assertive language—becoming more direct so the other person can't ignore your request. Parents could say, "Something will have to be worked out because I cannot consent to Joe's placement and individualized educational plan unless I'm comfortable with his assessment. I'm thinking of having outside tests done. However, we could avoid the additional costs if the school's assessment could be improved."
4. Confrontive language—describing what actually happened in comparison to what the other person indicated would happen. Parents could say, "We approved the individualized educational plan with the inclusion of additional speech services. It's been three months since the school tried to provide the services. What plans do you have to provide a teacher now?"

MELD SPECIAL

Working With Community Resource Personnel

In the same publication, Betty Binkard pointed out that assertive parents have common beliefs that they remind themselves of. They say to themselves:

- "I will try to do my best even if I find it necessary to try many tasks that I am not good at yet."
- "I would like people to act they way I want them to, but I know they might not act that way. I can be disappointed without falling apart."
- "Other people won't see things my way and they won't work for my best interests. It won't help me to try to get even with them. It will help me more to concentrate on solving the problem we're facing."
- "I do have the ability to control my own feelings and to shape my reactions to the events in my life."
- "I may do or say something that other people won't like. No one is going to love me all the time. I can still have a good, healthy relationship with those people who don't like everything I do and who don't always love me."
- "I'm not the same person I was ten years ago. I can try all sorts of new things."
- "Something bad might happen. But I'll act as if good things will happen. Even if bad things happen, I'm a pretty strong person and I've handled bad things before. I know I can achieve the most happiness when I take positive action."

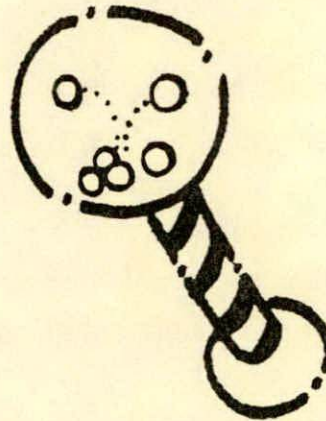
MELD SPECIAL

Working With Community Resource Personnel

Parents can help themselves act assertively by remembering their basic rights as parents. In Getting Help for a Disabled Child—Advice from Parents, the authors say that parents have these rights, even though they aren't necessarily legal rights.

Parents have the right:

- not to be intimidated**
- not to be blamed**
- to understand what is happening**
- not to be exploited**
- to accept help**
- to make decisions**
- to be angry**
- to survive**
- not to feel guilty toward their children**
- not to give up**



Once parents feel confident that they do have rights, they will be able to act more assertively. Then they can prepare for assertive actions in many ways. They can role play and talk through a situation before they enter it. Other parents in the MELD Special group can listen and practice with them. They can read their children's records so that when they go to meetings they can have enough information; they can also offer to add written comments to the records if they think something is missing. They can find out about the system they are dealing with before they go to a meeting. They can ask the public relations department what the administrative structure of the agency is so that if they need to talk to someone with more authority they will know who that person is.

MELD SPECIAL

Working With Community Resource Personnel

When they go to appointments, parents should dress as if they are applying for a job. They should look as if they mean business and are organized. They can bring someone else along for support, to provide information, and to listen.

If parents think that the professionals they are talking to are giving them incomplete explanations, they can say, "I'm sorry. Help me to understand that. It doesn't make sense to me." If they feel very emotional and think they might cry, they can tell the professional they might cry but that the professional can go on talking, or they can ask to take a break. It is okay to cry even if professionals are uncomfortable with crying. And if they feel angry, the parents can remember that that's okay too.

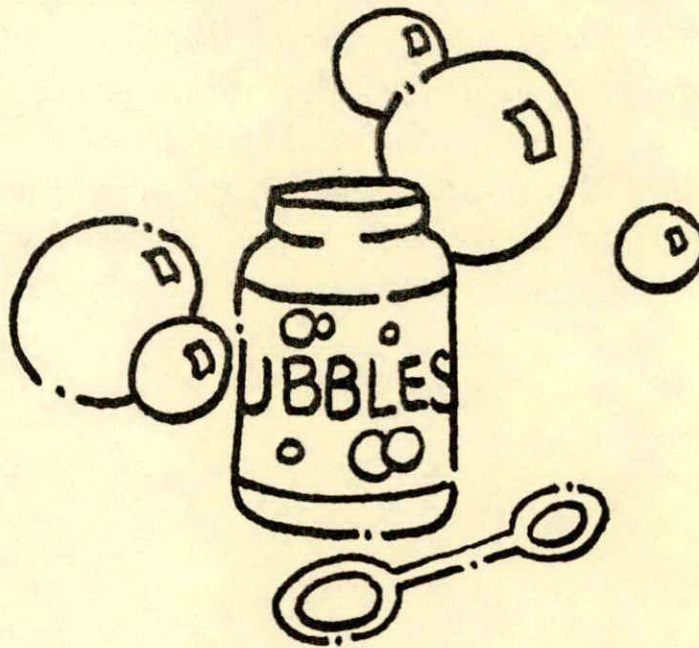
After the meeting, parents need to express their feelings. They can call a friend and go over when happened. They can talk with the MELD Special group. They need to be prepared to make many contacts and telephone calls. Sometimes they are referred from one place to another. The important thing is not to give up. They should feel free to get second and third opinions. If they feel they need more support, they can see if the agency has a parent advocate person and enlist that person's help.

MELD SPECIAL

Working With Community Resource Personnel

When parents act assertively, they are treated as worthwhile individuals and listened to. They truly become part of the treatment team. One father said, "The doctor really does listen to us now. We make eye contact and he encourages us to express our feelings and think about the alternatives."

Parents of special needs children are, first and most importantly, parents. When they face all the decisions and arrangements they need to make with professionals, they might think, "How am I going to do all this? I have a little child who happens to have a disability, and all I want to do is love my child and learn to deal with the disability." Assertive parents know that they can do just that.



MELD SPECIAL

Working With Community Resource Personnel

Resources for Families:

Association for the Care of Children's Health (ACCH), 3615 Wisconsin Ave. NW, Washington, D.C. 20016, 202/244-1801.

National Center for Education in Maternal and Child Health, 3520 Prospect St., NW, Washington, D.C. 20057, 202/625-8400.

National Information Center for Handicapped Children and Youth (NICHCY), P.O. Box 1492, Washington, D. C., 20013, 703/522-0870.

Federation for Children with Special Needs, 312 Stuart St., Boston, MA, 02116, 617/482-2915 V/TDD.

PACER, 4826 Chicago Ave., Minneapolis, MN 55417, 612/827-2966.V/TDD. PACER is a leading national resource for information about educational rights for students with all kinds of special needs. PACER provides information for parents in every aspect of the educational system, including a parent training project called "Parents Helping Parents." It is one of the new computer resource centers in the country and has printed materials on a vast range of educational issues.

Pilot Parents Minnesota, 201 Ordean Building, Duluth, MN 55802, 218/726-4745. Pilot Parents offers supportive networking among experienced and "new" parents of children with all kinds of disabilities.

MELD SPECIAL

Working With Community Resource Personnel

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MELD SPECIAL

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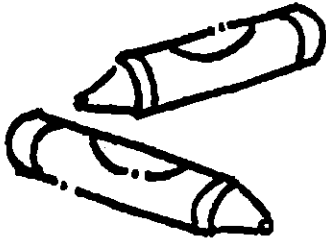
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Learning Activities

INTRODUCTION TO RESOURCE NETWORKS

Set the tone by setting up a display of brochures, posters and books from a variety of service agencies.

Get acquainted by having the parents each share one instinct that they've had about their children that proved to be correct but about which they had to convince professionals.

Have each parent share a dream or a goal they have for their child.

Invite a professional or a panel of professionals and other parents of children with special needs to speak and answer questions at your group. You might invite professionals in social services, education or medical services, for example, to be on a panel with some other parents of children with special needs. MELD Special members could interview them about the concerns included in this chapter. Ask the professionals to explain in detail the various disciplines, assessment tools and terminologies they use. The purpose of this time is to help parents understand the systems before they try to be advocates.

MELD SPECIAL

Working with Professionals

Possible questions to ask panel members or speakers might include:

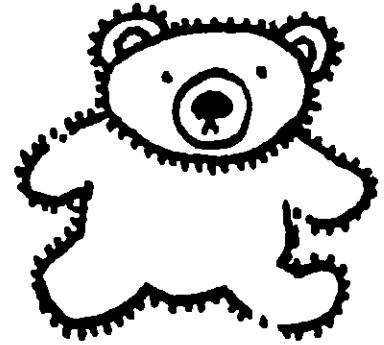
- How can parents find social workers, specialists or therapists?
- What specific assistance or services do these professionals provide? What are their roles? What is *outside* their areas of service or expertise?
- How can parents express the complaints they have about professionals? How can they switch professionals if they're dissatisfied?
- How do parents "get through" the system?
- Why do some professionals know more than others?
- What kinds of community services are available for children with special needs and their parents?
- What are the differences in services between counties?
- What financial aid programs are available? What kinds of financial help exist for equipment for children with special needs?
- Do the professionals have lists of educational or therapeutic programs and contact persons at those places? If not, can they tell the group where to find lists like that?
- Can the professionals help parents plan discussions with other professionals? Can they, for example, help the parents know what kinds of questions to ask? Can they help parents learn advocacy skills?

MELD SPECIAL

Working with Professionals

Invite an adult with a disability as a guest speaker to discuss their personal experiences with professionals and service agencies.

Organize mini-lectures by dividing up the material between two or three of the parent group facilitators. Have them present the material and then allow time for discussion and questions. If there are questions the facilitators can't answer, make notes and call someone before the next meeting to find the answers. Report back on the answers at the next meeting.



Set up a "Veteran Parents Fair" by inviting several parents who have successfully negotiated one or more situations. Some situations could be working with a system, such as a school district, welfare department or hospital; advocating for persons with a particular disability, such as speech disabilities or cerebral palsy; or working through a particular developmental stage issue. Set up several small groups, or "stations," of chairs and have one of the guest parents sit at each station. MELD Special parents can casually move from station to station to consult with the "veteran parents."

Parents of children with special needs can be parents *and* advocates or case managers for their children.

Encourage group discussion about begin advocates. Have parents discuss the question like, "What makes a good parent advocate?" "How can parents get the support they need?" and "How have these parents learned to trust their own judgment when it comes to finding services that 'fit' their children and their families?"

MELD SPECIAL

Working with Professionals

Encourage discussion among parents of their feelings about giving each other emotional support. What do group members think they can offer each other? How will they handle their own fears and parenting concerns that might be triggered by the discussions?

Identify and discuss the skills and qualities needed by parents to be effective advocates for their child. Ask what has worked for MELD Special parents and what clues would they give another parent.

Share ideas for organizing information that must be kept at home. See what organizational tips parents can share with one another. Types of materials that must be organized include:

- Notes about growth and immunizations, names and addresses of services used perhaps to be kept on a calendar).
- Reports of surgeries and in-patient hospitalization with dates, assessments, and treatment plans.
- Ancillary or educational services (like physical, occupational or speech therapy) and when they were received.
- Copies of all medical and dental records with evaluations, test results, and correspondence.
- Notes on all conferences and discussions with professionals.
- Dates the child attended various facilities, schools and programs.
- The child's behavior at home.
- The child's reactions to behavior guidance that the parents have tried.
- The parent's concerns and priorities?

MELD SPECIAL

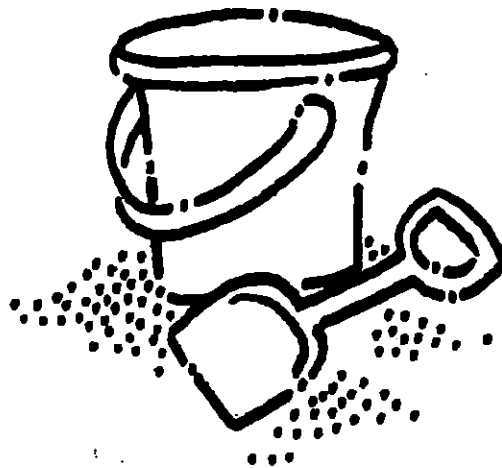
Working with Professionals

Types of materials that must be organized include (continued):

- The child's allergic reactions.
- The child's schedule.
- The child's likes and dislikes.
- How to operate child's equipment.
- Everything that is discussed about the child on the telephone or at \ meetings.
- Decisions and plans that are made about care and programming and the next steps that will be taken.

Lead parents to discuss their concerns, needs and wishes for their children. Do they want their children to develop social skills? Do they want their children to develop self-advocacy skills for use later in life? Do they want programs their children are in to focus on teaching them tasks? What must they do to be their children's advocates in meeting these needs?

Share ideas about resources for screening, diagnosis, services, financial help, information, support, child care, equipment and supplies. You can use the list at the end of this section and have parents add their own ideas.



MELD SPECIAL

Working with Professionals

Share information or invite a guest speaker to talk about federal and state laws. The basis for contemporary services and programs for children with special needs is found in laws, such as:

- Section 504 of the Rehabilitation Act;
- The 1963 Mental Retardation Facilities and Community Mental Health Center Construction Act;
- Social Security Amendments for Intermediate Care Facilities for the Mentally Retarded, 1965 and 1971;
- Title XVI of the Social Security Act, 1972;
- Vocational Rehabilitation Act Amendments, 1965 and 1973;
- Education of All Handicapped Children Act, Public Law 94-142;
- Family Rights and Privacy Act;
- Developmental Disabilities Act, Public Law 100-146;
- and Amendments to the Education of the Handicapped Act, Public Law 99-457.

For copies of any legislation, simply contact your state senator's office.

Have small groups of parents identify examples of unsatisfying relationships with professionals involved in their children's health care or education. Have them use problem-solving skills to develop ideas about dealing with the situations.



MELD SPECIAL

Working with Professionals

Review the decision-making steps. Ask parents to briefly describe a current problem they need to deal with. Provide copies of Handout (a) on problem-solving. Choose two or three examples mentioned by the parents during discussion and work through the problem-solving steps with these situations. Talk about:

- The advantages of using a problem-solving guide.
- Whether individual parents think this guide would work for them. Why? Why not?
- How decision-making affects partners, the communication between them, their expectations of one another, and their roles and how it affects single parents.

Parents of children with special needs can build a resource team of professionals, friends, and others in order to help their children develop to their full potential.

Have MELD Special parents discuss how diagnostic situations have gone for them. Suggest that they share about:

- The general processes with doctors or other specialists.
- The outcomes for the children.
- Their feelings throughout the process.
- What they would do differently next time.
- How the experience changed the way they deal with their health care providers.

MELD SPECIAL

Working with Professionals

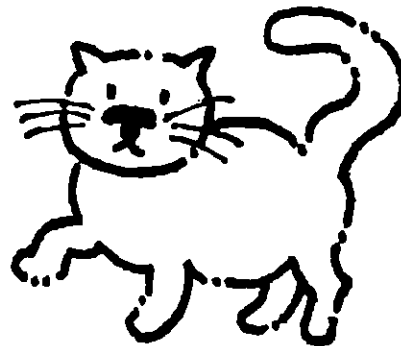
Have parents list their current sources of information, support and service. They should list friends, relatives, books, programs, services, groups—anything or anyone that they depend on for information, support and service. Parents might be surprised by all the resources that come together to help their children. A form for this exercise can be found in Handout (d) for this chapter.

List non-professional and professional sources of support available to families with children with special needs. Make lists on newsprint or chalkboard as parents give ideas. You might want to provide a handout of local organizations or professionals with addresses and phone numbers. Discuss the support or services parents anticipate needing that these sources couldn't offer.

Discuss how parents determine what is best for their child. Whose input besides their own do they consider: physicians, social workers, therapists, staff of special needs agencies, relatives, friends?

Lead the group in discussing:

- The feeling that privacy is lost because of the intrusion of the team of professionals.
- How to handle what seems like an ever-changing chain of professionals (Just when they get used to one person, a different person is assigned.)
- Getting second opinions. (Some families automatically decide not to see a professional who is reluctant to have them seek a second opinion.)



MELD SPECIAL

Working with Professionals

Assertiveness skills will help parents of children with special needs let professionals know what they, their families, and their children need.

Examine why parents may not have behaved assertively. Have parents individually identify three situations in which they wanted to behave assertively but did not. Encourage them to try to remember the thoughts they had at the time. They can discuss these reactions in small groups. (From "Unlocking Doors – A Guide to Effective Communication," by Betty Binkard. Minneapolis, MN: PACER Center, Inc., 1982.)

Discuss the differences between assertiveness, aggressiveness and non-aggressiveness. Divide the parents into small groups to complete the "Assertiveness Quiz" included as Handout (c) in this chapter.

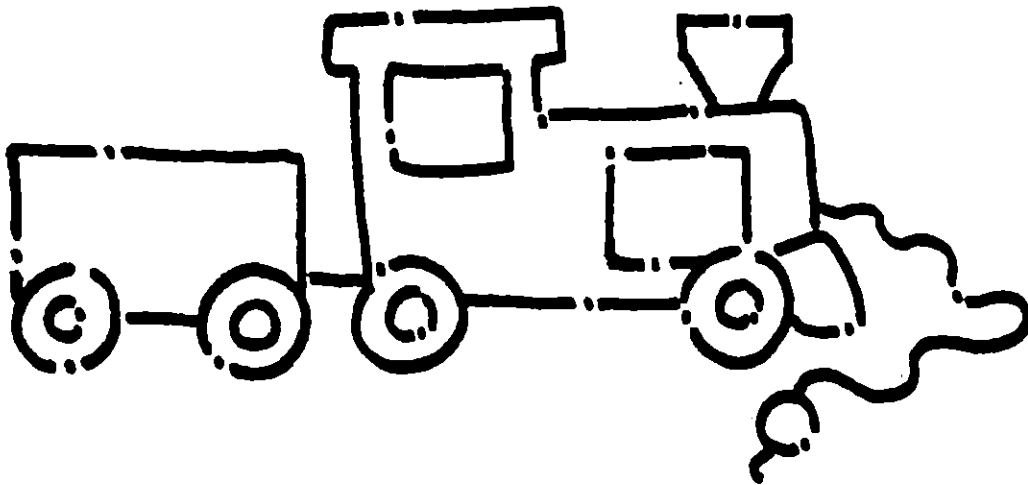
Have parents role play situations they have encountered with professionals. It would probably be very helpful to select first a situation that will be coming up in the near future for one of the MELD Special parents. For example, a mother of a child with special needs may have to discuss the situation with a physician who is usually very vague about her child. The mother usually feels a lot of fatigue, anger, frustration, and lack of support. Encounters with this doctor don't seem to help much, and some of her frustration comes out as anger at the doctor. You could use group discussion to identify the skills and techniques that would help the mother deal with the doctor (like having a companion or carrying folders of notes). Then you could have parents role play the situation. Ask them afterward what they can do for themselves when their energy is depleted and they feel they won't make it through the next conference. Ask whether heavy involvement with professionals makes them feel less in charge or less like parents.

MELD SPECIAL
Working with Professionals

Have parents role play situations in which they would need to practice assertiveness:

- asking questions,
- defining and resolving problems,
- collecting resources,
- making decisions,
- letting professionals know what they, their families, and their children need.

Generate a list of questions that parents can take with them to their next staffing, doctor's appointment, therapy session, or meeting with a school teacher. For example, they might need to ask a teacher, "Is the learning time needed to acquire new skills and behavior reasonable?" "Will acquiring these skills open new opportunities for my child to enjoy a range of experiences?"



MELD SPECIAL

Working with Professionals

Generate a list of information for parents to take with them to their next staffing, doctor's appointment, therapy session, or meeting with a school teacher. For example, have them complete sentences such as the following:

1. I describe my relationship with my child this way . . .
2. A typical day with my child includes . . .
3. When around other children, my child . . .
4. My child likes or is really good at . . .
5. My child needs help with or avoids . . .
6. My child and family together like to . . .
7. Recent progress or changes are . . .
8. Questions I have . . .
9. My child does best when . . .
10. I would like my child to learn or get better at . . .



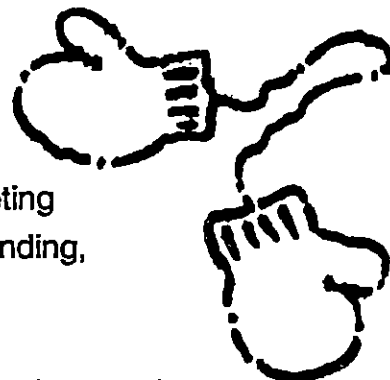
(From "Early Intervention: Tailor Made," Eagan, MN: Project Dakota, 1986.)

Role play how parents can use observations of their children at home to communicate with professionals, such as doctors or teachers.

MELD SPECIAL
Working with Professionals

Lead group discussion about two questions:

1. What would you do if the professionals you're meeting with do not express or convey feelings of understanding, empathy, compassion, or politeness.
2. What would you do if you did not agree with the individualized educational plan developed for your child?



Discuss parents' rights. Have small groups of parents look over the list of rights included in this chapter. Have them pick one from the list that they feel uncomfortable about accepting. Have them imagine that they have accepted this right. How would their lives change? Have them imagine that someone took this right away from them again. Ask them how they would feel now? (From "Unlocking Doors – A Guide to Effective Communication," by Betty Binkard. Minneapolis, MN: PACER Center, Inc., 1982.)

Homework: Perhaps you'll want to make some assignments. For example, you could ask one parent or a couple to find out what kinds of information parents can get from a community education program, or a public health department, or a local hospital.

Have parents write a journal entry describing one or more times when they were successful advocates in acquiring services or resources for the children.



Chapter 6

Handouts

**Working with
Professionals**

PROBLEM SOLVING

Problem Definition. Ask yourself—

What's the problem? What is my concern? What else can I say about this?
How do I feel when this problem happens?

Problem Sharing. Ask—

Who else has a similar problem? What happened for other people?

Problem Causes. Ask yourself—

Why does this problem exist? What are the underlying issues? Why do I think this problem happens?

Problem Solutions. Ask yourself—

What solutions have I tried? What varieties of strategies have other parents tried? What have I done when the problem arises?

Solution Evaluation. Ask yourself—

How did the solutions work? How did other strategies work? What happened after each solution was tried?

Brainstorming. Ask yourself and others—

What are some other ways of solving this problem? Can anyone think of any other ways of solving this problem before it happens?

WHERE TO GET HELP AND SERVICES

We do not have names and telephone numbers of professionals and services in your area. However, we can tell you some of the kinds of places that will be able to give you specific names and numbers. We encourage you to keep a file with this kind of information so that if and when it's needed, you will be ready.

Screening: pediatrician, professional screening services, public health department clinics, public health nursing services, state health department, local school districts.

Diagnostic work-ups: pediatrician, children's hospital, pediatric department of hospital, university centers or teaching centers, local school districts.

Financial help for screening/diagnosis: medical assistance programs available through welfare departments, parents' health insurance, local or state health department, The March of Dimes, United Cerebral Palsy, Shriner's Hospitals.

Diagnosis and treatment of mental health problems: child guidance clinic, community mental health services, private health and mental health clinics, Easter Seal Society referrals.

Names of medical specialists: family doctor; professional associations such as county medical society, county psychiatric association, association of speech pathologists, state university school of medicine, physician referral services, local school districts.

Home visits by public health nurses: city or county public health department, public health nursing association.

Locations of parent support groups for child's particular disability: local children's hospital and/or rehabilitation center social workers, local libraries, state health department, state services to children with handicaps.

Locations of special day care programs: county/state department of public welfare, human services, or social services which handles licensing of day care facilities.

Voluntary health associations which may offer information about a disability: state department of health; local librarian; National Easter Seal Society: 2023 West Ogden Avenue, Chicago, IL 60612; A Closer Look, Box 1492, Washington, D. C. xxxxx; National Health Clearinghouse, 1-800-336-4797.

Special pre-school programs: Head Start, state health department, local children's hospital social worker, colleges or universities, office of special education within department of education, local school district special education offices.

General information and referral: local librarian, local chapter of the Easter Seal Society.

Other ideas for resources: community education courses, council on family relations, United Way agencies, the Red Cross, agriculture extension services, YMCA/YWCA, etc.

ASSERTIVENESS QUIZ

Place the correct number before each of these statements to indicate whether it is (1) aggressive behavior, (2) assertive behavior, (3) non-assertive behavior.

- ___ 1. (Remark made to a friend.) I'd love to say something about the gaps in the program they're planning for John, but I'm afraid that if I do a couple of the staff will make it rough for him in other ways.
- ___ 2. I'm sorry my child can't learn as fast as the others. Maybe I can work with him at home since you say the regular classroom teaching doesn't have time to give him extra help.
- ___ 3. Either you get a special program set up for Amy right away or I'm going to write a letter to the newspaper and let them know what kind of rotten program you have here.
- ___ 4. The long-term goals you've set up for Mary sound fine. However, I can't agree with the types of exercises you have planned. When she's learning something new, she needs to work with several approaches, not just a single way.

(From "Unlocking Doors - A Guide to Effective Communication," by Betty Binkard, Minneapolis, MN: PACER Center, Inc., 1982.)

Current source of Information, Support, and Services

	Check here if this source will continue to be available
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10.	

EXPECTED ROLE OF PATIENT AND DOCTOR

*Diane M. Erlandson, RN, MS
Brigham and Women's Hospital, Boston*

PATIENT

Be knowledgeable about self and illness.

Participate in care, don't expect to be passive.

Prepare for visits.

Identify reason for visit immediately and any concerns, problems, etc.

Don't save "Bombs" for the end of the visit.

Report all changes. Don't self-diagnose or determine what is important when it comes to physical symptoms.

Don't go into a visit with anger and/or hostility.

Keep relationship professional no matter how close you may feel to the doctor.

Outline your expectations and goals with doctor and determine how feasible and realistic the goals are.

Don't expect your doctor to be a mind reader.

Don't expect a full physical each visit or blood work each visit.

Carry out treatment program.

Ask doctor what his/her expectations are of you and your illness.

DOCTOR

Be knowledgeable about your illness and who you are as a person.

Diagnose, guide care, make decisions, prescribe treatment, identify changes.

Involve patient in plan of care even if it is just explaining the "whys" of the decisions.

Educate the patient.

Keep patient informed of status.

Outline personal expectations and goals.

Determine patients expectations and goals.

Involve family as patient wishes.

Keep relationship professional and confidential.

Be honest and caring.

Respect patient as an individual and as a person.

Don't go into a visit with personal feelings "on the outside".

Don't expect patient to be an expert in communication.

PATIENT

Ask doctor what his/her goals are for you and what are the time frames.

Keep relationship 100% honest.

Outline treatment with doctor at end of each visit and ask questions.

Make change in relationship or discontinue if all efforts to salvage fail.

Realistically determine what degree of importance you have placed on visit with doctor and why. Know the rules of the game.

DOCTOR

Outline treatment and any changes or additional information at end of each visit.

Make referrals to other professionals to help meet all of the patient's needs.

Don't be threatened by a knowledgeable patient.

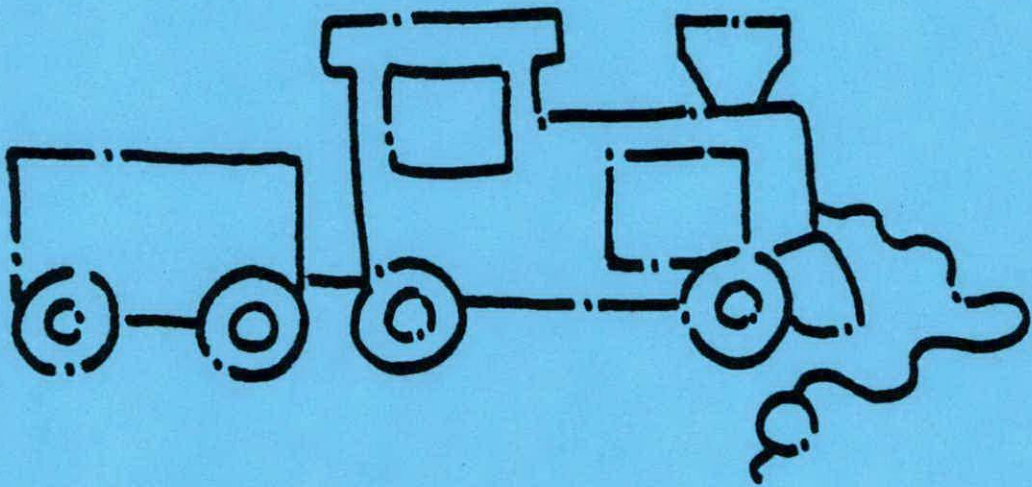
Speak in patient language.

Stick to time.

Make change in relationship or discontinue if all efforts to salvage fail.

Chapter 7

Play



MELD SPECIAL

Play

Play

Table of Contents	Pages
I. Introduction For Facilitators	3-10
A. Main Ideas	5
B. MELD's Biases	6
C. Facilitator Focus	7
D. Group Issues and Tips	8-10
II. Content For Facilitators	11-47
A. What Play Is	15-21
B. Helping Children Play	22-25
C. Play Is For Parents Too	26-27
D. Parents' Role In Children's Play	28-34
E. Family Fun	35-36
F. Helping Children Who Have Difficulty Playing	37-46
G. Conclusion	47
III. Resources and Chapter References	49-53
V. Learning Activities	55-66
VI. Handouts	a-h
A. The Sixteen Joys of Peek-A-Boo	a
B. Toys for Children with Special Needs	b
C. Toys for Young Children	c
D. Container Toys for Young Children	d
E. Things to Do When There's Nothing to Do	e
F. Tips for Traveling	f
G. Questions and Answers about Play for Children with Special Needs	g
H. Selecting and Adapting Toys and Games	h

Introduction For Facilitators

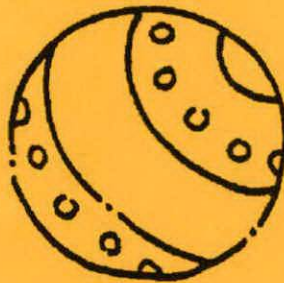
Think about when you last played. . . What were you doing? Playing tennis? Refinishing old furniture? Watching a stock car race? Spending a few hours doing nothing? How did you feel afterward? Relaxed? Filled up? Or did you feel a little guilty about “wasting time” when you had work to do?

Even though you may have at least some mixed feelings about taking time to play, we are encouraging both parents and their children to play and be playful. Why?

Because without play, life is generally dull and boring. Children give adults reasons to be playful, spontaneous, experimental—to rediscover a sense of becoming in life.

Because play generally allows us to enjoy each other more. Families that play together can be close without being overly dependent.

Because playful people are more creative and versatile. In a world where work often deals with ideas, these qualities are important.



MELD SPECIAL

Play

Why we are encouraging both parents and their children to play and be playful
(continued):

Because children don't know instinctively how to play even though it is serious business for them. Many adults do not realize that playing is the most important learning activity for children and that children learn to play more imaginatively and fully from watching adults and from being played with.

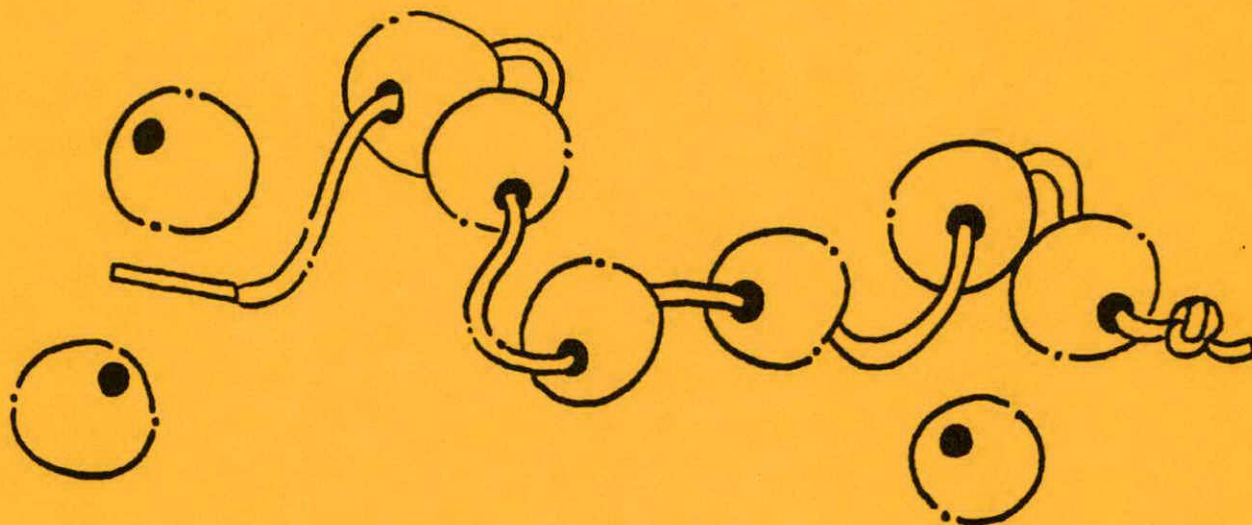
Because many adults don't know how to play or have forgotten what they used to enjoy. But adults who can learn to play again find it easier to enter the world of children.

(Adapted from How to Play with Your Children: And When Not To, by Brian Sutton-Smith. New York: Hawthorn Books, 1974.)

The purpose of this chapter is to help parents identify and observe ways that play relates to children's growth and development. It should also help them assess their children's developing capacity for play in order to provide play opportunities that are appropriate to their children's special needs. It should teach them ways to make or obtain adapted toys and activities to broaden their children's opportunities for enjoyable and challenging play. And, finally, it should describe ways to have fun as a family.

Main Ideas

- Children's play is a necessary support for all the ways they grow and develop.
- Children develop particular play preferences, styles, and abilities.
- Parents can provide opportunities for children to play.
- Toys and activities can be adapted to broaden the play opportunities for children with special needs.
- Having fun as a family is important for children's growth and development.



MELD's Biases

- It is important for families to have fun together.
- Play is important.
- Each person's idea of fun is unique. If you enjoy what you are doing, then it is play. If an activity is boring, stop trying to "play" it.
- Observing children's learning is delightful.
- Having a parent who enjoys playing and is curious about the world is a wonderful gift to a child.
- Reviewing how normal children might play at a given age helps parents of special need children adapt those activities for their children.

Facilitator Focus

As you read this material and think about facilitating meetings on this topic, consider the following questions:

- How do you most enjoy playing with your children?
- What's the most enjoyable activity you and your child do together?
- Were you ever — or are you still — self-conscious about being silly with your child?
- What play did you yourself enjoy as a child?
- How do you schedule play time for yourself?
- Are you looking for new ideas for playing with your child?
- How much do you value play in your own life?
- Have you enjoyed playing with your child or is it hard for you to find things to do that you both enjoy?
- Have you learned when to step in to your child's frustration and when to let him or her handle it?
- What did you most enjoy doing when you were 5, 10, or 15 years old?
- How do you play now?

Group Issues and Tips

- Talking about play could trigger grief, anger, and frustration for some MELD Special parents. Feelings about their children's disabilities or chronic illnesses may be expressed in negative feelings about play itself, especially if the disabilities interfere markedly in the children's abilities to play in ways the parents expect.
- MELD Special parents might not use all this information immediately, but it may be useful for them as their children grow older. Also, because of the variability in the disabilities and illnesses of MELD Special children, the ideas suggested here will not apply to all children. Encourage the parents who cannot immediately relate to the material to just let it be interesting.
- Many books and speakers state that parents can "maximize their children's potential" by following certain directions or procedures for play and parenting. Parents may have been convinced that there's one right way to play or to parent. . . but then they get confused because they don't seem to know what that one right way is. Every time they encounter a new theory or idea or procedure, they either embrace it completely or feel guilty that they don't try it. They might want the group facilitator to quote studies and experts to reassure them that they're providing enough stimulation and the right kind of stimulation. Instead, parents need to find out that no one way is the right way to play for them and their children. We can reassure them that theories are not facts and that they need to explore various approaches to find out which methods "fit" their own approach to their children and their own particular families.

MELD SPECIAL

Play

- Children pick up their parents' feelings, including feelings about how they are developing and about how it is okay to play. We can encourage parents to develop friendly, warm relationships with their children as a secure base from which their children can take risks and discover new ideas and relationships. We can encourage them to feel relaxed about their children and their children's ways of playing.
- Some groups have enjoyed toy-making workshops. The workshops are good ways of demonstrating appropriate play for different ages and stages. In addition, the groups have fun together. Toy-making workshops also appeal to people who learn in sensory, physical, and imaginative ways. If you plan a toy-making workshop, you'll need to collect scissors, glue, and other materials ahead of time.
- If you don't enjoy being playful, you might want to ask a parent group facilitator who enjoys being playful, even corny, to lead these sessions with you. It's harder to get parents in a playful mood if you as the discussion leader feel foolish.
- For the activity that encourages parents to remember how their parents played with them when they were children, we've found it best for parents to pair up rather than having a large group discussion. After pairs have had a chance to talk, they can report back to the larger group.



MELD SPECIAL

Play

- Any creative dramatics activities you decide to do in MELD Special will probably help parents be more playful with their children. One parent group played Charades. Parents were asked to act out names of toys like Raggedy Ann and popcorn machine. If people feel uncomfortable doing something in front of the entire group, they can work in pairs or trios.
- The issue of sexist play (boyish games vs. girlish games) may come up. You may want to figure out where you stand before you try to help parents sort through their own feelings.
- Be sensitive to the difficulties faced by single parents. They may feel overwhelmed by their sole responsibility for their children. They may have great difficulty finding time for play with their children and for leisure activities of their own.
- Toys are, of course, good resources to bring for this evening. Try also bringing some children's records to play. Family photo albums are good play resources; pictures can be of parents' childhoods or of more recent family gatherings. A file of area activities would be useful. Ask parents to record these activities on their own, but bring your contributions, too. Contact the National Lekotek Center for resources about adapting toys for children with disabilities; their address is 2100 Ridge Avenue, Evanston, IL 60204, 312-328-0001.

Content For Facilitators

Reasons Children Play
by Nancy Kristensen

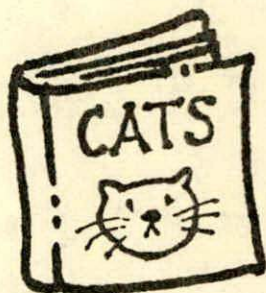
Children play because it is fun. They find enjoyment in throwing a ball or playing house. It is a way that they can express themselves and find out more about who they are. Children learn about themselves and other children through play.

Because children are curious and want to learn, they use play to explore and learn about their world. As they pull pans and bowls out of your cupboard, they are learning about the shape, use, feel, and size of the objects in your kitchen. They empty the waste basket because they want to see what is inside. They are curious about their world. However, this doesn't mean you should not put limits on their curiosity both for safety and convenience.

Children also play because they want to be like those important adults in their lives. They work at playing the role of their mother or father. They pretend to wash dishes just like dad does or play golf like mommy does. They imitate big sisters and brothers, grandparents, teachers, and other adults with whom they spend time. They pretend to be the doctor after a trip to see the pediatrician, and then they try on the role of mail carrier when they see her deliver the letters to their house. Play helps them understand the social world around them.

MELD SPECIAL

Play



Social play, in large or small groups, also helps the child learn about the pleasure of warm human contacts. Learning to get along with others and practicing his ability to express him/herself are facilitated in social play.

Play is also a creative activity. It allows the child to work out dreams and fantasies and discover new ways of reordering the world. Creative play allows the child to use materials in new, unique ways, and to use all senses to explore the world. Providing an outlet for expression of ideas and feelings is another way in which play is a valuable tool for the young child. The child can both enjoy good feelings or work off negative feelings through play.

Furthermore, play helps the child to develop large and small muscle abilities and to exercise a developing body. Large muscle equipment, such as climbing bars, wagons, tricycles, and slides, can provide many hours of fun.

Enlarging the child's information and ideas about the world is also provided for in play. Opportunities to explore music, art, books, and creative movement can be given at various times during the day.

MELD SPECIAL

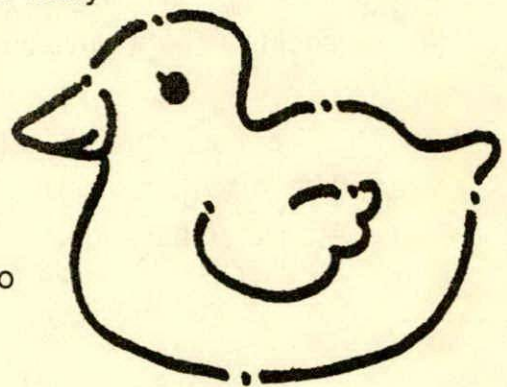
Play

Play has many purposes, and you can probably add several more to this list. Watch your children at play, and you can see all the things they are learning in play. It is true that play is indeed the very serious and joyful work of children. Often adults may say about children's activities, "But all they do is play all day. How can they be learning anything?" All it takes is a few minutes in observing the play of small children to realize that children learn best through play.

(From Nancy Kristensen, Coordinator and Parent Educator, Central Parent Early Childhood Family Education Program, Winona, Minnesota. Used by permission.)

Children come equipped to play and be playful. They can play intently with their own bodies and sounds and with simple objects. They seem to have a natural tendency to be creative. They are serious about play.

This chapter is also serious about play. Play is vitally important for children, parents, and families. One child in a MELD Special family was ten years old and still did not know how to play. Her teachers finally realized that she had been pushed so much to reach "her full potential" that she had not been free to play, so her parents enrolled her in a program where she, at last, learned how to play.



MELD SPECIAL

Play

Remediation or therapy usually starts with what the child cannot do and works on the child's weak points. Play starts with the child's strengths, with what the child already can do and builds from there. This chapter encourages play for children with special needs because play

- 1) encourages their growth and development,
- 2) makes them more equal with others in the family and more comfortable with their siblings, and
- 3) helps them notice their strengths and develop self-esteem and confidence.

A mother of a child with special needs said, "Nate feels good about himself when he can say, 'I can do this,' when he can play like other children." It is important to notice that, at the same times Nate was learning to play, he was also learning positive ways to relate to his parents, siblings, and friends.

The capacity for play is shared by all children and families—it is one of the "normal" aspects of any child with special needs. By playing with them, parents and other family members develop positive, enjoyable relationships with special needs children. Play broadens everyone's perspectives on what is possible.

MELD Special parents say they want to accept their children as they are and have some fun in life. This chapter is intended to help parents and their children have fun.

What Play Is

Play is of critical importance for all children. Professionals have long recognized its value in social, emotional, cognitive, linguistic, and physical growth and development. It fills a different role in the lives and development of children than it does in the lives of adults. Adults think of play as fun and relaxation, but children get much more than a "break" from routine when they play. Out of the laughter, hugs, surprises, rough and tumble, and simple playtimes, children learn to trust, to feel secure, and to begin to join society. Later, play is the way children find out who they are, what they can do, what the difference is between inner and outer reality, and how to get along with other people. Experts have found that:

- Playing with materials helps children learn problem-solving skills.
- Imaginative play relates to longer attention span, more self-control, improved self-knowledge, and increased ability to interact and communicate with others.
- Dramatic play helps children develop problem-solving skills as they work together to develop the dramatic play situation.
- Play serves as a way for children to work out their fears and anxieties.
- Children want to play in order to achieve mastery and control over their environments.
- Play allows children to cope with normal conflicts, such as separation and sibling rivalry.
- By playing, children cope with stressful events, such as illnesses and hospitalization, and re-enact painful or unpleasant events to develop imaginative solutions that give them a sense of control.

MELD SPECIAL

Play

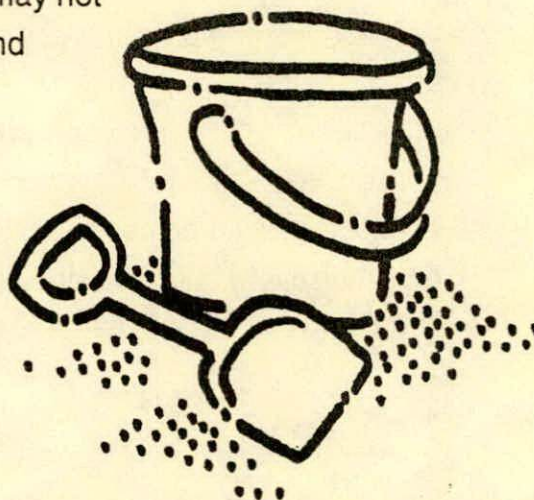
Experts have found that (continued):

- Play helps children integrate and assimilate new experiences and new behaviors.
- Through playing children participate in parent-child communications and interact with siblings or neighborhood children.
- Play lets children become more aware of themselves, other people, and their surroundings.
- Children who are curious and interested in new materials are most likely to be seen as creative by their teachers.

Some child development experts say that play is a child's work. However, adults often get play and work mixed up. In several important ways, play differs from the way most people view work.

Play is voluntary; children play because they want to. It is an activity children can feel they have some control over. Although it encourages relaxation, it can be intense and vivid, too.

Play involves experimenting and risk-taking with what is otherwise familiar. It can be humorous or quiet. It may or may not be productive. For instance, hobbies and physical activity can become work, depending on the person's outlook and expectations.

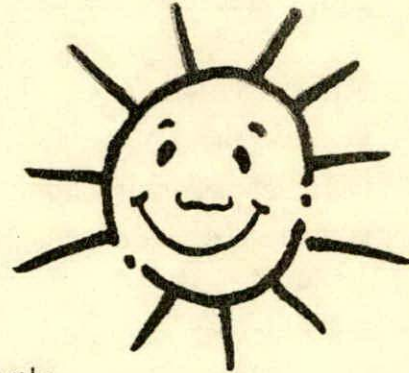


MELD SPECIAL

Play

Play is not easy to define. It often involves:

- new ways of looking at things,
- self-amusement,
- games of skill,
- pretending or imitating,
- fun,
- jesting or joking,
- acting in ways not intended to be taken seriously.



Stages of Play

Children generally grow through a sequence of stages or styles of play. Younger children tend to play alone. As they reach the ages of about 4 and 5, they may spend more time in play related to or cooperating with others. The stages they go through roughly follow this pattern:

1. solitary play (playing alone)
2. onlooker play (not playing with others, but watching them)
3. parallel play (playing alone, but close to another person)
4. associative play (talking with others, borrowing and loaning toys, but playing alone)
5. cooperative play (playing with a small group of children and letting each child make up part of the play activity)

Play

Different Kinds of Play

When children are very young, nearly all of their interactions (over 80%) involve objects, usually toys. But there are other types of play. Children with disabilities or chronic illnesses need adults to encourage them to play with more than objects. The four main types of play include:

- **play with objects**

Children use objects to express feelings and interests or to develop social interactions. They go through several stages in exploring and using objects. For instance, they could play with a cake pan and wooden spoon first by exploring; children look, taste, touch, shake, and throw pans and spoons. Then they may manipulate; the children try to find out what the objects will do. They try putting the spoon inside the pan or putting the pan on their heads. Next they may practice; children discover what they can do with the objects, for example, banging on the pan with the spoon. They repeat the action over and over, banging and banging. After that they may expand; the children may invent new ways to use the objects. They may carry the pan and spoon with them around the room in imitation of a parade.

- **play with motion and interaction**

Children enjoy clapping, running, jumping, skipping, face-making, hopping, chasing. They like to learn what their bodies can do. Adults could sew bells very securely to their children's socks to make kicking even more enjoyable.

MELD SPECIAL

Play

- **play with language**

Children enjoy playing with noises, silly sounds, rhythms, laughter. One child used to say, "Read silly, Grandma," and her grandmother would read a well-liked book but put in some wrong or silly words along the way. Parents could chant a rhyme like this with their children,

"Pop, pop, pop, pop.

My popcorn pops.

Pop, pop, pop, pop.

And now it stops."

- **play with social materials**

Children may use objects for pretend and dressing up as they take on different characters and dramatic themes. Parents can provide hats, telephones, plastic dishes, and stuffed animals for their children to pretend with.

Styles of Learning

Another difference in how children play involves their primary styles of learning. Each person has a style that determines how they most easily take in information from the environment and fit that information into what they know already. Some children prefer to learn by listening, some by looking, some by tasting, some by touching, and some by moving their bodies.

Very young children or very disabled children may not yet have a clear primary learning style. Therefore, their parents will probably want to include enough variety of play to appeal to all the styles. Following is a description of the styles with examples of activities children might enjoy.

MELD SPECIAL

Play

Listening activities for auditory learners:

These children enjoy music, wind-up toys, toys (like bells) that can be moved to make a sound, strings that make noise when they are pulled, elastic across their viewing or grasping area with bells or plastic containers attached to them. They like to play hide and seek with transistor radios when adults will hide the radios behind chair or under cushions and let them find it.

Looking activities for visual learners:

Visual children like mobiles with intense colors and interesting shapes, unbreakable mirrors, bright pictures and posters, fish bowls or aquariums. They like sitting near busy windows or in the kitchen, having red mittens on their hands, playing peek-a-boo, using busy boxes. If adults will blow bubbles for them, they will enjoy watching them float around and may start imitating the blowing action.

Tasting activities for oral learners:

Oral learners like to put safe items of different textures into their mouths. Objects like thick, soft cords with knots tied in them or bibs with snaps, or rings on ribbons will work. Parents must check to make sure that the items cannot come apart and stick in children's throats. These children enjoy tasting, but they may need to be guided by having an adult place the children's hands in the cereal and then in their mouths. After some time the children will probably learn to feed themselves.

MELD SPECIAL

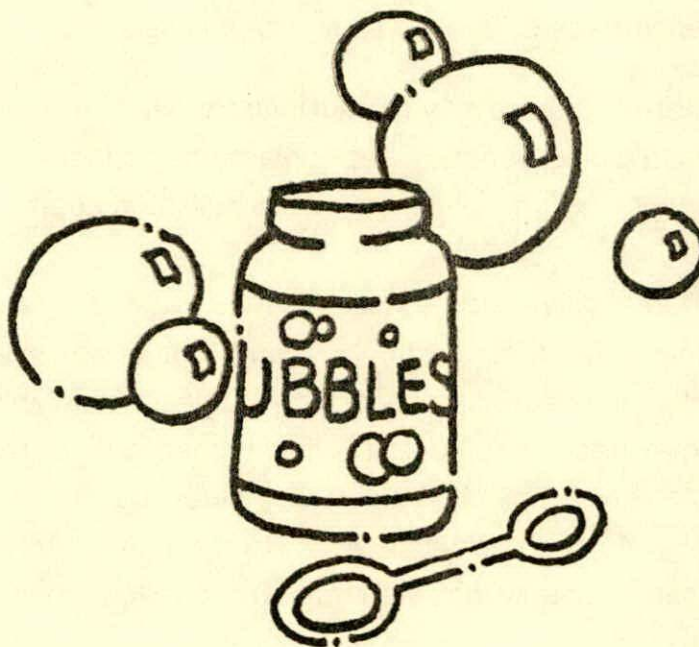
Play

Touching activities for tactile learners:

Children who like to touch enjoy balls made of different materials; patchwork quilts with different textures in the blocks and with bells around the edges; boards with textures like sandpaper, foam rubber, or foil glued on; clean powder puffs and objects with contrasting textures to rub on their bodies.

Movement activities for kinesthetic learners:

Children who like movement enjoy having toys to grab and wave around, toys just out of reach for them to strain toward, drums placed at their feet. They like having their bodies manipulated into different positions. They enjoy being seated in plastic wading pools that have been filled with different textures like crumpled newspaper, plastic golf balls, or foam packing pieces. Parents could hold the two ends of a crib sheet between them and gently swing their children in this "hammock" while they sing softly.



Helping Children Play

We know play is an important way that children come to understand the world, themselves, and their capabilities. For example, peek-a-boo helps children learn that objects (and people) do not disappear when they are out of sight. Pat-a-cake helps children learn to time and anticipate events. Play is always a learning experience for children. While they play, they grow socially, emotionally, physically, intellectually, and creatively.

Surprisingly, most of the ways children play are not instinctive; they are learned by watching and by being played with. For example, children don't know how to make car noises as their wooden car cruises the floor unless someone demonstrates. They won't know songs, rhymes, and two-person games without partners who can lead. The games of blowing bubbles, capturing a toy, or seeing their faces in the mirror require a playmate of any age.

Adults can encourage children to play in many ways.

To help children explore and manipulate the environment. . .

Parents can collect various sizes of plastic hair curlers, fit the curlers inside each other, and let children try to pull them apart.

To help children solve problems. . .

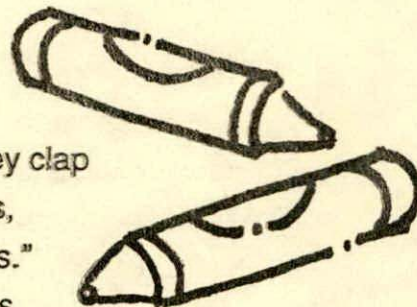
Parents can cover their children's favorite toy halfway with a diaper. The children can learn to recognize the toy and uncover it, but the parents may need to demonstrate finding the toy first. Then the parents can have their children watch as they hide the toy behind a plastic tray. Often the children will try to reach through the tray to get the toy, but eventually they will learn how to reach around the tray to get the toy.

MELD SPECIAL

Play

To help children express their feelings about the world. . .

Parents can sing songs with their children as they clap the children's hands together. One song to try is, "It you're happy and you know it, clap your hands." (The words are included in the Learning Activities for this chapter, page 60.)



To help children coordinate large and small muscles. . .

Parents can make use of their young children's natural inclination to kick when they are placed on their backs. At first, their kicking is uneven; later, it becomes more rhythmic. Kicking gives children exercise and helps them learn about their own bodies and how they are located in space. Parents can try placing their children on the floor on their backs. When the children start to kick, the parents can play music and observe how the children's activity changes. Often the rhythm of the kicking changes with the music.

To help children use their imaginations. . .

Parents can let their children play with an old telephone that the cord has been cut off of. The children are likely to mimic their parents' telephone conversations. This helps them learn role-playing and imagination. They learn the turn-taking qualities of conversations. And they may be kept busy when their parents' are on the telephone themselves!

MELD SPECIAL

Play

To help children learn to use equipment. . .

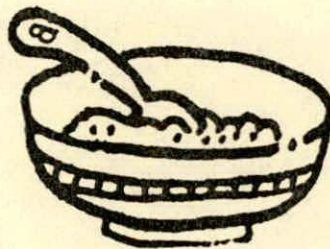
Parent can attach string or yarn to their children's wheel toys or favorite table toys. They can place the toy out of the children's reach but with the string within reach and see if they pull the string to bring the toy near them. Later parents can show children how to drop the toys from their high-chairs and use the string to pull them up; however, parents must be sure to allow children to play with string toys only with supervision to be sure the string doesn't become wrapped around the child's body.

To help children develop basic skills through manipulating materials. . .

Parents can tie rattles or bells securely to short lengths of fabric or ribbon and string the mobiles they make this way between two sturdy chairs. They can place their children on mats between the two chairs so they can kick at the mobiles and listen to the rattles or bells. The parents need to always stay close by so the children don't become entangled.

To teach children to enjoy themselves. . .

Parents can put large towels on the bottom of the bathtub and fill the tub with about 2 inches of water. While they watch, the children can lie on their backs in the water and practice splashing, enjoying the sounds and the feelings.



MELD SPECIAL

Play

To encourage children to collect information and ideas. . .

Parents can let their children play in front of safety mirrors that have been set up at their own level either on the floor or at a table.

Sometimes the children will connect what they see in the mirror with themselves. Parents can try putting hats on their heads or interacting with them in other ways and see if the children reach for the hats or become involved with the other activities.

To help children understand the world. . .

Parents can introduce words that their children can experience. For example, they can say "down" when they put the children into their cribs. They can say "mouth" as the children put food into their own mouths. They can say "cold" when the children touch cold water or snow.

To show children how to communicate with others. . .

Parents can play "show me" with their children. They can start with things that interest the children, such as shoes or the cat. They can also exchange greetings with the children, saying "hi" when they approach the children and "goodbye" when they leave. In this way, the children learn that words stand for objects and actions.

To strengthen family relationships. . .

Parents can play together and talk about what they are doing by reporting actions "play by play." When they toss balls to their children, they can say, "Here comes the ball. You caught it. Great. Now push it back to me."

Play Is For Parents Too

Because many adults were raised by parents who were busy, they often find themselves at a loss about how to play with their children. Or they may have forgotten what they used to know about play. The ideas in this chapter should help parents observe play and enter into it. In order to do that, parents must get in touch with their own playfulness. This chapter endorses play for adults as well as for children.

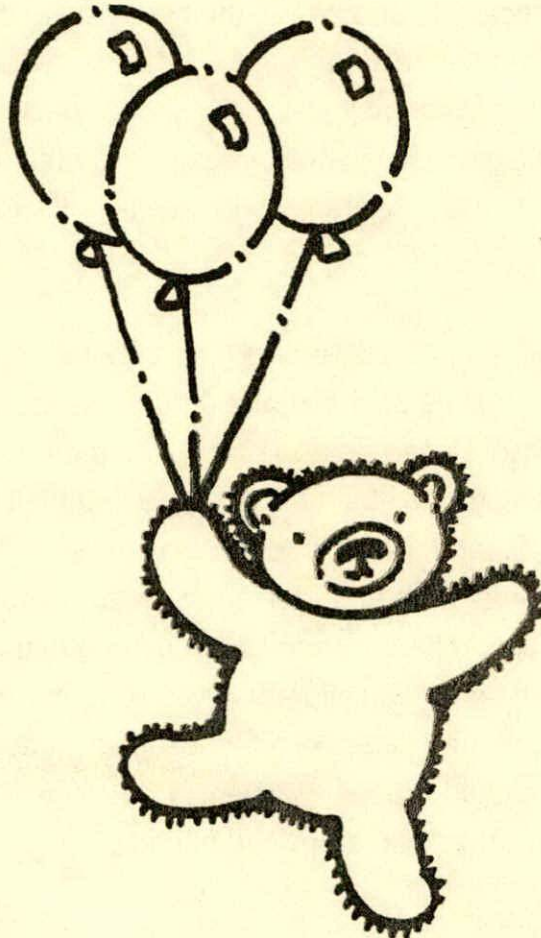
To start, parents can identify their own attitudes toward play. They can think about a favorite activity that they experienced in play as children. If they still have a much-loved toy around, they might want to bring it out again. They can recall how they played as children, what they enjoyed doing. Some direct questions might help.

- How did your parents play with you? What did you do together? Did your parents take time for adult play? What did they do? Have you followed their patterns or set some of your own?
- When did you last take time to play? How did you feel afterwards? What was the purpose of doing it?
- What's the difference to you between play and work?
- Has a hobby or activity ever changed for you from being play to being work?
- Do you want to set any new goals in your life with respect to taking time to play? What would you like to see happen?

MELD SPECIAL

Play

If parents play, both they and their children benefit. Children gain from the sense of joy and release in their parents, from their parents' enhanced ability to enter into the children's worlds. Children can join their parents in being spontaneous and experimental and in discovering the sense of becoming in life. Author and play expert Brian Sutton-Smith says that play is important because it allows people to enjoy each other more and encourages them to be more creative and versatile. He's right.



Parents' Roles In Children's Play

Children with disabilities may seem to lack either the desire or the ability to play like other children. Developmental delays and other conditions may interfere with or inhibit early play interactions between parents and children. The children's disabilities may limit their abilities to initiate or respond to play. Parents may need to extend themselves repeatedly and sometimes dramatically to encourage their children to play or even to make it possible for their children to play. Parents will probably have to redefine certain aspects of play just as they have had to redefine so many other areas of their lives. They must keep in mind that if they are playful on their own *without* their children, it will be easier for them to play *with* their children.

Parents of special needs children who play with their children acquire a more positive perspective on their children and realize that there are many things that their children can do and enjoy, that there are many things that *they* can do and enjoy with their children, and that their children are similar to other children in many ways. Through play, parents also receive rewards for the time and energy they spend with their children. Parents' self-esteem may be improved when they play one of their children's favorite games and see their children's eyes light up. A parent's exhaustion at 5 a.m. may dissolve when his child claps to a song he sings while changing the child's diaper. Parents pride increases as they watch their children grow and begin more and varied play.

MELD SPECIAL

Play

Sometimes parents who have children with special needs have difficulty feeling comfortable in playful times with their children. The demands of therapy, developmental interventions, and medical and educational visits can leave little emotional or physical energy left for play. Parents' feelings of anger, sadness, and loss might inhibit their own ability to play with their children. Sometimes parents feel compelled to make every minute count toward developmental progress and they don't want to waste time playing. These parents might want to look at the booklet, Let's Play with Our Children: Ideas for Families of Children with Severe Handicaps, by Pat Downey (Washington, D. C.: Association for the Care of Children's Health, 1986). The Growth and Development chapter and the material in this chapter should give even parents who feel compelled to work constantly numerous reasons for including play in their lives with their children.

Here are some ways that parents can take a role in their children's play:

- They can provide safe play environments for their children. Shelves at the children's level are appealing to children and easy to take care of. Special drawers in the kitchen can be filled with objects that are okay for children to use.
- They can talk frequently with their children at their own level, both in terms of language development and by getting down on the floor to be at the children's own physical level.
- They can show interest in their children's activities by offering play times when the children choose activities that they want to do.
- They can provide a wide range of materials and activities and select toys that are appropriate for their children's ages, stages, interests, and abilities.
- They can reinforce and praise success and competence as they focus on the abilities, not the disabilities.

MELD SPECIAL

Play

Ways that parents can take a role in their children's play (continued):

- They can promote independence but provide help when it is needed. They can take a back seat sometimes and let their children direct the play while the parents follow the children's suggestions. They can get their children started playing but avoid feeling they always have to play with them.
- They can present their children with imaginative suggestions.
- They can strengthen their children's own desires to learn by encouraging short interactions of about 2 or 3 minutes repeatedly during the day.
- They can help their children feel that it's important to do their best.
- They can find things at which their children are successful and build on their strengths, for example by encouraging visual learners to play visually.

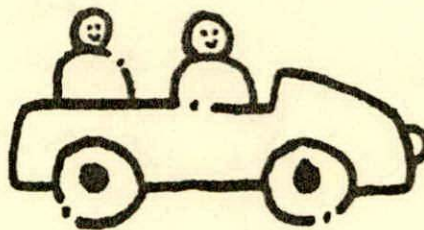
Things to Remember When Playing with Children

- Probably the most important thing parents can do for children and their play is to believe in the importance of play themselves. Adults need to play, families need to play, children need to play. . . it's essential to the business of growing up.
- Brian Sutton-Smith's first rule of parent/child play is: "If it's not fun for both of you, forget it. If it is fun, do it a lot. . . no matter how odd it is." Face it, some of the things parents do with their children are almost embarrassingly silly. Parents feel less silly about being silly after they've had a family for awhile. They recognize whether a particular play activity is fun for them or not. Their children give them clues. . . a turn of the head, a pushing away, a look of interest or disinterest. Parents need to remember to check their children's moods and feelings of well-being during their playtimes.

MELD SPECIAL

Play

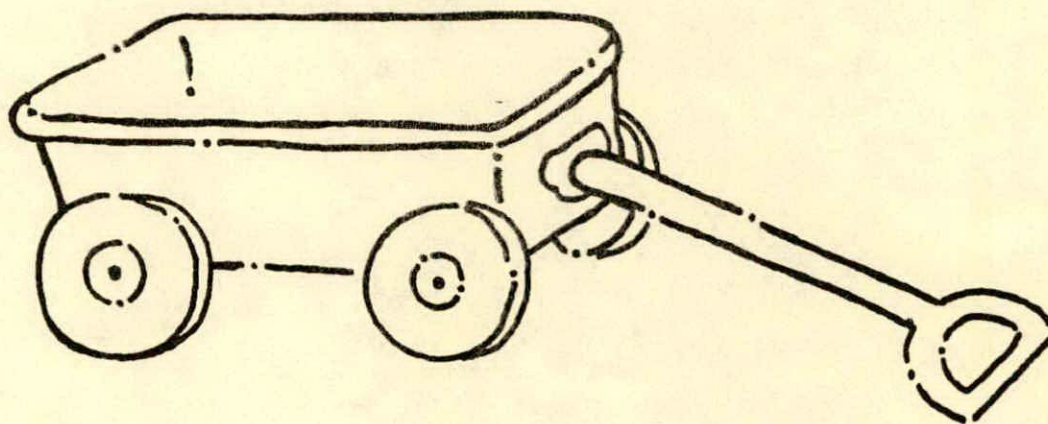
- Parents shouldn't expect play to last for very long. They need to check their children's attention spans. Short play periods may be better than longer ones. . . seconds or minutes rather than hours. Parents who claim to play "a lot" with their children really play only 10% or less of the children's waking time.
- Parents should play with children, but try not to play for them. When children let their parents know they want them to join in their play, the parents should be there for the children whenever they can.
- The parents' roles are like those of advisors or consultants. Parents shouldn't let themselves be bosses. The more they know their children, the better they will be able to suggest ways to play and have materials around that the children need. Children need freedom and opportunity to experiment . . . but not too much at one time.
- Parents should try to let their children work out their own troubles. They don't need to rush in with quick solutions. Other chapters have discussed the value of frustration.
- Parents need to pay attention to and recognize their children's play. Parents support their children by witnessing their children's activities, by saying something as simple as "I see you. . . I see what you are doing." This kind of confirmation helps children develop inner standards of "good" work and fulfilling activity.



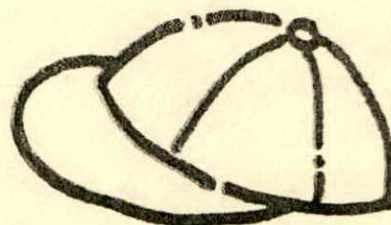
MELD SPECIAL

Play

- Parents should be aware that their own needs (for doing things the "right" way, for cleanliness, for organization) may not be what their children need at all. They need to find a workable compromise. If they absolutely don't want one room of the house damaged, they can't allow play in that room. But if they've restricted all their children's play to a basement room, they might want to reflect on what that says to the children about how their parents value their play and how their parents value them. Parents who live in apartments, on the other hand, have some difficult realities to deal with. They can talk with other parents in the MELD Special group to get ideas about how to handle noise and clutter in small spaces. Parents who can feel freed up from their adult concerns will probably find that their children can teach them a lot about being spontaneous, about looking at things in new ways, about giving up standards that may be too high anyway. Children can teach adults about fun in marvelous ways.



Fathers' Roles in Play



The special way men play with their children is important. There appears to be a difference in styles between men and women. Fathers engage in significantly more physically stimulating games such as bouncing and lifting. Mothers play more verbal or conventional games, such as pat-a-cake or peek-a-boo or they play with a toy. When infants vocalize, men are more likely to vocalize back to the children, while women are more likely to hold, touch, or pick them up. Dr. T. Berry Brazelton noted that the difference in parents' play styles helps children learn to expect the reactions that characterize each parent. Discriminating and responding appropriately to each parent prepares children for relationships with others; children learn to develop expectations about the kinds of experiences associated with certain individuals. Fathers' play—more than mothers'—seems to affect their children's cognitive development. One researcher suggested that fathers' probably make their primary contribution to their children's development through play. (From

A Handbook for the Fathers' Program, by Donald J. Meyer, Patricia F. Vadasy, Rebecca R. Fewell, and Greg Schell. Seattle, WA: University of Washington Press, 1985.)

Children do not seem to be bothered by differences in the play styles of men and women. They most likely come to accept and enjoy the differences. Parents who play in different ways are still providing for their children's development. Sometimes one parent prefers active play and the other parent prefers quiet play. However, it is a good idea if both parents use both kinds of play at various times with their children. Single parents may want to seek out other adults with whom their children can play. They could try the Big Brothers or Big Sisters organization.

MELD SPECIAL

Play

Ending Play

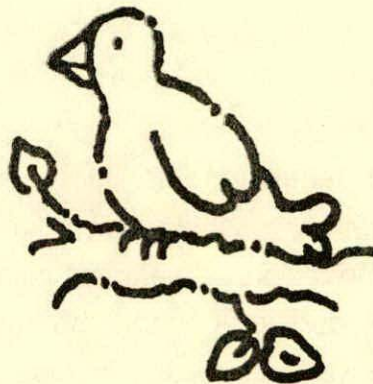
Parents need to recognize their need sometimes to back off and relax. There may be a tendency for parents of children with special needs to feel they must constantly stimulate their children in order to help them make progress. Play itself may have several ulterior motives. One fear is that without constant stimulation, special needs children will lose all they have gained. Parents may feel that they must always be "doing" something, and that their children must always be "getting something out of" whatever it is they are doing at the moment. In fact, our consultants remind us that overwhelming or constant stimulation can have negative effects. Youngsters who have Down Syndrome, for example, need time to take in new information. If their parents are playing a drum-banging game, the children may ignore the first few bangs. The parents shouldn't just bang louder because that might make the children fearful. Instead they need to give their children time to get used to the banging and to build up interest. The children can decide when to do the banging themselves. When parents do all the "work" of play, children might not develop their own resources for play and growth and may continually expect other people to amuse them. Parents can seek advice from other parents, from teachers, from doctors, and even from their own children about how to tell when "enough play is enough."

Family Fun

Having fun as a family is important for children's growth and development. Parents of children with special needs will want to save some time to play with each of their other children, too.

Dolores Curran has identified 15 traits of healthy families. She reports that one trait is that healthy families have a sense of play and humor. Experts who participated in her survey reported that a sense of humor in the family keeps things in perspective and is an antidote to drudgery, depression, and conflict within families.

"The primary hallmark," Curran writes, "seems to be this family's absence of guilt at times of play. Individuals and the family collectively give themselves permission to sit back, relax, dream, and enjoy. They schedule play times into the calendar; they don't wait for free time, a mistake made by families which do not find time to play." (From Dolores Curran, Traits of a Healthy Family. Minneapolis, MN: Winston Press, 1983, p. 126)



MELD SPECIAL

Play

Family members who have a sense of play and humor help de-fuse potentially explosive family situations. Such families might hang on to a quip that recalls an earlier humorous family episode. These memories become part of the family folklore. When these quips are spoken at the right time, they relieve tensions. Usually, these little comments mean nothing to outsiders; they may not even make any sense. But to the family, the comments are invaluable. Curran mentions one family she interviewed that reported that many years earlier, one brother had punched another brother because "he was thinking bad things about me." Now, whenever one family member is acting badly without reason, someone else in the family will say, "Who's thinking bad thoughts about you?" thereby telling the offender to shape up and take responsibility for his or her own mood. (From Dolores Curran, Traits of a Healthy Family. Minneapolis, MN: Winston Press, 1983, p. 131)

Humor between parents and children in healthy families is usually spontaneous, based on the unexpected, on surprises. It is difficult to analyze. Dr. Carol Weyland, a California psychologist, suggests that "when people laugh together, it promotes a feeling of unity. They can feel energized by the experience. . . . When a parent can get a child to laugh with her, that overflow of delight actually seems to break down negative ways of thinking."

Leonard G. Epstein, a behavioral scientist in San Francisco, reports that research has shown that shared laughter reduces tension. "Good-natured humor bridges communication in healthy families and promotes cohesion." Healthy humor relaxes people enough to be able to talk about problems when they need to. If we want children to laugh, we need to laugh with them. (From "Family Laughter," by Susan Isaacs in Parents, August, 1983, pp. 42 - 46)

Helping Children Who Have Difficulty Playing

Children do not have to be disabled to have difficulty playing. Dr. T. Berry Brazelton has observed that some children avoid exploring and trying new skills. These children may be protecting themselves against the insecurity they feel when they act independently; their fear becomes obvious if they seem unable to play. Dr. Brazelton suggests that parents can help such children learn to play by providing toys and other people with which to play and by modeling play behavior. (From Toddlers and Parents: A Declaration of Independence, by T. Berry Brazelton. New York: Dell Publishing Co., 1974, p. 227)

Disabilities can cause special difficulties with playing. A disability might:

- inhibit activities that may appear naturally with non-disabled children.
- cause children to play at one level of development for a longer time than other children do.
- mean children take longer to move on to more complex play activities.
- cause parents to feel less confident about initiating activities.
- decrease the kinds of responses children can give.
- mean children are limited to certain levels of ability.
- mean that some activities may be impossible and that, therefore, substitutes may need to be explored.
- cause parents and children to feel frustrated.

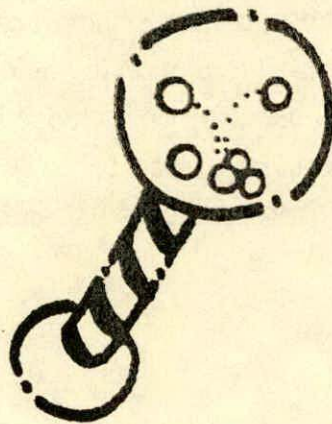
MELD SPECIAL

Play

Even with these difficulties, special needs children can learn to play. For example, children who are physically impaired can play a special version of "Push-Pull." Their parents can have the children sit on a mat between them, and the parents can take turns pulling the mat and the child toward them. Each time the child comes to one of them, that parent can greet the child with a big smile and "Hello!" As another example, parents can make a set of cardboard stacking blocks out of sturdy boxes of milk cartons leaving one side of the box open and gluing different pieces of fabric or textured paper on the inside of several of the boxes. The children will enjoy putting their hands inside the blocks to discover the interesting textures. Such activities are not just for the children's sake, but are for both parents and children. Games and activities help form a relationship.

Adapting Toys and Activities

Toys and activities can be adapted to broaden the play opportunities for children with special needs. Most children with special needs can do things a non-disabled child can do if their special needs are taken into account. Here are some suggestions for adapting activities for special needs children.



MELD SPECIAL

Play

Children who cannot get around easily can enjoy a variety of activities as long as they are in a comfortable position. Use materials with tactile interest and with sounds. For some children, a space with "inflatables" might provide enjoyment. Children might play on large air mattresses or inside an empty plastic pool with low inflatable walls. In such a space, children have a place free of hard surfaces where they can roll and push and prod and lift. A pile of fallen leaves outside might provide a similar play experience. Think of the sensory stimulation that comes with leaves! "Roller boards" are useful if children can use their arms to push their bodies around. This strengthens arm muscles and fosters independence. If children have difficulty picking up toys, toys can be placed in a flat box with sand in it. The sand will keep the toys from slipping away as the children reach for them. Children without muscle control can have play created for them to watch, such as sounds and lights.

Children who have mental disabilities benefit from clear directions. Their parents need to get their attention and then give simple, clear cues. They should keep a slow pace, use motions along with verbal directions, and repeat often.

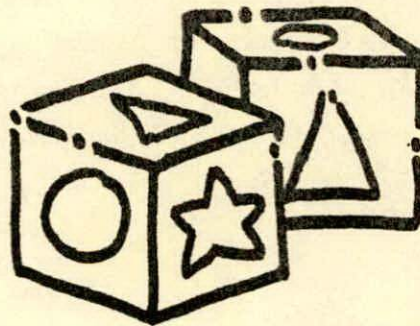
Children who are very active and have a hard time concentrating will benefit from songs with motion and repetition and from basic toys. Parents should offer only one toy at a time and give lots of encouragement and appreciation for the play that results. Sand and water play might be enjoyable and calming for these children. They can be encouraged to run and throw in acceptable ways; for example, they can throw foam cubes into a laundry basket.

MELD SPECIAL

Play

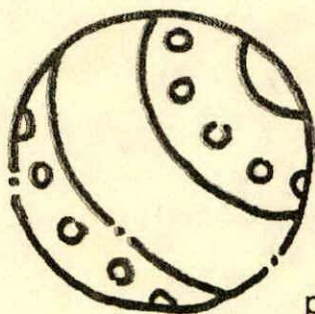
Children with hearing-impairment will enjoy toys that spin, vibrate, or light up. Parents can place their children's fingers on their own fingers or throat while they sing. They can use songs that can be signed or that have motions. They can use low-pitched toys, like drums or cowbells. And they can use repetition.

Children with visual-impairment (and other children as well) enjoy toys with lots of tactile interest. Parents can find objects of different weights, sizes, and textures. Children will want to bite or taste the toys or rub them against their faces. The toys can be anchored securely to the child, so that they can learn to risk dropping the toys because they know they can pull the toys back on the strings. These children like to use toys that "activate" others, such as drums and drumsticks or spoons and mugs, so the children learn to use toys in combination with each other. Their parents can find a container like a small "cage" in which they can put various items, such as small toys, keys, old scent bottles, or biscuits, so the children can explore the contents with their fingers before solving the problem of opening the "cage." These children need to use play equipment that has its own boundaries, such as sandboxes, babybaths with water or rice, and plastic wading pools. The children can feel secure and relax within those boundaries. Adults need to remember to always speak to visually-impaired children before they touch them and to use repetition.



MELD SPECIAL

Play



Parents should be aware that children can become overstimulated in any sensory area during play. When children are excessively or inappropriately stimulated, they may withdraw from the play. They are taking "time out" to develop a strategy to deal with the person who is providing the stimulation. Parents playing with their children should watch for the children's reactions. Are they responding? Or are they withdrawing? Parents can follow their children's leads in finding play that is enjoyable if they avoid imposing their ideas on their children all the time.

Parents should tune in to their own reactions also. They might become discouraged if they are reaching out but their children are withdrawing. If play is **not** fun at a particular time, they can try something else or postpone play until another time.

Selecting Toys and Materials

For children between birth and age three years, parents should provide a variety of play equipment.

Creative toys: blocks, paints, crayons, playdough, rhythm instruments.

Small muscle toys: pegboards, lacing cards, pounding benches, puzzles.

Large muscle toys: riding vehicles, punching bags, wheelbarrows, climbing bars.

Pretend toys: dolls, doll houses, dress-up clothes, telephones (for girls and boys).

Experimental toys: magnets, simple games.

Books

Non-toy items: boxes, pots and pans, etc.

MELD SPECIAL

Play

Parents can also buy toys that serve many purposes (such as blocks or wagons) instead of a single purpose (such as a See 'n Say). They can rotate toys so that their children will fully use the toys that are out. They can provide a variety of play activities during the day, such as quiet play, active play, creative play, group play, and make-believe play. And they can select toys that are safe.

Toys for Growing: A Guide to Toys that Develop Skills, by Mary Sinker (Chicago, IL: Year Book Medical Publishers, Inc., 1986), offers suggestions for various toys that would be appropriate for different stages of development. Each toy has been tested and evaluated for durability and safety. The toys suggested include:

- For infant stimulation: toys to look at, bat at, grasp and handle; balls; suction toys; pull toys.
- For fine motor and visual perception: busy boxes; in and out toys; pounding toys; pegboards; shape boxes; stacking toys; piling and nesting toys; two-handed toys; threading toys; construction and building toys; design and pattern sets.
- For gross motor play: walking, push, riding, throwing, balancing toys.
- For auditory and musical play: passive and active sound toys.
- For tactile play: textures and shapes.
- For language play: language games, sequencing games.
- For number play: materials, games, puzzles.
- For electronic play: electronic toys, battery operated toys.

MELD SPECIAL

Play

Sources for Materials

Lekotek is a world-wide network of resource centers to support families with children who have special needs. For more information, contact the National Lekotek Center, 2100 Ridge Avenue, Evanston, IL 60204, 312/328-0001. Lekoteks are located in a variety of settings throughout the world. Leaders model and demonstrate play strategies for use at home, give practical ideas, lend useful toys, and provide encouragement and support. Lekotek publishes excellent resources for building adaptive toys for children with special needs.

One Lekotek book, the Plan Book of Adaptive Toys, Volume I, 1987, by Carl Gulbrandsen and Bill Grogg, includes information about making floor tables, slides, attention lights, attention switches, battery-operated toys adapted for remote control, busy boxes, battery packs for signaling systems, push-button switches for remote controls, remote controlled buzzers, fish wiggler tracking toys, corkscrew tracking toys, ball-roll tracking toys, posts with 5 rings, toy handle extensions, bead counters, large and medium and small switches.

Another Lekotek book, the Plan Book of Adaptive Toys, Volume II, 1987, by Carl Gulbrandsen and Bill Grogg, includes round switches, zig zag trackers, vibrating pillows, turn 'n learn activity centers, texture covers, noise boards, tactile stackers, colored cones, clown boxes, busy box II's, stretchy bands, notebook switches, crank boxes, mechanical boards, pegboards, tic-tac-toe boards, disc rollers, tricycle pedal adapters, reflection boxes, floor stilts, and door boxes.

MELD SPECIAL

Play

Songbooks with signed songs are available from Gallaudet College Press Distribution Office, Kendall Green, Washington, D. C. 20002.

The New Friends Program (Chapel Hill Training-Outreach Project, Lincoln Center, Chapel Hill, NC 27514, 919/967-8295) has materials that provide mainstreaming activities to help young children understand and accept individual differences. They offer patterns for \$3.00 for making almost-child-sized New Friends dolls with proportionally scaled accessories (wheelchair, hearing aid, appliances, etc.). Other materials include teacher's manuals and notebooks, slide/tape programs ("Introducing New Friends" and "Issues in Mainstreaming"), and the New Friends Family Album with illustrations of New Friends dolls.

Toys To Grow On is a toy company that is concerned with safety in the home. They have available a No-Choke Test Tube that was designed by the Consumer Product Safety Commission to determine whether small toys are too small for certain children. Contact Toys To Grow On, P. O. Box 17, Long Beach, CA 90801.

Participation in Integrated Play Programs

"It's not necessary to put all the kids with problems in one place like some unnecessary club. . . Because [Sophie] is doing well, I believe that Mommy and Me classes and many other activities would benefit her just as much. We don't need to immerse ourselves in 'the disability' any more than is absolutely necessary; it's overwhelming as it is." (From Bittersweet Baby: A family Meets the Challenge of a Child with Disabilities by Jolie Kanat. Minneapolis, MN: CompCare Publishers, 1987, pp. 105 - 106)

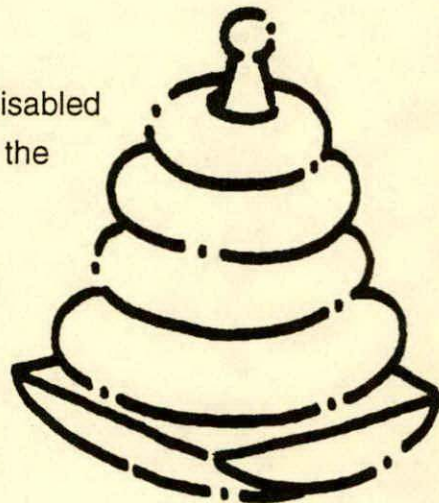
MELD SPECIAL

Play

It is healthy for children with special needs to socialize. Eventually, parents will want to help their children find ways to make contact with other children. Many MELD Special parents say this is a great benefit of their group. Parents will find that if their attitude is open and friendly, their children will imitate them and learn social skills. However, parents will want to be sensitive about the frustrations of being the only child with special needs in the whole group or being with children who have greater ability in certain areas.

Generally, the positives of integrated play experiences far outweigh the negatives. Integrated play programs give children an opportunity to associate with their peers. When children participate in play programs with children without disabilities, parents can see how much alike children are: they enjoy playing, they attend school, they have common human traits. Children with disabilities and illnesses can learn lots of normal behavior from children who are not disabled. Staff in community programs have described increased responsiveness in the youngsters with special needs when they play with other children.

Integration into play groups will affect the non-disabled children. Some day, these children will take on the roles of teachers, administrators, bus drivers, police officers, and landlords, or they will have children with disabilities or chronic illnesses. It will be beneficial for them to have known children with special needs.



MELD SPECIAL

Play

Parents can take advantage of existing community resources. Children with special needs can attend library story hours with other youngsters. They may enjoy visiting playgrounds and playing with other children. It may take some time to teach them how to use equipment that's already there. Parents can help children figure how to make the environment work for them rather than limiting their activities. They can encourage children to "find another way" to use the equipment. Here are some other ideas:

- health and social service agencies for special events or for referrals,
- the Red Cross or Catholic Social Services,
- the Big Brother and Big Sister programs,
- YMCAs, YWCAs, Boys' and Girls' Clubs,
- nursery schools or preschool programs and daycare settings.

Conclusion

We're hoping that this chapter will rekindle parents' enthusiasm for what they can do as a family. There are two important considerations:

First, parents need to recognize their own limitations—and those of their children—as they ease their ways into family fun. Some parents are comfortable going about in public with the whole entourage. Others don't really enjoy this. Some parents will be very patient and low-key when encouraging their children to do cooking projects with them, but others will have discovered that these projects leave them frazzled and frustrated. They can remember that if they can't enjoy something, chances are their children won't either. Their own temperaments, energy levels, and interests need to be considered as well as those of their children. Parents need to be careful not to measure their family's success with that of others. The purpose of play is to promote their own enjoyment, relaxation, and fun.

Second, parents need to be careful not to neglect their own adult needs to do things apart from their children. . . even if they work. Some of the time, family fun is more giving than getting. Most of the time, parents have to compromise their own agendas. So parents need to take into consideration their own needs to get "filled up" with enjoyments of their own. Doctors are finding that people who can laugh, relax, and love what they're doing are more resistant to serious illness and are often faster healers during recovery. Fun may actually change body chemistry for the better, just as stress changes it for the worse.

It might help parents to list ten things they enjoy doing. . . things they find relaxing and fun. Then they could check three they could do this month. All people need to take care not to let life get away from them!

MELD SPECIAL

Play

Resources For Parents:

Resources for Families

Gallaudet College Press Distribution Office, Kendall Green, Washington, D. C. 20002.

National Lekotek Center, 2100 Ridge Avenue, Evanston, IL 60204, 312/328-0001.

The New Friends Program, Chapel Hill Training-Outreach Project, Lincoln Center, Chapel Hill, NC 27514, 919/967-8295.

PACER, 4826 Chicago Ave., Minneapolis, MN 55417, 612/827-2966.V/TDD. PACER is a leading national resource for information about educational rights for students with all kinds of special needs. It provides workshops for parents in every aspect of the educational system. It is one of the new computer resource centers in the country and has printed materials on a vast range of educational issues.

"Project Dakota Early Intervention: Tailor Made," Linda Kjerland, 1986, a free brochure available from Project Dakota Outreach, 680 O'Neill Drive, Eagan, MN 55121, 612/455-2335. The brochure describes a successful program for providing toddlers with integrated early intervention activities.

MELD SPECIAL

Play

Books with Activities for Children with Disabilities

Atack, Sally M. Art Activities for the Handicapped: A Guide for Parents and Teachers. Englewood Cliffs, NJ: Prentice-Hall, Inc., 1982. Art activities for each of six stages of development. Includes a good introduction to the use and care of clay.

Caston, Don. Easy-to-Make Aids for Your Handicapped Child: A Guide for Parents and Teachers. Englewood Cliffs, NJ: Prentice-Hall, Inc., 1981. Specific directions for construction of useful items, including: seats, raisers for beds, walkers, portable toilets, parallel bars, and more.

Downey, Pat. Ideas for Activities with Hospitalized Children. Washington, D. C.: Association for the Care of Children's Health, 1982.

Downey, Pat. Activities for Children with Special Needs. Washington, D. C.: Association for the Care of Children's Health, 1986. Specific activities for children with specific disabilities, including those restricted to the use of one hand or to the use of feet only, those with restricted trunk movement, those with respiratory problems, those with no use of extremities, etc. The book also has a very good bibliography.

Downey, Pat. Let's Play with Our Children: Ideas for Families of Children with Severe Handicaps. Washington, D. C.: Association for the Care of Children's Health, 1986. Play ideas for families to help children develop new skills and interests. Includes a description of the benefits of play and directions for observing the child's interest level and for designing more activities.

McKonkey, Roy and Dorothy Jeffree. Making Toys for Handicapped Children: A Guide for Parents and Teachers. Englewood Cliffs, NJ: Prentice-Hall, Inc., 1981. Discusses the role of toys in play and how to choose toys. Includes many ideas for making toys and playing games that are appropriate for children with disabilities.

MELD SPECIAL

Play

Books with Developmental Descriptions and Activities for Non-disabled Children

Miller, Karen. Ages and Stages. Marshfield, MA: Telshare Publishing Co., Inc., 1985. Includes descriptions of the developmental milestones for children at various stages between birth and eight years, including: emotional, social, physical, language, self-help, and cognitive development. Many, many ideas for activities for parents and children are described.

Parks, Stephanie. Make Every Step Count: Birth to 1 Year, Developmental Parenting Guide. Palo Alto, CA: VORT Corporation, 1986. This is a parent-child interaction guide to help parents enhance each step of their child's development. There are six sections: cognitive, language, gross motor, fine motor, social emotional, and self-help. Many, many strategies are included for parent-child play.

Shephard, Linda. Parent's Helper - Ages 1 - 5. Palo Alto, CA: VORT Corporation, 1981. This book will help parents make their child's everyday activities into more than routines. Areas of learning included are motor skills, language skills, perceptual skills, thinking skills, social skills, and math and reading readiness.

MELD SPECIAL

Play

Chapter References:

- Brazelton, T. Berry. Toddlers and Parents: A Declaration of Independence. New York: Dell Publishing Co., 1974.
- Downey, Pat. Let's Play with Our Children: Ideas for Families of Children with Severe Handicaps. Washington, D. C.: Association for the Care of Children's Health, 1986.
- Featherstone, Helen. A Difference in the Family: Living with a Disabled Child. New York: Penguin Books, 1980.
- Fewell, Rebecca and Patricia Vadasy. Learning through Play.
- Gulbrandsen, Carl and Bill Grogg. Plan Book of Adaptive Toys, Volume I. Evanston, IL: National Lekotek Center, 1987.
- Gulbrandsen, Carl and Bill Grogg. Plan Book of Adaptive Toys, Volume II. Evanston, IL: National Lekotek Center, 1987.
- Hanson, Janice P. and Elizabeth S. Jeppnon. Seasons of Caring. Washington, D.C.: Association for the Care of Children's Health, 1986.
- Isaacs, Susan. "Family Laughter," in Parents, August, 1983, pp. 42 - 46.
- Johnson and Johnson Baby Products, Co. The First Wondrous Year. New York: Macmillan, 1979.
- Jones, Monica Loose. Home Care for the Chronically Ill or Disabled Child. New York: Harper and Row, Publishers, 1985.
- Kanat, Jolie. Bittersweet Baby: A Family Meets the Challenge of a Child with Disabilities. Minneapolis, MN: CompCare Publishers, 1987.
- McLane, Joan B. "Lekotek: A Unique Play Library for Families with Handicapped Children." CHC, Winter, 1986, Vol. 14, No. 3. pp. 178 -182.
- Meyer, Donald J. and others. A Handbook for the Fathers' Program. Seattle, WA: University of Washington Press, 1985.

MELD SPECIAL

Play

Chapter References (continued):

Newson, John and Elizabeth Newson. Toys and Playthings in Development and Remediation. New York: Pantheon Books, 1979.

Schliefer, M. J. and S. D. Klein (editors). The Disabled Child and the Family: An Exceptional Parent Reader. Boston, MA: Exceptional Parent Press, 1985.

Segal, Marilyn. In Time and with Love: Caring for the Special Needs Baby. New York: Newmarket Press, 1988.

Sinker, Mary. Toys for Growing: A Guide to Toys that Develop Skills. Chicago, IL: Year Book Medical Publishers, Inc., 1986.

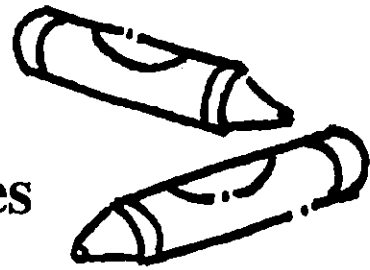
Strom, Robert D. "Too Busy To Play," Childhood Education. November-December, 1977.

Sutton-Smith, Brian. How to Play with Your Children: and When Not To. New York: Hawthorn Books, 1974.

Sutton-Smith, Brian. Play and Learning. New York: Gardner Press, 1979.

Thompson, Charlotte E. Raising a Handicapped Child. New York: Ballantine Books, 1986.

Winton, P. J. and others. Selecting a Preschool. Austin, TX: PRO-ED, Inc., 1984.



Learning Activities

Set the mood by bringing some playthings from home and arranging displays around the room. Be sure to bring enough so each parent can select one item. Ask the parents each to select one plaything that describes who they are. Encourage them to be as creative and imaginative as possible. In small groups, have the parents each use three minutes to describe how the plaything reflects their personality.

Get acquainted by having parents share something they've done recently that they enjoyed doing with their children.

Have parents share answers to questions such as: "What are you doing now to play with your child?" and "How do you feel about this activity?"

Invite a speaker or panel of professionals and other parents of children with special needs. You might invite one or more professionals in areas related to play and play therapy or adaptive play.

Arrange for a playtime with parents and children together. Set up a room with appropriate toys and equipment and encourage parents to take time during the meeting to play with their children. Parents who attend MELD Special without their children might be able to sit and observe the play of other children.

Organize mini-lectures by dividing up the material between two or three of the parent group facilitators and having them talk about each topic. Allow time for discussion and questions. If there are questions you can't answer, make notes and call someone before the next meeting to find the answer. Report on answers at the next meeting.

MELD SPECIAL

Play

Encourage discussion to help parents get in touch with their attitudes towards play and how they value or don't value play in their own lives. You might want to bring a toy or game you had as a child — something familiar to most adults like hats, scarves, jacks, a ball and mitt — as a way of opening up this discussion.

- What do parents remember about how their parents played together or with them as children? How do parents wish their parents had played with them? You might want to begin with an example from your own life. What did parents in your group learn from how they were or weren't played with? How did parents enjoy playing alone and with others as children?
- Ask the members what they were doing the last time they played? What made the situation playful? What was the purpose of doing it?
- What's the difference between play and work? Some ideas were listed earlier in this chapter. See how many ideas parents in the MELD Special group can come up with.
- Finally, you might summarize, "For us adults, play seems to mean. . ."

Encourage discussion about how playing with children brings out the playfulness in adults. One of Brian Sutton-Smith's rules of parent/child play is: "If it's not fun for both of you, forget it. If it is fun, nurture it. . . no matter how odd it is." Some of the things we do with our children are almost embarrassingly silly. Maybe some parents in MELD Special can share some of the private play they enjoy with their children. Here's an example of what can be done with a non-walker: If you have a nice, old dog that runs away from children, carry the child around chasing the dog; the child might not be able to chase the dog alone.

MELD SPECIAL

Play

Set up small group experiences. Bring several objects from home that are not intended to be children's toys. Divide into small groups and give one object to each group. Have each group make up a story about their object and think of a way to use it for a game. Have each group share with the larger group. As a facilitator, make a point about playfulness, creativity, everyday qualities of play, the adult's ability to play, and the ability to make something ordinary into an amusing game.

Children's play is a necessary support for all the ways they grow and develop.

Encourage discussion about the meaning of play in children's lives. You might want to mention the tendency of experts writing about children's play to call it a child's "basic research," "education," "learning medium," or "work." These descriptions may have been used partly because of the puritan work ethic in us. . . but they also do reflect play's role in the child's life. When children play, it is partly fun, relaxation. . . but it is also serious business.

Lead discussion about these questions:

- Ask the parents in the group to each describe their children playing. What were their children doing?
- After each play description, ask parents to consider what their children were getting out of that kind of play. Were those ways of getting to know their parents? Were they ways of testing new skills? Were they ways of learning about how their bodies work? Or were they a combination of these?

MELD SPECIAL

Play

Lead discussion about these questions (continued):

- How have the skills that the children have developed influenced their play?
- Have parents think about what their children did during the last few hours and describe the learning that they think has been going on.

Present a mini-lecture by listing for the group some of the things included in this chapter about what children learn through playing. Then ask the parents to describe 2 or 3 things their children like to do and match the activity with the list. Ask, "Did you know play accomplishes all these things?" at the end of the discussion. This same list might be used as a discussion tool for ideas about toys, games, and play areas.

Lead parents to think about their children's play as ways to gather information and make observations that can form some basis for communicating with professionals. Spread out a collection of toys appropriate for the children of your MELD Special group. You might include blocks, noisemakers, puzzles, picture books, dolls, crayons and paper, balls. Ask the parents:

- Why do you think your own "stuff" (such as keys, dishes, magazines) are so interesting to your children?
- What is your definition of play? How do you think this is different from the way your children think about it?
- What developmental abilities do you notice while watching your own children play with these toys?
- What abilities do your children show both when playing alone with the toys and when playing with another child or adult?
- What can we learn from our children as to what's important to other children their age?

MELD SPECIAL

Play

Role play this situation:

A 3-year-old child with cerebral palsy has just received a developmental evaluation as part of the process for entering a preschool program. The testing room and evaluator were both unfamiliar to the child. In the parents' opinion, the test results underestimated the child's abilities. Since the school will use the test results to plan the child's program, the parents want to include additional information about the things they have seen their child do at home. Role play how these parents could use observations of their child's play at home to communicate with the person who evaluated their child and the child's future teacher. Ask the parents to give examples of other situations where using observations of their child's play activities and abilities would help them communicate with doctors or teachers. (*From Seasons of Caring, by Janice P. Hanson and Elizabeth S. Jeppnon. Washington, D. C.: Association for the Care of Children's Health, 1986, pp. 48-49*)

Analyze play activities by presenting several play activity ideas. Have parents think of all the possible benefits to a child.

Children develop particular play preferences, styles, and abilities.

Have parents describe a special game that they play with their children, explain what they particularly enjoy about it, and explain their children's reactions to it and what their children seem to enjoy about the game.

MELD SPECIAL

Play

Lead discussion about the following questions:

- What are the things your children enjoy playing with, including things like mobiles that they may not be able to reach but like to look at?
- Why do you think they enjoy these toys so much?
- Describe how your child plays.
- What are some of the styles of play you see in yourself? in your partner? in your children's grandparents? in your children's babysitters?

Observe the children at play together. Suggest that parents watch for:

- How children treat each other (passively, aggressively, disinterestedly, etc.)
- What children do with the toys (grab, throw, hold, mouth, etc.)
- How the parents feel about watching. . . do they move in at any point and re-direct or change the activity?
- Clues that the children are overstimulated.

Learn a song to sing with the children. Try, "If You're Happy and You Know It, Clap Your Hands."

"If You're Happy and You Know It, Clap Your Hands."

If you're happy and you know it, clap your hands.

If you're happy and you know it, clap your hands.

If you're happy and you know it,

and you really want to show it,

If you're happy and you know it, clap your hands.

Adaptations: Use different actions, such as "give a cheer" or "touch your nose." Use different emotions, such as "if you're mad and you know it, stomp your feet" or "if you're sad and you know it, say boo-hoo."

MELD SPECIAL

Play

Videotape children playing. As you observe the videotape later, analyze and discuss their play preferences, their use of toys and equipment, and their general behavior. What ideas from this section do you see on the videotape?

Parents can provide opportunities for children to play.

Have the group observe as a parent plays with his or her child. Ask the group to watch for the benefits for both parent and child that they see while they watch. Possible toys include: pile of inflated balloons, large mirrors, noisemakers, dolls, cups, spoons, large cloths for peek-a-boo. After the play session, discuss:

- What are the advantages of play for a parent?
- What are the advantages of play for a child with a serious disability?
- When do you find opportunities to play with your child?

(From Seasons of Caring, by Janice P. Hanson and Elizabeth S. Jeppnon. Washington, D.C.: Association for the Care of Children's Health, 1986)

Lead a discussion of these questions:

- How do you define your own role in relation to your child's play?
- What kinds of activities or play would you like to be doing with your child?
- In what ways do you and your partner differ in how you play with your child?
- How does your child handle these differences?
- How much time do you spend with your child?
- How comfortable are you with the time you spend with your child in play and the time your child plays by him or herself?
- What aspects of your child's play or your play with him or her are not going as smoothly as you had hoped?
- What does your child do when you don't want to play with him or her?
- What is your child's play environment like? What playthings are available?

MELD SPECIAL

Play

Help the parents problem solve about difficulties in parent-child play.

Consider:

- What if children refuse to participate in play that would be good for them?
- What if children get frustrated and quit?
- What if children get bored and quit?
- What signs of overstimulation do children show?
- What about the child who just watches others play?
- How do some parents overprotect their children?
- How do parents know when to get into play with their children and when to stay out of the play?

Toys and activities can be adapted to broaden the play opportunities for children with special needs.

Show a videotape called "Understanding Disabilities." This 45-minute videotape is about specific disabilities and their educational implications. A pediatrician who specializes in physical and rehabilitation medicine describes in detail the characteristics of spina bifida, Down syndrome, cerebral palsy, and hearing and visual impairments. Children with these disabilities are shown in Lekotek play sessions. "Understanding Disabilities" is available from National Lekotek Center, 2100 Ridge Avenue, Evanston, IL 60204, 312/328-0001. Rental for two-weeks in 1988 was \$25.00, plus \$3.50 postage and handling. Purchase price was \$50.00.

Let the parents role play. Brainstorm ways to help children "try another way" to play with certain objects or actions. Then role play the situations.

MELD SPECIAL

Play

Let the parents examine toys. Bring in toys available on the market and brainstorm ways to adapt them to be meaningful to children of MELD Special parents. Try shape sorters, puppets, rattles, etc.

Having fun as a family is important for children's growth and development.

Encourage the parents to talk about what play means to them.

Discussion questions could include:

- Do you have any feelings about play that bother you? Some that please you?
- Where do you think those feelings come from?
- What do they tell you about yourself?

Assemble toy boxes. These boxes are intended to encourage more spontaneous play because they will be readily available when the parents and children need or want them. Bring a shoe box for each family or have each parent bring one to the meeting. Bring an array of play materials for them to choose from: red yarn to make pom-poms for visual tracking activities; aluminum foil to crumple into balls or hang on mobiles; old socks to stuff with old nylon stockings for making balls or to draw faces on for making puppets; fabric swatches of different textures for rubbing and massaging; empty margarine tubs; L'eggs eggs with dried beans and masking tape to make rattles; small, empty squeeze bottles for blowing puffs of air; different kinds of paper (paper bags, waxed paper, newspaper, etc.) to crumple to make sounds. While they make their boxes, discuss:

- When during the day would you find this box useful? (waiting for the bus, waiting for dinner to cook, after bathtime, waiting in a car or doctor's office)

MELD SPECIAL

Play

While they make their boxes, discuss (continued):

- How might the box help siblings play with children who have special needs? (by making toys easily available, giving them ideas, encouraging them to think of new things to put into the box)
- How might the box encourage friends and relatives to play with children who have special needs? (helping with an easy explanation about some activities your child enjoys, giving them ideas for toys to have at their house when you go to visit)

(From Seasons of Caring, by Janice P. Hanson and Elizabeth S. Jeppnon. Washington, D. C.: Association for the Care of Children's Health, 1986)

Set up an open forum about ideas for having family fun with children.

Lead a discussion about family fun. Ask each family the following questions. (Someone may want to take notes for future reference.)

- What have you discovered that's fun to do as a family, either at home or elsewhere? How did your child respond? Who planned it?
- How do you share planning responsibility with your partner? Would you like to? (This is to encourage dads to take a more active role.)
- What kind of preparation made that activity fun for you?
- What were your expectations of your child's behavior?
- What have you tried that didn't work? Why not?

MELD SPECIAL

Play

Help parents discuss the idea that humor and relaxation are weapons against serious illness, that fun isn't simply an extra, but an essential to life-long well-being. Types of humor include kidding, being silly, telling jokes, and laughing at situations. Discussion questions:

- Who gets to joke with whom in your family?
- Does your humor include your children or do they often get left out?
- How often do you and your children laugh together?
- What type of humor do you enjoy most?
- Do you vent hostility through humor?

Plan for play. Have each parent list ten things they enjoy doing. Make them list things that are relaxing and fun and have them check three things they can do this month. Provide paper and envelopes to be self-addressed. Facilitators should mail the lists back to parents in four weeks with a note, "Did you do the three things you checked?"

Exchange ideas about programs that have adaptive activities, such as park boards, campgrounds, children's theatres, etc.

Plan a family activity together as a MELD Special group. If parents have done a great deal lately with their children, they may wish to make this a parents' only get-together.

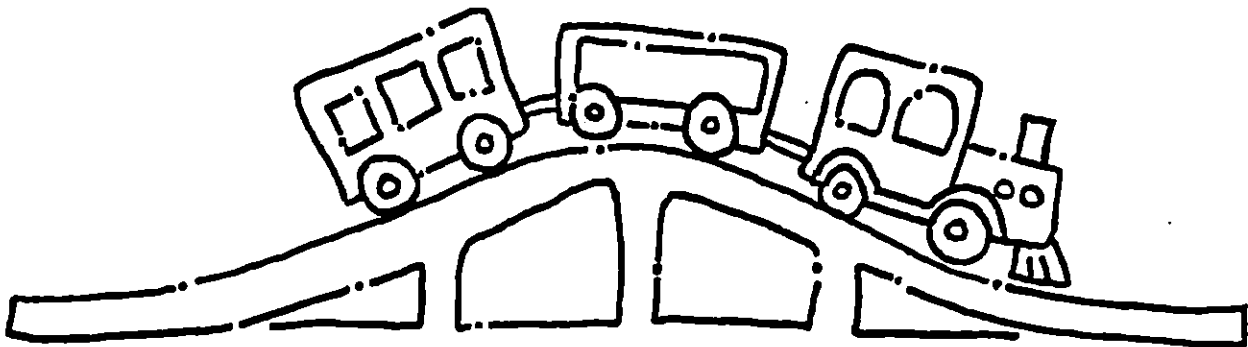


MELD SPECIAL

Play

Homework: You might want your group to develop a file for your community with respect to activities for families and children with special needs. Have them use this activity to think about how they might go about researching their community to find out what's available. One family might want to check the newspaper, another local and neighborhood publications, another the YMCA, and another the nursery school bulletin boards. Your group may decide to keep a file and update it.

Have parents write a journal entry. They can describe their own definitions of play and outline things they can each do during the next month to provide some playtime for themselves.



Chapter 7

Handouts

Play

THE SIXTEEN JOYS OF PEEK-A-BOO

(Source unknown)

Peek-a-boo is a Cognitive, Motor, Emotional, Social, Learning, and Fun activity. Infants learn a great deal from it; adults learn nearly as much when they engage in this very human interactional activity. Yet, surprisingly, many parents feel embarrassed about initiating or participating in peek-a-boo games with their babies. Here is a partial list of peek-a-boo benefits that may help adults to better understand the qualities of this valuable activity.

1. PEEK-A-BOO is absolute, pure, unhampered, creative FUN.
2. PEEK-A-BOO exercises the INFANT'S MEMORY. Adults go from sight, then return. Losing is part of gaining and vice versa. Out of sight is not out of mind.
3. Child-initiated PEEK-A-BOO demonstrates the child is SOCIAL in his/her play.
4. Child-initiated PEEK-A-BOO demonstrates the child as an INITIATOR.
5. PEEK-A-BOO EXERCISES facial muscles.
6. Child-initiated PEEK-A-BOO demonstrates that the child is most RESPECTFUL OF SELF when s/he creates his/her own SOCIAL learning pleasure.
7. PEEK-A-BOO exercises EYE-HAND COORDINATION. Timing is of the essence.
8. PEEK-A-BOO exercises CONTROL OF THE BODY. Players move slowly, then pause, then move quickly.
9. PEEK-A-BOO allows practice in MOVEMENT SEQUENCING. The root of the game is properly updated behavioral syntax, which is a basic principle in all of life.
10. PEEK-A-BOO exercises PATIENCE: putting the hands over the eyes and waiting a certain length of time is an exercise in patience. Good timing always demands patience.
11. PEEK-A-BOO promotes appropriate REPETITION. It's so much fun, you hate to quit.
12. PEEK-A-BOO is a simultaneous PHYSICAL-SOCIAL-EMOTIONAL-INTELLECTUAL activity.
13. PEEK-A-BOO exercises a child as a person who is learning to CONTROL OTHERS. PEEK-A-BOO is mutual control in interactional content, which is, of course, the definition of a game.

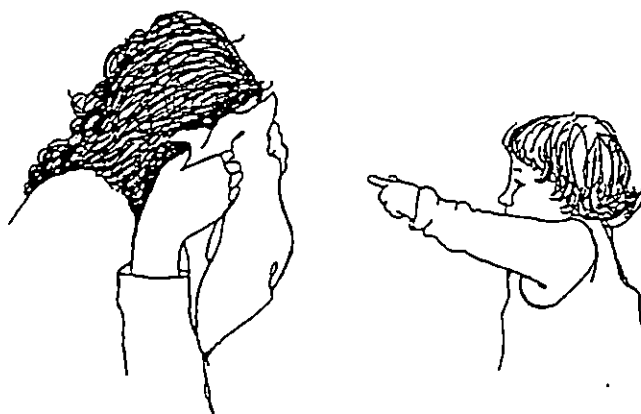
Continued...

14. PEEK-A-BOO is practice in social-motor HUMOR.
15. PEEK-A-BOO encourages the knowledge that EYES DO THE SEEING, but are not necessary for remembering.
16. There was once a child who played PEEK-A-BOO with his grandmother. The grandmother always sat in the same chair during their game. After many games, the child took the grandmother's role by sitting in her chair, assuming her postures, and intoning in a grandmotherly voice. Role-taking of this kind exercises beginning, valuable elements of EMPATHY.

Variations:

1. Put your hands in front of your face and remove them, as you say PEEK-A-BOO.
2. Pop up and down from behind a piece of furniture, as you say PEEK-A-BOO.
3. Put a scarf over your head and pull it off, as you say PEEK-A-BOO.
4. Put a scarf over your child's head and pull it off, as you say PEEK-A-BOO.
5. Use a stuffed animal to pop up and down, as you say PEEK-A-BOO.
6. Put the stuffed animal inside a box with a lid for your child to open and discover, as you say PEEK-A-BOO.
7. Turn the pages of a book back and forth, as you say PEEK-A-BOO.

Almost anyone who likes children will like peek-a-boo. Peek-a-boo behavior thrills most adults because it offers an opportunity to witness the emergence of a complicated and beautiful human being: the child. Adults should understand peek-a-boo is a very complex activity, as well as one which is FUN. It will teach you again and again that seemingly simple things are not always really simple; that healthy complexity grows mature where simple activities are shared.



TOYS FOR CHILDREN WITH SPECIAL NEEDS

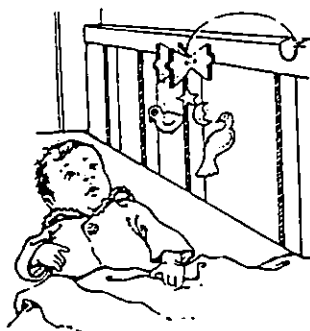
From In Time and With Love: Caring for the Special Needs Baby by Marilyn Segal, New York: New Market Press, 1988, pp. 163 - 165.

For Babies Who Are Tuning In: mobiles, mirror toys, toys attached to crib, rattles, velcro rattles attached to baby's wrists, squeeze toys, puppets, brightly colored socks for hands and feet, musical toys, beach balls.

For Babies Who Are Reaching Out: telephones, books with sturdy pages and large pictures, jacks-in-the-box, dolls, stuffed animals, puppets, roly-poly toys, musical instruments, rattles, squeeze toys, pull toys, clutch balls, beach ball, streamers, wind chimes, kites.

For Babies Who Are Making Discoveries: books, hats, dolls, stuffed animals, plastic dishes, telephones, cars and trucks, small playhouses, puppets, rocking toys, riding toys, balls, pull toys, push toys, punch balls, filling and dumping toys with large pieces, inset puzzles, shape sorters, pounding toys, scarves, boxes, water toys, musical instruments, jacks-in-the-box.

Sensory Awareness Toys: a small bathtub or inflatable pool with: feathers, corn meal, whipped cream, bubbles, water, rice, crinkly acetate paper, ice cubes, soap suds, yogurt; records and music.



TOYS FOR YOUNG CHILDREN

Source unknown.

One of the best toys available to your child is you! You can talk back and forth, vary your voice tones, feed, play with your child's fingers and toes, and cuddle. All these activities develop your child's senses. He will hear, touch, see, taste, and smell many things while playing with the you.

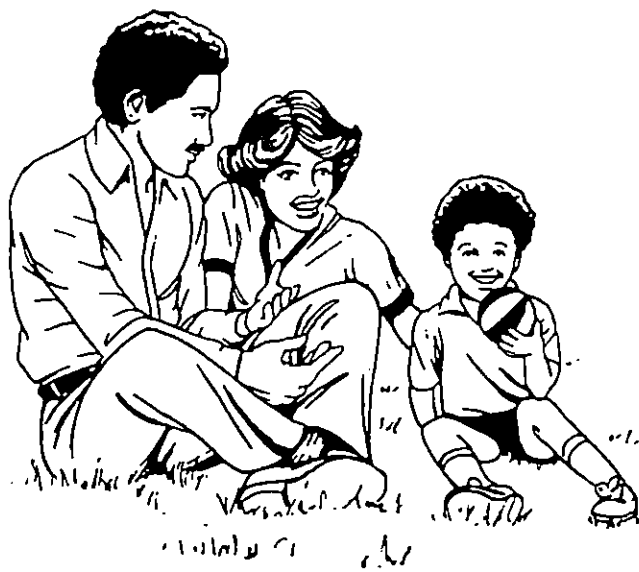
Collect items from your home: **wooden spoons, plastic containers, yarn, blocks, raisins, old socks, paper bags, handkerchiefs, scarves, chenille balls, cheerios, cups.**

Try to arrange for your child to play in many different positions. You can talk and play while she is in the crib on her back, on her stomach on the floor, propped up to sit in a chair, held in your lap, etc.

1. Make your own mobiles. Hang brightly colored objects, bells, and unbreakable mirrors on a rod at a level high enough so your child cannot reach them.
2. Play music for your child and pat his hands in rhythm. Let him drum on a can with a spoon. Sing, hum, whistle.
3. Put a clock, wind chimes, or music box near your child's crib.
4. Move your child from room to room with you.
5. Talk to your child. Reward your child's attempts to talk with smile and praise. Change your tone of voice sometimes.
6. Give your child things to grasp.
7. Make squeeze toys from pieces of worn toweling sewn together and stuffed with old stockings. A doughnut shape is easier for small hands to pick up.
8. Give your child safe household objects with which to play: smooth clothespins, sponges, smooth plastic bracelets, unbreakable mirrors.

Continued...

9. Play games with hiding things.
10. Give your child different textures to crawl or roll on: tile, carpet, sand, towels.
11. Let your child have her own drawer or cupboard with her toys.
12. Tie toys to your child's high chair, play pen, or stroller: metal cup with handle, small aluminum pie tins, colorfast ribbons, wooden spoon, bean bag.
13. Cover foam squares with colorful fabrics of various textures.
14. Sew a book from fabric. Talk about color, shape, texture when you look at the book together.
15. Use a pan with water or ice cubes for water play.
16. Create a "comfort bag" to use for outings, trips to the doctor, fussy times: paper, playing cards, small box of raisins, cereal, a new or favorite toy.
17. Collect bathtub toys: paint brush, empty dish detergent bottle, sponges.
18. Stack or nest cans or boxes.
19. Make blocks out of milk cartons or oatmeal boxes.
20. Fill a wastebasket with discarded letters.
21. Create pull toys. Tie a string to a metal cup, empty thread spool, pine cones, hair curlers, boxes, paper towel tubes.



CONTAINER TOYS FOR YOUNG CHILDREN

Source unknown.

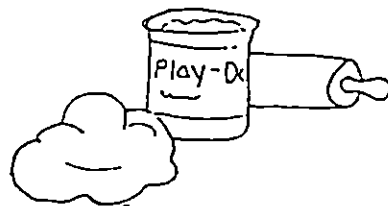
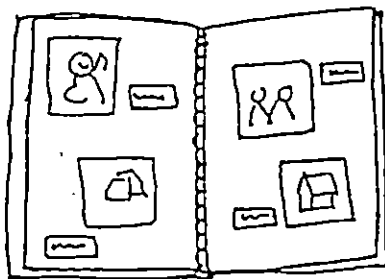
Many young children enjoy putting things into or taking things out of containers. Most parents struggle with the "dumping out" part of this play!

Holding objects and releasing them into a container is an important motor skill. Removing the lid of a container is another good motor skill. These skills usually develop along with the understanding that certain things will fit into other things. Children learn the meaning of "in" and "out." Later, they can learn "big" and "little" and "in between." Parents and children can take turns putting items in the container, shaking them, and dumping them out. Add words to your actions to facilitate learning language.

1. Plastic golf balls into a coffee can.
2. Orange juice can lids into a slot in the lid of a coffee can.
3. Knotted scarves tied together to pull out of a covered plastic bucket.
4. Blocks and spools pushed through round-shaped and square holes in the lid of a coffee can.
5. Laundry basket or dish pan for balls, stuffed animals, and other toys.
6. Clothes pins into a small-necked plastic bottle.
7. Nesting measuring cups.
8. Small toy inside nested boxes.
9. Cereal into a small-necked plastic bottle.
10. Cut the end off a large sock. Connect one end over the open end of a coffee can. Children can put their hand and arm through the sock, into the coffee can to pull out small items.

THINGS TO DO WHEN THERE'S NOTHING TO DO

1. Listen to music.
2. Look at family snapshots.
3. Yogurt or pudding fingerpainting on a plastic tray.
4. Blowing bubbles.
5. Tossing balloons.
6. Blow a small, lightweight boat across a dishpan of water.
7. Throw beanbags, tennis balls, or ping-pong balls into baskets.
8. Plant some seeds.
9. Pull out the dress-up box: hats, scarves, gloves, boots, costume jewelry, mirrors, blankets, handbags, bright fabric, umbrella, aprons, etc.
10. Draw on a roll of white shelf paper.
11. Cut or tear old wallpaper samples.
12. Make puppets out of brown paper bags.
13. Use playdough or thawed-out frozen bread dough to mold into shapes.
14. Make a collage out of old greeting cards.
15. String macaroni noodles.
16. Make a tent (a blanket over a table) and go inside with a flashlight.
17. Play with a long piece of masking tape.
18. Move magnetic numbers and letters around on the refrigerator.



TIPS FOR TRAVELING

Traveling requires thought and preparation for any of us. When you add a child with special needs, the complexity increases, but they are not insurmountable. Here are some ideas from Raising a Handicapped Child by Charlotte E. Thompson, New York: Ballantine Books, 1986.

1. Check for accessibility of parks, museums, etc. before you leave home.
2. Write down information you need about prescriptions for medicines and eyeglasses.
3. Take along letters from doctors and therapists about special care your child requires.
4. Take along telephone numbers of doctors and therapists.
5. Contact the Society for the Advancement of Travel for the Handicapped for a brochure about travel in the U. S.: 5014 - 42nd St., N. W., Washington, D. C. 20016, 202/966-3900.
6. Contact the Rehabilitation International U. S. A. for an International Directory of Access Guides: 20 W. 40th St., New York, NY 10018.

QUESTIONS AND ANSWERS ABOUT PLAY FOR CHILDREN WITH SPECIAL NEEDS

1. How do parents decide when to help their children play and when to stay out of their children's play?

Watch your child's behavior cues. It may be time to end your interaction if you notice your child gives signs of ending the interaction by:

- turning her face away
- becoming irritated
- becoming agitated
- throwing things
- reaching for something else
- crying or fussing
- avoiding looking at you
- shutting his eyes
- spitting up
- straightening her arms to the sides
- breathing rapidly or shallowly
- arching his neck and back
- changing color

Your child may be ready to play when she:

- is quiet and has an alert expression
- looks directly at you
- reaches out to you with hands or feet or eyes
- holds his hands near his chest or mouth

If your child is playing appropriately and with a variety of toys over time, parents need not intervene. Children need to be allowed to play alone sometimes.

If a child is playing inappropriately or immaturely or repeatedly with the same toy in the same ways, parents might want to intervene in their child's play.

Parents might try parallel play. Without directly interacting with your child, play with a toy yourself nearby. Let your child observe your play.

Also, be sure to avoid correcting your child's play. Follow their lead in choosing and using materials. Try to just augment their play or assist in enriching their play. This will reduce your child's frustration and perhaps extend their play.

If mainstreaming is the goal of a particular play activity, parents may want to persist in helping their child. For example, when you are playing a lotto game and your child can indicate where the cards go but cannot easily put the cards in place, you will probably want to help or let another child help get the card in place. This will simply keep the game going. However, if mainstreaming is not the goal, you can let your child continue trying until he gets the cards nearly in place.

2. **How can parents tell if their child is becoming withdrawn or frustrated or bored with play?**

Again, watch your child's behavior cues. It may be time to end your interaction if you notice your child gives signs of ending the interaction by:

turning her face away

becoming irritated

becoming agitated

throwing things

reaching for something else

crying or fussing

avoiding looking at you

shutting his eyes

spitting up

straightening her arms to the sides

breathing rapidly or shallowly

arching his neck and back

changing color

increasing jumpiness

self-stimulation

blowing bubbles

fluttering eyes

tapping on the table

poking other people

dumping the toys on the floor

When such signs come, parents can say, "It looks like you 've had enough of this game." Let the child "answer" in some way. Then say, "If you want to play, then you need to pay attention."

If this is a teaching time, the parent might want to maintain "control" of the game by saying, "We'll each have one more turn and then we'll do something else." Then the adult is in charge of the activity. Your child will learn that it doesn't work to misbehave in order to get out of an activity.

3. What can parents do if their child just prefers to watch others play?

It can be frustrating to have a child who simply watches. However, some children just are more "watchful" than others. Maybe their parents are, too! Some children instinctively watch others for long periods of time to break down the play into tasks so they can figure out. Some children do this after much frustrating experience at play in which they can't seem to participate and feel they've failed.

Parents can help by saying to a watcher, "That looks like fun, doesn't it? Would you like to try it with me?" Then, help them go through the steps. Find ways for them to accomplish that activity, where to put their feet, for example. Give yourselves lots of time to go through the tearful frustrating moments until your child can succeed at the activity. It might help your child "save face" if you do this together without an audience.

If your child refuses to play for long, long periods, return to reinforcing the basics of interaction. Reinforce even their eye contact with you or any other small physical movement toward interaction or play, such as hitting a drum or playing peek-a-boo. Reinforcements might include: your smile, laughter, clapping, or a hug. You can encourage play if you nod, smile, talk quietly, pause during play to let your child respond, sing, tell your child what you're doing, let your child play while seeing her reflection in a mirror.

Follow the suggestions for turn-taking included on another MELD Special hand-out. If you practice turn-taking, you can be confident that you won't "overtake" your child in play.

Try something different to stimulate your child. Perhaps he has different interests than you do.

Check your child's hearing, vision, and language processing ability.

For children who usually do participate in play, consider whether they need a nap at this time more than they need to play? End playtime for a while and resume it later.

4. **How can parents realize that they're limiting play too much, even for their child's protection?**

Know your child's abilities. Talk with your child's doctors and therapists to discuss what is possible and good for your child. Sometimes children show different skills in different settings. Your child may be capable of things you cannot imagine. Copy their play therapy activities rather than branching out on your own.

Evaluate the safety issues and really child-proof your home, so you can set as few limits on your child as possible.

Listen to yourself. Do you find you say "no" repeatedly? Are your gut feelings about your child's activities usually negative?

Observe your child for a while. Set appropriate goals. For example, is it absolutely essential that he learn to wash behind his ears? Does she have to tie her shoes or can you buy shoes with velcro flaps?

Limit the comprehensive goals for your child. Maybe this is the time to emphasize social skills and de-emphasize motor skills.

Sometimes, allow your child with special needs to wait his turn just like other children. This will build the self-esteem of all children concerned. The other child (perhaps a sibling) will feel less ignored and the child with special needs will realize he is being treated just like everybody else.

5. **What about the child who gets frustrated in play?**

Perhaps your expectations or those of your child are too high. Ease up on what you want your child to do.

Watch yourself as you play with your child. Perhaps parents are over-participating in play and taking over the lead from the child.

Be playful yourself and model play in order to show your child new ways to use the same materials. A child, for example, may be stuck in just trying to slap a puzzle piece into the puzzle board. Break the activity down into smaller steps for him. Show him how to look at the puzzle piece's shape and how to twist and turn the piece to try to get it into the board.

A frustrated child may pretend to be bored because it is more socially acceptable. Identify the issue. "Oh, the end of the lace is frayed. That's why you cannot get the lace through the beads." Try modifying materials to encourage success in play. For example, find toys with bigger handles or provide larger paintbrushes.

Avoid blaming the child for being unable to do a play activity.

Finally, avoid doing the activity for the child. It is good problem-solving experience for a child to work out her frustrations at playing.

6. **What about the child who gets bored in play?**

Perhaps your expectations or those of your child are too low. Try some different kinds of stimulation. Provide a variety of materials. You might check out some new toys. Or you might show your child new ways to play with her old toys. One of our consultants observed, "Really, usually we offer our children the most boring stuff imaginable. If you were your child, you might be thinking, 'String beads again!!' or 'Eat more bland food!'"

Build on your child's interests and then incorporate the skills he is learning.

Perhaps parents are over-participating in play and taking over the lead from the child.

Sometimes we give children too many options, and they are overwhelmed. They find they cannot choose. Present just one or two options.

Try modifying materials to encourage success in play. For example, find toys with bigger handles or provide larger paintbrushes.

Give them some language to describe their feelings. "Are you getting board? I'd be bored, too, if I had to string all those beads. Let's do two more beads and then look at your good work."

Help them plan their next activity. "Now, you're almost done. Be thinking about what you'd like to do next."

7. What about the child who is overstimulated?

Reduce the amount of stimulation:

talk in a soft voice

give your child some quiet time alone

change his position

remain quiet

turn your own eyes away from your child

rock him in a rocking chair

bring her hands close to her chest

reduce all auditory, visual, and social stimulation

play quiet music

seat the child next to a washing machine or dishwasher so he can feel the vibrations

watch fish swimming

put away some of the toys

Check your own behavior. Don't incorporate visual, listening, and tactile elements of play all at once.

Create a quiet corner to which your child can go to settle down. This might be a tent made from a blanket and table, a barrel on its side, or a space between two file cabinets. Introduce this corner to your child as a good place in which he can be quiet, perhaps to go there with friend, a book, and a flashlight. This can become a positive “time out” corner if it’s a place your child is familiar and welcomes as a place where he can get himself under control. Offer it before your child loses control. He may often choose it himself as a place to pull himself together. When you sense your child is becoming overstimulated, you can say, “The quiet corner might be a good place for you to calm down.”

8. How can we help children gain a sense of control over their own play?

Avoid asking, “What would you like to do?” Their selection might take 15 minutes! Rather, give them a choice such as, “Shall we do a puzzle or a game?” As your children gain experience with play, they can select from three or four choices.

When your child has lots of experience with play and knows about making choices, you can suggest play by saying, “Let’s do something that has lots of pieces!” or “Let’s do something that is messy.” or “Let’s do something that is quiet!”

Selecting and Adapting Toys and Games

Parents, relatives and friends often feel stumped when doing their shopping for youngsters with disabilities. Something happens when we enter the store. The know-how we have acquired in buying for children, the guidelines on the tags and game boxes, the sales people, all seem of little help.

We wonder about what kinds of games or activities can not only interest our children, but what kinds of physical, intellectual or social skills are necessary. Perhaps we forget we are shopping for a child who will enjoy what all children enjoy. A child with a disability is a child first. The child's disability, no matter how severe, is secondary.

There are many new games being sold but more likely they either use new materials or have been renamed. However, those games that were available when we were growing up and have stood the test of time are still the best.

Many toys and games are marked as to the age level of the child for whom they are appropriate. These age guidelines can be very helpful, but they are created on the basis of children who are not disabled. Accordingly, they do not take into account difficulties children may have with intellectual understanding, ability to concentrate for a period of time, and ability to manipulate objects in the world.

You may have had some experience with changing games when you tried playing with your own children. If you have not, a teacher, occupational therapist, or a recreational therapist can help you. The most important guidelines will come from your knowledge of your own youngster.

We are including an article by Barbara Bruno-Goldman and Barbara Coyne Cutler (published originally in *THE EXCEPTIONAL PARENT*, August 1979) which will describe how to modify board games for your child's enjoyment. The same principles can be used for other activities.

First, here is a shopping list of games and toys that can be adapted for the pleasure of children with disabilities. The age groups—preschool and school-age—are merely guidelines. For some school-aged youngsters, the preschool suggestions may be quite appropriate.

BUILDING

All children like to put things together. Preschool children prefer toys that fit easily and can be put together and taken apart in only one way. Parents may have to help their child to start a project; then the child can continue on his or her own.

Slightly older children like toys where the same pieces can be used to build many different structures. Older grade school children enjoy the challenge of building complex toys and models that include motors or moving parts.

Preschool Children

- Blocks (soft and hard)
- simple put-together toys (popbeads, Lincoln Logs, Tinker Toys and others)
- hammer and pegs
- large blocks/small blocks
- picture dominos

School-age Children

- pegboard and other pattern-making toys
- Lego, two levels
- wood working tools
- beginning models
- complex models: small pieces, may include engines; model planes that fly; visible engines
- erector sets, similar building materials
- large cardboard boxes
- Constructo Straws

ARTS AND CRAFTS

Your child does not have to be talented to enjoy arts and crafts. Paints are popular with children, but they can be messy. Crayons and magic markers are good for drawing and for coloring objects such as doilies. Scrap books are fun. Family pictures or pictures from colorful magazines can be used to make a scrap book. Working with clay is also fun.

Most craft projects-making baskets or mats, for example-are generally successful if the child can see what the finished product will look like before he or she begins work. These materials can all be used to decorate the child's room.

The school-aged child is likely to be interested in several different hobbies. Providing materials the child has already shown interest in will probably be most successful. However, providing new materials in an area of established interest, like giving materials for macrame to a child interested in sewing, can expand a child's fun.

Preschool Children

- scrap books
- Spirograph and Etch-A-Sketch
- cooking materials
- finger paints
- easel and paints
- printing sets
- hand or finger puppets
- shoestring sewing
- PlayDoh or clay
- crayons, magic markers
- rub-on pictures
- coloring books, sketch pads
- animal shapes for tracing



School-age children

- candle making
- beginner enameling kits
- embroidering, sewing
- weaving, small looms
- macrame
- mobiles
- pipe cleaner designs
- bead jewelry
- origami (paper folding)
- linoleum blocks for printing
- leather craft
- mosaic tiles
- soap sculpture
- threading materials: macaroni, cheerios, string
- making picture collages
- paper cutting and pasting
- scraps and scrap books
- decorating the room
- paper mache sculptures
- mural painting

IMAGINATIVE PLAY

All children love to pretend. Fantasies and imaginative play are especially important to children whose physical activities are restricted. These activities provide escape from the limits of the bedroom and help to deal with concerns about him or herself. Puppets, dolls, and doctor kits are especially helpful.

Preschool children

- doctor/nurse kits
- hand puppets and finger puppets
- play telephone
- stuffed farm and zoo animals
- dolls and doll house
- large cars and trucks
- toy boats
- cardboard villages and stores
- cars, trucks, wagons, motorcycles, tricycles for riding or pulling
- action figures

School-age Children

- puppets
- stuffed animals and dolls
- simple microscope
- musical instruments
- magnets
- tops
- gyroscopes
- jacks and marbles
- play villages and people
- dolls and doll houses: G.I. Joe, Barbie, action figures, robots, superheroes
- walkie-talkie
- costumes, old clothes for dress-up
- microscope
- binoculars
- telescopes
- yo-yo
- printing press

GAMES

Children enjoy table games. Games for younger children should be short and easily completed. The older child will like adult games like Careers, Clue, or Monopoly.

Table games will often require parents or siblings to play with the child. Some games can be played alone with the child taking the turn of different imaginary players.

Preschool children

- simple card games such as "go-fish"
- easy board games such as Candyland
- puzzles
- marbles
- table games
- games using Nerf ball
- bubble blowing
- bean bag games
- beach ball
- bowling games
- racing track with cars
- board games with simple instructions and rules: Scrabble with fitted or magnetic pieces; checkers; backgammon; Sorry; geo-boards; Yahtzee; bingo

School-age Children

- puzzles—simple to complex
- board games with complex instructions and rules: Clue, Careers, Monopoly
- electric table games: hockey, basketball, football, pool
- dominos

ADDITIONAL PLAY THINGS

Preschool Children

- rattle
- beads
- sorting toys
- books
- magazines
- pop-up toys, such as jack-in-the-box
- music box
- view master
- squeaking toys
- musical instruments and toys
- trucks, cars, boats
- floating toys and objects used in bathtub or sink water play
- aquarium
- plants
- cloth or cardboard picture books
- punching bag
- jump rope (and other toys for large-muscle development)
- puzzles of under 50 pieces

- mobiles
- brightly colored objects strung across bed (balloons, soft materials, bells)
- photos, pictures, posters- especially family pictures or action pictures
- flashlights

School-age Children

- collections: stamp, coin, picture card, bottle cap, insect, mineral
- membership cards: library, museum, neighborhood centers
- Boy Scout and Girl Scout equipment
- cleaning the house
- water toys (pouring and mixing)
- wood working
- pets

BOARD GAMES

Board games can be enjoyed by the entire family. Often, children with disabilities do not get the opportunity to play board games. Like workbooks, commercially sold games are often too complicated.

They may also involve a variety of difficult skills, such as counting, following directions, or matching items. Sometimes these games require being attentive and waiting turns for longer than a child might find possible. Or, the player may be required to grasp a small object and position it in a small space. This is a difficult feat for a child with coordination impairments.

Parents and teachers (and helpful brothers, sisters and friends) can begin to teach these games by creating "revised" directions to allow a child to take part. With some ingenuity, adults can create "individualized" games that are similar to ones in stores, but are more usable.

The directions involved in playing a board game can be confusing. Some children do not know how to start and how to stop (i.e. "win"). They may not understand what a move is, the number of moves to make, or which direction to move in. Homemade games which take two or three minutes to play can help to reduce confusion and teach these concepts.

Here is a color-matching board game which can be used in developing game concepts.

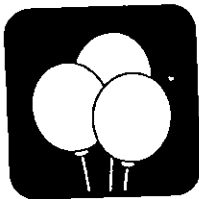
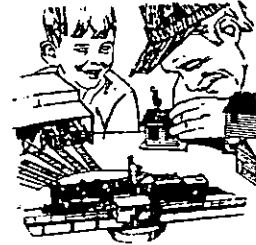
Using the traffic signal colors (green=go, red=stop), make a row of colored squares (red, green, red, green). The child places the marker or playing piece on green. (The size of the squares and the marker can be varied to meet the child's skills.) Then the child draws from a deck of a few colored cards. The deck is "stacked" if necessary—it has no green and only one red card. When the child draws the red card, he or she moves the marker to the square of the same color. The child continues and draws the red card, moves to red (stop) and wins a prize (e.g. star, treat, etc.). The combination of red (stop) and prize signal means that the child is a "winner," the game is over, and perhaps he or she is ready to play again. Soon, the child will learn to take turns. (The teaching of taking turns may require adding other players one at a time.)

If movement on a board game is a problem, create bigger spaces between positions. For example, you can make a town with pictures of stores on separate cards, which you place far apart. This gives the child a larger area for movement. It also illustrates the concept of

what a move is. The child can move a toy car from store to store, one, two, etc. spaces after (s)he draws a number from a deck of cards as above, or uses a spinner or dice. Once (s)he learns to move from store to store, you can gradually pull the picture cards closer together.

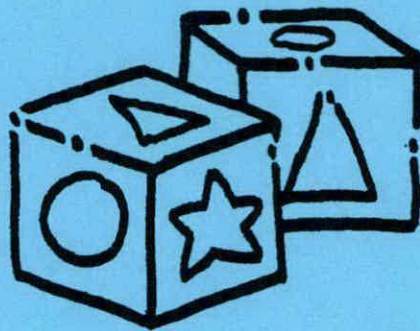
Once these game concepts are learned, you can continue to build on these skills. Your child can gradually learn to play more complicated games and to take turns with other members of the family.

From: The Disabled Child and the Family: An Exceptional Parent Reader edited by M.J. Schleifer and S.D. Klein. Boston, MA: Exceptional Parent Press, 1985.



Chapter 8

Growth and Development



MELD SPECIAL
Growth and Development

Growth and Development

Table of Contents	Pages
I. Introduction For Facilitator	3-9
A. Main Ideas	5
B. MELD Biases	6
C. Facilitator Focus	7
D. Group Issues and Tips	8
II. Content For Facilitators	11-49
A. Typical Early Childhood Developmental Stages	14-24
B. Developmental Diversity in all Children	25-28
C. The Parental Role	29-35
D. Special Developmental Concerns	36-48
E. Conclusion	49
III. Resources for Parents	51-53
V. Learning Activities	55-65
VI. Handouts	a-e
A. Stages of Growth and Development	a
B. Varieties in Children's Temperament	b
C. Turn-Taking	c
D. Used Equipment Marketplace: A Strategy for Cutting Equipment Costs	d
E. Your Baby's Temperament	e

Introduction For Facilitators

The ways children think differ significantly from the ways adults think. Most 2 or 3 year olds believe that everything is alive and that the world revolves around them. Therefore, they think they must be the cause of everything that happens, including illnesses and accidents. Understanding that children think in unique and changing ways can make parenting both easier and more enjoyable.

Sometimes, parents indirectly bring up the need for information about growth and development at a MELD Special meeting; a parent may, for instance, wonder if a behavior is a result of a child's disability or just the result of a "stage." When parents bring up questions and concerns, the facilitator can help them make the connection between their experiences and typical child development stages. Parents who are looking for big changes may need help recognizing and rewarding the small developmental steps their children accomplish.

Most MELD Special groups need to devote two or three meetings to discussing this material. It should also be used as part of the discussion about behavior guidance because guidance methods must always match the age and stage of the children.

MELD SPECIAL

Growth and Development

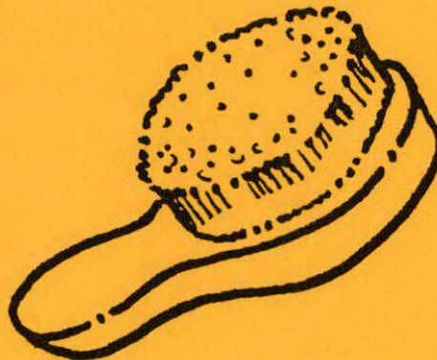
Being a parent yourself should help you relate this material to MELD Special parents. However, you may want to bring in an outside resource person, such as a pediatric nurse or child development specialist, to assist with the presentation and discussion. This chapter has been designed to help parents in your MELD Special group learn the general parameters of “normal” development and relate those to the special developmental needs of their own children. It will help parents understand how their children think, how they feel, and how they approach the world. This material should help parents:

- understand the sequence of development,
- identify parental roles that promote growth and development (such as teacher, consultant, friend, coach, audience),
- learn specific ways to provide opportunities for their children to grow and become competent and achieve mastery over their environments,
- identify differences between ways adults think and ways children think,
- acknowledge individual differences in temperament and learning styles,
- learn ways of communicating through language, touch, sound, and sight.

By and large, parents find information about growth and development rewarding. Interestingly, fathers sometimes find it easier than mothers to contribute specific examples of their children’s behavior to the discussion. Fathers seem to enjoy being analytical and may be somewhat more objective than mothers because they are less enmeshed in the parent/child relationship.

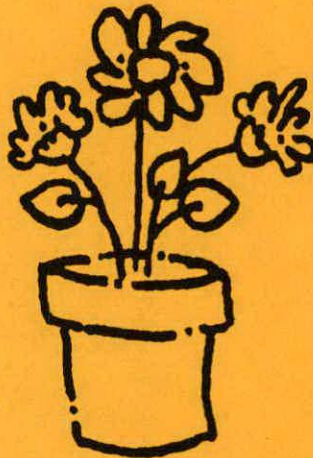
Main Ideas

- Development usually occurs in predictable stages.
- Disabilities and chronic illnesses affect how children achieve developmental milestones.
- Parents can provide opportunities for children with special needs to grow and become competent and achieve mastery over their environments.
- Young children actually think differently than adults think.
- Individual differences in temperament and learning styles affect how children interact with their world and how they learn.
- Parents and children can use a variety of ways to communicate.



MELD's Biases

- It is important to know the milestones of children's growth and development and the range of typical behavior.
- All children need love and caring.
- Children sense adults' feelings, attitudes, and opinions, and they often act according to the ways they are treated.
- Many of the needs of MELD Special children, emotional and social as well as developmental, are the same as any children's needs. Over-emphasis on children's special needs may keep parents from seeing them as a whole people.



Facilitator Focus

As you read this material and think about facilitating meetings on this topic, consider the following questions:

- What examples of your own children's behavior come to mind as you think about various developmental stages?
- Does this material give you any new appreciation for what your children have learned and for how they are growing?
- If you had had this information when your children were at earlier stages, what might you have done differently? Are there any specific behaviors you think you may have misinterpreted?
- What child-rearing approaches does this material suggest to you? What might you try in the near future?
- What examples do you have of your child tuning into you or a situation non-verbally by sensing the tone of things?
- Have you enjoyed watching your child grow and develop?
- What have you liked about your role as your child's consultant? teacher? role model? What has been hard for you in these roles?

Group Issues and Tips

This chapter is best done in two or three different meetings. Focus on it before doing behavior guidance, because it provides the background for any discussion of guidance methods and techniques.

Because MELD Special parents have children close in age and with various special needs, it is difficult for them not to make some comparisons when discussing this information. Be aware of the possibility that this can be a problem. One infant was very delayed in sitting up and crawling, but she was the most socially responsive in the group; her mother loved having this pointed out. As the group facilitator, you can stress the uniqueness of each child.

If you use development charts to show at what points learning is likely to occur, you may want to cover up the ages at which stages are supposed to happen and emphasize sequence. Point out that children often drop some skills while they are working on others.

This material may become an emotional topic when it touches on parents' feelings about behavior guidance. Parents have widely differing feelings and practices of discipline; you may need to identify your own biases about behavior guidance for the group to model acknowledgement of differing views. Refer also to the behavior guidance chapter.

Some groups have enjoyed holding a toy-making workshop as a good way of focusing on what's appropriate to the stages of the children. This workshop also appeals to people who learn in sensory, physical, and imaginative ways. See the chapter on play for ideas about toys to make.

MELD SPECIAL

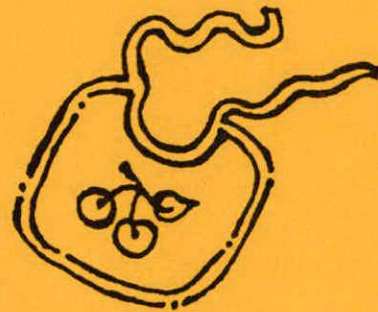
Growth and Development

Encourage parents to be learners too. If they trust themselves as learners, they will have more confidence in their children's abilities to learn and in their abilities to help them learn.

Children may have more than one disability or illness. In this chapter, situations have been separated for simplicity; in reality, MELD Special parents will be dealing with more complex situations.

Encourage fathers to try the activities too.

Parents may find that this chapter brings up additional grief as they recognize milestones their children will never accomplish.



You will need to gather resources ahead of time. A toy-making workshop needs special preparation so you are sure you have sufficient materials. You may want to play some children's records during the sessions. And if you decide to invite a guest speaker, be sure to contact the person in advance and provide possible questions for them to consider.

Content for Facilitators

The latest attitude to have is 'treat your baby with Down Syndrome like a normal baby.' To that, I say, 'How can we?' First of all, she's in physical therapy twice a week. . . I'm going to begin signing to her as soon as I start class, and she'll be attending speech class one morning a week. Yes, we expect *at least* normal development from her, but we treat her as if her development is an emergency. . . Sophie's drive is sometimes in low gear or stalled, and we are the ones pushing her uphill by the back bumper. Yes, I have *higher* than normal expectations for her, but I can't treat my child with Down Syndrome completely like a normal child. When I work with Sophie, I sometimes feel like I'm working on a show that's opening in a week with a month's work left to be done.

Today I *do* have dreams for Sophie. I dream of a normal IQ. I dream of standard school placement. . . it's *having the dream itself* that will cause it to come to fruition. That's why it needs to be gently encouraged and nurtured. This is *my* dream and it's valid. The dream . . . changes *me* and in doing so changes my daughter's chances for success. . . She'll have the opportunities I expose her to. And I will expose her to those things that I feel she can accomplish or that will challenge her to reach new goals.

(From Bittersweet Baby: A Family Meets the Challenge of a Child with Disabilities by Jolie Kanat, Minneapolis, MN: CompCare Publishers, 1987, p. 79)

MELD SPECIAL

Growth and Development

This chapter encourages parents to look at the growth and development of their children in all its aspects—physical, intellectual, social, and emotional. Understanding usual childhood patterns of development and the variations that may occur in those patterns because of special needs will help parents anticipate changes in their children, encourage independence, and avoid problems. Importantly, understanding development lets parents develop realistic expectations for their children and be their allies and encouragers instead of blaming themselves or their children for actions that they don't realize are normal.

All the ways children grow and develop work together. Physical changes allow the children to learn new skills. Typically, growth and development proceed in a sequential fashion; we can predict with pretty good accuracy which stage will follow another, what children will learn next once they have mastered a skill. We know that each stage is made up of several smaller steps and tasks and that children usually do one of those steps after another. However, rates of development vary greatly among children. We know what a child will probably learn next, but we do not know how soon the child will begin to learn that or how long the learning will take.

Many factors influence children's development. Heredity, what the children get from their inherited biology, is important. So is what they get from their culture and their environment: some children are presented with more opportunities than others; the opportunities all children are presented with are unique. People around the children, especially their parents, greatly influence how they learn. And so do the children themselves; their varying temperaments and their special needs both determine what they decide to do, what they can do, and how quickly and proficiently they can do those things.

MELD SPECIAL

Growth and Development

Some children develop in a hurry; others take their time. Some children develop quite uniformly—taking on new challenges of social, physical, linguistic, and intellectual growth together. Other children focus on one or a few areas of growth and catch up on the others later. Often, growth periods are followed by periods when development seems to stand still. During periods of change and stress, children frequently return to earlier developmental stages where they feel more secure. Whatever the pace a child follows, that child needs support for the stage he or she is in and not for a stage someone else thinks that child should be in.

If they know about normal development, parents of special needs children can distinguish between behaviors that are expected for the developmental stage their children are in and behaviors that are a result of their children's special needs. Special needs children usually develop in the same sequence as other children. However, they may learn more slowly in some areas. Sometimes they will seem to spend a huge amount of time working toward one behavioral milestone—but that doesn't mean they aren't learning.

In fact, parents of special needs children may find that their children's progress seems extra special. Children who have to work very hard to hold their heads up or to roll over without assistance can cause great celebration for their parents and themselves when they master these tasks. The growth steps of children with special needs may be slow, but they may also seem more miraculous.

Parents of special needs children need to remember that, while some aspects of development are affected, other aspects will probably proceed in a usual fashion. For example, children with severe limb deficiency that results in physical disability probably have normal intellects and normal social and emotional capacities. Their parents may need to create unique opportunities for encouraging development in these other areas so that they are not unnecessarily held back by lack of physical opportunities.

Typical Early Childhood Developmental Stages

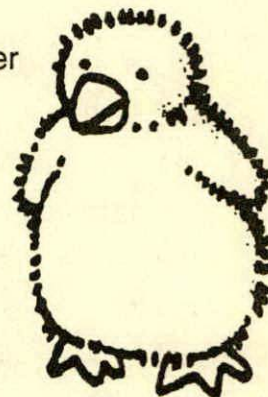
Young children have so much to learn! They need to find out how their bodies work, how their hands move, and how they can find objects. They need to learn that they have power—that they can make other people smile by smiling themselves, that they can get attention by crying. They need to trust the predictability of the world by noticing that a ball always bounces when it is thrown and that mother always comes back after she leaves. They need to learn that things are different from each other but that some are similar to others, that things and people have names, that things and people have edges where they start and edges where they stop.

Small children live in a world different from the one their parents live in. Psychologist Jean Piaget pointed out that they can't take another person's perspective. Only slowly do they learn to recognize symbolic concepts and to deal with two ideas at the same time. They think that everything that happens and everything they see has a purpose. What they know about themselves they think is true about everything else.

During the first developmental period, normally from about birth to age one, children think that only the things they can see or taste or feel are really there. They won't look for an object when they can't see it because for them it no longer exists. They think everything is for their use. They think they are a part of their mother or primary caregiver. They don't realize that other people differ from them, so they expect their needs to be filled by those other people immediately. They learn about the world only through their senses, not through language.

MELD SPECIAL
Growth and Development

A little later these children are able to realize that their mother or primary caregiver is a separate person, so they become afraid when that person leaves. They still don't realize that other people are very different from themselves, so they still expect their needs to be filled right away. But they are learning about the world through moving (still not through language) and they are trying to taste and chew everything they can reach so they can figure out what those things are. They like to drop objects; by doing that they are beginning to learn about gravity and cause and effect.



When the children are between two and seven, they learn to store mental images and symbols. Once they can do that, they can learn to use language. They spend more and more time in pretending and in dreaming. They have difficulty separating fantasy from reality, so it is natural for them to say they were playing with a bear if they were pretending to play with a bear. What would be lying for an adult is not lying for them.

Early in this stage they may overgeneralize the meanings of words (they may think, for example, that all animals are dogs) or they may undergeneralize words (thinking that fruit only means apples). They may think that taller people are older than shorter people. When someone says it's "raining buckets," they may wonder where the buckets are. Because they can get hurt, they will probably think their toys and other objects can feel hurt too. They will not realize that listeners who cannot see them can not understand if they respond non-verbally, so they will, for instance, nod when talking on the phone.

MELD SPECIAL

Growth and Development

Parents who know that their children think differently from them will be better able to accept their children's behavior without reading in intentions that are not there. Children do not drop objects from their high chairs to get attention but to experiment. However, if their parents respond as if they were offended personally by the dropping objects, then the children will learn to get a response from their parents by continuing to drop those objects. Adults who do not understand child development frequently think that children are manipulating them when the children are simply learning.

The following chart gives some typical developmental milestones for each stage. Each major milestone of development consists of several smaller steps and tasks to be learned along the way. The ages at which those tasks are accomplished are only very rough guidelines of usual development. Children with special needs may spend a great deal of time between milestones; they *are* learning and they will probably learn in the order indicated on this chart. (It is also found as Handout [a].)

INFANCY (birth to about 12 months)

Physical Development Tasks:

growth, achieving a stable sleep pattern, achieving feeding skills, basic muscle control (head, neck, trunk, and arm coordination).

Intellectual Development Tasks:

making sense of all things heard, seen, felt, and tasted, organizing themselves, getting their bodies to react to the world.

Emotional and Social Development Tasks:

basic trust (reliance on continuity of care, relaxation and trust of self), security and safety.

MELD SPECIAL
Growth and Development

INFANCY (birth to about 12 months), continued:

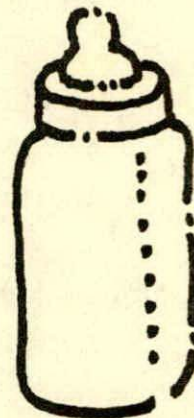
Parents' Supportive Tasks:

attachment, competence in caretaking, providing predictability and consistency, adjustment in family roles.

EARLY TODDLER (about 1 to 2 years)

Physical Development Tasks:

growth, carrying things, walking and mobility, bowel and bladder control, some self-help skills (eating, carrying objects).



Intellectual Development Tasks:

knowing body parts, learning "no," being alert to routines, imitating, using one- and two-word phrases, being possessive.

Emotional and Social Development Tasks:

becoming a unique individual through separation, independence, autonomy, control of their own activities and impulses.

Parents' Supportive Tasks:

encouraging independence, helping development of self-control, avoiding overprotection.

MELD SPECIAL
Growth and Development

LATER TODDLER (about 2 to 3 years)

Physical Development Tasks:

growth, climbing, running, throwing, developing small muscle skills, scribbling, bowel and bladder control, more self-help skills (feeding, carrying).

Intellectual Development Tasks:

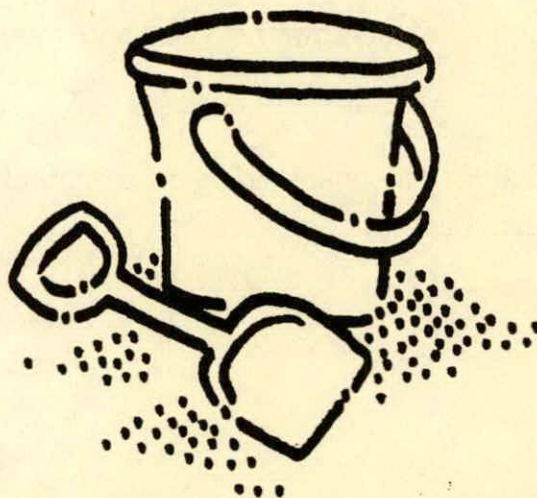
following simple directions, making transitions, solving problems with movements and experimentation, speaking in phrases.

Emotional and Social Development Tasks:

separation, independence, autonomy, controlling one's own activity, controlling impulses, sometimes taking turns, playing parallel, having a sense of ownership, having a sense of identity, toileting.

Parents' Supportive Tasks:

encouraging independence, helping development of self-control, avoiding overprotection.



MELD SPECIAL
Growth and Development

EARLY PRESCHOOL YEARS (3 to 4 years)

Physical Development Tasks:

growth, coordination (gross and fine motor), strength and speed, self-help skills.

Intellectual Development Tasks:

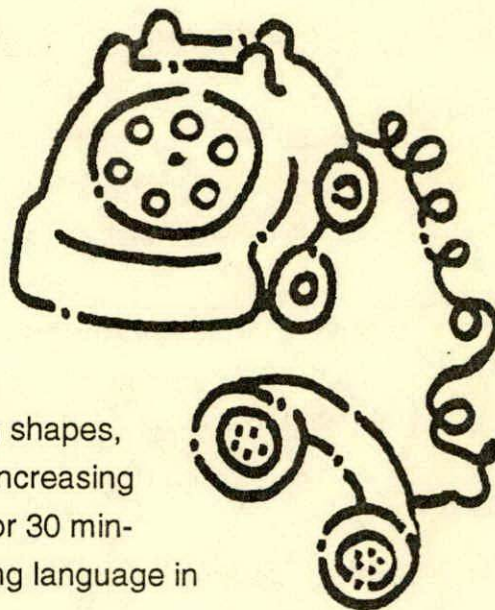
understanding others' feelings, learning shapes, colors, and numbers, making choices, increasing attention span, playing independently for 30 minutes, learning to manipulate adults, using language in play with others.

Emotional and Social Development Tasks:

developing mastery, gaining a sense of values and self-worth, achieving goals, differentiating between sex roles, playing, gaining a body image, expressing feelings, taking turns, interacting in play, accepting suggestions.

Parents' Supportive Tasks:

encouraging initiative, maintaining discipline, helping understand right and wrong, modeling behavior of same-sex parent, avoiding overprotecting.



MELD SPECIAL
Growth and Development

LATER PRESCHOOL YEARS (4 to 5 years)

Physical Development Tasks:

growth, coordination (gross and fine motor), strength and speed, self-help skills.

Intellectual Development Tasks:

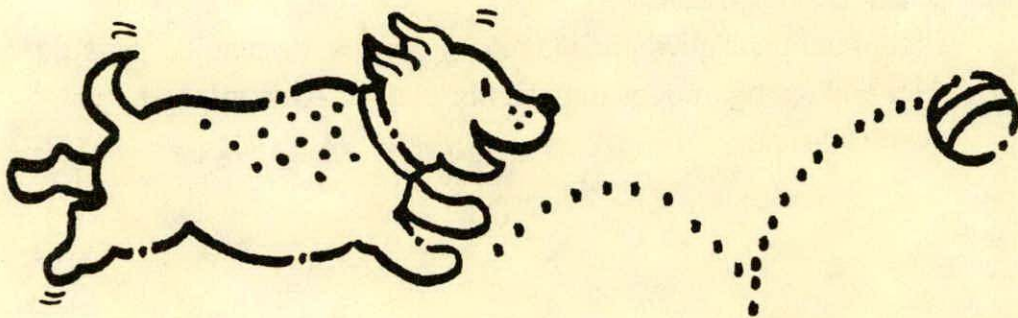
recognizing numbers and patterns, writing names and letters, developing definite areas of interest, speaking in sentences, explaining why.

Emotional and Social Development Tasks:

developing mastery, forming a sense of values and self-worth, achieving goals, differentiating between sex roles, playing, accepting body image, sharing, playing without adult supervision.

Parents' Supportive Tasks:

encouraging initiative, maintaining discipline, helping understand right and wrong, modeling behavior of same-sex parent, avoiding overprotecting.



MELD SPECIAL

Growth and Development

SCHOOL YEARS (5 to 12 years)

Physical Development Tasks:

growth, coordination (fine motor), strength and speed, physical games.

Emotional Development Tasks:

working and being productive, developing competence, planning and follow-through, developing peer relations, accepting body image.

Parents' Supportive Tasks:

fostering skill development, encouraging exploration, encouraging peer relations (movement out from the family).

Developmental Stages of Special Needs Children

Special needs children develop as other children do, but they may take longer to learn tasks that are affected by their illness or disability. Some of them face very real limitations on what they can learn to do—deaf children cannot, for instance, learn to differentiate meanings based on tone of voice although they can learn to differentiate based on non-verbal clues. Parents' expectations of their children's development will have to be altered depending on the specific needs their children have.

MELD SPECIAL
Growth and Development

In "Play and Playthings for the Handicapped Child," Elizabeth Newson and Joan Head wrote, "In some ways, 'special' needs are ordinary needs prolonged over time or intensified. In other ways, they are very unique to the child concerned, but still demand the same kind of skills which parents of 'ordinary' children try to use all the time: an intimate, even if not very confident, knowledge of the child as she is; an ability to sort out priorities from her point of view and the family's; the insight and ingenuity to meet problems usefully as they arise; and the patience to make extra allowances and go to extra trouble during times of difficulty or crisis."

(In Toys and Playthings in Development and Remediation by John Newson and Elizabeth Newson. New York: Pantheon Books, 1979, p. 140)

Parents need to consider their children's unique needs when they try to determine the developmental tasks those children are working on. Disabilities and chronic illnesses can affect the over-all development of children if the specific area affected by the disability inhibits other areas. As examples—

Children with physical disabilities or extreme tactile defensiveness may have problems getting the experiences they need in order to develop socially, intellectually, and emotionally.

Children who cannot get around easily according to their own desires will not have many opportunities to explore their homes and yards. They cannot independently roll a ball repeatedly down a slope, find objects to play with, or empty kitchen cupboards. They cannot seek out other family members but must wait for them to come.

MELD SPECIAL

Growth and Development

Examples, continued:

Some children who have mental disabilities are very inactive and, therefore, receive little stimulation. Inactivity itself deprives the children of interaction that would encourage their full development.

Children who are very active and have a hard time concentrating find it difficult to follow through with activities. They, in turn, miss out on the opportunities to build their understandings about their environment.

Children with severe sensory deprivation may feel shut into a dark or quiet room. They are not attracted by the sights and sounds and movement that compel other children to explore. Such children need help to find out that exploration is worth the effort of overcoming their fear of the unknown.

Children who are extremely anxious or autistic may cut off the world with barriers of repetitious and ritualistic behaviors: rocking, head shaking, or spinning objects. By retreating from the confusion of the world, they miss out on learning about the world, including their families and themselves.

Parents are often relieved to have their children's disabilities or illnesses labeled. The label helps them find treatments, talk about the difficulties, and get special services and financial support. In addition, the labels may help them understand their children's developmental difficulties and potentials.

MELD SPECIAL

Growth and Development

However, labelling can also restrict the parents' and the children's ideas about what is possible. Sometimes the labels are not correct. More often they are correct, but they ignore the range of possibility for development within a particular diagnosis. Labels should not be used to keep children from attaining skills that are not expected for children with that diagnosis. Each child and each situation is unique.

Parents may want to resist labels to keep their children's options more open. Florence Rogers pointed out in Parenting the Difficult Child that, "Resistance to labelling is not the same as denial of the problem. To resist labels is to hold open the doors of opportunity and growth. To deny the problem's existence is to slam the door and lock it from both sides." (Radnor, PA: Chilton Book Co., 1979)

Parents may be helped by reading a book called HELP for Parents of Children with Special Needs. (By Setsu Furuno and others. Palo Alto, CA: VORT Corporation, 1986) The book offers clues to help children gain control over their worlds—to learn to sleep at night, to pay attention longer in the daytime, and to cry for short periods to become better organized at the end of a day. It includes sections on health, physical growth and nutrition, hearing and vision, genetic counseling, illness, behavior, temperament, and other concerns. The book can help parents observe growth patterns, keep records, and notice what their children are like. It suggests ways to recognize what children like to do, what their rhythms are, and what their special qualities and unique responses are.

MELD SPECIAL
Growth and Development

ADAPTABILITY

.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|

feels at home in a new situation in a week or less	doesn't feel at home for several months
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SENSITIVITY

.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|

responds quickly to heat, lights, rough clothing, noise	doesn't seem to notice noise, temperature, scratchy clothes
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POSITIVE AND NEGATIVE MOODS

.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|

easily upset, fussy, irritable	optimistic about almost everything
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DISTRACTIBILITY

.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|

sticks to activity in great distractions	distracted by small events
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PERSISTENCE AND ATTENTION SPAN

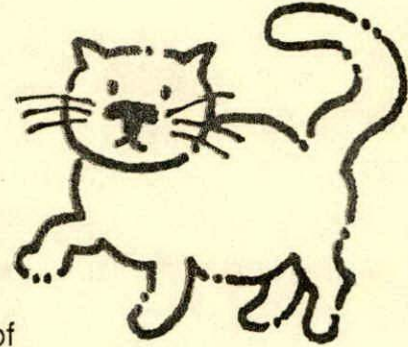
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sticks to task or toy forever	gives up after minor discouragement
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MELD SPECIAL

Growth and Development

Parents are not responsible for their children's temperaments. Children come with their own temperaments, and sometimes those temperaments change. Disabilities can, for instance, change children's initial personalities. A child who enjoys new things may become more fearful of trying physical activities because of problems with balancing. Parents and others can enhance children's temperamental strengths or fight them. Parents have choices—



- They can constantly distract persistent children—or they can let the children finish what they are doing.
- They can contain active children—or they can find outlets for the children's enormous energy.
- They can stimulate very quiet children—or they can leave them alone.
- They can react angrily and personally to children who seem to be naturally glum—or they can give the children extra time to wake up in the morning and extra loving to calm down when they are upset.

Two children with similar temperaments may develop very different personalities as adults because of how they were treated as children.

Parents who are interested could read Please Understand Me: Character and Temperament Types by David Keirse and Marilyn Bates (Del Mar, CA: Prometheus Nemesis Book, Co., 1984) if they are interested in other ways of looking at individual differences.

MELD SPECIAL

Growth and Development

Learning Styles

Learning styles are the ways in which people prefer to get information and develop new skills. It seems they are present at birth and that they continue to be used throughout life. When people get new information, they usually use their preferred style to make sense of that information.

Young children often do not have a clear preference, but as they grow they begin to favor one style or another. Certain disabilities may cause children to favor particular styles. Obviously, blind children are not likely to become visual learners even if they would have been if they could have seen.

By identifying their children's primary learning styles, parents can channel new activities in ways that help the children succeed. Children who like to move have trouble obeying parents who tell them to sit still; they do better if their parents plan ways to give them wiggle room. Parents can make their requests in forms that their children are able to respond to.

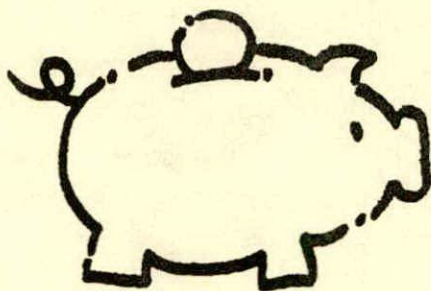
There are three basic learning styles:

- **Visual learners** – These children use their eyes to learn. They prefer to watch objects, movements, and colors. They enjoy creating and playing with things. They can be quieted by seeing familiar faces or familiar toys. They may be interested in exploring small objects.
- **Auditory learners** – These children use their ears to learn. They prefer to learn from sounds and spoken words. They can be quieted by the sound of a familiar voice or by music. They may be more interested in babbling than in walking.
- **Tactile learners** – These children use their body and hands to learn. They prefer to learn through touching and moving their arms, hands, and legs. They can be quieted by rocking and cuddling. They may kick at mobiles and take toys apart.

The Parental Role

The parental role is complex. It is even more complex for parents of special needs children than for other parents. But all parents have three basic roles—caregiver, loving parent, and teacher. The loving parent role is the most important for ensuring that children grow and develop well, but the other two roles take a great deal of time and effort, too, especially for a special needs child.

All parents need to provide basic care—food, clothing, and shelter. For the parents of special needs children, this often means they must provide adapted clothing, adapted storage space, and adapted living space and sometimes special food. The parents' task is to provide an environment in which their children can succeed, an environment that is nurturing and safe and has safe, interesting materials in it to explore and touch and look at. Clothing that is easy for the children to get on and off themselves, shelves that are in places the children can get to, rooms that accommodate the children's bodies and equipment—all of these are essential for special needs children. In addition, children all need their own possessions, things that they can call "mine," things that demonstrate that the children are each unique. To make sure children have this, parents must often follow their children's lead in selecting clothing, toys, and equipment that the children are drawn to and can attach themselves to.



MELD SPECIAL

Growth and Development

But parents need to focus on being parents and on interacting lovingly with their children more than on providing for their basic needs. A child who has both physical *and* emotional needs met is a child who is likely to succeed. Parents and children live together and get to know each other. Out of that relationship comes the basis for all other relationships the children will have. If the parents and their children love each other and take pleasure in each other, even if they have to take pleasure with each other in times of continuing pain, the children will have a basis on which to build their lives.

Love and work are the essential components of mental health. By loving them and encouraging them to develop meaningful loving relationships with other people, parents will lead their children into supportive human interaction. By encouraging their children in their daily work of sleeping, eating, playing, dressing, toileting, and hand washing, the parents will set up the basis for successful human activity.

In showing love, parents respond to the initiatives of their children. They let their children lead them into interaction and then they tailor their behavior to the things the children do. For example, responsive parents giggle back when their children giggle at them. If their children pat their hands, the parents frequently think to pat their own hands in response. Researchers have found that adults who respond quickly and appropriately to their children's social initiatives encourage their children to be more alert. These responsive interactions also contribute to the attachment between the parents and their children and serve as a basis for the children's desire to learn. Responding to children is the essential act of communicating with them. Both verbally and non-verbally, through silence, listening, gesturing, and talking, parents reveal their world and themselves to their children. In doing that, they let their children learn to know themselves.

MELD SPECIAL

Growth and Development

Obviously in all of this, parents will have fun with their children. Even if they have to adapt their activities and do things in ways that seem strange to others, parents and children can enjoy what they do. They can even laugh about doing things differently from others. In every way possible, parents should let their children feel good about themselves. They should have their accomplishments, even their little accomplishment, recognized and enjoyed.

But children don't have only enjoyable emotions, and all their emotions need to be acknowledged. Parents should notice their children's feelings in actions, in facial expressions, and in sounds of joy or frustration or anger. They can give words to those feelings. But the most important thing is to help their children recognize the feelings they have and learn that it is okay to have all of those emotions.

The role that may seem most difficult for parents of special needs children is the role of teacher. Typically, parents struggle with deciding whether or not to push their children in development. In After the Tears: Parents Talk about Raising a Child with a Disability, Robin Simons mentioned a mother who said, "I have to push David for all he is capable of. If I don't live up to my potential, it doesn't matter. If David doesn't live up to his, it will seriously affect the quality of his life. People don't want to expose handicapped kids to failure. But that's shielding them. You have to push them and challenge them or they'll never grow." Simons added, "Sometimes that means letting a child learn from his mistakes. Sometimes it means letting him try things that you know will be difficult." (New York: Harcourt Brace Jovanovich Publishers, 1987.)

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Growth and Development



Parents can start their roles as teachers by trusting their children to learn. Learning does not require sophistication, so parents can relax and believe in themselves as teachers and in their children as learners. The biggest teaching children need from their parents is the chance to play with them and enjoy them.

Beyond that, parents need to observe their children to see what they are interested in and what they are ready for. They can consider what their children enjoy looking at—probably that activity or object interests them. They can make sure that children can reach safe objects that they try to get, things that they apparently want to explore. And parents can notice when their children are restless and uninterested in activities or objects; then it may be time to model interest, but it is often time to wait for the children's interest to grow on its own.

As they watch their children, parents can consider whether their expectations for their children are realistic, whether they have set goals that are too high or unnecessarily limited what they dream of their children doing, whether they have accepted the actual limits their children's conditions place on their achievements or further limited their children by remaining resentful and discouraged.

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Growth and Development

If their goals are realistic, parents can be confident that they will be able to support their children's learning. Then they can model for their children the fun of learning by entering new learning situations with confidence and an expectation of success. They can enjoy the learning and so teach their children to enjoy it. They can notice tiny achievements and praise them and enjoy them; they can avoid being discouraged if the learning takes a long time and does not meet their initial standards of perfection. Parents who are calm about learning will not re-button their children's shirts to make the two sides of the shirts match up perfectly; instead they will rejoice with the children that they were able to put the buttons through the holes. These parents will be flexible and creative; by being role models, they will teach their children to be flexible and creative too.

As parents try to teach new skills, they should first analyze the skill themselves. They can think of why the skill is important. They can take it apart into its smallest possible components. They can consider the easiest ways of doing it. Then they can explain to their children why the activity is important; children have trouble practicing without some reward. The parents can teach the activity one tiny step at a time, allowing plenty of time for each skill and allowing for much repetition. They can consistently teach that task again and again, reinforcing every attempt and celebrating every tiny success. When a skill is accomplished, they can pause for awhile. Every learner needs a break from constant trying.

Even as teacher, the parents' role is not always direct. More often they must simply support learning, by providing easy-to-remove clothing when their children are trying to undress themselves, for instance. They need to be consultants—giving their children new ideas for ways to do things when their children appeal to them for help. They can give their children boosts when they try to get into chairs, but they need not lift them in. The children can work it out for themselves with a bit of help. And the parents can be coaches, not playing the game for the children but encouraging them to play it for themselves.

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Growth and Development

It takes patience to let children do things for themselves. All children learn by trial and error, so they need opportunities to experiment with things in different ways to figure out how the world works. By giving their children the time and space to work things out in their own ways, parents are supporting them more than if they jumped in and showed their children how to do things the "right" ways. Having patience and standing back is showing respect for the children.

Children with chronic illnesses or disabilities often take even longer than other children to do things, so they are more often denied the opportunity to learn independence by taking their time and doing things in their own ways. Yet, they probably need this chance even more than other children do. If they are allowed to experiment by trial and error, their self-esteem and feelings of independence grow. Children learn from frustration, so long as the frustration does not grow too great. Parents must learn to gauge when to step in and when to let their children struggle on their own.

Often when children learn to do something in one way, they think that is the only way to do it. To help them be more flexible, their parents can show them other ways of doing the same thing. One young boy learned to do dishes at home, but he wasn't willing to wash dishes at his day care center without a great deal of encouragement and training. As they are helped to grow more flexible, children will understand better the strange ways adults do things; one girl learned how to put underpants under her clothes, but she couldn't figure out why she shouldn't put them on under her swim suit. Some children, especially those with communication disorders, will be too upset by such seemingly nonsense rules that they won't be able to adapt their behavior to usual adult practice.

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Growth and Development

Children's sense of mastery is challenged again and again by adults, by peers, and even by their own bodies. They can often be encouraged by parents and siblings who maintain interest in an activity and keep on believing that the special needs children can master it even when the children themselves are discouraged. Sometimes a brother's, a sister's, or a parent's excitement is enough to encourage a child to try again.

Children also develop feelings of mastery by playing. They can use play to defend themselves against real or imagined challenges. They can pretend they are superheroes, more powerful than even adults. By playing that they are competent, they can come to believe in their ability to conquer real-life threats.

As their children change and grow, parents' roles and expectations must change too. Sometimes children's abilities decline, as when an illness becomes worse. Then the parents must accept the change and decrease their expectations. But even these children need challenges. Parents can consult with the professionals on their treatment team about what expectations are realistic and what expectations are too great or too small. But the challenge of knowing how to work with their children and what to work for will always be primarily their own job. And it is not an easy job with clear answers. Each child and each parent is unique and must find their own way.

Special Developmental Concerns

Stranger Anxiety and Transitional Objects

All children go through at least one period of being afraid of strangers. Some children are, temperamentally, more afraid of strangers than others. Some children are intrigued by strangers and tend to crawl right over to check them out. Life experiences, too, can cause children to be more or less afraid of people they don't know. Children who have been "hurt" frequently by doctors and other strangers who give them medical treatments may not be able to tell the difference between friendly strangers and strangers who are going to hurt them again. Children with delayed emotional development may be more hesitant than other children of the same ages to separate from their parents, join in with a group of peers, or try something new. Their parents need to consider their developmental needs rather than their chronological ages and respond to their stages of emotional development instead of insisting that the children put up with as much separation as other children do.

When children feel threatened, they cling to that which is most familiar. During periods of their development, their immediate family may be all they can tolerate. Even grandparents may not be accepted. At times like these, their parents need to recognize that reassurance that familiar people will be around is a deep emotional need of the children. They will need to patiently provide love and support while at the same time encouraging their children to slowly learn to accept others, maybe just one friendly stranger at a time.

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Growth and Development

Parents can also help their children by limiting visits during times when their children are particularly vulnerable. They should not force their children to go to strangers, but should allow them to remain on their parents' laps or in near proximity when acceptable strangers are present. As the parents model friendliness to the strangers, their children will learn that some strangers really can be trusted.

It helps to remember that children who develop strong attachments to their parents or caregivers usually become independent later in life—stranger anxiety passes. In fact, children must learn to trust one adult before they are able to generalize that trust to other people. It harms them if that one adult they feel they can rely on betrays them by forcing them to trust other people too quickly.

Children can also learn to trust objects. Often a favored blanket, doll, or stuffed animal can get a child through the horror of having to depend on a strange babysitter or grandmother for an evening. They learn to trust these objects through touch.

Gentle, loving touch from the people who care for them is essential for the emotional development of children. Some children who have experienced a great deal of painful touch during hospitalizations or treatments may, however, draw away from any kind of touch, even that of loving parents. They need to be given time and space to come to accept touch again. These children may also be helped by having objects to cling to, objects they can touch that they know will not hurt them.

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Growth and Development

Sometimes parents worry that their children's attachments to "lovies" is too babyish, and they try to remove the objects or get their children to give them up. But most experts believe that these objects are essential for establishing emotional maturity in children. The children themselves will know the right time to set them aside—probably long after their parents thought they should have outgrown them, but actually at just the right time for themselves. Dr. T. Berry Brazelton believes that transitional objects, or security objects, are ways to help young children learn how to comfort themselves and calm themselves down. He says children who use their "lovies" to help them adjust to the world are not in trouble emotionally—they are instead showing good adjustment and personal strength by being able to trust their loved objects. Dr. Brazelton thinks that the children who are resourceful enough to care for objects are the children who learn best how to love other people. (From To Listen to a Child: Understanding the Normal Problems of Growing Up. Reading, MA: Addison-Wesley Publishing Co., 1984.)

Communication and Crying

Videotapes have captured the behavior dialogues between young children and their parents in which the babies and the parents take turns responding to each other. The children move or smile or make a noise, and the parents respond. Then the children respond to their parents and the parents make a similar "statement" back. The back and forth play becomes a kind of dance between partners. Young babies find out early that when they make noises, they get results. They begin to see that language is a way to get their needs met, that it is basic communication. So they initiate "conversations" like this by alternating with an adult in making noises.

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Growth and Development

In the relationships where there is a good "fit," where the children and the parents are able to tune in to one another, the back and forth dance is beautiful. The exchanges form the foundation for the children's intellectual, social, and emotional development. They are the beginning of all communication skills. Successful parenting seems to depend on the parents' ability to recognize and interpret their children's cues.

However, children with disabilities sometimes have unstable behavior patterns so that the cues they send are more difficult to interpret. They may be slow to respond; they may lack the energy to maintain their part of the dance. These children can appear inattentive, unresponsive, or fussy. Eventually, their parents may become frustrated about how to respond to their children and they may begin to feel helpless and think of themselves or their children as failures.

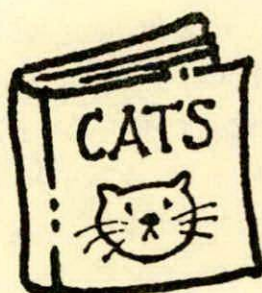
It may help these parents to think about their children's cues in the ways that all parents must think about crying. For babies, crying can mean many different things: "I'm hungry," "I'm tired," "I'm wet and uncomfortable," "I'm bored," "I need to burp," "I'm over-stimulated," or "I'm lonely." For some children, crying means only, "Leave me alone so I can cry and get my emotions organized." But parents have to be quite alert to figure out what message their crying babies are sending them. Research shows that babies who are picked up right away and cared for in a responsive way are more content and compliant in the second half of their first year and later in toddlerhood, but how should the parents "care for" them? The parents have to experiment. They can feed the children, lay them down, change their diapers, change their positions, give them new toys to look at, burp them, take them to a quiet, dim place, or talk to them. They can rock them, sing to them, walk them, give them pacifiers, or give them a backrub. Sometimes, when their children are sorting out the stresses of the day, they need to just let their children cry.

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Growth and Development

Gradually, parents will learn which cries carry which meanings. They will find special ways to comfort their special children. They will figure out when to let their children cry. Night crying may be a big problem for them. Often night crying is related to night feedings, so that around four months (for children who are not premature and who do not have other specific health needs) the need for night feedings will end and so will the crying. But sometimes, night crying continues because the children have received reinforcement for waking up. If their parents play with them, talk with them, or wake them up thoroughly in an attempt to make them tired enough to go back to sleep, the children will only learn to wake up even more regularly at night to get this continued attention.

Instead parents can let their children cry alone for 5 to 10 minutes to see if they can go back to sleep. Then they can try comforting their children briefly by tucking in their covers, rubbing their backs, or changing their positions without stimulating them. They should comfort for only about one minute. If their children are still crying 20 minutes later they can go through the same process. Before long, most children learn to sleep instead of crying at night. Of course, some children are in pain or have great trouble sleeping. In those cases, their parents will have to consult with their children's doctors to determine the trouble and make plans for dealing with it.

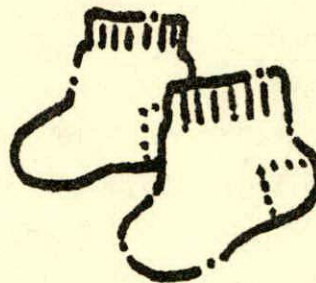


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Growth and Development

Parents with children who have other methods of communicating that seem difficult to interpret can try some of the same ways of figuring them out. They can consider all the possible messages, and then they can think of all their possible responses. They can also consider the degree of alertness their children are displaying during the times they give these cues. There are six general stages of alertness—

- awake active
- alert inactive
- crying or fussy
- drowsy
- irregular or light sleep
- regular or deep sleep



Cues that children send are likely to mean different things if they send them when they are awake and active than when they are drowsy, and different things again than when they are fussy. By looking at the degree of alertness in their children, parents may be able to interpret the cues they are sending. Parents also need to take into account subtle variations in the cues. They can use words, gestures, sounds (even crying), and touch to communicate back and try to set up a back and forth “conversation” with their children.

And, of course, some cues that children send need at times to be ignored so that the children can learn other more effective ways of meeting their needs, like night crying needs to be partially ignored so that children learn to sleep instead of crying when they are tired.

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Growth and Development

Parents may be especially concerned if they feel their children's verbal language is delayed. If they feel language acquisition is going slower than they would have expected, they should, of course, have their children's hearing checked. But there are other reasons than deafness for delayed speech.

Physically active children who are always moving may spend more time learning motor skills and may learn to talk in a rush later.

Children who are pressured to speak may avoid speaking because they recognize their parents' tenseness about their language skills or because their parents try to make speaking a complicated business.

In large families where siblings respond to speech efforts in constantly changing ways, children may withdraw into a protective quiet.

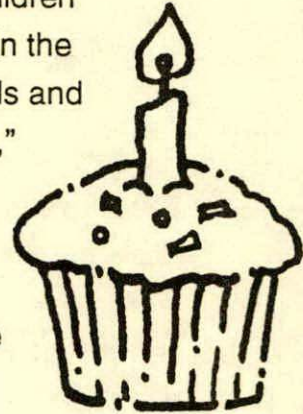
In other large families siblings may meet the younger children's needs quickly without waiting for language requests or they may understand the younger children's baby-talk so well that there is little need for the younger children to develop mature speech.

In bilingual families, children may become confused and refrain from talking until they are well into their third year; usually they catch up in language skills after some time.

MELD SPECIAL
Growth and Development

No matter what the cause for a language delay, except for physical inability to learn to speak, parents can make language learning easier for their children. A few tips can be useful reminders:

Parents should make their language with their children very clear and be aware of the level of the noise in the room. They should use visual cues with the words and be specific: saying "Brian, put the red block here," while pointing to the red block and to the place where it should go. They should look directly at their children while they talk, using simple words and phrases and increasing their language complexity only as their children increase their language skills.



Parents need to wait for their children to make some response to their short sentences before going on to say more. This is especially important for children with language delays. Too often, adults do not allow them the opportunity to respond because it takes so long to come. But the adults must learn to wait, and then they need to learn to celebrate any kind of communication, even crying or tantrums. They can say, "Thank you for letting me know how you feel." Temper tantrums may last longer in children with language delays, but even they can be seen as ways of communicating and the children can be given simple words like "no" and "don't like" to gradually replace the tantrums.

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Growth and Development

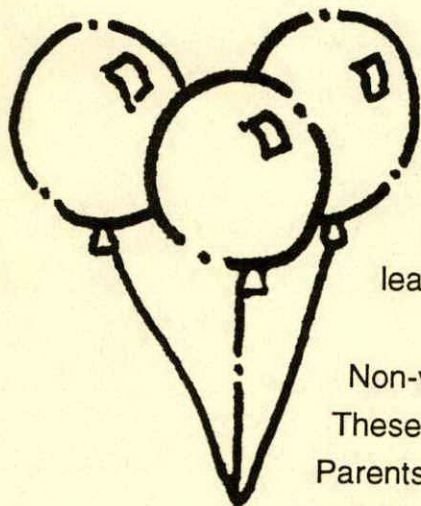
Parents can talk about their daily routines and the objects they are using as they move about the house. They should explain out loud what they are doing as they go through their usual tasks: "I'm putting the bread in the toaster to make toast." They should include time and space words like "in front of," "behind," "under," "first," "later." They should talk about comparisons, using "bigger," "smallest," "fattest."

Parents need to keep their talk positive and make their praise specific. Instead of saying, "You're a nice girl," they can say, "You smiled at me just now. I like that." They need to avoid giving mixed messages like offering their children choices that aren't really choices. They need to keep the promises they make; children are learning that adult speech can be depended upon but they will not learn that if their parents' speech cannot be depended upon. Parents can model positive social skills such as saying "please" and "thank you" by saying them themselves. They should be courteous when they talk so their children can also learn to speak courteously.

Parents should sing songs, make faces, be silly. Children love silly things and they love catching their parents making mistakes. In this way they learn that it is okay to be imperfect and that it is okay to play with language. Wise parents make silly, obvious mistakes to delight their children and themselves.

Parents should also read to their children every day. They can use other media as well. Tape recorders can be used to play music and let children listen to other children's and adults' voices.

MELD SPECIAL
Growth and Development



Language learning can be great fun if parents are not too up-tight about it. It can be just as fun for children who are unable to learn verbal language. The adaptations are more difficult for their parents, but the learning can still be enjoyed.

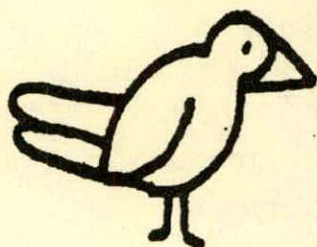
Non-vocal language is used by people who cannot speak. These people may use signs, signals, or electronic devices. Parents of children who use non-vocal languages probably learn to read their children's signals better than anyone else does. These parents will have two tasks—to help their children learn to communicate and to help others learn to communicate back with the children. As the children's language skills develop, they will have greater success in making others understand them. Speech and language therapists are often essential helpers in this process.

Often children need to begin with signs for "yes," "no," and "I don't know." If children can make even one response that is distinctive from other movements, they can signal "yes." Once they can signal "yes," anyone can have a conversation with them by asking clear questions. Children who can make two distinctive responses can signal "yes" and "no," and a third distinctive response will allow them to signal, "I don't know." Signals can be turning their heads, moving their eyes, or activating a buzzer or light. If children have more responses available to them, they can develop many other non-verbal signs.

MELD SPECIAL

Growth and Development

Once parents have developed systems of non-verbal signals with their children, they can let others know how to communicate with the children. A parent could make a sign like this and hang it from the child's chair or wrist—



“Hello! My name is Greg.
I cannot talk because of motor problems.
I can think. Please give me time to express myself.
I say “yes” by looking up.
I say “no” by looking down.
Please look me in the eye.
Take turns so we can have a conversation.”

Parents can help their children by teaching them to make signals as clearly as possible. Then the parents must themselves be clear. They must ask one yes or no question at a time and allow time for the children to give a response. They can ask, “Is it about home? about school? about some place else?” and continue the conversation until the message is clear. The children's ability to communicate often depends on how well their parents reflect on what yes or no might mean; the children depend on others to think about, guess, interpret, or restate what they want to say. Parents can repeat and clarify what they think the children are saying. If they don't understand what their children are trying to say, they need to admit it. They can say, “I really don't understand. Do you want me to keep trying?” (From Home Care for the Chronically Ill or Disabled Child: A Manual and Sourcebook for Parents and Professionals, by Monical Loose Jones. New York: Harper and Row, 1985.)

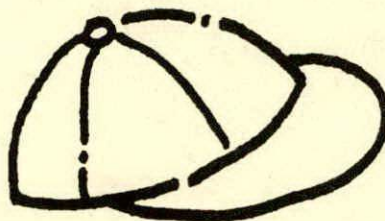
MELD SPECIAL
Growth and Development

Parents can find other ideas about non-vocal language in Help Me Say It: A Parent's Guide to Speech Problems by Carol Barach. (New York: Harper and Row, 1983.) For older children who understand the meaning of symbols and language, the Microcomputer Resource Book for Special Education by Dolores Hagen can provide information about the many communication devices on the market, including communication boards, charts, and computers. (Reston, VA: Reston Publishing Co., Inc., 1984.)

Selecting Pre-School Educational Programs

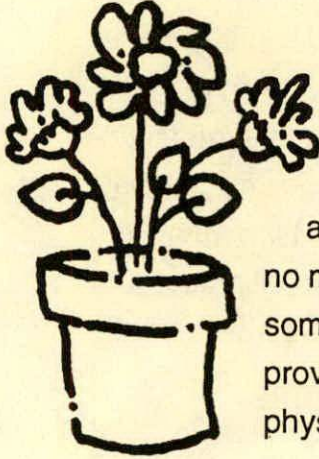
Parents who must use day care or who feel their children will benefit from pre-school educational programs have to look carefully to find programs that suit special needs children. Although legislation requires programming for special needs children after age three, programs for children younger are more difficult to find. Local hospitals and the Easter Seal Society may know of available resources.

In general, parents should wait for their children to be healthy enough to benefit from an educational stimulation program. Newborns with multiple problems must become medically stable before they can participate in a program. Children who were premature or have multiple conditions must continue to be protected from programs that offer them too much stimulation.



MELD SPECIAL

Growth and Development



If it is necessary for children to be in full-day programs, they should be in programs that have rest periods and free-play periods. Children with visual or hearing impairments will need programs that provide teaching about how to play. Young children should be in groups of no more than four children with one adult; and they all need some one-to-one time with the teacher. All programs should provide for stimulation of children's language development, physical growth, and pre-academic concept learning.

Parents need to visit programs before they enroll their children. When they visit they should watch to see if the teachers and children seem to like and respect each other, if the children are enjoying themselves, if the children are relaxed and interested in what is happening around them, and if there is special equipment that is well used. The parents should talk with the teachers and ask them about specialized activities like art, music, and specialized play for specific problems. They should find out how the staff handle hygiene, toileting, and food preparation and what their policies are about sick children, especially with respiratory infections such as colds and sore throats.

Parents don't need to find ready-made programs. They can consider forming cooperative play groups themselves with parents of other young children. They may find those parents in their MELD Special group, among their neighbors, or among people they have met while their children were in treatment programs.

MELD SPECIAL
Growth and Development

Conclusion

Children are an enormous responsibility. Taking the process in small, daily steps can help parents retain their positive attitude and their sense of humor. Parents may find it useful to go over these resolutions as they face their days.

- Today I can take the time, make the time to have fun with each of my children. I can play and laugh and join in their youthful enthusiasm for life.
- Today I can protect my children from dangers beyond their control with supervision, a safe home, a healthy environment, and seat belts.
- Today I can teach my children to assume responsibility for themselves within their abilities. I can encourage them to be capable by not doing for them what they can do for themselves.
- Today I can plan for my next outing away from the children and these responsibilities. I can demonstrate the importance of my own happiness.
- Today I can watch for and sincerely praise appropriate behavior in each of my children.
- Today I can ignore the inevitable worries and doubts and simply appreciate my children for who they are and what they are.
- Today I can provide my children with firm guidelines and loving encouragement.
- Today I can be courageous and accept the challenges of each child's unique temperament and special needs.
- Today I can allow myself room for growth and change because every parent makes mistakes.
- Today I can hug, kiss, and hold each of my children. I can show them how much they are loved.

(author unknown)

MELD SPECIAL
Growth and Development

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MELD SPECIAL
Growth and Development

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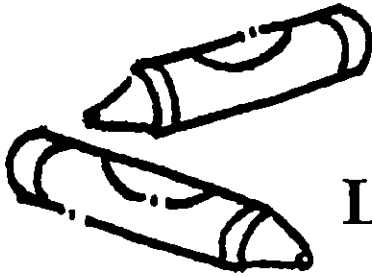
“Stepping Stones: Pathways to Early Development..” 30 video programs available for lease or sale from the Agency for Instructional Technology, Box A, Bloomington, Indiana 47402-0120, (800) 457-4509.

MELD SPECIAL
Growth and Development

Resources for Parents (continued):

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Used Equipment Marketplace: A Strategy for Cutting Equipment Costs. Minneapolis, MN: Metropolitan Center for Independent Living and United Cerebral Palsy of Minnesota, 1984.



Learning Activities

Set the mood by playing some children's records as group members arrive.

Get acquainted by having parents to talk about what their children are good at doing and are interested in. Use this as a background for talking about the sequence of development.

Encourage a sharing time about things the parents like about their children.

Invite a speaker or panel of professionals and other parents of children with special needs. You might invite one or more professionals in areas related to child health or infant stimulation programs.

Arrange for mini-lectures by dividing up the material between two or three of the parent group facilitators and having each one talk about a topic. Allow time for discussion and questions. If there are questions you can't answer, make notes, find the answers before the next meeting, and report back to the group.

MELD SPECIAL
Growth and Development

Assemble toy boxes. These boxes are intended to encourage more spontaneous play because they will be readily available when the parents and children need or want them. Bring a shoe box for each family or have each parent bring one to the meeting. Bring an array of play materials for them to choose from: red yarn to make pom-poms for visual tracking activities; aluminum foil to crumple into balls or hang on mobiles; old socks to stuff with old nylon stockings for making balls or to draw faces on for making puppets; fabric swatches of different textures for rubbing and massaging; empty margarine tubs; L'eggs eggs with dried beans and masking tape to make rattles; small, empty squeeze bottles for blowing puffs of air; different kinds of paper (paper bags, waxed paper, newspaper, etc.) to crumple to make sounds. While they make their boxes, discuss:

When during the day would you find this box useful? (waiting for the bus, waiting for dinner to cook, after bathtime, waiting in a car or doctor's office)

How might the box help siblings play with the child who has special needs? (by making toys easily available, giving them ideas, encouraging them to think of new things to put into the box)

How might the box encourage friends and relatives to play with the child who has special needs? (helping with an easy explanation about some activities your child enjoys, giving them ideas for toys to have at their house when you go to visit)

(From Seasons of Caring, by Janice P. Hanson and Elizabeth S. Jeppnon. Washington, D. C.: Association for the Care of Children's Health, 1986)

MELD SPECIAL

Growth and Development

Discuss feelings that come up for MELD Special parents around the topic of Growth and Development. How do they feel about comparing their children to “typical” stages of development? What are the positives of such comparisons? the negatives? What are some differences about their feelings between static disabilities, such as visual or hearing impairment, and chronic illnesses which might change and create more uncertainty for parents? Have parents identify their children’s developmental age level and list examples of children’s tasks and parents’ tasks.

DEVELOPMENT USUALLY OCCURS IN PREDICTABLE STAGES.

Brainstorm some of the factors that parents can identify in how their children develop differently from others. The list can include family size, physical differences, birth size, temperament, etc. Next, have parents share incidents in which their children accomplished “firsts.” How did they and the children respond?

Have parents discuss in large or small groups whatever behaviors of their children have been hardest for them to deal with and how the information on growth and development helps make that behavior more understandable.



MELD SPECIAL

Growth and Development

Encourage problem-solving. In order to emphasize why knowing something about typical development and careful observation is so important, discuss the following situations:

- A three-month-old cries continually and seems inconsolable. The parents are at their wits' end. If you were the parents, how would you deal with this?
- An eighteen-month-old makes some sounds, but doesn't try to say words. How should the parents deal with this?

During your discussion, check information on typical child growth and development. Then, talk with other parents. Are their concerns similar? different? How? Do they have comforting ideas that parents could try? You can suggest that parents talk to their own parents about their development as children. Are some differences more understandable in light of the family history?

DISABILITIES AND CHRONIC ILLNESSES AFFECT HOW CHILDREN ACHIEVE DEVELOPMENTAL MILESTONES.

Encourage empathy by asking parents to "get back into" the stages of the children they are focusing on. Suggest that each parent accomplish this by doing and experiencing something as their child would. The parent should feel what it is like emotionally to be the child. For instance, if a parent's child attends a day program, that parents could spend one or two hours there, trying to experience the situation the way the child might, trying especially to experience the program as if the parent had the child's disability. At the next MELD Special meeting, have parents discuss what it was like to feel like their children and what the experience helped the parents remember about being children.

MELD SPECIAL

Growth and Development

At the next meeting, ask parents to describe themselves at the stage their children are at.

Were they shy or outgoing, active or quiet, fearful or happy?

Did they feel comfortable or awkward or strong being in a small body?

How did they feel about other children the same age?

How did they feel about their parents and teachers?

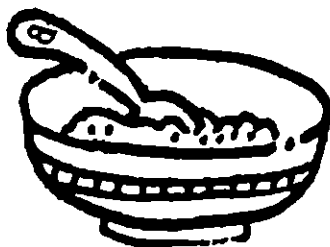
What were their fears and worries?

What did they feel proud of?

What insights did this activity give them into their children?

Lead a group discussion about rites of passage. In many cultures a celebration or significant event happens when a child moves into a new stage of development. These are called rites of passage. Ask parents to share ways that their families have marked significant turning points in children's lives, such as dedications or baptisms, birthdays, beginnings or endings of school, milestone birthdays, Bar or Bas Mitvahs. Encourage parents to talk about how they mark significant family changes like moves, vacations, visits to extended family members, and other events.

Discuss problems in helping children accomplish tasks, such as dressing themselves, eating, and playing. Brainstorm ideas for helping children adapt to those tasks. How can parents show the children to "try another way" to do those things?



MELD SPECIAL
Growth and Development

**PARENTS CAN PROVIDE OPPORTUNITIES FOR CHILDREN WITH
SPECIAL NEEDS TO GROW AND BECOME COMPETENT AND
ACHIEVE MASTERY OVER THEIR ENVIRONMENTS.**

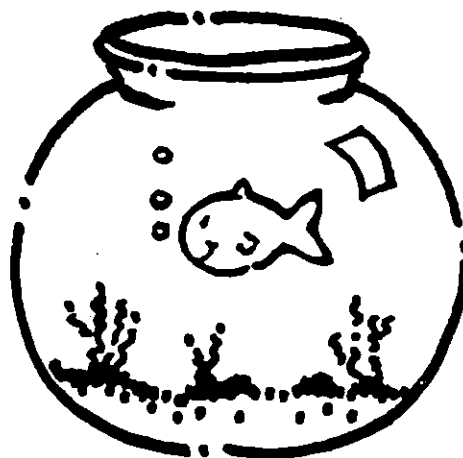
Lead parents to discuss these questions:

- With what is your child most fascinated now?
- How are you getting to know what interests your child?
- Can you think of a time you acted as a “consultant” for your child?
- Have you noticed times when your child seems to be trying to solve a problem? What happened? What was your role?
- What things can your child count on happening in a day?
- What kinds of rituals would you like to add to your child's day?

Encourage parents to talk about what they are already doing to help their children practice and master new skills.

Brainstorm ways that parents can stimulate exploration in their children by providing experiences in areas, such as:

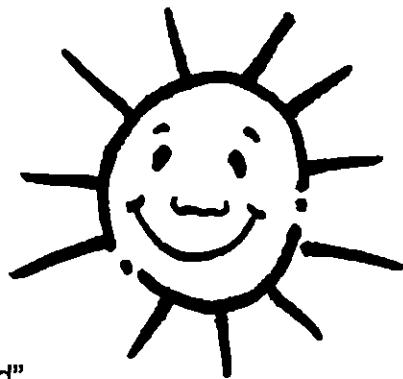
- listening
- following directions
- storing and recalling information
- solving problems
- thinking independently
- gaining social skills
- working independently



MELD SPECIAL

Growth and Development

Lead parents to role play and discuss three situations in which a parent might help a child with disabilities or a chronic illness learn something. You could have then begin with a situation like crossing the street or getting dressed. Ask one volunteer to play the parent and one the child, with the "parent" actually teaching the "child" and the "child" displaying a certain disability. Have the other parents observe and keep track of what the "parent" does to teach the "child." After the role play, discuss what took place.



- What methods did the parents use to teach the child?
- How did the parents and child feel during the skit?
- What did the parent do that seemed especially helpful?
- Did any problems develop? How were they handled?
- How might the situation have been handled differently?

Carry out other role plays and discussions. Finally, summarize the different teaching methods that could be used in such situations.

Lead a parent discussion about ideas for encouraging self-help. Parents can discuss ideas they use now, ones they would like to use, and ones they wonder about. They may wish to discuss ways of adapting their home environments to makes dressing, playing, eating, and other routines easier for their children. They may have examples of songs, games, and books they use with their children. Encourage them to discuss their varied levels of patience in allowing their children to help themselves. Ask them how they feel about letting go of some of their children's dependencies.

MELD SPECIAL
Growth and Development

Have parents brainstorm ways they can help their children develop positive self-concepts as they:

- show their children they are loved,
- avoid overprotecting their children,
- use the children's interests to guide play,
- are realistic about typical behavior,
- appreciate their children for who they are, not for what they do,
- avoid belittling their children,
- let their children know their feelings are important,
- show their children that they are respected.

Talk about how much non-verbal "back and forth" communication takes place before children actually develop language.

**YOUNG CHILDREN ACTUALLY THINK DIFFERENTLY
THAN ADULTS THINK.**

Have parents brainstorm ways that they can encourage growth. They could consider ways of allowing children to manipulate objects, ways of allowing children to develop at their own rates, and ways of being sensitive to what the children are ready to learn and what they choose to work at.

List difficult situations the parents are dealing with that might be explained by their children's developmental stages. Discuss whether or not particular disabilities affect the situations. Have the parents suggest ways of handling the situations positively. Some sample situations may be when children hit other children who accidentally bump them, when children refuse to share, or when children have difficulty separating from their parents even for short times.

MELD SPECIAL
Growth and Development

**INDIVIDUAL DIFFERENCES IN TEMPERAMENT AND LEARNING
STYLES AFFECT HOW CHILDREN INTERACT WITH THEIR
WORLD AND HOW THEY LEARN.**

List difficult situations that parents have experienced that might have been explained by their children's temperaments. Consider what special help might have made these experiences more constructive and how parents could react differently to these situations when they are aware of the role temperament plays.

Discuss temperament differences. Have parents consider:

- whether this information frees them a bit from taking total responsibility for their children's behavior,
- whether they can recognize their children's own temperaments,
- whether they can recognize their own temperaments,
- whether they and their children are alike or different and what problems that might create,
- how they can minimize the problems and maximize the positives of their children's temperaments.

Have parents discuss how they could deal with negative comments like:

- "Doesn't your child ever get excited?"
- "He's going to try this new babysitter even if he screams for hours."
- "My other child could concentrate longer."

Have small groups of parents discuss the idea of "turn taking." Bring in some toys and have the parents role play a variety of back and forth "turn taking" non-verbal activities.

MELD SPECIAL
Growth and Development

**PARENTS AND CHILDREN CAN USE A VARIETY OF
WAYS TO COMMUNICATE.**

Help parents think about what makes a conversation with another person satisfying. You may want them to consider the differences between listening to a radio or television and listening to another person. Make a list as the discussion proceeds. Encourage consideration of qualities such as these:

- There is time for both listening and responding.
- What is being said is of interest to both people.
- What is being said matches how it is being said; it is without conflicting messages.
- There is frequent eye contact.
- There is some spontaneity and naturalness.
- There is trust.

Talk about the importance of these same qualities in parent/child conversations. Emphasize the importance of being tuned in.

Discuss the importance of paying close attention to children during daily routines, such as diapering, dressing, eating, and coming and going in the car. Have parents consider the times when they and their children are in closest contact with each other. Suggest that these are times for playful interaction as well as for the parents to narrate the events of the interactions to their children.

Play a children's record. Talk about how we all respond to love songs, lullabies, and poetry and how they can help to bond love relationships.

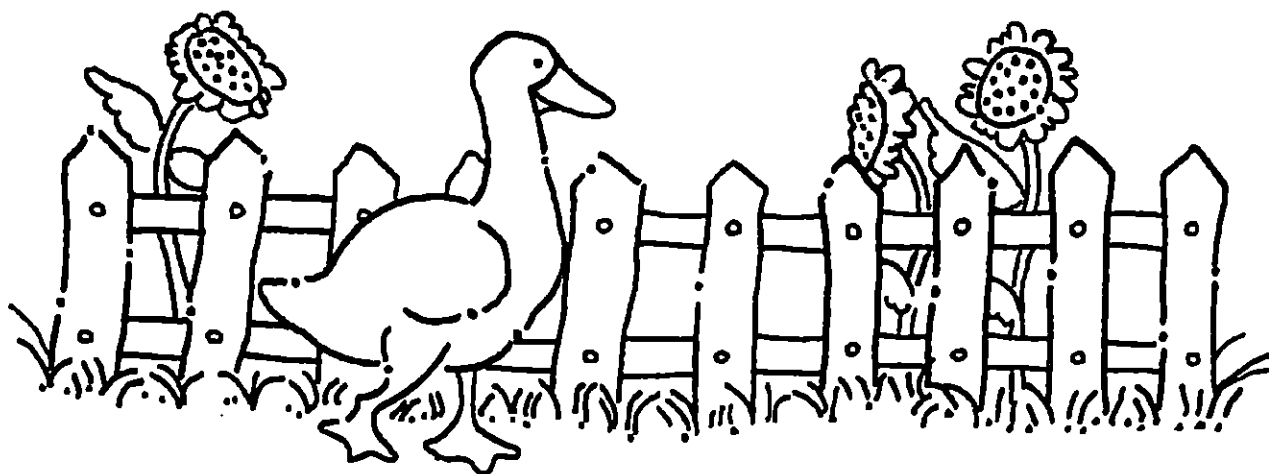
MELD SPECIAL

Growth and Development

Show a film. You might consider "It's Harder for Patrick" (WGBH-TV, released by Films, Inc., 733 Gren Bay Road, Wilmette, IL 60901) or "James Is Our Brother" (BBC, 1975, released by Time/Life Multimedia, 1271 Avenue of the Americas, New York, NY 10020).

Have parents do the homework of observing their children in new situations and writing down how the children react, how the parents react themselves, and what they think the children are learning.

Have the parents make a journal entry describing how the information about growth and development helps them in their feelings of responsibility for their children's development.





Chapter 8

Handouts

**Growth and
Development**

STAGES OF GROWTH AND DEVELOPMENT

The following chart gives some typical developmental milestones for each stage. Each major milestone of development consists of several smaller steps and tasks to be learned along the way. The ages at which those tasks are accomplished are only very rough guidelines of usual development. Children with special needs may spend a great deal of time between milestones; they are learning and they will probably learn in the order indicated on this chart.

INFANCY (birth to about 12 months)

Physical Development Tasks:

growth, achieving a stable sleep pattern, achieving feeding skills, basic muscle control (head, neck, trunk, and arm coordination).

Intellectual Development Tasks:

making sense of all things heard, seen, felt, and tasted, organizing themselves, getting their bodies to react to the world.

Emotional and Social Development Tasks:

basic trust (reliance on continuity of care, relaxation and trust of self), security and safety.

Parents' Supportive Tasks:

attachment, competence in caretaking, providing predictability and consistency, adjustment in family roles.

EARLY TODDLER (about 1 to 2 years)

Physical Development Tasks:

growth, carrying things, walking and mobility, bowel and bladder control, some self-help skills (eating, carrying objects).

Intellectual Development Tasks:

knowing body parts, learning "no," being alert to routines, imitating, using one- and two-word phrases, being possessive.

Emotional and Social Development Tasks:

becoming a unique individual through separation, independence, autonomy, control of their own activities and impulses.

Parents' Supportive Tasks:

encouraging independence, helping development of self-control, avoiding overprotection.

LATER TODDLER (about 2 to 3 years)

Physical Development Tasks:

growth, climbing, running, throwing, developing small muscle skills, scribbling, bowel and bladder control, more self-help skills (feeding, carrying).

Intellectual Development Tasks:

following simple directions, making transitions, solving problems with movements and experimentation, speaking in phrases.

Emotional and Social Development Tasks:

separation, independence, autonomy, controlling one's own activity, controlling impulses, sometimes taking turns, playing parallel, having a sense of ownership, having a sense of identity, toileting.

Parents' Supportive Tasks:

encouraging independence, helping development of self-control, avoiding overprotection.

EARLY PRESCHOOL YEARS (3 to 4 years)

Physical Development Tasks:

growth, coordination (gross and fine motor), strength and speed, self-help skills.

Intellectual Development Tasks:

understanding others' feelings, learning shapes, colors, and numbers, making choices, increasing attention span, playing independently for 30 minutes, learning to manipulate adults, using language in play with others.

Emotional and Social Development Tasks:

developing mastery, gaining a sense of values and self-worth, achieving goals, differentiating between sex roles, playing, gaining a body image, expressing feelings, taking turns, interacting in play, accepting suggestions.

Parents' Supportive Tasks:

encouraging initiative, maintaining discipline, helping understand right and wrong, modeling behavior of same-sex parent, avoiding overprotecting.

LATER PRESCHOOL YEARS (4 to 5 years)

Physical Development Tasks:

growth, coordination (gross and fine motor), strength and speed, self-help skills.

Intellectual Development Tasks:

recognizing numbers and patterns, writing names and letters, developing definite areas of interest, speaking in sentences, explaining why.

Emotional and Social Development Tasks:

developing mastery, forming a sense of values and self-worth, achieving goals, differentiating between sex roles, playing, accepting body image, sharing, playing without adult supervision.

Parents' Supportive Tasks:

encouraging initiative, maintaining discipline, helping understand right and wrong, modeling behavior of same-sex parent, avoiding overprotecting.

SCHOOL YEARS (5 to 12 years)

Physical Development Tasks:

growth, coordination (fine motor), strength and speed, physical games.

Emotional Development Tasks:

working and being productive, developing competence, planning and follow-through, developing peer relations, accepting body image.

Parents' Supportive Tasks:

fostering skill development, encouraging exploration, encouraging peer relations (movement out from the family).

VARIETIES IN CHILDREN'S TEMPERAMENTS

The chart below describes varieties in temperament in children.
Children can fall anywhere between the two extremes.

ACTIVITY LEVEL

.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|

always on the move	likes to sit
wiggles, squirms	sleeps quietly

PREDICTABILITY

.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|

like structure and regular routine	fights structure spontaneous
---------------------------------------	---------------------------------

ADAPTABILITY

.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|

feels at home in a new situation in a week or less	doesn't feel at home for several months
--	---

SENSITIVITY

.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|

responds quickly to heat, lights, rough clothing, noise	doesn't seem to notice noise, temperature, scratchy clothes
--	--

POSITIVE AND NEGATIVE MOODS

.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|

easily upset, fussy, irritable	optimistic about almost everything
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DISTRACTIBILITY

.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|

sticks to activity
in great distractions

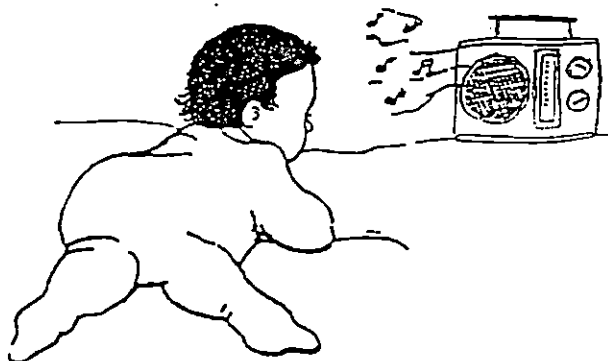
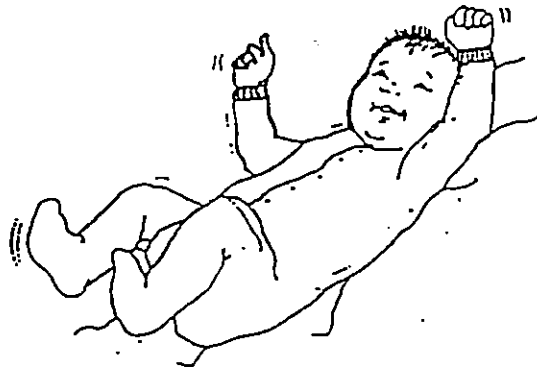
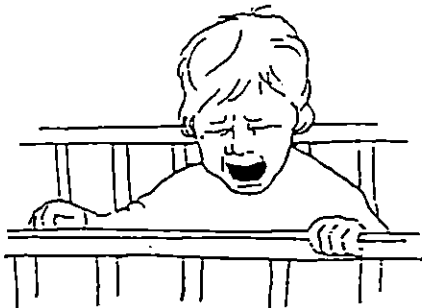
distracted by
small events

PERSISTENCE AND ATTENTION SPAN

.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|.....|

sticks to task or
toy forever

gives up after minor
discouragement



TURN-TAKING

Turn-taking is basic and necessary to parent-child interaction. It involves one person acting or communicating, then stopping and waiting for the other person to act or communicate in response. By taking turns, children learn the "give and take" necessary for further development, and parents play active roles in facilitating that development.

Children communicate first through actions. Therefore, parents should begin turn-taking with actions and then move on to actions with language and then to language alone. Parents can choose touching, laughing, facial expression, noises, and gestures for early turn-taking actions. They can pick an action that their child does first. Then they can wait for a response. If the child does not respond, they can help the child through the imitation and take another turn.

Depending on the developmental level of the child, early actions can be followed by more complex actions or activities, such as stacking blocks, drawing, putting together puzzles, and tossing bean bags or balls. Turn-taking can also include gross motor activity, such as hopping, jumping, walking the balance board, or standing on one foot. Once the child is taking turns with motor responses, the parents can expand to motor actions paired with sounds or words to provide a basis for communication development.



An example of turn-taking

Parent: Puts one block on floor. Says, "my turn." Points at a pile of blocks.

Child: Takes a block and puts it on parent's block. Says, "me."

Parent: Takes a block and stacks it. Says, "on."

Child: Says, "on." Stacks a block.

Parent: Stacks a block. Says, "block on."

Child: Takes a block and stacks it. Says, "ba on."

Parent: Claps. Points to stack. Says, "over."

Child: Knocks block stack over. Claps.

Evaluating turn-taking

In turn-taking

the people alternate between being leaders and followers
both people do and say about the same amount of things
both people take turns watching and doing
the two people are partners.

Change strategies if turn-taking is unsuccessful

If the interaction between parent and child is unsuccessful or the activity does not elicit a response from the child, parents can:

Add another person to the game.

Clap after every turn.

Make a funny noise when they take their own turns.

Do the activity in front of a mirror.

By Linnea Grey and Lynn Maier, Developmental Learning Center, Eagan, Minnesota.

Used by permission.

Used Equipment Marketplace: A Strategy for Cutting Equipment Costs

The Used Equipment Referral Service, sponsored by the Metropolitan Center for Independent Living (MCIL) and United Cerebral Palsy of Minnesota (UCPM), saved consumers more equipment dollars in its first year than either of the organizations anticipated. MCIL and UCPM urge readers to use their successful experience as an outline, and consider setting up similar projects in their own communities.

A used equipment referral service (UERS) is a clearinghouse which matches people who want to donate or sell used equipment with people who need equipment. The service does not store any equipment in its own or other facilities.

Problems

For disabled people, employment, independent living, recreation, and physical development all depend on their obtaining assistive equipment such as wheelchairs, van lifts, adaptive furniture, and communication aids.

The following factors work to restrict the availability of assistive equipment:

1. *Expense.* Assistive equipment is often expensive, and the price continues to rise even further out of the reach of disabled people and their families.
2. *Size.* As children with handicaps grow, their equipment needs change. Their families find it difficult to locate the new equipment needed and pay for it.
3. *Lack of coordination.* The various organizations which provide equipment for disabled people have not coordinated their efforts in the past, making proper information and referral difficult and leading to duplication of effort.
4. *Lack of third-party funding.* Third-party funding sources such as personal health insurance and medical assistance do not pay for all types of equipment. In addition, not all people are eligible for third-party funding. Many third-party funding sources have been cutting their costs by cutting benefits for purchasing equipment. Many people do not even know what kinds of third-party funding alternatives are available to them.

Solutions

A used equipment referral service alleviates these problems by providing:

1. Information about used equipment, which is less expensive than new equipment.
2. A "revolving door" where parents of children who have outgrown equipment can offer it for sale and can purchase used equipment in the new size from someone else who has outgrown the equipment.
3. Improved coordination among individual and retail sellers of used equipment, people who do maintenance on assistive equipment, and organizations and individuals who provide services to disabled people. Working together through a UERS, service providers can inform disabled people about the full range of equipment and service alternatives available to them, increasing the number of disabled people obtaining needed equipment at a reasonable cost.
4. Information on third-party funding and reduced equipment costs through recycling equipment. Sources of third-party funding generally come under the categories listed below.
 - *Private health insurance.* Basic and major medical insurance coverage available to individuals through nonprofit Blue Cross and Blue Shield or from private, for-profit insurance companies.
 - *Group health insurance.* Basic and major medical insurance coverage available to employees of companies which carry a policy covering all the employer's personnel and their dependents.
 - *Health maintenance organizations (HMOs).* Groups of medical practitioners offering comprehensive medical care for prepaid monthly premiums, rather than on a fee-for-service basis. People can belong to an HMO either as a member of a group (usually with the employer paying some part of the monthly premiums) or individually (with the covered person or family paying the total monthly premium).
 - *Public plans.* These include Medicare, Medicaid (or Medical Assistance), and services received under the Hill-Burton Act. Details on these programs are available from state, county, and/or local public health departments or social service agencies.

How to Set Up A UERS

The following is a step-by-step description of how to set up a UERS, using the Minneapolis-St. Paul UERS as an example. It is important that these basic steps be followed to assure a successful outcome.

Conduct a Needs Assessment

It is very important, before starting out, that the community or intended service area be surveyed to see whether any other agencies already offer the service in some form and whether other agencies working with handicapped and disabled people see a need for such a service. Also try to get some idea how many people living in the area would use a UERS, and project how they might be contacted.

In Minnesota the assessment was accomplished as a part of a larger total needs survey of the metropolitan Minneapolis-St. Paul area by United Cerebral Palsy Associations, Inc. (UCPA) for UCPM. During a nine-month period, a team of interviewers met with consumers, key observers, parents, and staff in 43 human services agencies to assess needs and to get recommendations on how UCPM might meet those needs.

The UCPA study uncovered a major unaddressed need for a centralized service which would bring sellers and buyers of used equipment together and provide a regularly updated information resource. It was clear that people needing used equipment had no means of finding sellers, and sellers did not know how to find buyers. UCPM suggested a clearinghouse approach to the problem to a number of service providers. Their favorable responses led to joint planning with the Metropolitan Center for Independent Living, Inc. (MCIL).

MCIL brought to the project the agency's experience with a passive UERS it had operated for the previous 11 months. Lacking adequate staffing, the UERS had operated with little outreach and no formal links to other disability agencies and organizations. It served adults primarily and handled about 20 to 25 calls each month. UCPM brought to the venture its organizational contacts with outside agencies and the fundraising and statistical evaluation capabilities of its staff members.

It is not necessary to do a total needs assessment in order to establish the need for a UERS. The following information should be gathered:

- Are any other agencies already offering all or part of the service?
- Do the other agencies working with handicapped and disabled people see a need for such a service?
- How many people who live in the proposed service area would use a UERS and how can they be reached?
- Could agencies collaborate to provide the service?

Form an Advisory Task Force

Forming an advisory task force is a way of establishing vital links with other community organizations serving handicapped and disabled people and with rehabilitation professionals. The task force provides a forum in which agencies, rehabilitation professionals, and consumers can:

- Assist in developing the UERS
- Identify specific markets for the service
- Assist in the public relations effort to make potential consumers aware of the project's existence
- Provide connections with rehabilitation professionals, organizations, and individuals working with disabled and handicapped people to form channels for input as well as a point of referral for clients' needs
- Provide a network to exchange information about equipment needs and availability and to disseminate information about the existence of the UERS.

Develop and Write a Funding Proposal

Decide how the service will operate—which tasks will be performed and by whom. Decide which tasks will need staff people to perform them and which ones might be performed by volunteers. Decide what kind and how much staff supervision will be needed. Explore what kinds of credentials and/or experience staff and volunteers will need to successfully operate the service.

Write a funding proposal which includes the results of the needs assessment and how the UERS will fill a community need. It should also include a precise description of how the service will be operated.

Set Up the Operation

Once funding has been obtained, a simple, efficient means of implementing the program includes the following:

- Set up a system for operating the service
- Design simple forms for operating the service, keeping statistics, and reporting on the operation to the funding organization and the Advisory Task Force.
- Establish a bookkeeping system.
- Design training methods and materials for staff and volunteers.
- Recruit and train volunteers.

In addition to providing ammunition for further fundraising efforts, keeping good records and compiling statistics can help to determine the strengths and weaknesses of the operation and its outreach efforts. This will make it possible for the Advisory Task Force and the staff to modify, improve, and expand the service to meet changing needs.

Publicize the Service

The success of the service will depend to a great extent on an ongoing publicity effort. The intended public may not see the initial announcement or may not need the service then. The widest possible coverages is the best way to ensure that people who need the service know about it. Increased visibility helps in future fundraising efforts and in recruiting the volunteers needed to maintain the service.

An ongoing publicity campaign includes at least the following:

- Press releases to all the major newspapers serving the population area, the neighborhood papers, TV and radio stations (both AM and FM), and all the organizations which serve people with disabilities in the service area for use in their newsletters.
- Attractive posters and flyers which can be posted on bulletin boards in stores, churches, and union halls—wherever people gather.

Evaluate the Service and Examine Outcomes

It is important to periodically evaluate the service to see whether the UERS is:

- Providing the service it is intended to provide, and in a courteous and efficient manner
- Saving its clients money, as intended, and if so, how much
- Working as intended internally, i.e., whether the forms are useful as designed, whether the cross reference system is working well, whether staff and volunteer training is effective
- Keeping in contact with other community agencies.

One outcome of periodic evaluations in the Minneapolis-St. Paul UERS has been some discussion of expanding the UERS to serve as a statewide program. However, it is not likely that the funding can be found to make this possible at the current time.

Restructure The Program As Needed

Any parts of the program that the evaluation process shows could be done more effectively should be restructured. This is an essential part of a successful operation, commonly called "learning by doing."

From "The Exceptional Parent", July 1986, pgs. 48-49.

YOUR BABY'S TEMPERAMENT

Infants are born with distinct personality traits. Different temperaments require different parental responses.

By Carol Byrd

Sally Shannon's first child, Justin, was the kind of infant who demands continuous attention. "He would really pitch a fit if I ever tried to leave him by himself," she recalls. "He *would not* go to bed by himself at night. I'd have to lie down in the twin bed next to his crib. And if I tried to slip out of the room, he'd wake up and cry his head off."

Sally didn't really mind attending to these extra demands—that is, until her second son, Ben, was born. "I just didn't see how I could take care of two babies like that," she says. "There were two of them and only one of me." As it happened, though, Ben was almost totally different from Justin. He was content to lie quietly in his crib, cooing and smiling until his mother came for him. "I don't know why Ben was so different," she says. "Maybe he just sensed that I didn't have as much time for him."

Maybe. But a more likely explanation is that Ben and Justin were born with different ways of approaching the world. Justin's personality was one that demanded constant interaction; Ben's temperament was more easygoing.

As parents know from comparing notes with other parents, babies do not behave alike. One infant may eat and sleep on a regular schedule within two months, while another may be unpredictable for six; one may welcome attention from strangers, while another may cry if anyone other than his parents tries to hold him.

What causes these differences? This point has been debated for several thousand years. Until recently, the prevailing theory among behavioral scientists was that the baby's environment made the difference—in other words, the child's personality was determined for the most part by the way he was raised.

Yet when distinctly different children are born to the same parents, who provide the same home environment for each, environment seems less satisfactory as a complete explanation. As one child-development researcher wrote 25 years ago, "We're all environmentalists until we have more than one child."

Temperament is now thought to be influenced by *both* environment and heredity—nurture and nature. Few researchers willingly speculate on which factor plays a greater role. “How can one disentangle heredity from environment?” asks Dr. Robert Plomin, an associate professor at the Institute for Behavioral Genetics at the University of Colorado. “Where does one stop and the other begin?”

“Why a child is the way he is may be due to genes or it may be due to environment,” says Dr. William Carey, clinical associate professor of pediatrics at the University of Pennsylvania School of Medicine. “There’s no question that both are involved. What’s hard to determine is how much one or the other is operating in any given behavior.” Researchers are also debating whether a cranky baby will eventually grow up to be a cranky adult. No one knows for certain, although some studies indicate personality characteristics *do* remain somewhat stable through the years.

About the only fact *not* being debated is that babies have very distinctive personality traits from the moment of birth. This should come as welcome news to parents who sometimes feel their every action has a permanent impact on their child.

“Too often parents blame themselves for their baby’s temperament, while in fact it has existed from the very start of life,” says Dr. Michael Lewis, professor of pediatrics at Rutgers Medical School. “For example, parents may have a child who won’t sleep through the night. They ask, ‘What did we do to make him do this?’ But then their next child may very well be completely different.”

Dr. T. Berry Brazelton, a pediatrician whose Neonatal Behavioral Assessment Scale measures the remarkable behavioral and reflexive differences among newborns, is pleased that the new research in temperament has taken the blame for so-called “difficult” children off parents’ shoulders. “Parents are not responsible for everything that happens to their baby, because the baby is already having a pretty strong effect on his own future,” says Brazelton. “New parents can have more fun with their baby if they relax and realize that the baby is already a pretty powerful individual.”

Dr. Eleanor Galenson, an infant psychiatrist at Mount Sinai School of Medicine, also hopes that parents will find reassurance in the new infant-temperament discoveries. “It is my hope that mothers can respect and enjoy these differences, instead of worrying whether their baby will conform to the so-called norm,” she says.

This does not mean, however, that parents of a difficult baby should simply throw up their hands in exasperation and tell themselves "that's just the way he is." "The fact that children are different is not a reason for parents to abdicate and let the young raise themselves as their individuality dictates," says Dr. Stella Chess, who, along with Drs. Alexander Thomas and Herbert Birch, conducted a landmark study of infant temperament in the 1960's. "It does mean that the child's temperament should be taken into account when parents are trying to plan ways to guide his growth."

Parents who observe closely and obtain some insight into their baby's individual personality traits can react appropriately to the child's individual needs. "Accommodate a child's nature, don't resist it," advises Rutgers's Lewis. Brazelton sees adaptation to the particular rhythms of a child as the key to good parenting. "But adjusting to an infant is not magical or instinctive, and it doesn't happen over night," he adds. "It is a learning process that takes time." Dr. Daniel Stern, chief of the Laboratory of Development Processes at Cornell University Medical Center, suggests that parents attempt to see the world from their baby's point of view. "It's important for parents to appreciate what their baby is feeling internally," he explains. "For instance, if the baby is very exuberant about something, like reaching and grabbing an object, but it's seen as just a ho-hum event by the parents, then that isn't very encouraging for the baby."

To succeed at sharing a baby's point of view, parents must try to understand the baby's individual personality. A major focus of research has been to label and categorize various infant personality traits. Although many scales have been developed in the past 20 years, perhaps the best known is the one created by Chess, Thomas, and Birch. In their New York Longitudinal Study of temperament, which involved 141 children in 85 families, the doctors asked parents to fill out a questionnaire with details of their baby's behavior. Did their infant coo or cry upon wakening? Did the baby readily accept a new food or a first bath? Was the baby able to nurse through all kinds of distractions?

By means of these surveys, the doctors recorded tremendous variations in temperament, with the differences very much in evidence by 3 months of age. In their book *Your Child Is A Person*, Chess, Thomas, and Birch suggest that nine inborn characteristics are the ultimate building blocks of personality—among them, activity, regularity, adaptability, mood, and intensity. (For help in determining your infant's temperament, see the test accompanying this article.)

Chess and her colleagues found that many babies follow a consistent pattern in their reactions to eating, sleeping, strangers, and new stimulation. Most babies, they found, have one of three basic styles of behavior.

"Easy" babies are comfortable most of the time and adapt with little difficulty. They react with interest and pleasure to new foods, new faces, and new experiences. They eat, sleep, and move their bowels on a fairly regular schedule, and they make their needs known in a mild fashion.

"Slow-to warm-up" babies are generally withdrawn. They tend to reject new foods and withdraw from new experiences, and they are unhappy with changes in routine.

"Difficult" babies proclaim their hunger by crying vigorously. They nurse intensely and announce they are full by rejecting food. They are easily distracted by noises, have irregular schedules, and reject new foods, faces, and experiences.

Parents of "easy" babies *do* have an easy time of raising their children, since these infants respond readily and positively to almost all situations. The main thing they have to be wary of is taking the baby for granted—not giving him enough attention, because he demands so little of them.

Although "slow-to-warm-up" babies require little attention or soothing, they can cause parents a considerable share of concern and frustration. Parents may take it personally when, for example, their baby turns his head to avoid further eye contact. "This baby isn't rejecting his mother; he's just trying to shut off too much stimulus." says Dr. Serena Weider, director of the Clinical Infant Development Program in Lanham, Maryland. "But if the mother misinterprets the baby's actions as rejections, she in turn may withdraw her support." To avoid the possibility of too much stimulation, Mount Sinai's Galenson says, parents should respect the baby's need for gentle, gradual exposure to new situations. "The mother should introduce things that might be of interest to her baby at an easy pace. And she shouldn't get stuck in a pattern of repeating things if her baby clearly isn't responding." The key is to steer a middle road between forcing the issue and backing off entirely, says Dr. Mary Ainsworth, professor of psychology at the University of Virginia. "Some mothers are content to leave these quiet babies to their own devices, but I think the sensitive parent does persist in a gentle sort of way."

As for "difficult" babies—intensely driving, active infants—"these babies are best left in an atmosphere where noise tends to be lower and where there aren't so many people moving around," says Galenson. "Parents just need to approach these babies at a slower tempo. Difficult babies tend to startle easily—so the cure is just to tread more quietly." Brazelton suggests toning down the environment to help overly active babies. If an infant's environment is responsive but *quietly* rewarding, Brazelton says, the baby can learn to control most overreactions.

Sometimes babies don't seem to respond to even the best parenting efforts—which leaves parents with a confused feeling of self-doubt. They may also feel anger. "But I think it's perfectly normal for parents to have emotions other than love for their babies," says author Chess. "It just proves that parents are people." And pediatricians say parents must understand that a child's difficult temperament isn't necessarily their fault. "A colicky baby isn't the result of inadequate parenting, says Rutgers's Lewis. "It's just the nature of the child."

Parents who go through difficult times with their baby may wonder whether their child will retain the same personality throughout life. "It's very obvious to any clinical person who sees a lot of babies, as well as to any parent who has watched a child mature, that there are enormous continuities in temperament," says Cornell's Stern. "But then when you ask, 'What was it that was really continuous? Activity level? Soothability?'—that's where we still have a lot of questions." Specialists say parents shouldn't jump to the conclusion that because their baby is continuously fussy, for example, he will be that way for years to come. "Research has shown that temperament doesn't substantially predict adjustment problems later in life," says Colorado's Plomin. "Of course, I don't know how comforting that may be when the parent is up with a crying baby for the umpteenth time at 2 a.m."

While suggestions for effective parenting are many and varied, pediatricians still fall back on the golden rules of raising children: Relax and be yourself. Tune in to your baby's world, and learn to adapt to his own particular rhythms. "We simply can't give a cookbook recipe as to what will work with each child, because the world just isn't made up of homogeneous children," says Chess. "And really, wouldn't it be boring if they were all just alike?"

TEST FOR TEMPERAMENT

Here is a very simplified version of the questionnaire Dr. Chess used to identify differences in temperament among babies. You might find it interesting and perhaps helpful as a *general* guide to help you figure out the kind of baby yours tends to be.

1. REGULARITY

Does your baby sleep and wake at approximately the same times (within half an hour) day after day? Does he get hungry and have bowel movements at fairly predictable times?

- A. Yes = Regular
- B. On the whole = Variable
- C. No = Irregular

2. MOOD

When awake, is he usually contented? Fussy or crying?

- A. Contented = Positive mood
- B. It varies = Midpoint
- C. Fussy or crying = Negative mood

3. INTENSITY OF EXPRESSION

When contented, does he smile and coo or giggle and vocalize lustily?
When discontented, does he fuss or bellow?

- A. Giggles lustily and bellows = High intensity
- B. In between = Moderate intensity
- C. Smiles and fusses = Low intensity

4. APPROACH/WITHDRAWAL

How does he react to new experiences: a different bed, new bathtub, first food, new foods, new people? Does he accept changes as though they were old stuff? Or does he resist the first time?

- A. Immediate acceptance = High approach
- B. It varies = Variable
- C. Immediate rejection = High withdrawal

5. ADAPTABILITY

If he tends to reject change (new experiences) on the first go-round, how long does it take him to adapt? A few repetitions or a few days? A long time or many repetitions (six to 12)?

- A. Short time and few repetitions = Quick to adapt
- B. Between = Moderate rate
- C. Long time, many repetitions = Slow adaptability

And the Answers Are...

If you answered "A" to all the questions (A or B to Question 3), your infant shows the traits of an "easy" baby—one who is usually in a good mood, enjoys attention, and is quick to adjust to new situations. If you answered "C" to all of the questions, your baby may be a "difficult" infant—that is, difficult to handle in daily routines.

Detecting a "slow-to-warm-up" infant isn't quite as simple, since this category is a mixed bag of temperamental traits. However, Chess says that as a rule "slow-to-warm-up" babies are generally in a sour mood (2-C), alternate between smiling and fussing (3-A or B), immediately reject anything new (4-C), and are slow to adapt (5-C).

Since these questions represent only a small part of the detailed questionnaire used for scientific temperament studies, you should not consider this sampling the final word on your baby's temperament. Chess also advises parents to remember that "each type of child has positive potential."

(Questions reprinted from the book *Daughters: From Infancy to Independence* by Stella Chess, M.D., and Jane Whitbread. Copyright 1978 by Stella Chess and Jane Whitbread. Published by Doubleday and Company Inc.)

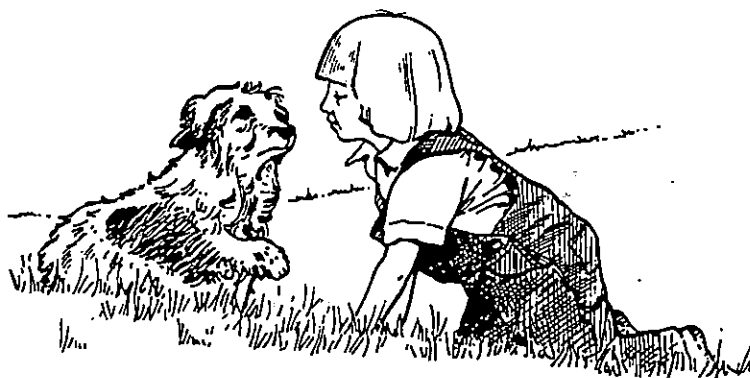
NATURE OR NURTURE?

Differences in temperament are in evidence from the first months of life, but what causes them? The question has been debated since the time of ancient Greece, when Hippocrates theorized that personality traits were caused by a balance of four bodily fluids. He reasoned that if a person had too much or too little phlegm, blood, black bile, or yellow bile, his temperament would reflect that imbalance. Even today, a chronically sad person is said to be melancholy, which literally means "black bile."

By the 17th century, the temperament-theory pendulum had swung from a physical basis (nature) to an environmental basis (nurture). English philosopher John Locke advocated the theory that each baby was a "tabula rasa," or blank slate, at birth, and that the day-to-day experiences of life were totally responsible for the child's personality. Locke's theory held firm even through the early decades of the 20th century, when John B. Watson, the father of behaviorism, said newborns were little more than squirming flesh. "Parents take this raw material and begin to fashion it to suit themselves," he wrote.

The trend of placing the blame (or credit) on the parents' doorstep continued with Sigmund Freud's psychoanalytical argument that the mother was at the root of a child's neuroses. Parents, he said, exert a decisive influence on a child's personality from infancy onward.

Locke, Watson, and others were in agreement on one basic building block of temperament: Environment was everything. They maintained that a child's personality was a direct result of the manner in which he was raised.



"But *clearly* there was something more to the story than environment," says Dr. Stella Chess, a specialist in infant temperament. "The most prominent theory in which I was trained was that the child was a 'blank slate' and what personality existed was molded by the parents. But I was a clinician—I saw dozens of children, and of course I observed my own children." It didn't take a very critical eye, says Chess, to discern that very different types of personalities were emerging in children of the same parents.

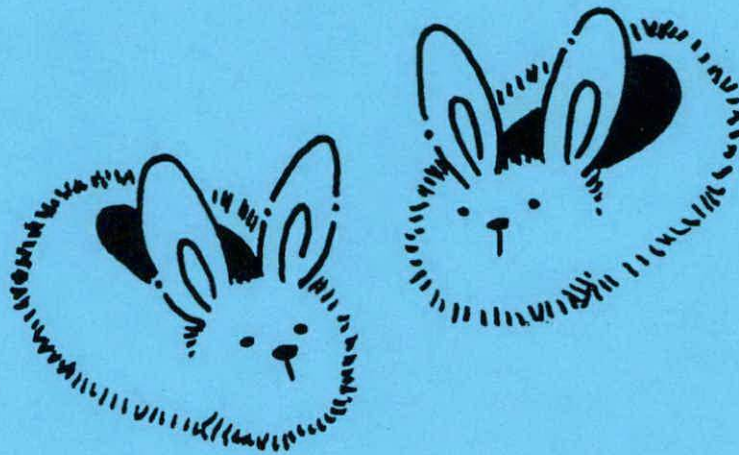
That revelation brought child-development researchers back to square one—is it nature or nurture that ultimately determines a child's temperament? "The prevalent thinking today is that it is a combination of the two," says Chess. "Now you don't find anyone asking, 'Is it a bad seed or bad environment?'"

But which, if either, has more influence on a baby's personality? Although temperament has been the subject of intensive research in recent years, specialists admit that they are a long way from a definitive answer. "Today if someone said, 'This is the truth about temperament,' I would raise my eyebrows and go in the other direction," says Chess.

Reprinted from: "Your Baby's Temperament" by Carol Byrd, Parenting Adviser, 1985.

Chapter 9

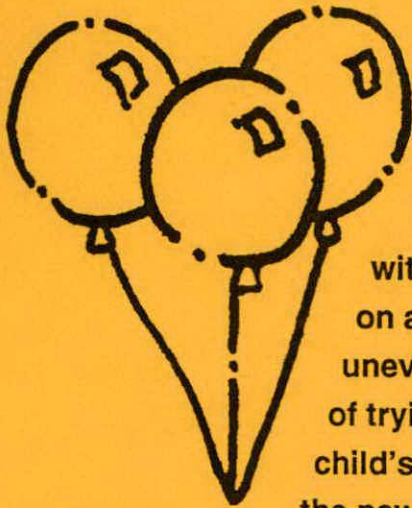
Behavior Guidance



MELD SPECIAL
Behavior Guidance

Behavior Guidance

Table of Contents	Pages
I. Introduction For Facilitators	3-11
A. Main Ideas	5
B. MELD Biases	6
C. Facilitator Focus	7
D. Group Issues and Tips	8-11
II. Content For Facilitators	13-49
A. Discipline and Special Needs Children	15-19
B. Discipline Must Suit Children's Growth and Development ...	20-22
C. Planning for Behavior Management	23-25
D. Various Behavior Management Techniques	26-39
E. Deciding on a Plan for Behavior Intervention	40-48
F. Conclusion	49
III. Resources for Parents and Chapter References	51-53
V. Learning Activities	55-65
VI. Handouts	a-e
A. Behavior Guidance Techniques	a
B. Questions and Answers about Behavior Guidance for Children with Special Needs	b
C. Family Values	c
D. Experiences with Conflict	d
E. Characteristics of Young Children	e



Introduction for Facilitators

What the child needs, if he is to become comfortable with mastering new experience is an ally who cheers him on and not an adversary. Parents who can recognize that unevenness of behavior in their young children is not a way of trying to win a battle against them but a reflection of the child's inner struggles with letting go of the old and mastering the new, are able to avoid battles with their children.

Helen Reid, M. S. W., "The Warm Line: A Telephone Counselling Service for Parents" in Pediatric Annuals.

In considering behavior guidance, parents will first of all wonder about what is "normal." "Normal" covers a wide range. Rather than telling parents what can be expected during each month, facilitators would be wise to emphasize the order in which development happens and to talk of behavior in relation to other developmental aspects, such as language and thinking.

MELD SPECIAL

Behavior Guidance

Parents also wonder what to “do” for their children’s growth and development. Other than good nourishment, appropriate clothing, and shelter, children need:

- opportunities to learn and practice new skills,
- safe and reasonably interesting environments,
- their parents tolerance of a fair amount of disorder,
- their parents’ patience when they are frustrated and their parents’ insight about when to help, when not to help, and how to help,
- their parents to be on their side instead of interpreting their accomplishments as ways of testing their parents,
- their parents to share their delight in themselves because of new skills,
- to feel that their parents like them just because of who they are.

This chapter is designed to help parents set limits for their children that reflect their needs to to protect their children’s well-being and to promote their children’s growth and development. It should also make clear to them the differences between discipline, guidance, and punishment and encourage them to develop problem-solving techniques to work out conflicts in behavior management. Discussing this process as a group can help parents see how universal their concerns are; parent groups provide an effective setting for airing the issues and inevitable frustrations of being a parent.



Main Ideas

- The children's efforts at independence are related to their growth and development.
- There are differences between discipline, guidance, and punishment.
- Rules may be different for each sibling in order to treat each child uniquely rather than identically.
- Using problem-solving techniques will help to work out the conflicts in behavior management.



MELD's Biases

- The purpose of behavior management is to teach children to manage as much as possible for themselves. Our bias is that independence is desirable, although not all cultures agree.
- Limits are good when they are used for the children's benefit and welfare. Using parental authority simply to prove that the parents are in charge leads eventually to power struggles.
- Discipline differs from punishment in important ways. Harsh physical or emotional punishment is undesirable. It teaches children they are bad people and leads to poor self-esteem.
- Like the role of discussion group facilitators, parents' role in children's development are to encourage, support, and provide opportunities.
- Parents who have good problem-solving skills can get through everyday conflicts with greater ease than parents who don't have those skills.
- Parents can be more objective if they recognize that their children's behavior is part of the children's development.
- Parents who understand various approaches to behavior guidance and who acknowledge that their personal values affect the behavior guidance techniques they use can be prepared and consistent. They don't have to be tossed around by their feelings and by what other people say to them.

Facilitator Focus

As you read this material and think about facilitating meetings on this topic, consider the following questions:

- What have you learned about letting your child deal with and learn from frustration, as opposed to providing for his or her every need?
- How have you learned to set limits?
- How have you resolved difficult situations and power struggles?
- Are you finding the support you need for yourself from your partner or from other adults? Can you discuss your child's more negative behavior and your own negative feelings with your partner or friends?
- Can you empathize with parents who have difficulty with their children's behavior?
- Have you received much advice and criticism from your own parents or friends about how to handle misbehavior? How do you react? Keep your reactions in mind as you watch the parents in your group react to this discussion.
- How have the special needs of your child affected your behavior guidance practices?

Group Issues and Tips

Behavior guidance discussions deal with sensitive issues and can be controversial. MELD Special groups have found this one of the most difficult topics to discuss, so be prepared for strong opinions. Remember that parents' decisions about discipline will have to reflect their own values; they may become defensive as they try to explain what those values are. Many parents may feel guilty for trying to guide the behavior of children with disabilities and chronic illnesses at all; some people think it's too much to ask children with special needs to honor behavioral limits.

Many MELD Special parents want specific ideas to solve their child's behavior problem; they do not want to talk about theories. If this happens for your group, you might use the section on behavior guidance techniques. Help the group talk about the techniques and, as they discuss, the facilitators can add definitions and background information about theories.

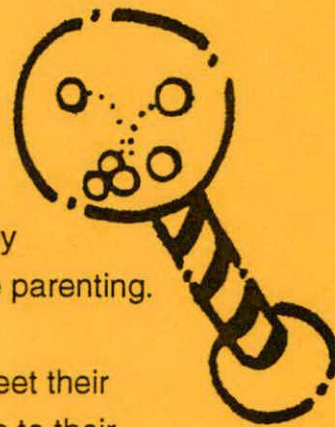
You may need to allow a great deal of time at the beginning of this discussion for parents to complain about what isn't working for them. They need time to vent their observations and feelings, and this venting is valuable for getting feelings on the table and helping parent verbalize their values and approaches. Later the discussion can focus on what techniques work, why they work, and how to guide behavior with consistency.

MELD SPECIAL

Behavior Guidance

Remember the special concerns of single parents.

- Single parents may feel guilty that they are not providing their children with two parents; hopefully they will discover that such guilt just interferes with positive parenting.
- Single parents may become exhausted by trying to meet their children's many demands and by trying to be all things to their children.
- Single parents may feel insecure because people they date or their extended family members may disagree with them about behavior guidance and may make comments that undermine their approaches with their children.
- Other people may attribute the misbehavior of the children of single parents to the fact that they have only one parent in the home; single parents will have to work through their feelings about those judgements.
- Single parents need a lot of ego strength to be able to set and maintain guidelines by themselves. Because they have no one in the home to share frustrations with, single parents may want to find supportive people who can reinforce their behavior guidance approaches and can give them a break from feeling like the only disciplinarian for their children. They can use parents support groups, classes on child-rearing, books, and other parents who are positive models.
- Single parents may appreciate noticing that one "advantage" they have is that their children cannot play one parent off the other.



MELD SPECIAL

Behavior Guidance

Special concerns of single parents, continued:

- They may also feel the advantage of not having to compromise their approach to behavior guidance or negotiate behavior guidance techniques with another adult.

Group discussion should acknowledge that parents are influenced by public opinion when they decide what kinds of behavior guidance to use. They may be more strict or more easy-going than they really want to be because of the way others view their actions.

There are too many ideas in this chapter to use in any one MELD Special session. Facilitators have to use their own discretion in selecting material that suits their group of parents.



MELD SPECIAL

Behavior Guidance

You will need to plan ahead for the resources you will need during these group sessions.



- You may want to review several books about behavior guidance and discipline; Without Spanking or Spoiling, Positive Discipline, and Your Child—Birth to Five are all useful.
- If you choose to play quiet music or use films or videotapes, preview your music, films, and tapes and check your audio or visual equipment ahead of time.
- Give any speakers you invite plenty of advance notice. Let them know ahead of time the questions your group is likely to ask about behavior guidance.
- Collect examples of observation recording to suggest various methods of “sampling” children’s behavior.
- Make a sample recipe of home-made playdough; make “Aggression Cookies” for a snack.
- When parents raise concerns about specific behavior guidance issues, make copies of the techniques that are appropriate to that concern.

Content for Facilitators

Many parents have difficulty expressing authority toward their children or setting limits. There is a tendency among parents to view love as a positive force, and authority, or discipline, as a negative one. Instead of communicating authority to their children directly, they do so apologetically or they beat around the bush or procrastinate with pleadings, reasoning, threats, and second chances, making all the more inevitable that which they are trying to avoid—the anger, the guilt, the resentment. . . . In the real world, love is no more important to a child's well-being than the consistent presence of authority figures. Love brings meaning to life, a reason to strive. Authority provides directions for striving. . . . In the absence of authority, love becomes over-indulgence. Without the tempering effect of love, authority becomes tyranny.

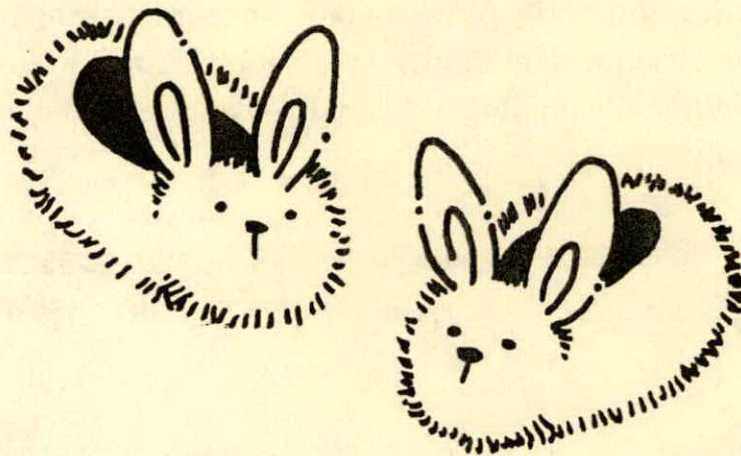
(From John Rosemond, Parent Power: A Common Sense Approach to Raising Your Children in the '80s. Charlotte, NC: East Woods Press, 1981)

Discussions about behavior guidance can become controversial and laden with guilt. Opinions vary widely about what appropriate behavior is and about when and how firmly limits should be set. One parent may believe in spanking any child who "talks back" while another may value the self-determination children learn by expressing their differing opinions to their parents.

MELD SPECIAL

Behavior Guidance

Because opinions about discipline can diverge so much and because some people seem to be sure their way is the only right way, thoughtful parents often feel that their public image undercuts their ability to guide their children's behavior effectively. For example, one MELD Special mother said that whenever she disciplined her son in public she feared that others would feel sorry for him in his wheelchair. Another mother worried that people would think she was too easy-going when they saw that her daughter was overactive. Because of other people's reactions, parents may become either more lenient or more strict than they want to be. It takes planning, encouragement, and perseverance for parents to come to wise decisions about discipline and then to trust those decisions and follow them consistently.



Discipline and Special Needs Children

In order to effectively direct their children's behavior, parents need to first consider the purposes of behavior management. This consideration is necessary whether the children have special needs or not. Because parents of special needs children sometimes feel additional conflict about limiting their children's behaviors, this consideration may be even more important to them than to other parents.

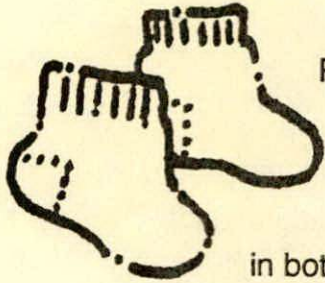
Discipline is the way in which parents guide and limit behavior so that children can learn to be responsible for themselves. The goal is for children to eventually govern their own behavior by their own internal self-discipline. Parents teach their children how to use their bodies to do things, how to handle their feelings, how to work, how to meet their own needs, and how to make sense out of being a man or a woman. They also teach their children about their behavior, about what is safe and unsafe, what is acceptable and what is not. Children learn to follow rules: first their parents', then society's, then finally their own. At early stages, they learn through imitation and because they want to please. Later their parents can use a variety of techniques to help them learn.

Punishment, Discipline, and Limits

Throughout the whole process of behavior management, parents need to remember that discipline is not the same as punishment. Punishment is a penalty that one person imposes on another because of a wrong that the first person thinks the second has done. Punishment can include criticism, scolding, beating, condemnation, blaming, depriving, spanking, yelling, and criticizing.

MELD SPECIAL

Behavior Guidance



Punishment is not a very effective way of managing behavior because it usually does not teach children to be responsible for their own behavior. It allows the adult to let off steam, but it leaves a feeling of emptiness, often in both the adult and the child. It focuses on what *not* to do instead of on what *to* do. The child who is punished is usually hurt, either physically or emotionally, and is made to feel guilty and like a bad person. Punishment puts the adult in the role of the accuser and the child in the role of the accused. Often discipline leaves feelings of hatred, anger, sadness, and revenge.

Discipline, on the other hand, occurs when the adults work with children to help them learn acceptable behavior. It offers the children the possibility of feeling better about themselves and gives them constructive solutions and alternatives. By labeling behavior as unacceptable instead of labeling children as bad, discipline builds a positive self-image, saying that all people are worthy human beings even when their behavior is not appreciated. Discipline structures the environment for children's safety and then fosters their independence by giving them the ability to direct their own behavior. Used well and consistently, discipline can lead to stronger love, to caring, and to happiness.

But how can parents be sure they are disciplining instead of punishing? Later in this chapter, specific examples of discipline techniques will be presented to give parents ideas about ways to discipline. But any kind of discipline can turn into negative punishment, especially when parents are very tired or angry or exasperated. Parents need to give themselves permission to be imperfect; they need to give themselves time to cool off and start over again. No one is perfect at disciplining another.

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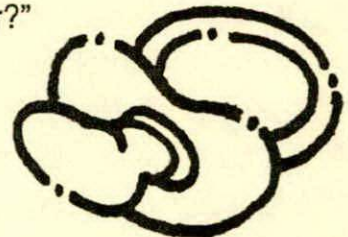
Behavior Guidance

It helps parents to keep in mind that consistent and loving behavior guidance tells children, "You are important people. You deserve love, attention, and guidance. We will give you that love, attention, and guidance." Unless parents accept the responsibility of limiting their children's behavior and using appropriate discipline when necessary, they are deserting their children.

Children realize that total freedom means danger; they find that when they get out of control they become anxious, so they appreciate limit-setting and discipline from their parents even if they may fight against it. Children who head toward a forbidden place while looking back with a gleam in their eyes at the parent who has said, "no," are looking to see if the limit will be maintained. Children cannot at first control their own actions and need to feel the security that someone outside of themselves will help them follow rules until they are able to follow them by themselves. Parents need to remember that they are the ones in charge even when their children have the louder voices.

Concerns of Parents of Special Needs Children

Parents of children with disabilities are often uncomfortable setting limits. Parents in MELD Special groups may say, "Yes, I want to guide my child's behavior but he can't *understand* why he shouldn't bite," or "When I say no, she goes into a terrible tantrum and cannot settle down and I fear she will get sick," or "We just want to get her healthy first, then we can discipline," or "How would you like to be unable to hear?"



MELD SPECIAL Behavior Guidance

Parents have varying reasons for fearing to discipline their special needs children. If they blame themselves for their children's problems, they may feel guilty when they take the upper hand and try to guide their children's behavior. Parents of children who are physically fragile may be afraid they will endanger their children's health by upsetting them with limits. Other parents may be afraid that their children will use their disabilities to manipulate them to gain sympathy and avoid limits. Most parents of special need children will wonder how they can find the patience for behavior guidance when they are tired and discouraged, when they need to start over again and again without seeing clear progress.

These discomforts are natural for parents of special needs children. However, they need to be alert to the possibility that they will be putting their children at an additional disadvantage by not teaching them appropriate behavior. Wanting to make life easier for their children, they may become overprotective and inhibit their children's development. If they feel guilty when they set limits, their children will notice their ambivalence and be less comfortable with the clarity of the guidelines. Parents need to talk about their conflicts in disciplining their children so that they can decide what they are comfortable doing and be able to stick to their decisions.

Behavior guidance is really about social learning. One mother said that one of her goals is to help her children become people she would enjoy living with and would choose as friends. This is not too lofty a goal for special needs children, but it is not always easy to attain. MELD Special parents sometimes want a magical way to mold their children's behavior, but they learn and are able to say in their groups that the process takes time. They realize that they need to sort out their personal values so they can be consistent and trust themselves.

MELD SPECIAL

Behavior Guidance

The techniques each parent chooses will differ from those of the other parents. When the child of one child development specialist is about to chew the leaves from a plant, the specialist picks up her child and says firmly but with love, "Hey, I love you too much to let you do that." A second specialist tries to distract her child by saying, "Plants aren't for eating, but if you want to chew on something you can chew on this rattle." For each child and each parent, the approach will be different.

Parents of special needs children will also find that they have to develop different approaches for their children with disabilities than they do for their non-disabled children. Sometimes this difference becomes a problem. They may under-discipline the child with special needs while over-disciplining the children without special needs, or they may try to force the special needs child to compensate for the disability by being perfect in other ways while they let their non-disabled children be more imperfect in behavior.

It helps parents to remember that each child is unique and that even children without special needs must have limits that are unique and appropriate to them. All children are developing emotionally, socially, intellectually, and physically, and they all need behavior guidance that is suited for their particular development stages as well as to their unique personalities. The techniques parents use will have to be different for children with severe mental retardation than they are for children with a limb deficiency but normal intellectual abilities. They will differ again from those for children without any language skills and from those for children with severe learning disabilities. The MELD Special discussion groups should help parents adapt methods to their own particular situations.

Discipline Must Suit Children's Growth and Development

To understand how to approach behavior guidance for children, parents need to think about the stages of development that their children are in. They must remember that development stage is not the same as chronological age and consider what behavior is expected at certain stages rather than at certain ages.

Children with disabilities and chronic illnesses go through the same social and emotional stages as other children, but for them the stages may last longer. In addition, they may experience extra doses of frustration because they cannot do what they see other children doing and what they want to do, so their misbehavior may be more fierce and last longer than that of other children. Parents need to match their behavior guidance techniques and behavior expectations to their children's developmental stages and expect some of those stages to last a long time. If they do that, they will be able to discipline a six year old who functions like a three year old as if the child actually were three instead of building up frustration by disciplining that child as a six year old.

One mother in a MELD Special group was concerned about constantly responding to her baby's cries. Another group member asked her what she would have done in that situation with any of her other children when they were at the same developmental stage. By thinking in terms of the stage of development instead of the age, the concerned mother was able to see what her child was working on and needed from her. She determined her method of response based on that information.

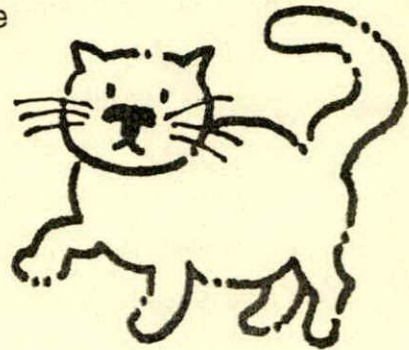
MELD SPECIAL

Behavior Guidance

Young children have a common set of characteristics. Parents need to recognize these traits and consider them as natural instead of seeing them as problems. Recognizing that all children behave this way, parents can use these traits to mold their behavior.

Young children, and children who are young developmentally, usually have these characteristics:

- They learn by exploring and experimenting with their senses.
- They have limited experience on which to base decisions.
- They are extremely curious.
- They have short memories.
- They need attention.
- They need to move almost all the time.
- They are easily distracted by themselves and others.
- They learn from the examples of others and from feedback they receive about their own behavior.
- They understand the feelings their parents express more easily than they understand the words they hear.
- They understand the meanings of words before they can use the words themselves.
- They cannot understand long or complicated explanations.
- They go through a phase of being afraid of strangers and a phase of being afraid of being left by their primary caretakers.
- They go through a phase of saying "no" a lot when they begin to be aware of themselves as separate individuals.



MELD SPECIAL

Behavior Guidance

Taking those as the natural behaviors of young children, what are parents trying to encourage through their behavior guidance? It may help MELD Special groups to consider the characteristics that people who are successful later in life had in common when they were about three. Special needs children who reach the developmental age of about three need to have these characteristics encouraged:

- They need to be able to get and keep the attention of adults.
- They need to go to adults for help and support.
- They need to show their feelings to adults—whether those feelings are angry or affectionate.
- They can be either followers or leaders when they are playing with peers.
- They need to be able to show affection and anger to peers.
- They need to be able to compete.
- They need to feel and express pride in themselves and their accomplishments.
- They need to pretend and act out roles; this play helps them know how other people feel.
- They need to understand what people say to them and to make others understand them.
- They need to anticipate consequences.
- They need to be able to notice when things aren't quite right, when the people around them are out of harmony.
- They need to make interesting associations.
- They need to plan and carry out activities that require several steps.
- They need to be inventive in their use of materials.
- They need to be able to pay attention to several things at once.

These are the developmental needs of young children. Other behaviors should be limited only in so far as they inhibit these behaviors, endanger the children, or make life too unpleasant for people around the children.

Planning for Behavior Management

Frequent outburst of uncooperative behavior are typical for young children. They were also typical for the parents of those children when the parents were young. Parents who consider their own childhoods and remember how they were disciplined are better able to decide if they want to continue those same methods with their children or to change them. If parents do not consciously think about the ways they were disciplined, they will usually act in the same ways as their parents did even if they don't intend to.

Most people who are adults now were taught by their parents that disagreement was not okay and that they should do what their parents said even if it was unreasonable. But, of course, conflict is a natural part of family life and disagreement is part of healthy living. Only if people give themselves permission to accept disagreement as inevitable, even as healthy, will they be able to develop tools to deal constructively with discipline and disagreement. To do this, adults may have to change the messages they learned from their parents and modify the ways they deal with power and authority.

Parents do well to consider how they were taught to deal with disagreement and whether those messages from childhood continue to influence their dealings with disagreements as adults. They need to consider whether their methods are productive and in what ways they could be improved. Several of the learning activities included later in this chapter help parents reflect on the values they hold and what those values say about their expectations for their children's behavior.

MELD SPECIAL

Behavior Guidance

There is no one right path to behavior guidance. It doesn't seem that variations in child-rearing practices are directly related to later behavior problems. Just the same, children may be vulnerable to particular discipline practices at certain stages of their lives. During the very early years, when children are learning to be independent, authoritarian discipline may be more harmful than at other times. In later years, when children are learning to make adjustments and be independent outside the home, permissiveness may be more harmful because children may think that their parents do not care enough to help them make the transition from home to the larger world.

Behavior guidance works best, however, if there is not conflict among the primary caretakers of the children about that guidance. In any family there is the potential for conflict when there is disagreement about acceptable behavior or about appropriate behavior guidance techniques. But it is often not easy to achieve agreement about behavior and guidance techniques among parents.

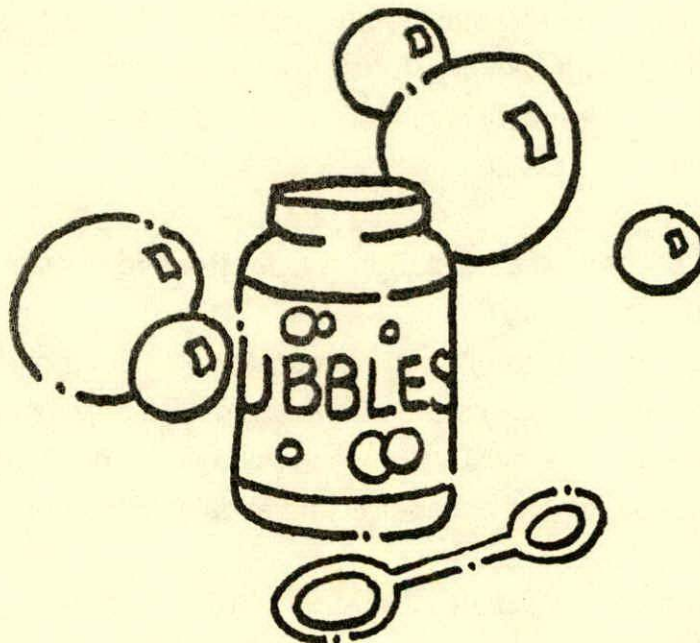
Partners can think critically and creatively as they consider alternatives. They can communicate with each other as clearly as possible and recognize what has created their current opinions. Then they can choose the alternatives that best fit their circumstances and act as consistently as possible based on those alternatives. Strong families have achieved a high degree of unity with common values and goals. These families can differentiate their values from those of others, such as grandparents, relatives, and friends, who have different beliefs from the parents. The parents can stand by their choices without guilt and confusion because of the different opinions of others.

MELD SPECIAL

Behavior Guidance

The parents are the ones who can best judge the causes and implications of their children's behavior. They are the ones who can best decide on the appropriate methods of discipline.

Parents must also recognize their own needs and consider those needs when they determine which methods of discipline to use. If parents choose methods that put too much strain on them, they will begin to be frustrated and angry. When they are angry, almost any approach they use becomes ineffective. They need to give themselves permission to take time away from their children and to pick methods of discipline that make sense to them, even if those methods don't make sense to grandparents or neighbors or friends.



Various Behavior Management Techniques

There are several behavior management techniques that all parents can consider using.

- **They can ignore inappropriate behavior.**
If parents deliberately ignore misbehavior that can be tolerated—if it is not endangering the child or other people—then the behavior often goes away. Children do not usually continue behavior that receives no attention.

- **They can reward or reinforce appropriate behavior.**
Parents can catch their children being good. They can tell their children what pleases them and at times reward it with praise or a small present (like a glitter star or a gum drop or a toy car). Children want very much to please their parents, so reinforcement usually works well.

- **They can remove their children from the scene or involve them in some other activity.**
Often children can be distracted into doing another activity that is okay. Parents can also remove them from objects and situations that are too tempting. They can put away things that shouldn't be touched and lock cupboards that shouldn't be opened.

- **They can verbally distract their children.**
With words, parents can sometimes redirect their children's attention to something that is okay for them to do. Again, they can remove their children from tempting situations and objects and place them among objects that interest them suitably.

MELD SPECIAL
Behavior Guidance

- **They can say “no.”**

Parents can explain the limits they set in a few simple words and then enforce them. They can emphasize the behaviors they want to see and simply say “no” to other behaviors. Several cautions about using “no” are explained later in this chapter.

- **They can remove their children for brief periods of time from the group or activity.**

Before children lose control completely, parents can take them to another room or to a special corner or chair to give them a chance to cool off. This may help the children save face by allowing them to remain in control of their behavior. However, the time away should be limited to about one minute for each year of the child’s age. Parents need to consider other cautions when using “time out”; these are described more fully later in the chapter.

- **They can move closer to their children or hold them to help calm them.**

Young children are often calmed by having an adult nearby. Sometimes all that a misbehaving child needs in order to regain control is a sudden hug.

- **They can show interest in the children’s activity.**

A child who is about to use a toy in a destructive way is sometimes easily stopped by an adult who expresses interest in playing with or looking at the toy with the child.

MELD SPECIAL

Behavior Guidance

- **They can ease the tension by non-sarcastic kidding.**
Sometimes kidding children who are about to burst into angry, destructive behavior can give the children a break in their emotion and allow them to express themselves appropriately. Parents must be sensitive, however, to children who don't yet recognize the difference between positive kidding and negative teasing.

Whichever actions parents choose, it is wise if they don't wait too long to respond to problem behavior and if when they respond they use as few words as possible. Children learn from their parents' behavior much more than they learn from their parents' words.

Suggestions for Specific Behavior-Change Goals

Some concerns are common to almost all parents. The following list makes suggestions for ways to encourage specific desired behaviors.

To help children express emotions—

Parents can teach children to use words or symbols to express their emotions instead of acting them out by hitting, grabbing, or spitting. Children can learn to say, "Mad!" or "Me now" or "Stop it. I don't like being hit." Parents can help them focus their comments on the actions that they don't like instead of on the person who does the action. Sometimes children's emotions come under control simply by being expressed.

Children with disabilities often need to be given brief phrases instead of long sentences. If they don't have words to use, they can be taught to sign. They can use facial expressions, foot stomping, or actual sign language.

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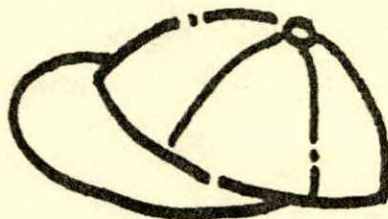
Behavior Guidance

To help children learn to share—

It's not reasonable to expect young children to share naturally. Very young children aren't intellectually or emotionally capable of putting themselves in another's place on a regular, predictable basis. Also, children might become confused about the difference between "sharing" and "giving away." Another way to communicate the idea of sharing might be to call it "taking turns." Children will then get the idea that eventually, they can use the item again. Adults can model sharing behavior themselves and talk about what they are doing; children cannot understand sharing unless they are shared with. Adults can also express spontaneous appreciation when the children, in turn, share with the adults.

To help children control their tantrums—

Young children frequently exhibit temper tantrums. They have little power and few words to express themselves, so tantrums are one of their few options for asserting themselves, for feeling separate and powerful. Most of their behavior is extreme—they do not have the ability to make polite responses. Parents do want their children to express their feelings; they do well to remember that children who are throwing tantrums are doing just that.



MELD SPECIAL
Behavior Guidance

To help children control their tantrums, continued—

All the same, children need to learn that tantrums are not effective ways of expressing themselves. It is best not to let children get their way just because they are having tantrums. Parents can remain calm (even when the tantrum happens in a public place), make sure that the children cannot hurt themselves, and try to distract the children with something else as soon as the tantrum slows down. It is best not to draw attention to tantrums. Parents can instead give their children words to use to express the same feelings as they were trying to express with the tantrums.

As language develops, tantrums typically subside or become more manageable. For language-delayed children, the state of temper tantrums may be prolonged. But even then it helps parents to remember that their children are probably more cooperative with other people. Only their parents are dependable enough to throw tantrums around; they are sure of their parents' love and so can experiment with a greater range of behavior around them.

To help children control their aggression—

Aggressive behavior is sometimes the only way young children know to get what they want. Their worlds necessarily revolve around themselves and their needs. But as they grow older they need to learn to get into the shoes of other people and respect the feelings and needs of the others as well as their own.

MELD SPECIAL
Behavior Guidance

To help children control their aggression, continued—

When children hurt other people, it is important to react clearly. Parents can comfort the children who are hurt as well as the aggressors. They can tell the aggressors clearly that it is not okay to hurt others. They can be serious and stern without yelling. They can say, "What you did hurt Timmy. Look at his eyes. He's crying because it hurt him. It's not okay to hurt people." To be more brief, parents could say, "No hitting. Touch gently." Parents can also let the children know that if they continue to hurt their playmates, they won't be able to play with their friends for awhile. The adults can actually remove the children from the play situation and repeat, "No hitting."

Young children often respond with physical aggression when frustration and anger have built up inside them. Parents need to watch their children to see when their tolerance is becoming low. If they are becoming angry and frustrated, the parents can step in, distract the children, and help them deal with their feelings in acceptable ways before it explodes.

If parents slap or spank aggressive children, they are likely to become more aggressive because they will be copying their parents' behavior. If parents force young children to apologize before the children are old enough to really understand how another person feels, the children may learn to say "I'm sorry" to manipulate their way back into favor. The children may simply be learning to become hypocritical.

MELD SPECIAL

Behavior Guidance

To help children lengthen their attention spans—

All young children have short attention spans. Sometimes parents appreciate this characteristic. It allows them to distract their children from harmful or unacceptable behavior.

Just the same, parents can be frustrated by children who get bored and want to get away from diaper changing or eating. They can try many tactics to make the activities more interesting to their children. They can flop down on the floor and start to do themselves what they want their children to do. They can bring something different out of a surprise bag and interest their children in an activity that is new for the day. They can try giving their children undivided attention; getting complete attention help children attend to any activity longer. They can let the children decide which activity to do next.

To help children accept change—

Young children thrive on routine. They like feeling comfortable that they know what will happen next. If parents develop a basic routine with plenty of rituals around the things that are done exactly the same way every day, their children will be more likely to accept changes in between those reliable activities. If parents do the same caregiving actions in the same order during times of dressing, eating, and going to bed, their children will accommodate more easily to those activities and be more ready to accept other activities.

MELD SPECIAL
Behavior Guidance

The Meaning of "No"

Parents usually expect their children to understand what they mean when they say "no" and to stop whatever activity the parents are trying to control. But children do not learn the meaning of "no" very quickly and they don't always respect the word when they do understand it. On top of that, almost before they learn to obey "no," the children learn to use it themselves. This is often not the outcome the parents were hoping for!

Parents will do better with the word "no" if they pay attention to when it might really work for them to use it. Until children have learned to pay attention to differences in their parents' tones of voice and facial expressions, they probably can't understand what "no" means. They will come to understand it more clearly if their parents get them to look into their parents' faces as they say "no" and if their parents keep their voices calm and firm and use actions, like removing them from the dangerous situation, when they say it. It works better if parents save "no" for situations of clear-cut danger. Then they can say "no, hot" as they move their children away from the stove. If they say, "No digging in the garden," they do well to add, "Digging is okay in the sandbox." Alternatives make "no" easier to accept.

Children with special needs will take longer to learn "no." When they stop for a moment, look at the adult who is saying "no," and then continue the behavior, they are beginning to learn what the word means. They are starting make a connection between stopping the behavior and the word "no." Parents need to just keep trying. But when their children continue their unwanted behavior after their parents have said "no" four times, the parents need to try distracting them and continue teaching them about "no" on the next occasion.

MELD SPECIAL

Behavior Guidance

As soon as they understand what “no” means, children will probably begin using the word themselves. They may mutter “no, no, no” as they approach unsafe situations like a hot stove. In saying that, the children are taking their parents’ rules into themselves and learning about impulse control. They may say “no” quite firmly whenever they dislike an action or activity their parents propose to them, like going to sleep or eating supper. They need this word to give them a sense of control over their own lives, to allow them to say clearly what they want. “No” is one way that children tell their parents that they understand that they are separate people, that there are differences between themselves and their parents.

Parents may understand better what children mean by saying “no” if they try to put themselves into their children’s positions. They can imagine trying to communicate with gestures, babbling, and acting out, trying hard to make themselves understood. They can imagine the feeling of wanting action, of wanting some control. If they say “no” they may not be wanting a big power struggle; they may just want to feel effective. Saying “no” can mean many things—

“I want to do it myself in my own way.”

“I don’t want to give it to you now.”

“It’s mine.”

“Don’t give me so much.”

“It’s too hot.”

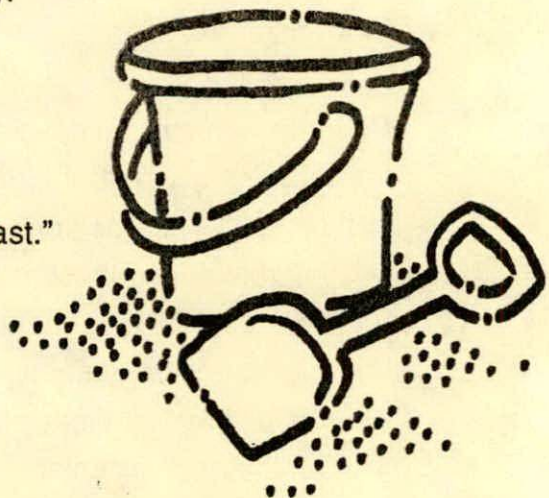
“It’s too hard for me to go so far so fast.”

“Let me try it once.”

“It’s all gone.”

“Something’s missing.”

and even—“Yes.”



MELD SPECIAL

Behavior Guidance

The Meaning of "Don't"

Usually if a child who has just hit his mother is told "Don't hit Mommy," he will hit his mother again. It seems that when children are told "Don't to this," they almost always do it.

Researchers have tried to figure out why this is. It may be that being told not to do something requires the child to imagine doing that action and then it requires the child to decide not to do what has just been imagined. That may be too many steps for young children. They end up stopping at the first imagining and they do what they were told not to do.

The best plan for parents may be to avoid saying "don't." Instead they can tell children what is okay to do. They can say, "Tell Mommy you are angry," or "Let's throw stones at that piece of wood," instead of "Don't throw any more stones at Mommy." They can distract their children or use any other behavior techniques, but they may be happiest if they don't say "don't."

Using "Time Out"

Many children respond well to appropriately-used times out. When they are sent apart from the group or activity that they are no longer handling well, they are often able to get themselves together and rejoin the group or activity with more appropriate behavior. For older children, times out can be less structured; one MELD Special mother suggested to her daughter that she go to the other room to calm down when she was "owly" and the girl learned to use times away to focus herself.

MELD SPECIAL

Behavior Guidance

But there can be dangers in using "time out." The practice emphasizes conformity and sometimes parents neglect to help their children understand the purpose of the time away. It is an authoritarian solution to problems and may reduce exploration and initiative; especially if times out are given without warning, they may cause children to avoid new situations. Children may begin to think of themselves badly for being made to take time out; they may be hurt when they do not know any alternatives to the behavior for which they are being sent away. Some children may become anxious in the presence of an identified "time out" chair even when that chair is not in use, and when they are given a time out they may be timid about returning to the group at all. On the other hand, some children actually like to take time out and may act inappropriately in an attempt to get their caregivers to give them a "time out."

These dangers can be reduced if parents follow some general guidelines for using "time out." Time out should be reserved to serious misbehavior such as intentional destruction and then the time out should be used immediately after the misbehavior occurs. It is also well used as a prevention to teach children to take time away to slow down and think things over or distract themselves. For young children, time out should be about one minute for each year of age. Children should not be humiliated before or during their time out, they should not be put in a place without supervision, and they should not be talked to during the time out. It may be best not to use the child's room for time out because then the room may become identified with punishment; instead some other dull but safe and unfrightening place should be chosen. As soon as the time out is over, the adult should return to the child and explain what alternative acceptable behaviors could be used and then help the child re-enter the group or activity. The adult should make an extra effort to notice and reward good behavior after the time out has been used. Finally, time out should be used in a consistent, not a sporadic, fashion and it should be coupled with lots of praise for appropriate behavior.

MELD SPECIAL
Behavior Guidance

Positive Behavior Guidance

The book by Adele Faber and Elaine Mazlish called How to Talk So Kids Will Listen and Listen So Kids Will Talk has many excellent ideas for behavior management. Among them are these.

To encourage positive action and self-esteem, parents can describe what has happened instead of evaluating—

First, parents can describe what they see: "I see that all the towels are picked up."

Then they can describe what they feel: "It's a pleasure for me to come into this room."

Finally, they can sum up their children's praiseworthy effort with by using one descriptive word: "You sorted out all the colored disks and put them on separate spindles. That's what I call organization."

To engage children's cooperation—

First parents can describe what they see: "There are wet towels in the bathroom," or "It's time for bed."

Then they can give information: "The towels will get moldy when they are all scrunched up," or "We go to bed at night."

They can also remind with one brief phrase: "The towel," or "To bed."

They can describe what they feel: "I don't like moldy towels," or "We need our rest."

Finally, they can write notes or make charts: "Please put me back so I can dry. Thanks!" or "John went to bed" followed by a gold star.

MELD SPECIAL

Behavior Guidance

To respond to negative behavior without punishment—

Parents can express their feelings strongly without attacking the child's character: "I'm mad. The dog food spilled."

They can then state their expectations: "Dog food stays in the dish."

They can show the child how to make amends: "Put the food back in the dish. Here's the dustpan. I'll sweep." And then take the child's hand, put it on the food and guide the child in putting the food back in the dish.

They can give the child a choice: "Dog food in the dish or the dog stays outside."

Finally, they can take action: if the dog food is spilled again, they can put the dog outside.

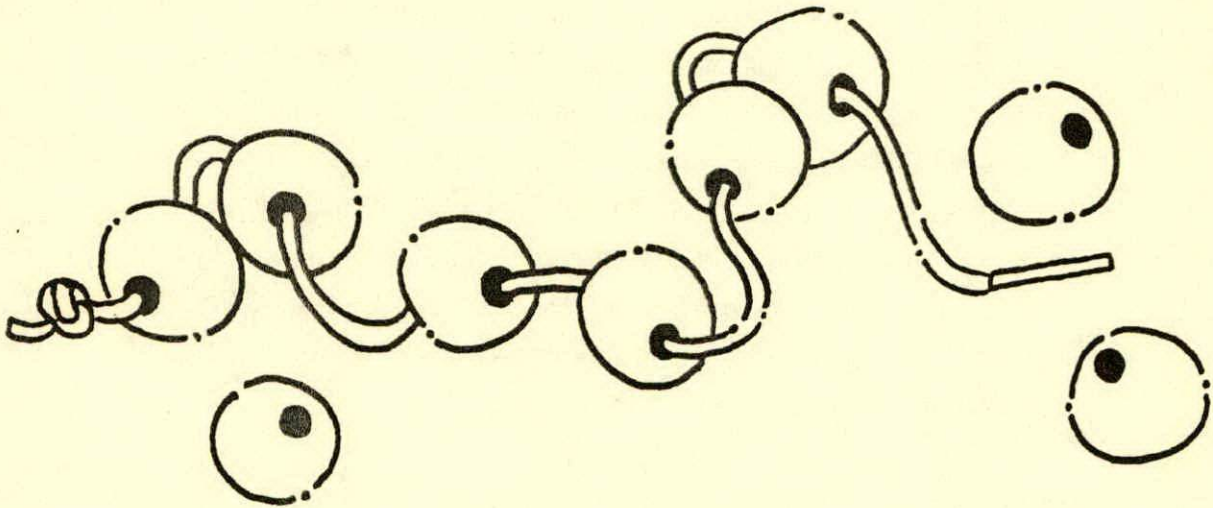
Behavior Modification

Advocates of behavior modification believe that all behavior is learned, so negative behavior can be un-learned and replaced with new learned positive behavior. They say that the only behavior a person can change is their own, so that if they want their children to change, parents have to change their own actions first. They must learn to consistently reinforce the desired behavior as soon as possible after it happens.

Behavior modification is a systematic, highly structured approach to altering behavior. It can be used to strengthen, weaken, or maintain certain behaviors. But because behavior modification programs are often quite complicated, parents may want to develop them in consultation with the professionals who are working with them and their children.

MELD SPECIAL
Behavior Guidance

Parents can start with some basic understandings of the process. They need first to pinpoint the behavior they want to encourage and then record it and how often it happens. Any behavioral rule that the parents decide to encourage should be short, positive, and easy to remember. The rule should also be enforceable. Then the parents need to start reinforcing that behavior when it occurs and evaluate their progress as they go. If the child's behavior does not change, the parents have to think about what they have been doing and try another approach. Throughout the process, they need to be sure to work on only one behavior at a time and remember that they are changing the behavior, not the child.



Deciding on a Plan for Behavior Intervention

The ideas given so far in this chapter should offer parents possibilities for dealing with their children's behavior. But they still need to evaluate their individual situations and come up with plans that will work for them. Parents need to go through a three step process to develop a behavior intervention plan. They must first assess the situation, then decide what behavior they want to encourage and how they will encourage it, and finally they must consistently use their plan.

Assessing the Situation

When parents encounter behavior in their children that they don't like, they need to collect as much information as they can about that behavior. Parents' observations of the behavior are often improved if they write down when the behavior appears, how often it appears, and under what circumstances it appears. Parents need to decide exactly what the problem behavior is and how severe it is. Sometimes when they begin to write down the actual occurrences of the problem, parents notice that it is not as bad as it seemed to be. In any case, careful observation gives them good material for deciding what to do.

Parents also need to notice what other people's reactions to the behavior are. What have they been accustomed to do when the behavior comes up? What do their children's siblings, playmates, and other caretakers do? How does the child act before and after the behavior?

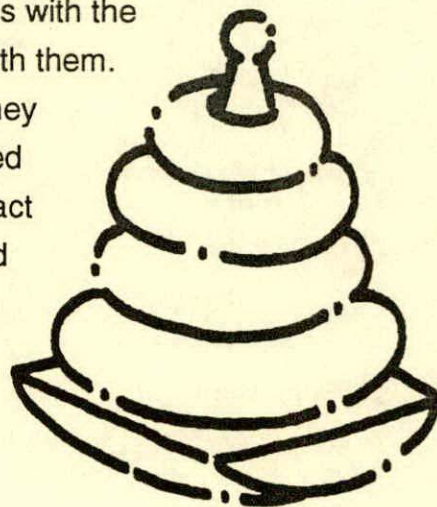
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Behavior Guidance

These observations will help parents consider various possible causes of the behavior. Do the children feel incompetent and unsuccessful even when they are using appropriate behavior? If so, could the problem behavior be a reaction to stress and low self-esteem? Do the children use the behaviors when they become frustrated, overstimulated, or angry? Sometimes behaviors are caused by special needs conditions resulting in, for example, headaches, anger about limitations, or specific developmental delays. Sometimes they are caused by medications or triggered by changes in scheduling or routines or by upsetting events in the children's lives.

The environments children are in can contribute to behavior difficulties. Parents need to consider space arrangements and materials and equipment they use with the children. Do the children need more space? Would adaptive equipment reduce their frustration? If the times for naps or meals were changed, would the behavior change?

Parents need to also examine their interactions with the children and the interactions of other adults with them. Sometimes children only get attention when they misbehave. One MELD Special mother noticed that the only time she gave her child eye contact was when she was scolding the child; the child had a good reason to misbehave as often as possible. If parents can find ways of giving them attention for positive behavior, the negative behavior may decrease.

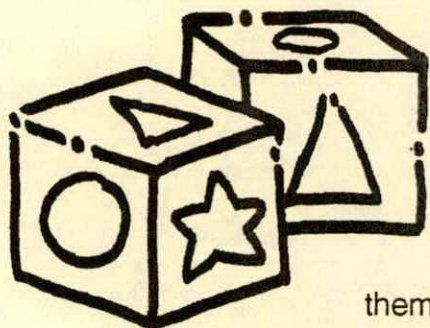


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Behavior Guidance

Another important consideration is whether the behavior is a normal part of a developmental stage. Sometimes what parents think are problems are simply natural, necessary process that children must go through. If parents are clear about child development, they will be less likely to mistake necessary development for behavior problems. Sometimes the behavior arises simply because the children do not yet have skills to act in other ways; then parents can consider fostering further development and nurturing new skills instead of seeing the behavior as a problem in itself. Sometimes children just do not have the cognitive reasoning ability to notice that what they are doing is unacceptable to the people around them.

Whatever the causes, parents do well to observe the behaviors carefully and consider many possible causes for it. If they do this evaluation step carefully, they will be more successful when it comes to decided what behaviors they want to encourage and how they are going to encourage them.



Planning for Behavior Change

Once they have carefully assessed the situation, parents can decide what they want their children to learn and what behavior they want to encourage in their children. When they have clearly stated to

themselves what behaviors they are going to encourage, they must ask themselves if their expectations are realistic.

Rules should be limited as much as possible. Children appreciate the security of rules that are reasonable, clear, and simple, but too many rules will only make life difficult for both the parents and the children.

MELD SPECIAL

Behavior Guidance

Each time they determine a rule or a behavior they want to enforce, parents must ask themselves whether the rule is necessary for the safety of the child, other people, or property and whether it is a rule that can be reasonably well enforced. It should also be important for the long-term goals the parents have for their children. If, on the other hand, the rule is only for the convenience of adults, if it restricts the children from trying new activities, or if it is appropriate for a developmental stage the children have already passed, then the parents need to think seriously about abandoning the rule altogether.

Parents do need to make limits and set rules that support their own mental health. The time for them to set limits is probably when they feel pushed by their children, but parents have to determine individually what that point is. The right time to set limits will be affected by the parents' individual feelings, temperaments, values, and abilities to be flexible.

Once parents have decided that limits really must be set and that the behaviors they want to encourage are reasonable, they must decide how they will support those behaviors. They should remember of course, that harsh, physical punishment will have mainly negative consequences and does not teach positive behavior. Instead parents can choose from among the suggestions offered in this chapter or from other ideas that they come up with themselves. They can consider the advice of their friends, of other parents in the MELD Special group, of their pediatrician or professional helpers. They can think about what has worked with their children in the past and if the developmental stage of the children has changed so that new approaches must be tried.

MELD SPECIAL

Behavior Guidance

Parents need to consider what they will use to reinforce the behavior they want to encourage. Primary reinforcers could be actions like giving the children a piece of special food or a drink of juice or they could be allowing the children to choose a game or other activity they want to do.

Secondary reinforcers are more abstract. They include giving the children stickers on charts, verbal praise, hugs, pats on the shoulder, or being asked to sit close to their parents. (The provision of basic needs like food and clothing should, of course, never depend on children's behavior.)

Parents should consider the responses that are most natural to be behaviors their children are exhibiting. For example, when children throw their toys away, they could have those toys removed. They will learn that when they throw things away, those things are gone. When children hit people, those people can go away from the children for a short time; that way the children learn that people don't like being around people who hit them. With practice, parents can learn to select responses that really make sense.

Children do not benefit from playing one parent off another if the parents do not agree on appropriate behavior or if they have greatly differing responses to problem behavior. Parents who have differences of opinion about behavior management should try to work out those differences. If parents can work out their conflicts about behavior, they will be modeling healthy ways for their children to work through conflicts. No family or other group is free of conflict; one of the best lessons parents can give their children is the lesson that it is okay to have conflict and that it is possible to resolve that conflict.

MELD SPECIAL

Behavior Guidance

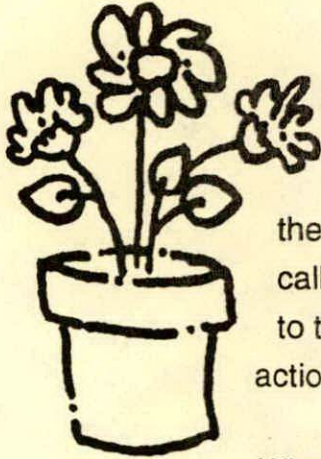
Instead of using verbal or physical abuse when they have conflicts and instead of ignoring the conflicts, parents can use basic problem solving techniques. They can first identify the problem (both the behavior of the child that they are considering and the behaviors in other that they disagree with). To do this, they need to be specific and thorough. Then they can identify each person's needs in the problem. They need to consider each of their own needs, the needs of each of their children, and the needs of any other people who may be involved. Next, they can list all the possible solutions, even if some of them are crazy. At this point no one should criticize the solutions that are offered. When as many solutions as possible have been listed, the parents can pick out several of them that are acceptable and choose the one that comes closest to meeting each person's needs and respecting each person's values. Then they can make a plan for carrying out that solution. It is important that they agree to stick with the one solution until a time that they set to evaluate it. At that time, they can change the plan if it seems best to change it.

Following the Plan

Once the plan is made parents need to set about using it consistently. They need to explain to their children as much about the plan as the children can comfortably understand. It is very important that children know what they are expected to do and what will happen both if they do that and if they do not.

At first, children should be given very simple reasons for the behavior change, but they cannot be expected to change their behavior because of the reasons. Their first reason for changing their behavior will be to please their parents. Later the reasons they have been given may make sense to them and they will begin to act because of the reasons; at this stage they will be learning self-control.

MELD SPECIAL
Behavior Guidance



Parents whose responses to behavior are consistent and predictable are more effective in behavior management. They need to plan what they will do and then do it as often as humanly possible when the situation calling for the plan arises. If they respond only occasionally to the behavior, the children may increase the unwanted actions instead of decreasing them.

When parents respond to their children's actions, they need to consider their tones of voice, their postures, and their facial expressions as well as the words they use. Children pick up on non-verbal meaning more quickly than they pick up on words. If parents say "no" with the same tone and expressions that they use when they say "yes," their children will not be able to tell the difference between the two meanings. In addition, if parents expect their children to learn a behavior, they must model that behavior themselves. Parents who hit their children when they say, "No hitting," will be giving their children a nonsense message. The children will learn to hit from being hit more than they will learn not to hit from being told not to hit.

Parents need to praise their children's success. They can say, "You really wanted to hit John, but you didn't. That shows you know how to handle your anger. You told him that you wanted your toy back instead." If parents always respond positively to the behaviors they want their children to continue, they will most likely succeed in their behavior management plans. Children will always continue to do what gets them the most attention.

MELD SPECIAL

Behavior Guidance

Parents need to be prepared to repeat their behavior guidance often. Young children have short attention spans and short memories, but they do learn if the lesson is repeated often and consistently. Above that, parents should not see continued behavior problems as a contest between them and their children. They need, instead, to be their children's allies and help the children learn the lessons they need to learn by standing with them in the learning, not opposing them as rulers. When parents react personally to behavior difficulties, they create an obstacle to dealing with the situation effectively.

Parents can give their children choices whenever the children are able to deal with them and whenever either option is truly acceptable to the parents. Having choices helps children learn that they can control their own behavior and living situations and that they must learn to live with the results of their own decisions. It is best to give only a few choices—"You can eat an apple or an orange now. Which one do you want?" Having too many options to choose among confuses children.

Finally, children need to be respected for their rights and abilities throughout the behavior guidance process. If they are respected themselves, children will learn to respect others. Respect will help children learn that it is more pleasant to make others feel good than it is to make others feel bad, and it will encourage them to take control of their own actions. One important aspect of respect is to let children know that it is okay for them to make mistakes. They will not always do what their parents want them to do, but they are still loveable people and they can try again the next time or correct the mistake this time.

MELD SPECIAL

Behavior Guidance

After parents have tried a particular behavior management plan for a period of time, they need to evaluate its effectiveness. Three or four weeks is a good amount of time to give to one method of discipline. If parents spend less time trying a technique, they may not get any positive results; often when a behavior change process is first started, the unwanted behavior actually increases before it begins to change. Sometimes a technique works on one day and not on another. Sometimes it works with one child and not with another.

Each child is unique. If a method is not working with a particular child, the parents can try to figure out what the technique is telling that child. A parent who has decided to show displeasure whenever the child spills milk may be teaching the child any of a number of things—that it's okay to be angry when something unpleasant happens, that the child is clumsy or bad, that the child must be more careful, that spilling makes the parent mad. The parent must evaluate what message the child seems to be getting from the child's reactions, and then adapt the method to give the child the message the parent means to give.

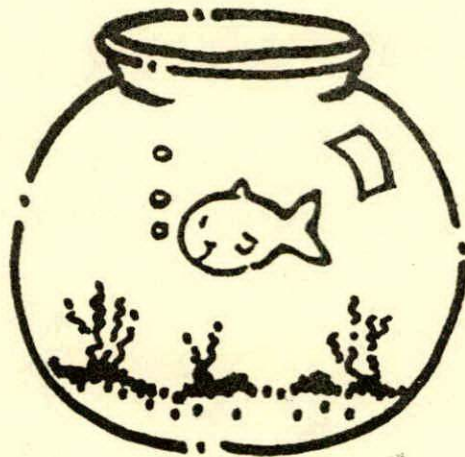
Parents can always think back through the options they considered when they set up their behavior management plan and select a different one to try next. They can use their children's reactions to the first plan as information to help them select their next option. They can also ask for help from a behavioral pediatrician, an early childhood special education teacher, or a school psychologist. It may help them to remember that they will have to change their methods of behavior guidance as their children grow and progress through later stages of development.

Conclusion

Whenever parents face problem behavior, they can first take a deep breath. Then they can ask themselves who's in charge. Are they in charge, or is some other adult, or is the child. If they are in charge, they can decide what to do. They can remember the goals they have set and the behavioral plans they have decided on, and then they can follow those plans. They don't need to be taken off guard and lose their cool.

If parents find their plans aren't working, they can change them. They can also get support from friends, from other MELD Special parents, and from members of their children's treatment teams.

No one is perfect. Parents need to give themselves permission to make mistakes. Then they need to give themselves permission to apologize to their children. After that, they can always try again.



MELD SPECIAL
Behavior Guidance

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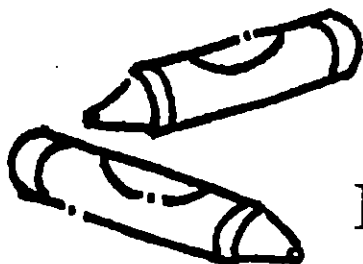
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MELD SPECIAL
Behavior Guidance

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Learning Activities

Set the mood by playing quiet music on the radio or audio cassette player as the group members arrive.

Get acquainted by having each parent share briefly about rules that their children must follow and various methods of discipline that have been effective for them.

Have parents share ideas about these questions:

What behavior guidance techniques have worked for them and why?

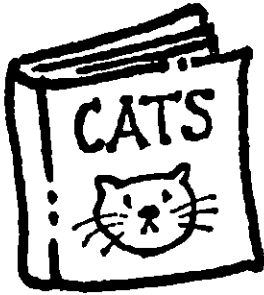
How did they feel about using those techniques?

What behavior guidance techniques have *not* worked for them and why?

How did they feel about using those techniques?

(You may want to save the last two questions for a later meeting.)

MELD SPECIAL
Behavior Guidance



Invite a speaker or panel of professionals and other parents of children with special needs. Consider inviting a behavioral pediatrician, a school psychologist who works with children with special needs, or an early childhood special education teacher. The speaker or panel might address the following questions:

- How does a parent decide when to intervene in behavior guidance issues and when to stay out of them?
- What can parents do about extreme behaviors, such as when children have tantrums that will hurt them or when they bite someone and break the skin?
- Can a parent overprotect a child?
- What can parents do to discipline children who cannot respond to adult directions at all?
- What happens to children who finally stand up for themselves when another child grabs a toy and then are punished for that?
- What are the best uses of time out?
- In which situations does behavior modification help?
- What can parents do who feel they have unsuccessfully tried everything?

Have the parents discuss various behavior guidance techniques.

Select several major behavior guidance problems and then use the section on techniques for discussion. Have parents examine the options and decide which would fit for their children. Ask them what principles each option are based on and which fit their own values.

MELD SPECIAL
Behavior Guidance

Organize mini-lectures by dividing the material up between two or three of the parent group facilitators and having each talk to the group of those topics. Allow time for discussion and questions. If there are questions the facilitators can't answer, make notes of the questions. find the answers before the next meeting, and report back to the group then.

CHILDREN'S EFFORTS AT INDEPENDENCE ARE RELATED TO THEIR GROWTH AND DEVELOPMENT. CHILDREN CAN INDEED UNDERSTAND EXPECTATIONS ABOUT THEIR BEHAVIOR IF THOSE EXPECTATIONS ARE RELATED TO THEIR STAGE OF GROWTH AND DEVELOPMENT.

Show a film or video about young children's development. During discussion, help parents consider what is typical in their conflicts with their children and what is due to the children's special needs. Possible films would be those in the series on "Conflicts Between Parents and Children," prepared under the supervision of the editors of Parents' Magazine. They emphasize methods that allow both the parents and the children to feel satisfied and happy as the children begin to learn the valuable lessons of successful behavior and self-confidence. They are available on a first come-first served basis for Minnesota residents from the Minnesota Curriculum Service Center, 3554 White Bear Ave., White Bear Lake, MN 55110. In the metro area the phone number is 612-77 0-3942; outside the metro area, call toll-free 800-652-9024. Titles include: "Daily Disagreements: Toileting Troubles, Dressing Disputes, Bathing Battles, Bedtime Bickering, Mealtime Misunderstandings" and "Parents Expect. . . Children Want: Desires and Demands, Learning the Rules, Helping at Home, Watching Television, Playing alone."

MELD SPECIAL
Behavior Guidance

Encourage discussion of the following questions in either large or small groups:

- How can parents get their children to cooperate when they ask them to do things? Why do they tend to refuse?
- When do have the parents felt most extremely angry at their children? Why does the anger come from and why is it so strong? How can parents take it less personally when, for example, their 2-year-old won't listen to them?
- Do parents tend to use different forms of discipline or punishment when they are extremely angry at their children?

**DISCIPLINE AND GUIDANCE DIFFER FROM PUNISHMENT.
PARENTS CAN REMEMBER HOW THEY WERE DISCIPLINED
AS CHILDREN IN ORDER TO CLARIFY THE ATTITUDES AND
BELIEFS THAT UNDERLY THEIR IDEAS ABOUT GUIDANCE.**

In small groups, have parents share some of the "tapes" from their own childhood experience that they still carry around in their heads. Have the groups consider these questions:

- What were the rules like in each of their families as they were growing up? What was off limits and what was permitted? What happened when limits were exceeded? What different ways do group members having rules enforced?
- From the experiences as children, what ideas about rules and limit-setting would group members like to enforce with their children? What would they do the same as their parents and what would they do differently?

MELD SPECIAL

Behavior Guidance

Have parents share with their partners or another parents what they learned from these questions. If partners find huge differences in their expectations, they may want to learn more about skills for resolving differences between parents. You may want to devote an entire meeting to problem-solving communication strategies.

Have parents complete the worksheet on "Our Family Values." Have them mark the statements that express their family values and then name one way their family shows that value. Encourage them to talk with their partners or with another supportive adult about their differences in values. Have them consider ways to demonstrate their values more concretely or consistently and about the support they will need to act on their values.

Have the parents complete the worksheet on "Our Experiences with Conflict." They can check the messages about disagreement that are similar to those they received as children.

Show the videotape "Spare the Rod" from the Footsteps (#8, Baltimore: University Park Press/Public Broadcasting Service, color, 30 minutes). In the tape various members of the Marshall family are used to exemplify different attitudes toward discipline and to indicate the effects that discipline has had on them. The tape shows that the goal of good child discipline is self-discipline not fear.

Stimulate discussion in either large or small groups. Have the groups consider why behavior guidance is such a difficult issue. Then encourage them to talk about whether they and their partners agree on what limits to set for their children and on how to enforce those limits.

MELD SPECIAL
Behavior Guidance

**DISCIPLINE OR BEHAVIOR GUIDANCE IS A MATTER OF CONFLICT
RESOLUTION. THIS IS AN OPPORTUNITY FOR GROWTH FOR
CHILDREN AND PARENTS.**



Encourage parents to discuss with their partners or in small groups:

- A behavior guidance problem they have been experiencing.
- How the behavior may be related to the “typical” development issues of young children or how it may be related to the child’s disability.
- Ways they have been handling the problem ineffectively or destructively.

Then have the group together brainstorm alternative ways to handle the various situations. The parents can each consider which methods they would like to try.

Talk about how observational recording of problem behavior will help parents understand how and why misbehavior occurs. Observations recording is an especially useful technique when parents and professionals disagree. However, parents of children with special needs are often under so much stress that talking about collecting information just makes them feel worse; evaluate the situation of your group before deciding whether to use this activity.

MELD SPECIAL

Behavior Guidance

Several ways to collect information for observations recording include:

- Anecdotal records—accounts of everything that is done to, with, for, by, or around the children. These records help parents identify the patterns of children's problems. Parents may learn that the behaviors happens only in certain situations or at certain times of the day or that every time the behavior occurs there is a positive reward for the children.
- Event recording—writing down the number of times a particular behavior happens during a specific time period. This helps parents understand the magnitude of the problem; sometimes what parents think is a problem really doesn't happen very much.
- Duration recording—writing the amount of time that a particular behavior lasts. The length of a temper tantrum, for example, may be more important than the number of tantrums.
- Interval recording—writing down the frequency and duration of a behavior. At the end of each timed interval, for instance each 30 seconds, the parents could write down whether or not that particular behavior is still happening.
- Time sampling—choosing a length of time, such as 10 minutes, and writing down whether or not that particular behavior is happening at the end of each of those lengths of time.

MELD SPECIAL Behavior Guidance

RULES MAY BE DIFFERENT FOR EACH SIBLING IN ORDER TO TREAT EACH CHILD UNIQUELY RATHER THAN IDENTICALLY.

Encourage discussion to help parents look at some of the differences between behavior management for children with special needs and for non-disabled children.

- How have the parents disciplined non-disabled children that they think would be inappropriate for their special needs children?
- What do these special needs children do when they check out their limits? How do the parents respond? Do they respond differently than to their non-disabled children when they check out limits? How do their partners respond?
- Do the parents have any special rules for their special needs children that they do not enforce for their non-disabled children?
- Are the differences in how the special needs children are treated due to their special needs or due to their unique personalities? Are there differences in how parents with several non-disabled children set and enforce limits for those children?

Lead the parents to imagine being their own children. Have them consider what their children think and feel and what kinds of limits would make their children feel safe and cherished.

Ask parents to think about what their notion of an ideal schedule for a 24-hour period with their children would be. Then have them think about what actually happens when they try to follow that ideal schedule. Let them brainstorm ideas that would make the ideal schedule more realistic or that would allow it to actually be what happens.

MELD SPECIAL

Behavior Guidance

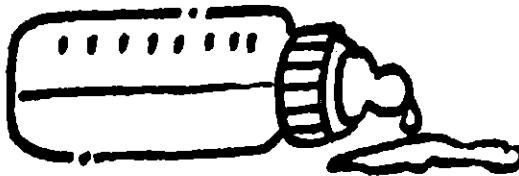
Ask group members to respond to the statement: spanking teaches a children violence and sets a bad example. What other opinions do group members have? Help them admit and consider their own and others' opinions about spanking.

Talk about the value of consistency in behavior guidance. Discuss techniques that parents have found they could use consistently in their behavior guidance.

Explain problem-solving techniques that could help parents work out conflicts over behavior management.

Have the parents consider—

- The safety limits (for water temperature, car safety, poison-proofing, crib safety, prevention of falling) they have set in their homes.
- What they would do if they differed with what professionals told them were good limits to set for their children.
- What areas of behavior they try to limit—eating, throwing, bedtime, safety, public displays.
- What the main types of conflict they have with their children, what their usual methods of responding are, and if they can think of other methods of response.



MELD SPECIAL
Behavior Guidance

Divide parents into small groups to discuss the ways they can resolve differences in styles of behavior guidance. They can use the following situation to stimulate discussion.

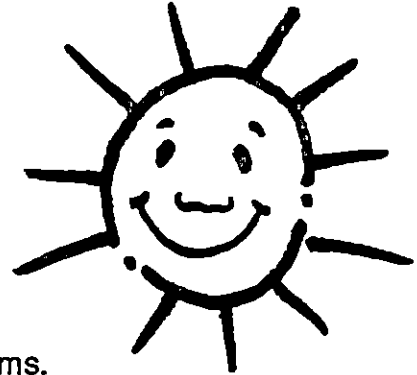
Pam and Tom are seated at the dinner table with a group of their cousins. Pam has seated their daughter, Sue, a child with special needs, at the children's table nearby. Tom feels it is not appropriate for Sue to be seated at the children's table because she is unable to behave in an acceptable manner under these circumstances. Tom draws Pam aside to discuss this.

- What are some ways Tom and Pam could use to resolve this difference?
- Is this a typical disagreement that parents have about their children's behavior management?
- What other types of disagreements do parents often have?
- How can parents determine what behavior they can realistically expect from their children?
- What difference does knowledge about a child's development level play in disagreements?
- What influences any parent's attitude about appropriate behavior in children? How do their own personalities and family backgrounds influence them?
- When parents know what their children's behavior problems tend to be, how can they structure situations to limit those problems?
- How can parents educate others (like grandparents, friends, or babysitters) or deal with the behavior of their children in the same way they do?

MELD SPECIAL

Behavior Guidance

Set up an open forum about resources parents can use in developing behavior guidance techniques. Let them share experiences about children with particular disabilities, such as decreased mobility, visual impairment, speech delays, or hearing impairment. Encourage them to share ideas about techniques, books, community agencies, and programs.



Homework: During the week, ask parents to observe what behavior guidance situations arise in their families. They can consider these questions:

- What do their children do that causes them to discipline them?
- Why do their children do those things?
- What did the parents do to discipline?
- What was their children's reaction?
- Why does it seem they reacted that way?
- What do they think their children learned from the experiences?
- How do the parents feel about the discipline experiences?
- What did the parents learn about handling their children?

Have parents write a journal entry describing a behavior that is a problem for them and their children. They can consider what development in the children might be causing the behaviors and what alternatives they have for dealing with the behaviors.



Chapter 9

Handouts

**Behavior
Guidance**

BEHAVIOR GUIDANCE TECHNIQUES

Often, parents are seeking answers for behavior problems in their children. With this need in mind, we are offering some general suggestions for responding to behavior problems. Please keep in mind that these are not THE ANSWERS. We prefer to think of them as ideas to get you thinking about what your options are and what you might want to do. You are the one who knows yourself and your child the best.

Please note: Never shake your child. Shaking is especially dangerous for young children because it could cause brain damage.

Contents:	Pages:
Bad language and name-calling	2-3
Bedtime	4-5
Biting	6-8
Crying	9-10
Disruptive and destructive behavior	11-12
Ignoring work to be done	13-14
Jealousy	15-16
Lying	17
Mealtimes	18-19
Misbehavior in public	20-21
Safety issues	22-23
Screaming and whining	24-25
Self-injurious behavior	26-27
Temper tantrums	28-30
Toilet learning	31-32

Bad Language and Name-calling

George was upset with his older brother, John. Once again, John had taken away the toy he was using. George screamed at John, "Gimme the truck, you dumb ____." George's father immediately began to lecture him about not using such language. When George realized that not only had he lost his toy, but he was in trouble for his words, he sat glumly and looked angrily at John.

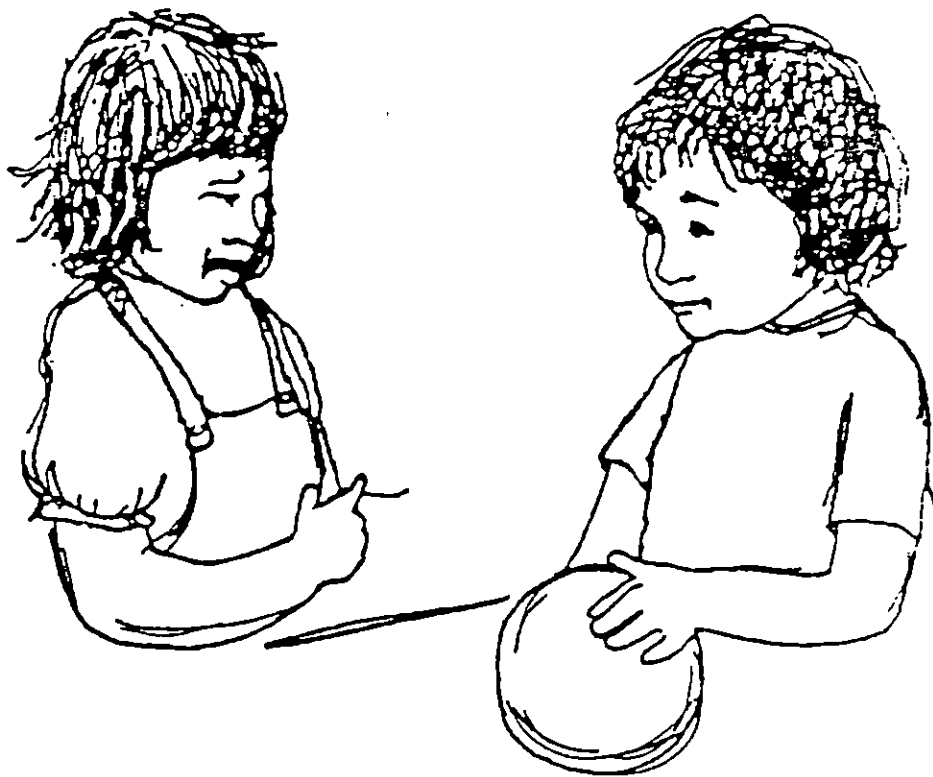
Parents don't need to lecture to express their disapproval. When they disapprove, their children can understand their feelings better through their face and body language than through their words. Instead of being told that they should not use the language they have used, they need to be shown other ways of responding that will get them what they want. If bad language "works" better than anything else, they will probably keep using it.

Here are some strategies you can try:

1. Tell your child, "Instead of using bad words, say, 'I want my truck back.'"
2. To replace "bad" language, teach your child some other words: "I'll teach you some big words. Try 'That's atrocious,' 'gobbledegook,' 'fun de doodle.'"
3. For name-calling: "She likes to be called by her right name, which is _____. You can make up names for your stuffed animal."
4. Make a game of releasing pent-up feelings by creating foolish sayings together. . . until you start laughing.
5. Ignore the language if you possibly can. Calling attention to undesirable behavior just reinforces it.
6. Redirect your child to an acceptable, quiet activity.
7. Explain results instead of using threats. "He doesn't like it when you call him names. If you do that, he won't want to play with you."
8. Tell your child exactly what is acceptable. "Aaron, please don't yell at your friends. Go over to them and use your quiet voice."
9. Be sure that you're a good model. Call your child's attention to others who show acceptable behavior. "John is letting us know he is angry with good words." Try not to compare them directly.
10. Avoid challenges. If you dare a child to use bad language, she will most likely take you up on it.
11. If you feel you must threaten, be sure you can carry out your threats. Idle threats weaken your position.

Questions to think about:

1. When does bad language tend to happen?
2. What is your first reaction? Do you immediately display shock and attention?
3. How does your child respond to your usual reaction?
4. Is your child overtired?
5. Are you a model of positive language?



Bedtime

Young children will continually test the limits we set to be sure that the limits do not change. There is security in knowing what to expect. One of the most regular events in a child's day is bedtime.

Establishing a sleeping pattern early is important for the child's development and for family life.

An example:

For three weeks, whenever two-year-old Mary's parents put her to bed, she started wailing. Her father went in to give her a drink and try to comfort her. When he left, the wails started again. Her mother picked her up and tried to walk with her. Mary quieted down immediately and was all smiles. Her mother felt annoyed, but was not up to putting her back in bed and listening to that wailing again. Neither parent wanted to put Mary back in bed and shut the door while she cried. For almost two hours, they waited for Mary to become tired enough to fall asleep. As she got more and more tired, she got more wound up and cried even more. Finally, Mary's parents put her back in bed. Fortunately, she soon cried herself to sleep.

Strategies to try:

1. Give your child advance notice. Talk to her as you are going to start getting ready for bedtime. "After we finish this game, it will be time for your bath."
2. Establish a bedtime ritual. Children thrive on the expected routine. Here are some elements of a bedtime ritual: regular time, 5-minute warning, bath, brush teeth, look at a book, sing a song, one last drink of water. Even for children who are non-verbal, these signals will help them calm down and realize that it is indeed bedtime.
3. Don't "overtalk." Be specific and give clear directions. You can sympathize with your child's feelings without giving in.
4. Give your child lots of praise for following the routine you've established.
5. Don't take "no" too seriously. Think of something that your child likes about bedtime. "You'll be able to cuddle Bo-Bo."
6. Accept security objects (blanket, thumb, toys, pacifiers). Young children need them for comfort when they are confronted with separateness and dependency, especially when in a strange place.
7. Avoid giving false choices.
8. Start winding down about 1 or 2 hours before bedtime. Keep the evening routine quiet.

9. Do NOT put your child to bed with a bottle. Milk sugars can pool in the child's mouth and cause dental cavities. Juice or water can trickle into the child's middle ear and cause ear infections.
10. Put your child in his bed while he is still awake, so he can learn to put himself to sleep.

Some questions to think about:

1. Has your child ever had a regular bedtime routine and the upset is a new stage?
2. Are any stress factors present (e.g. fever, cries for more than 3 hours, death in the family, severe anger or intolerance by some family member)?
3. Have you tried a regular bedtime routine for at least 3 weeks?



Biting

Infants usually have a strong urge to put everything in their mouths. Their mouth is the primary way in which they learn about themselves, their parents, and the world. People, too, are new objects that must be tested and tried by young children to see how they taste! Biting provides infants with comfort and opportunities to learn. But it can get youngsters into trouble when they try it on other people or animals!

Children bite people for many other reasons. It will help if parents can try to think of the many possible reasons that children bite others and then try solutions based on the specific reason that a specific child is biting. For children who repeatedly bite, it will help to keep observational records about the situations in which biting occurs.

1. Children may not yet be in control of their walking, running, bowel movements or speech. Sometimes the finger of another child can really "just happen" to get between a child's teeth.
2. Toddlers want to be separate from adults and have power over their environment. This is a normal development. Biting gives children power over other people.
3. Biting is part of exploring the world. The child seeks to taste toys, food, and people.
4. Teething can cause a child's mouth to hurt. Children need something or someone to gnaw on to comfort them.
5. Toddlers are just beginning to learn how to interact with others. They may express their interest in biting, pulling hair, pushing them over. They do not yet understand that they hurt others when they bite them.
6. Young children start to learn about cause and effect when they bite others. They find out the answer to "What will happen if I bite Josh?"
7. Sometimes babies bite in imitation of other children who have bitten them or who they have observed biting other things or people.
8. Research has shown that children who are physically punished are more likely to be aggressive with younger, smaller peers. They learn that hitting and biting others is an acceptable way to handle their anger.
9. Toddlers may bite others to get attention. When an adult gives lots of negative attention for a child's biting behavior, the child may experience that as positive attention, because *any* attention is *positive* attention to that child.
10. Youngsters might have feelings of anger and frustration at adults, at other children, or at their particular disability or illness.

11. Young children may experience "generalized anxiety" about events happening in their lives, such as parents' fighting, separation from loved ones, disabilities, hospitalization, etc. Anxiety may cause a child to bite to relieve tension, just as adults chew gum or overeat.

It is interesting to note that biting may actually be a sign of growth in high-risk or socially-withdrawn children who have not interacted with other children. Harsh treatment for these children may actually cause them to withdraw even more.

An example:

Almost before anyone could have intervened, 20-month-old Terry had bitten Josh again. Terry's mother was quite embarrassed and thought maybe she should bite Terry to show him how it felt.

Strategies to try:

1. Take the child's hand and say, "Touch gently; that makes him feel so happy. I know you like Josh, but I can't let you chew on him. You can give him a toy."
2. Ease a child's separation from parents by saying, "You're feeling sad that Daddy has to leave. It's hard to say goodbye. Daddy will come back after snack."
3. Give toys to the child for hanging on and letting go, such as blocks to drop into a bucket.
4. Don't pressure your child for toilet training.
5. Allow as many situations as possible when the toddler can choose and have power.
6. Let your child have long periods of time to explore in a relaxed manner.
7. Provide a variety of sensory experiences: water play, playdough, sand box, and a variety of toys that can be chewed on.
8. Give the teething child mouth toys, frozen bagels, and chewy food.
9. Reward positive interaction, such as one child hugging another, offering a toy, or smiling.
10. Provide toys that do something when the child acts on it. For example, when a button is pushed, a figure pops up.
11. Model loving, sharing, positive behavior.
12. Model words for the child to use: "I see that you are feeling very angry at Josh. He took your toy and that made you feel angry. You can say, 'mad!', when you feel angry."

13. A brief time-out may help the angry child calm down and avoid biting.
14. Overwhelm the child who seeks attention with positive, warm, nurturing attention.
15. Help the child learn to say, "NO!" to another child who grabs a toy.
16. Provide calming activities for children who have high anxiety.
17. Allow your child to suck a thumb or hold transitional objects, such as blankets or stuffed animals, to calm herself down.
18. Help the biting victim. Place ice packs on the bite. If possible, have the biter assist the victim.
19. Remember, when adults bite children for biting others, the child is learning that biting is okay if you are bigger and stronger than the other person.
20. If punishment for biting is too severe, the biter will nurse his own frustration and anger rather than helping the victim and learning positive ways to handle emotions.

Questions to think about:

1. When and where does biting tend to happen?
2. What is your first reaction? Do you immediately punish?
3. How does your child respond to your usual reaction?
4. Who else is involved in your child's biting?
5. Is your child overtired? hungry?
6. Does your child spend the whole day with people? Does she have time alone?
7. Is your child picking up tension from other family members?
8. What might be your child's reason for biting?

Crying

Parents want to let their children know that they care about them, so they respond to their child's cries and try to soothe them. For parents to understand why children cry and to anticipate their responses to the stress of children crying is important. Crying which is not understood and is prolonged can trigger even abusive behavior for parents. It helps to have ideas of how to cope and how to let out frustration.

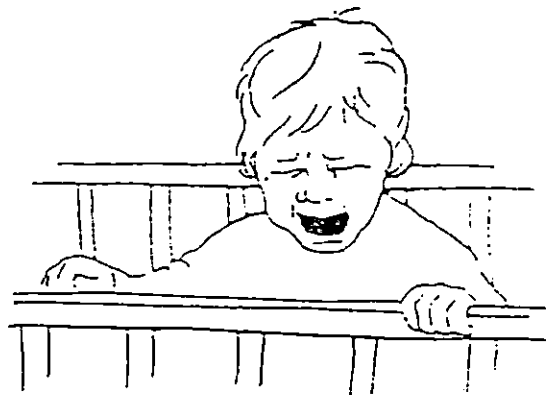
Prompt and regular attention to a child's crying builds the child's trust in people and the world. Usually, parents can put aside worries about "spoiling" the child. When a child gets the care he needs, usually crying for unknown reasons declines. Most children who are readily comforted actually cry less.

Strategies to try:

1. Use substitutions and distractions immediately. Tell your child what she can do, not what she cannot do. Find objects that catch light or are bright colored. Turn on some quiet music.
2. Tell others (and yourself), "It's okay for Jenny to be over there by herself. Don't worry about it. Sometimes people need to be alone for a few minutes to feel their feelings."
3. Control your child's level of stimulation by slowing down the activity or introducing a quiet activity.
4. See ideas for handling temper tantrums.
5. Respond positively to your child's attempts to communicate in order to build self-confidence.
6. Tell others, "Don't call Joey a baby. He feels unhappy. He is not a baby."
7. Tell your child, "Try to cry a little more softly. Your loud crying is hard for the other people. Here is a tissue."
8. Check for the basics: dry and warm? over- or under-dressed? in sun or cold draught? hungry? tummy ache? pinched? scrunched in an uncomfortable position?
9. Try a back rub or a bath.
10. Try some sort of motion: rocking chair, carriage or stroller, automatic swing, car ride, walk with a backpack.

Questions to think about:

1. Are naps, meals, and bedtimes on a regular or irregular schedule?
2. When does crying tend to happen?
3. What is your first reaction? Do you immediately give in?
4. How does your child respond to your usual reaction?
5. Who else gets involved in your child's crying?
6. Is your child overtired? hungry?
7. Does your child spend the whole day with people? Does he have time alone?
8. Is your child picking up tension from other family members?
9. Is your child sensitive to touch or does she need more touch?



Disruptive and Destructive Behavior

Young children need to have things to do and acceptable places to be disruptive. Sometimes their disruptive outbursts are because they miss these opportunities.

Young children also need to go at their own pace sometimes. Their disruptions might be due to the frustration of having to go at an adult's pace all the time.

An example:

Krista had been screaming and kicking since she was an infant. Because she seemed to cry continually, her mother had pointed this out to several doctors. Her parents had tried changes in feeding, medication, letting her cry, playing with her. As she reached her fourth birthday, she became intense and demanding. When she played around other children, Krista was often caught biting and hitting. She seemed to always be disrupting the situation with running, throwing, climbing, falling down, slamming doors, and kicking.

Strategies to try:

1. Allow your child to play with calming art materials, such as playdough, or with water, which may be soothing.
2. Hold your child until he regains his composure. "I'll hold you until you feel better, and then we will work this out together."
3. Accept your child's need for sameness and repetition. Have a predictable order for your activities.
4. Try to divert your child into more interesting activities.
5. Give your child an "out." "You can stop throwing sand, or I'll carry you out of the sandbox."
6. Set definite limits and use short directions. "Color on this paper. Walls are not for coloring on."
7. Redirect your child into quiet, directed activity. "Please don't climb on the tables. Feet belong on the floor. Do you want a helping hand to get down?"
8. Before a transition that might result in disruptive behavior, give several reminders that the activity will be changing.
9. Control your child's level of stimulation by slowing down the activity.
10. Don't expect extended times of sitting still from a mobile child.
11. Move yourself closer to your child when she is misbehaving. Possibly, without saying or doing anything, your child will calm down.

12. Remove your child from difficult situations when he cannot cooperate or when he cannot use something correctly or safely.
13. Encourage your child to express her feelings with words or gestures rather than actions.
14. Tell your child, "Don't hit Alan and hurt him. Tell us. Use the words you know. It's all right to feel angry, but you cannot hurt other people or throw things"; or "Gently, please. There's lots of room for you. You don't need to push."
15. Tell your child, "Children won't want to play with you when you knock their block buildings down. Let's pick the blocks up and help rebuild the tower. You can build something of your own. I'll watch you build."
16. Tell your child, "People don't like grabbing. Ask him and then listen to his answer. Let's go find something else for you. I'll go with you."
17. Remove objects that children find they want to throw.
18. Don't force children to apologize. Apologizing requires that the child be able to take the other's point of view. Very young children are simply not able to do this cognitively.
19. Do NOT be dishonest with the child and say, "David didn't mean to hurt you," but say instead, "David didn't know how much that would hurt you."
20. Do NOT make your child feel guilty by saying, "Only bad girls do things like that." Try to accept the child although you might not condone the behavior.
21. Provide other alternatives for your child to work off anger.
22. Use closeness and touching. Young children may be calmed by having an adult nearby.
23. Try making Aggression Cookies.
24. Let children know exactly what behavior is acceptable. "Sand hurts people's eyes. Keep sand in the box. We throw a ball."
25. Play soft music.
26. Get a complete physical and psychological evaluation of your child.

Questions to think about:

1. Are naps, meals, and bedtimes at regularly scheduled times?
2. Does your child spend the whole day moving from place to place?
3. Are the activities your child participates in appropriate for her developmental level or are they frustrating her?
4. Does your child spend the whole day with people? Does he have time to be alone?

Ignoring Work to Be Done

It's realistic to develop some kinds of "chores" for your child to perform in order to contribute to family life. Such tasks, when appropriate to their level of ability, will improve their self-image. They will feel productive, helpful, needed in the family setting. But just like most children, your child will probably ignore the work that is to be done.

Keep in mind that long, involved lists of directions are too hard for young children to handle. They can more often understand plain and straightforward language, especially if the words relate to objects.

Usually in parent-child power struggles, the child eventually wins. Several strategies help us avoid power struggles with our children.

Use face-saving techniques, including distraction, substitution, and giving your child an "out." Avoid ultimatums. When children don't want to cooperate, we can sympathize. Yet parents should remember that children cannot always have their own way. Others, including parents, are important, too. When you phrase an activity as "Let's do. . .," you can do most of the work without losing face.

An example:

Mike's mother was trying to help him get involved in putting his toys away on the shelves. She told Mike (3 years old) to pick up his room before lunch. Fifteen minutes later, when she checked on Mike, she found her son sitting in the corner rolling a ball.

Some strategies to try:

1. Children work best with short-range goals. So make the work quick and easy to do. "Put blocks in the bucket."
2. Reinforce your child with praise as soon as possible.
3. Structure the work so that the desired behavior is obvious.
4. Have an activity that your child doesn't like so much just before an activity that she does like. For example, "Let's get your bath done, and then we can make popcorn."

5. Express your request in a positive way. This will provoke a more positive response from your child, and it will help your child to learn more acceptable ways of expressing requests. "I noticed that you didn't put your toy on the shelf, Tom. I had to do it for you. Next time, please help a bit." Don't phrase your directions as a request unless it is really a choice. "Time for lunch," instead of "Are you ready to eat?"
6. Get down to your child's physical level, if possible, so he can see your face as you give directions.
7. Allow children to help clean up their mistakes. "Water on the floor is slippery. Here's a sponge for you and one for me. See if you can wipe up the water here, and I'll wipe up the water over there. You can do it."
8. While you work together, talk to your child frequently to keep her attention. "I'll help you put the toys away. It's a big job, but it's fun when people work together." Provide your child with direct attention.
9. Follow a clear routine that includes cleaning up, bathing, putting away, etc. Accept — and use — the young child's need for sameness and repetition.
10. Break the tasks into small segments that can be done in a short time. Prepare your child for these activities gradually by exploring the segments of work together.
11. While your child is "working," allow him to work at his own pace. Allow time for the activity. Often, the more you hurry, the more your child will dawdle.
12. Before a change, give several reminders that the activity will be changing. "Program" your child by telling her in advance what is going to happen. "It's about time to go inside." "When you finish with the playdough, it will be time to put it away and wash up for lunch."
13. Use reminders rather than questions when children get defensive. "You forgot to wash your hands clean. I'll help you if you need me to."
14. Young children forget easily, so reminders are important. Repeat reminders and directions as much as necessary.

Questions to think about:

1. When does disobedience and ignoring chores tend to happen?
2. What is your first reaction? Do you immediately give in?
3. How does your child respond to your usual reaction?
4. Who else gets involved in your child's refusal to do the tasks?
5. Is your child overtired?
6. Is your child given directions with abrupt commands?

Jealousy

Our relationships with our siblings constitute our first peer relationships. What is known as "sibling rivalry" often seems to be centered around the children's relationships with their parents. Children vie with each other for time and attention. When this becomes negative, we experience it as jealousy or rivalry. Many parents get involved in the rivalry by stepping in to interfere and "protect" the weaker or younger child. When parents do this, each child gets her own kind of reward: some form of attention, whether positive or negative. Children who are somewhat left to work out their relationship with each other will be able to avoid relating to each other only "through" their parent. Sometimes parents experience this pain in their children as if they were reliving their own past. We need to take care that we do not act like children ourselves. We are adults and should not blame our children for needs of our own.

An example:

Screams came from the next room. Tom's mother rushed in to see what had caused the baby to cry. Tom lay on his back crying half-heartedly. When he saw his mother come in, he put more energy into his cries. Tom's older brother, Drew, sat in the corner. Their mother gave Drew a quick spank and cuddled Tom. Drew watched, with his thumb in his mouth. When their mother left the room, Drew reached over and took Tom's toy away with him. This caused Tom to start crying again. Again, their mother came into the room and cuddled and rocked Tom. Drew looked on.

Strategies to try:

1. Let children know you understand how they feel and love them anyway when they feel upset with a sibling.
2. Let each child have an area that is respected as her own. Teach children to respect property.
3. Do NOT compare one child with another by saying things such as, "See how clean Jim's hands are." This might make the child dislike both Jim and you.
4. Suggest to your child, "Ask for the toy, don't grab it. Let's find another toy for you to play with."
5. Do NOT encourage the children to compete. You might think about having your child timed against his own best time to complete a task.
6. Reduce your expectations. Realize that you might not have a perfect family in which everyone gets along all the time.

7. Develop some emotional distance from the children. Try to remain calm instead of taking up one side or the other.
8. Love each child uniquely.
9. Reduce rage by allowing each child to express her hostility toward the others privately in pictures, conversation, etc.
10. Find out the limits of the children's ability to get along together. Try to separate them before the limits are reached.
11. Plan in advance that children not be together at their most tired times.
12. Ignore their demands for fairness. Make appropriate decisions.
13. Teach children problem solving techniques.
14. Let children settle their own quarrels. Stay out of fighting unless someone is actually getting hurt.
15. Give affection generously to each child in the family.
16. Substitute a toy or an activity when one must be taken away from your child.
17. Do NOT make fun of either child.
18. Provide opportunities to keep each child busy and fulfilled.

Questions to think about:

1. When your child is with family members is she always being told what to do?
2. Is your child frequently teased?
3. Has this problem escalated suddenly? What stress factors might be evident which lead the children to act out jealousy?

Lying

Young children seem to have little regard for the truth. There are many reasons for this:

1. The young child does not yet understand cause and effect, so something seems to have "just happened." Youngsters act before they think and they do not really understand their role in the happening of spilled milk or crayoned walls.
2. Children are dependent on their parents for love and approval. If they think that they may lose this because of their behavior, they will not want to acknowledge that they've misbehaved.
3. Young children have not yet identified the difference between truth and fantasy. What they imagine in their minds seems real. What they wish might in fact happen. Just as easily, what they wish had not happened, in their minds, didn't happen.

An example:

A glass vase lay broken on the floor. Pat's mother wondered which of the three children had managed it this time. She had just seen Bruce moving through the room. When she asked him what happened, he denied that he had anything to do with it.

Strategies to try:

1. Tell your child, "That was a funny story. It could have happened, but you seem to be teasing this time. I know it did not really happen."
2. Spend time as a family making up stories, the crazier the better.
3. Acknowledge to a child, "You wish that that did (or didn't) happen, but it did."
4. Help the child to correct the problem, for example, to wipe up milk.

Questions to think about:

1. What does your child understand about truth and pretend?
2. Has there been a change in the amount of time you spend with your child?
3. Is there more stress than usual in your child's life? (e.g. moving, new child care arrangement, new sibling, death of a pet, etc.)

Mealtimes

Mealtimes can become a challenge for anyone with a young child. . . and they can become a marvelous place for a fight. Avoiding power struggles requires a certain frame of mind. . . a letting go of your stake in the contest. Children may surprise you with sudden changes in eating habits: eating more or less, deciding to eat only one kind of food, experimenting with gravity by watching food go over the side onto the floor, demanding to get out of the chair. Evening meals especially may become disasters. All sorts of feelings come out in mealtime behavior.

An example:

Suzy had always liked to eat, but suddenly that had changed. As soon as she was put into her chair, she started to whine. Her mother was so surprised that she thought Suzy needed to be changed. When she brought her back to her chair, Suzy started to squirm and twist. She tossed her spoon overboard and pushed her plate away. Her mother was surprised again. Finally, Suzy let her mother feed her a few spoons of food. Then she knocked the spoon out of her hand. Her mother thought Suzy wasn't feeling well.

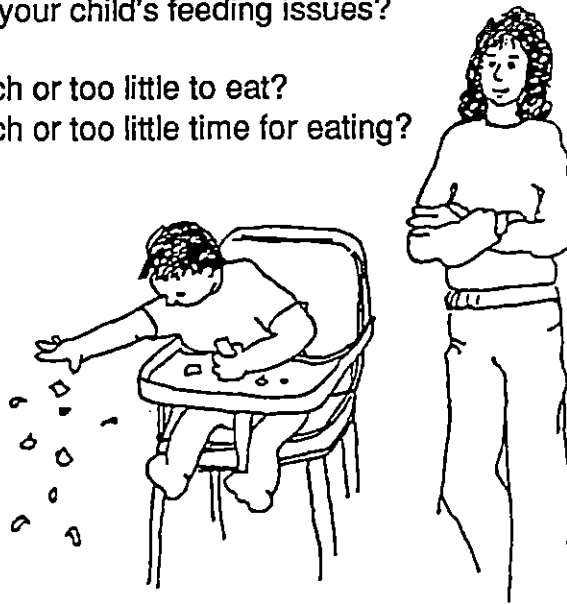
Strategies to try:

1. Provide food your child can eat alone.
2. A very young child may become frustrated if you frequently ask him to choose. On the other hand, young children may need to feel that they have some control over their lives. Therefore, they need a choice. Parents need to reflect on their own child's personality.
3. Young children can misbehave when a choice is not really a choice. Ask the child: "Pear or apple?" Do not ask: "Do you want lunch now?"
4. Children need ritual. Set up your own routines for mealtimes.
5. Allow time for transition from activity to meal. The more you hurry, the more likely that children will drag their feet.
6. Avoid asking questions if your child is likely to say, "no."
7. Don't take "no" too seriously if it's the automatic response.
8. Avoid using "no" and "don't" as much as you can. Use simple and positive directions. "Your hands must be washed if you want to eat." "This is your milk." "Drink out of your own glass."
9. Use demonstrations about eating to keep your child's attention.
10. DON'T expect long periods of sitting. Allow a short time for a young child's meal. If it might take longer, perhaps you can break meal time into several smaller snacks. Let the meal end when your child has had enough.

11. Believe that your child will not starve if offered adequate amounts of appropriate food. Keep weight records or meal diaries for reassurance.
12. No one food is absolutely necessary, including milk. There are substitutions for everything.
13. Use reminders instead of questions when children are defensive. "You forgot to wash your hands. I'll help you if you need me."
14. Let your child eat food in any order or combination.
15. DON'T automatically use food as a reward or bribe.
16. If your child is having problems managing the mechanics of eating, help him find another way that works for him. Explore special eating utensils, such as rubber spoons, scoop dishes, snap-on plate guards.
17. Combine eating with pleasant atmosphere and conversation so the child can focus on people, not just the food to be eaten.
18. Try to give your child a change of scene or position at mealtime, even allowing your child to lie on the table.

Questions to think about:

1. Is your child hungry at times when misbehavior occurs?
2. When do arguments about feeding tend to happen?
2. What is your first reaction? Do you immediately give in?
3. How does your child respond to your usual reaction?
4. Who else gets involved in your child's feeding issues?
5. Is your child overtired?
6. Is your child given too much or too little to eat?
7. Is your child given too much or too little time for eating?



Misbehavior in Public

It seems as if it always happens right in public where you wish no one could see!! Somehow, young children seem to sense our tenseness about other people's opinions and "act up" exactly when we wish they wouldn't. In such situations, our actions, voice levels, and gestures are important.

Very young children will not respond well to long discussions on why they cannot do something. Lots of words are only confusing. We can be glad that, usually, young children are easy to distract. . . by themselves and others.

An example:

While grocery shopping with his parents, two-year-old Danny was into everything. His parents tried to keep him in the cart, but then he would twist and turn and almost fall out, screaming all the while. When they let him get down, he was grabbing things off the shelves. His parents imagined that everyone in the store was staring at them.

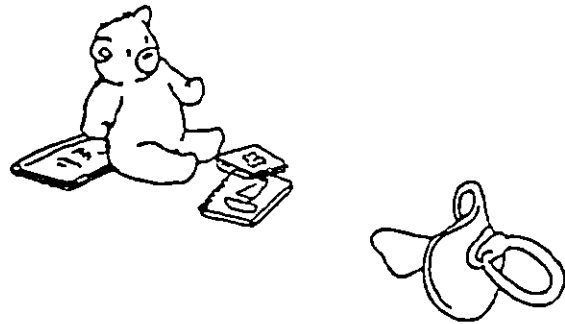
Strategies to try:

1. Use distractions immediately. Tell your child what he can do rather than what he cannot do.
2. Give warnings. Talk to your child about the changes in activities that will be coming up. "Good bye car. See you later."
3. It's okay to sympathize with your child, but it's also okay to physically move her to a quieter place.
4. Give your child lots of praise when he does what is acceptable.
5. Slow down. It's easy to get too busy and move too fast. Go at your child's pace for a while.
6. Use face-saving techniques. Give your child an "out." "You can walk or I'll carry you."
7. Set clear limits. "You can ride in the cart seat or in the cart."
8. Stop or change activities which are dangerous. "You should sit down while you eat."
9. Use reminders rather than questions. "I'll help you if you need me to."
10. Give positive directions. "We are going inside now."
11. Give warnings before changing activities. "We will be going to Auntie's house." "It's almost time to go home."
12. Remove your child from a situation when she cannot cooperate. "You will have to rest here since you cannot be quiet."
13. Don't expect long periods of sitting. Give your child a break and let him move around a bit.

14. Tell others, "Chris is just having some troubles with what is happening."
15. If you think you must threaten, be sure you can carry out your threats.
16. When you reprimand, do it privately with your child.
17. Security objects, such as blankets, toys, thumb, pacifier, may help in a strange place.
18. Give choices only when you are willing to live with the choice your child makes.

Questions to think about:

1. Is your child hungry or tired when the misbehavior happens?
2. Are naps, meals, and bedtimes regularly or irregularly scheduled?
3. Does your child spend the whole day with people? Does she have time alone?



Safety Issues

Young children must be protected, and safety precautions must be used. Parents are the ones who are responsible about assessing safety and appropriate limits in the home and elsewhere (e.g. water temperature, car safety, poison-proofing, crib, falling, etc.). This means that parents often struggle to stop or change activities which are dangerous.

A very young child cannot be expected to visibly like limits, but he can be expected to obey the important ones. Give your child dramatic praise with your words, voice, facial expressions, and hand gestures. Give lots of hugs for obeying safety rules.

Children learn a little at a time, sometimes a very little at a time. The young child forgets easily, so much repetition is needed. Be patient. Encourage and reward your child.

An example:

Jill continues to try to stick objects into the electrical outlets. Even when her parents are in the room, she moves toward the electrical outlet as she smiles at her parents.

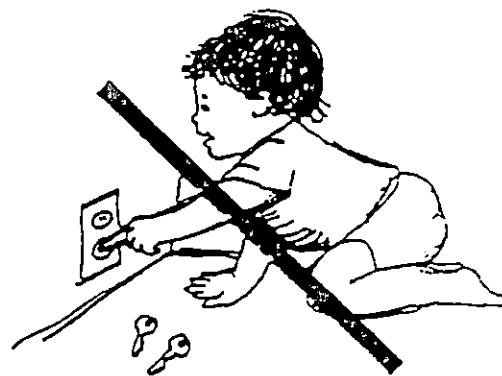
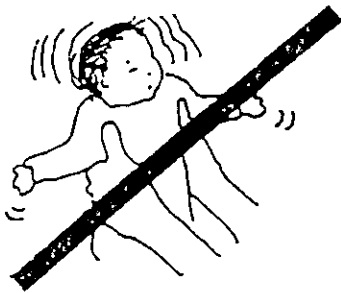
Strategies to try:

1. Do not be afraid of removing your child from situations which are dangerous.
2. Use positive and specific directions, such as: "We stay inside the fence." This comments tells what the child is to do. "Don't go out in the street," is negative and does not tell what the child should do. Other words to use: "Scissors are for cutting paper and fabric," instead of "Don't use scissors." "I will hold that while you get into your chair," instead of "Don't carry that while you climb." "Sit in the swing," instead of "Don't stand up in the swing." "Put the stick over the fence," instead of "Don't throw sticks."
3. Give notice in advance. Talk to your child about what behavior will be expected. "When we go for a walk, you ride in your stroller."
4. Talk less and act more. Children will respond better to what you do rather than what you say. So guide their shoulders onto the sidewalk. Move them away from the hot stove. Show them how to turn away from electrical cords.

5. Give your child a choice only when you will honor that choice. Usually, there are not choices about safety issues. So, check your voice and words. Do you say things like, "Don't put the knife in your mouth, okay?"
6. Explain results rather than using threats. "When you run away from me and you run into the street, a car might run into you."
7. Don't take "no" too seriously. Re-state the limits and guide your child physically to the safer place.
8. When children refuse to do something, offer some help and then have them do what they're supposed to do.
9. Stop or change activities which are dangerous. Do not be afraid to remove your child physically from the situation.
10. Avoid using "no" and "don't." Make directions short and simple. "We walk on the sidewalk." "Sit down in your chair."
11. Think of something appealing that is within the safety limits. "We can hold hands on the sidewalk."

Questions to think about:

1. What safety limits are really necessary?
2. Do you say "no" as little as possible or is it an automatic reflex response?
3. Does your child "test limits" in every situation or mostly at home?



Not OK!

Screaming and Whining

Sometimes, parents can prevent screaming and whining. Look for physical causes. Children may become screamers or whiners when they are hungry and meals or snacks are postponed. They may scream or whine when they are tired or when they need a hug.

Whining is often used for getting something or getting somewhere. If it works, it will be worth the effort to try it again next time. Your child will try whatever works.

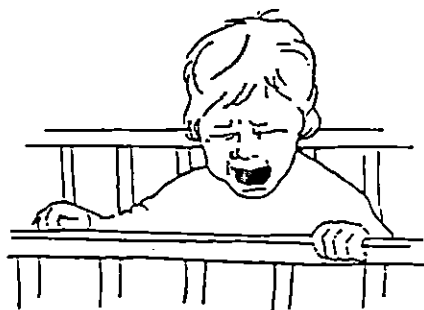
Some strategies to try:

1. Show that screaming and whining won't work but that a pleasant voice will. Tell your child, "I want to hear what you're saying and when it's too loud it bothers me. Whisper or use your smiling voice to help my ears feel better."
2. When it looks like screaming or whining is going to start, move the child to a quiet place with limited space.
3. Remain quiet until the screamer or whiner hears only herself.
4. Give your child something to hold.
5. Get to your child's level, look him in the eye, lower your voice and start talking very quietly. "Terry, you don't need to scream or whine at me. I can hear you. Listen to my voice. It's soft. Can you hear me all right? Now, you can use your quiet, soft voice to tell me what you need."
6. Use a set of earplugs for yourself.
7. When your child stops screaming and whining, play quiet music.
8. Find some times when it is acceptable to scream and whine. Imitate "The Whiners" from Saturday Night Live when someone is feeling cranky. Perhaps you'll end up laughing at yourselves.
9. Stop what you're doing and listen carefully to see if you can do anything about the problem. If not, find something that will distract your child.
10. Try to identify and verbalize for your child what she is feeling. "You sound mad because your toy is stuck." "You sound sad because it's not time for snack now."
11. Ignore it.
12. Give your child attention and eye contact before he starts screaming or whining. Many children find that those noises are the only ones which get their parents' attention.
13. If you think you might give in, give in right away so your child won't learn that persistence pays off.
14. When your child does ask for something in a nice voice or with polite gestures, respond quickly. "I'd be glad to give you a hug and a cookie. How nice you were to ask like that."

15. Encourage your child to use words or gestures instead of screaming or whining. "I know you're angry, but you don't need to scream or whine about it. You can tell me with words or show me with your face. Say 'no' or 'mad.'"
16. Give short, clear, and calm directions about activities and changes.
17. Slow down the activities or start doing quiet activities.

Questions to think about:

1. Have you had your child's hearing checked lately?
2. Do adults in your family scream and whine? Make sure your requests are polite.
3. Are naptimes, bedtimes, and meals regularly scheduled?
4. When under stress, does your child prefer to be held and cuddled or left alone to get things under control?
5. Are you looking directly at your children when they try to communicate with you?
6. Does your child have a self-comforting routine, such as thumb-sucking, holding a blanket or teddy bear, etc.?



Self-Injurious Behavior

Self-injurious behavior, such as head-banging, eye-poking, arm-biting, skin-pinching, repeated vomiting, and eating non-edible things can be a disturbing problem for children with disabilities. We recommend obtaining professional help for such situations. Effective treatment may not be easy because there are complex issues involved.

Such behavior seems to be learned and maintained because it produces some desired change for the child. The strength of a behavior is often affected by what happens immediately following it. When the consequences are positive (at least, as desired by the child), the behavior will be repeated. Consequences which may strengthen self-injury are:

1. positive rewards, such as attention, comforting, scolding, toys, food.
2. escaping or avoiding unpleasant situations or work.
3. sensory stimulating, such as sounds, touching, visual stimulation.

The goal of treating self-injury may be to reduce the strength of the behavior, rather than preventing the behavior. The strategies listed below will give you some ideas to try. Keep in mind that the problem may get worse before it gets better and that it sometimes improves very slowly.

An example:

Evan becomes very excited when getting ready to ride in the car. He jumps up and down and bites his hand. His parents usually rush him to the car, where he sits quietly until the rest of the family is ready. His parents wish they had a better strategy to use.

Strategies to try:

1. Avoid self-injurious behavior by controlling the situations to reduce frustration. Watch for signs that your child has reached the limit of tolerance for frustration. Eliminate the rewards and conditions that maintain the self-injury.
2. As you see a situation developing in which the child might begin self-injurious behavior, keep in mind that young children are usually easy to distract . . . by themselves or other people or things. Divert their attention to something else or another situation.
3. Give advance notice. Talk to your child as you are about to make changes in what she is doing. "Good-bye tree. We're going inside now." The more you hurry, the more your child will become frustrated.

4. Encourage your child to express his feelings with words or gestures rather than actions.
5. Increase the reward which children receive for behaving appropriately. Try food, liquids, toys, activities, attention, and sensory experiences. Select rewards that are important to your child.
6. Identify and extend situations where self-injury does not occur.
7. Provide protection for the child while providing as little reward for self-injury as possible.
8. Structure the environment when possible. Pad the crib. Use a waterbed. Have your child wear a cushioned helmet.
9. Keep your child interested in toys and games.
10. Provide motion for your child with a rocking horse, swing, or hammock.

Questions to think about:

1. What kind of self-injury happens?
2. How often does the self-injury occur?
3. How intense or severe is the self-injury?
4. Where and when does self-injuring behavior tend to happen?
5. Who is the audience?
6. What happens immediately after the self-injury occurs?
7. What is your first reaction? Do you immediately give in?
8. How does your child respond to your usual reaction?
9. Who else gets involved in the situation?
10. Are naps, bedtimes, and meals regularly scheduled?
11. Is your child overtired?
12. Does your child spend the whole day with people? Does she have time alone?

Temper Tantrums

A temper tantrum is like a blown fuse. It's a sign that the frustration load has become too much for your child to stand. It takes patience and ingenuity to avoid the cycle, but sometimes only the explosion of a tantrum gives release to the pent up frustration. As your child grows, he may become more skillful at handling emotions. Learning to talk or use sign language or gestures will help your child release anger and frustration through symbols.

In a sense, defiance and tantrums are signs of growth. Your child is trying to learn to express his feelings. He is becoming more independent. He is working out what it means to be dependent on you and yet to be an individual. He is developing a sense of self. For children with special needs, tantrums may simply happen more frequently, last longer, and be harder to prevent or control.

There are even "stages" to a temper tantrum. You can help your child identify these stages and move through them:

1. **rumbling and grumbling:** The child may be looking for an excuse to throw a tantrum that she has already decided to have. Often, tantrums will have a similar time and place, such as just before mealtime. When parents recognize the pattern, they can help the child verbalize or symbolize the problem rather than act out the tantrum.
2. **help-help:** The first loud, noisy stage of the tantrum. The child has found the issue and is signaling his need for help with a deliberate rule-breaking act which gets your attention. Parents may need to use physical restraint while talking to the child about helping him control the tantrum.
3. **either-or:** Alternatives to the tantrum can be proposed at this stage. Here is where we can offer distractions.
4. **no no:** The child responds negatively to any suggestion or statement by the parents. When a tantrum has reached this stage, it may be impossible to manage. At the end of this stage, the noise dies down.
5. **leave me alone:** A quiet stage when the child may be more open to help from the parent, but the child may not be ready to resume life in the world. A child's desire or need to be alone for a while should be respected. As little conversation or interaction as possible is desirable. The child is trying to get herself "together."
6. **hangover:** Some children have no painful memories of the tantrum and seem to return to normal. Others feel quite guilty and embarrassed about it all. Some feelings are desirable because we want to help children to feel a need to change their behavior pattern.

(From Trieschman, A. E. "Understanding the Stages of a Typical Temper Tantrum," in A. E. Trieschman, J. K. Whittaker, and L. K. Brendtro, eds., *The Other 23 Hours*. Chicago: Aldine Publishing Co., 1969.)

Keep in mind that for their own safety, we do want our children to be able to say "no" to situations that might hurt them. Parents walk a fine line between guiding behavior and setting children up for following *any* authority figure who appears, whether or not they have your child's best interests in mind.

An example:

When Jamie's mother tried to remove her snowsuit, Jamie's negativism emerged. Jamie lay down on the floor and kicked and screamed as her mother tried to take off the outfit. The intensity of her screams and physical resistance increased all during the time her mother tried to calm her down. When her mother tried to pick her up to comfort her, Jamie stiffened out and arched her back, while she cried and cried.

Strategies to try:

1. Avoid tantrums by controlling the situations to reduce frustration. Watch for signs that your child has reached the limit of tolerance for frustration.
2. Offer help, but don't interfere.
3. Don't say "no" to requests unless you really have to.
4. Ignore the tantrum. You need not stop it. "It's okay for Tim to be over there by himself. Sometimes people need to have time alone to let their feelings out."
5. Acknowledge your child's feelings, but don't get involved and try to control the feelings.
6. Help your child pull himself together. Sometimes it helps to hold them. Sometimes it doesn't! Give him an object to hold. Play quiet music.
7. As you see a tantrum coming on, keep in mind that young children are usually easy to distract. . . by themselves or other people or things. Divert their attention to something else or another situation.
8. Tell your child what she can do rather than what she cannot do. For example, "Touch kitty gently" and demonstrate, rather than "Don't pull the kitty's tail." Try to not "overtalk" with your child. Give clear and specific directions and then stop talking.
9. Give advance notice. Talk to your child as you are about to make changes in what he is doing. "Good-bye tree. We're going inside now." The more you hurry, the more your child will become frustrated.
10. It's okay to sympathize with your child's feelings, but you can physically move her physically to a safer, quieter place.

11. Young children like to try to do things for themselves. Let them try it when they are ready. Encourage them to use words or gestures when they need help. Let them know that it's okay to ask for help. "You forgot to wash your hands. I'll help you if you need me."
12. Avoid offering choices when your child is tired. The situation becomes complicated when your child cannot decide and when you feel it's important for him to choose. Say, "If you cannot come in alone, I'll have to help you," rather than, "It's time to come inside, okay?"
13. Use definite limits and define them with short directions. "You can play on this side of the fence."
14. Encourage your child to express her feelings with words or gestures rather than actions.
15. Control the situation to reduce the level of frustration. Don't wait too long to intervene.
16. Do not shout or discipline in the middle of a tantrum.

Questions to think about:

1. When do tantrums tend to happen?
2. What is your first reaction? Do you immediately give in?
3. How does your child respond to your usual reaction?
4. Who else gets involved in your child's tantrums?
5. Are naps, bedtimes, and meals regularly scheduled?
6. Is your child overtired?
7. Does your child spend the whole day with people? Does he have time alone?
8. Is your child given directions with abrupt commands?

Toilet Learning

Changing diapers is a nuisance that most parents look forward to outgrowing. Physically, the young child must be ready for using conscious control for toileting and for managing clothing when using the toilet. Sometimes we put more pressure on children than they can handle. This leads to power struggles that are unnecessary and undesirable.

This is a difficult situation for parents of children with special needs. Many children may need to be trained very systematically even before some of the readiness skills listed below are demonstrated. Toilet training might occur at a much later time than for other children. For special assistance, talk to your child's pediatrician.

Parents can avoid power struggles by recognizing some of the signs of readiness for toilet learning. Your child may be ready to begin toilet learning when she:

1. is anxious to please you and to imitate you; responds well to praise.
2. is not in the middle of a time of negative behavior.
3. imitates you in many ways.
4. is coordinated enough to pull his pants up and down.
5. wakes up in the morning or from a nap with dry diapers.
6. does not like wet or soiled diapers.
7. is aware of "going," followed by feeling the "need to go" followed by actually "going."
8. indicates she wants to use the toilet or potty seat.
9. is able to actually sit quietly for 5 minutes and pay attention to anything; perhaps able to sit on the potty seat for 5 minutes.
10. is able to follow a series of directions of 3 to 5 steps.
11. has some muscle control for grasping and putting smaller objects into bigger containers.
12. increases periods of daytime dryness.
13. shows satisfaction at having had a bowel movement.
14. uses potty seat in a self-directed manner.

An example:

At age two years, Rich showed great interest in the toilet. His mother decided that he might be ready for training. The first day went well. Rich used the toilet each time he was seated. Progress went well for a few days and she introduced training pants. Then things fell apart. Rich cried each time his mother suggested he go to the bathroom. He had accidents four or five times a day. At the suggestion of her friends, his mother decided to put diapers on Rich and to "forget" training for a while. One day after Rich turned 3-1/2 years, he took off his diaper and went to the bathroom. Training began again and was successful.

Strategies to try:

1. Give your child praise when he is following the toileting procedures.
2. Sometimes a young child needs to go at her own pace.
3. Older children can learn to keep track of their own behavior. Develop a reward system. Use checks, stars, or stickers on a chart to show the frequency of a particular behavior. This helps your child be responsible for his behavior, rather than you.
4. Provide the equipment, such as a child-sized potty chair, a footstool, some picture books, allow child to sit on it even with her diaper on.
5. Introduce your child to training pants. Refer to them as "pants."
6. Establish a regular toilet routine, such as before meals, after naps, first thing in the morning.
7. Allow your child to observe a parent or older sibling as a role model. Let your child role play toileting routines with a doll.
8. Let your child sit on the potty chair and look at books just to get acquainted with the chair.
9. Talk to your child about the process.
10. Allow your child to decide when to "flush" in order to dispose of the waste materials.
11. Put diaper with bowel movement in the potty seat. Acknowledge its "production." Dispose of it later.
12. Encourage use of potty seat regularly after a meal or at a time when your child regularly has a bowel movement.
13. Expect setbacks, at times of stress and also spontaneously.

Questions to think about:

1. Does your child show the signs of readiness for toilet learning?
2. What are some ways your child might be indicating without language that he is ready for toilet learning?
3. Are you and your child able to overcome power struggles?

QUESTIONS AND ANSWERS ABOUT BEHAVIOR GUIDANCE FOR CHILDREN WITH SPECIAL NEEDS

1. How do parents decide when to intervene in a child's misbehavior and when to stay out of it?

The first consideration is probably the safety of the child. You will always want to limit behavior if the child might be hurt. You will likely want to limit behavior if the child's behavior will hurt a person or animal.

Another consideration would be behavior that might cause medical complications.

You will want to think about what's really important to your family life. Choose your issues carefully and stick with the decisions. For example, a child might not really need to nap, but a parent might need some quiet time, so the parents can insist on some quiet rest time during the day. Respect each person's need to recuperate.

Another question of values relates to hitting children. Spanking is one way to handle misbehavior. Many parents prefer not to spank their children. There are many other alternatives.

Another consideration is whether the combatants are equal peers. Is this a fair fight or is one person being a bully? If the disagreement is between equals, then you might want to wait a while before intervening. Parents should avoid intervening too quickly. Perhaps the children can solve their own problems. It's okay to stand back for a while and let children try to handle conflict on their own. If they are unequal, be on your guard and intervene while both are still in control and able to talk about things. If you miss that point and tears start, don't waste time talking. Mend feelings and "owies." If necessary, separate the children until they cool off and then talk about things later.

Above all, parents, as the adults in charge, must try to avoid losing control over themselves.

Avoid giving attention for misbehavior. Be aware of the continuum of obnoxious behavior. On a scale of 1 to 10, you may observe that children often start out behaving at point #1, with a poke or an interruption when you're on the phone or a yell. If parents do not respond, the child's behavior may escalate until it reaches point #10, and the child is out of control. When this happens, you've probably taught your child to be a nagger. Intervening at point #1 will avoid this behavior. You can simply ask, "What do you need? How can I help you? Can you come here, please?" Then give the child eye contact, a smile, and perhaps a hug to acknowledge that you've heard them. With a brief interaction such as this, their behavior will probably not reach the extreme behavior of point #10.

Tune in to yourself to find out what triggers your child touches off in your personality. One parent reported that she could not stand whining, but she refused to give swear words "power" over her own behavior. Children will intuitively find out our triggers and play off of them. Such triggers give our children power over us, unless we manage them instead.

2. How can parents handle extreme behavior issues, such as tantrums when the child is getting hurt or biting which breaks the skin?

Intervene in safety issues immediately. Move your child to a place where she can finish the tantrum without hurting herself or others. Remove the biter from the scene immediately.

Remember that to some extent this behavior is common for children who have poor language skills.

Use your problem solving skills to analyze this behavior. When does it happen? How do we contribute to the problem? What are our alternatives? Can we eliminate the behavior or just redirect it?

See the child's pediatrician or therapist for some ideas which would fit the child specifically.

Schedule someone to be "on watch" for such behavior in order to intervene immediately and to observe what triggers the behavior.

Tell the child, "I will help you" and use language and action to walk slowly through the situation to deal with feelings.

Deal with that behavior consistently with safety in mind.

Tune in to find out what triggers this behavior in your child. Does it happen when he is tired? frustrated in play? on a new medication?

Perhaps you'll just need to physically pick the child up and move her to an area where she can carry out her tantrum without hurting anyone else or herself.

Prepare in advance a quiet area where children can "get themselves organized" such as a tent or a small place between furniture. After a while, your child may routinely choose to go to this place to calm down.

Allow at least three weeks for a behavior change.

3. What about children who are not processing communication and cannot respond to directions from adults?

First, ask yourself some questions about what is happening:

1. How old is the child? What is appropriate for his development level?
2. How much expressive language does your child have? You can feel sure that she will at least understand that amount of language.
3. What else is going on in his life? Is there lots of stress?
4. Is there a lot of visual or auditory distraction going on around her?
5. What is your child's primary learning channel? Is there a lot of visual or auditory distraction going on inside him? Maybe the child's primary learning channel is being overstimulated.
6. What time of day is this generally a problem? When getting up? Around 4 p.m. when your child is tired and hungry? When your child has to go to the bathroom and isn't able to?

Your answers to these questions will help you develop appropriate expectations for your child and also to structure the environment to reduce stress for your child.

Talk with others who know your child. They will help you understand if you have appropriate expectations for your child's age and stage.

Then, listen to your own speech style. Do you end all your remarks with "okay?" as if you were asking your child to approve or agree with you? You have presented your child with a pretend choice and your child probably has figured out that it's not a choice! Consequently, when your child goes his own way, it looks like misbehavior.

Use direct, firm, and loving physical guidance. Remove the child from the situation. Move her hands away from the problem. Carry the child to another room for time out. Give her a hug to help her quiet down.

The important thing is to increase your repertoire of actions and gestures and not count on the verbal directions. Hold up the jacket and use pantomime to show putting it on.

If you really must talk, break your verbal language down into one- and two-word sentences. You can repeat that over and over if necessary. "Put jacket on." Avoid giving paragraphs of lecture. You might try using sentences of one word if your child is functioning at the level of a one-year-old or two-word sentences if your child is functioning at the level of a two-year-old.

We are not advocating spanking as physical guidance. There are other, less traumatic actions you can take.

4. What about the child who has been withdrawn and finally stands up for herself by hitting a child who has taken her toy?

Such physical action might be the only avenue of action open to him at this time. You might choose to ignore this for now. Try to catch and reward positive behavior as soon as possible.

Model positive alternatives without punishing the child.

You might tell her, "I'm glad you stuck up for yourself, but a better way would be to say, 'NO!'" Give your child words or actions to try, such as facial expressions.

5. What if nothing seems to work?

It may indeed feel as if you've tried it all. But do review all the options you have.

Re-evaluate what you have really tried. What have you been doing? How long have you tried those alternatives? Perhaps you've been trying too many alternatives, and your child is overwhelmed by all the different reactions he gets to his behavior. Each option becomes even more complicated for your child to understand when you add in your emotional level and the speed (or lack thereof!) of your response. Select the one or two responses that seem most effective and try them quickly and consistently for at least four weeks.

Try some ideas over again. Maybe the first time you tried them, your child wasn't developmentally ready for them. Check: Does your technique fit your child's developmental level? Does your technique fit your child's emotional state?

Try some ideas consistently for a longer period of time. It takes over three weeks to build new habits.

Talk to your child's teacher. Maybe there are techniques that work at school that you could try at home.

Get some outside guidance from your child's behavioral pediatrician or therapist about what you've tried and what other options might be.

Consider that perhaps you, the parent, need some time out. Call a friend or another MELD Special parent to talk. Take a break. Consider trying respite care, a crisis nursery, or Parents Anonymous.

6. How do parents decide which behavior guidance techniques to use?

They consider:

- their preferred style of parenting.
- their values.
- their own comfort level with the technique.
- their child's ability to respond.
- their child's receptability to any type of behavior guidance.
- what seems to be working on this particular day.
- their perception of the degree of the child's misbehavior.
- the real degree of the child's misbehavior.
- their own emotional state at this moment.
- their child's emotional state at this moment.
- how parents were treated as children and how that felt.
- their temperament type.
- their learning channel.
- what other people will think about their parenting style.
- the time of day.
- the safety of the environment.
- their stage of grieving and coping.
- the level of problems and stress between partners.

7. What would complicate behavior guidance processes with children of special needs?

the child's low impulse control.

the child's difficulty in processing communications, for example, visual or hearing impairments or cognitive processing disabilities.

stress and frustration due to the disability or to medication or procedures.

younger developmental level.

parent's overprotectiveness.

parent's feeling sorry for their child.

child's frustration at not being able to do what others are doing.

the lack of diagnosis for the child's condition.

multiple disabilities.

the source of the special need (genetic, accidental, drug or alcohol use, etc.).

number of siblings.

ages of siblings.

family financial problems.

sources of family support.

parent's fatigue and worry.

Some syndromes or diagnoses are not amenable to modification or treatment at all. Others need very specialized intervention.

8. What if the child thinks that the parent's "NO" means only this one single electrical outlet on this very wall and only at this very specific moment?

Such behavior may mean that your child has persistence in his character, and that may be something to celebrate, if you can!

It may help to remember that generally we reward our children for their curiosity and exploratory behavior. Only in such a situation, there is a matter of safety to be considered.

Try to structure the environment—plug the electrical outlets! So much of life is frustrating for the young child with special needs. If we can limit some of the sources of frustration, it may be good for the child and for the parents. This can buy us some time to work on more important things.

Parents may need to lower their expectations about their child's ability to generalize behavior. It may be that their child's "toddler" stage, when children typically do not generalize such "rules," may last longer than usual or may be on-going. We may need to adjust ourselves to repeating the limits over and over for a longer period of time. Check with your pediatrician or therapist about this.

Take your child on a house tour and repeat "no" for each electrical outlet. In this way, you're doing the generalizing for your child.

When your child does remember, celebrate! Let her know you are proud of that achievement.

9. How can we calm down an overstimulated child?

- reduce visual, listening, and social stimulation
- put your hands gently on his shoulders
- hum or sing
- rock the child gently
- seat your child near a washing machine or ticking clock
- lower the tone and volume of your voice
- go for a car drive
- give your child a warm bath
- move away from other people
- reduce distractions
- maintain predictable routines
- rub her back

Ideas for at Home:

Aggression Cookies for Kids

6 cups quick oatmeal
3 cups margarine
3 cups brown sugar

3 cups flour
1 tablespoon baking soda
sugar

You and your child can knead, pummel, squeeze and pound this dough with your hands. The more you knead, the better the dough will be and the better you both feel. Roll the dough into small balls and place the balls on an ungreased cookie sheet. Butter the bottom of a small glass, dip it in sugar, and press it down on each ball. Bake the cookies at 375 degrees for about ten minutes or until they are brown. This recipe will make 10 to 15 dozen cookies.

Note: Young children who are being taught not to be messy with their food or not to eat playdough may be confused by this cookie making exercise. Parents will each have to decide if the cookies are appropriate for their children.

Playdough

Mix together with a spoon and your hands 3/4 cup flour; 1/2 cup cornstarch, and 1/2 cup salt. Add warm water gradually until the mixture can be kneaded. If it is sticky, dust it with flour. Poster paint or food coloring can also be added for color. The playdough can be painted when it is dry. It makes good jewelry, such as beads and pendants, and can have a hole punched in it with a wire or nail so it can be hung up by a string after it dries.

Experiences with Conflict

Check the messages about disagreement below that are similar to those you received as a child.

Turn the other cheek.

An eye for an eye, a tooth for a tooth.

If you can't say anything nice, don't say anything at all.

Little girls don't fight.

If you are in a fight, make sure you win.

Nice people don't fight.

Forgive and forget.

Get the other person before the other person gets you.

Don't get angry, get even.

Check the kinds of feelings you remember having in conflict situations:

fear	confusion	loser	intimidation
guilt	avoidance	winner	out of control
rage	unable to act	sadness	rejection
tension	resentment	martyred	loneliness
rejection	other:		

Check the words that describe how your body reacted to disagreement:

head ache	teeth clenched	stomach churning	eyes watering
knees weak	heart pounding	clenched fists	ears burning
neck tight	face blushing	shoulders tightened	
other:			

Discuss the changes you'd like to make in your behavior guidance techniques.

Characteristics of Young Children

Consider some typical characteristics of very young children.

1. They learn through their senses by exploring and experimenting.
2. They learn from the example of others and from feedback they receive from others about their own behavior.
3. They go through a typical phase of being afraid of strangers (stranger anxiety) and a normal phase of being afraid of being left by their primary caretakers (separation anxiety).
4. They go through a typical phase of "negativism," in which they begin to be aware of themselves as separate individuals.
5. They are extremely curious.
6. They have short memories.
7. They have limited experience on which to base decisions.
8. They may know words but do not totally understand their meanings.
9. They are physically undeveloped; they must move.
10. They need attention.
11. They test limits to be sure the limits do not change.
12. They understand the feelings adults express; non-verbal communication tells the children more than your words.
13. They cannot understand long and involved explanations.
14. They are easily distracted by themselves and others.