

October 5, 2004
Satellite Presentation on

“Working with Families
Who have Children with Special
Needs”

Presented by
Joan Debelak

Working with Families
Who have children with special needs

Presented by
Joan Debelak

The Family System

- When we hear the term families it is usually associated with certain mental pictures or images
 - Traditional nuclear family ---- mother, father, children and strong ties to an extended family network
- What many of us actually see is a kaleidoscope – images that change, redefine as families, partners and siblings change through divorce, separation, remarriage and death

The Family System

- In our work with families we recognize the remarkable range of family diversity and the many variations we see among families.
- Imagine a bulging family album

The Family System

- 2003 Census Figures: The population count for children between the ages of 5 and 20 is 63.5 million. A total of 4.1 million or 6.3% of these children have disabilities.
- There are some 310,000 children with Individualized Education Plans in Illinois (ISBE)
- There are some 15,000 children ages birth to 3 receiving services through the Illinois Early Intervention System.
- Some stats say as many as 40% of marriages end in divorce --- The divorce rate is very high among families who have children with special needs

The Family System

- **What do we see in ALL families today?**
 - Their Strengths
 - Their Challenges

When a family has a child with special needs?

■ **Factors to Consider**

- Coping mechanisms
- Relationships within the family system
- Support outside the family system
- Financial aspects
- Information/resources
- Severity of the disability

Ken Moses depicts the parent's struggle

"Parents attach to their children through dreams, fantasies, illusions and projections into the future.

"Disability, dashes these cherished dreams. The impairment, not the child, irreversibly, spoils a parent's fundamental heart-felt yearning."

The States of Grieving

- Denial
- Anxiety
- Fear
- Guilt
- Depression
- Anger

Denial

"I can't deal with this now, so it didn't happen"
"You don't see what I see"

Denial buys the time we need to blunt the initial impact of a shattered dream.

Anxiety

"You are now living in a world of "unknowns" and what you do know may be very scary"

Anxiety can mobilize the energy one needs to take action, or make needed changes in your life

Fear

"Fearful of what you know... Fearful of what you don't know.... Fearful of what you need to do"

Families may become fearful as they realize all the changes they'll need to make in their lives

Guilt

"What did I do wrong.... What happened....
What should I have done differently"

*The order of things in a family's life are
totally upset. Someone must be at fault.
Guilt may be expressed through a belief
that good things happen to good people
and bad things happen to bad people.*

Depression

"It is a profound loss. How can one deal
with this loss and all that needs to be
done"

"A family's way of looking at their child is
changed --- my child won't go to college,
my child may never be able to marry or
live independent of me"

Depression

*Depression can be the medium that helps
parents, others form new definitions of
what it takes to be loved, capable, valued,
competent, strong.....*

Anger

"This is not fair... I don't deserve this... How could God allow this to happen...Why won't they listen to me..."

Anger is a natural part of the grieving process. Unfortunately anger can form a very strong barrier between the family and those who want to help the family

What parents say

"Some days all I can do is damage control. I stick my finger into the dike and pray that I won't find another leak that day or week.

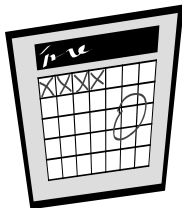
"It is so hard not to worry about what will happen down the road. Maybe it's about control because there is so much I can't control."

" I want someone to tell me what my daughter will be able to do in the future. But maybe, I don't really want to know?"

States, not Stages

It is not a step- by step process. Individuals, families experience these emotions at different times.

Specific events may trigger some of the states.



States and Coping

- Families often learn to cope as they grieve
- We all have different ways of coping
 - How do you handle difficult situations or events?

States and Coping



- Families are also coping with
- Demands placed on them because of their child.
 - Financial concerns
 - Attitudes and behaviors of other family members, friends, professionals, medical
 - Dealing with lots of people they never wanted to know

The Family Support Movement

- The Family Support Movement has received a great deal of attention nationally and internationally from policy makers and clinicians over the past several decades
- A very positive outcome we've seen from this movement is the focus on family in discussions about disability rights and services.

The Family Support Movement

- Family initiatives in the disability community have raised the importance of the family as the primary context for children's development
- The family unit is now viewed as the focus of intervention and support services

The Family Support Movement

- Our approach with families now focuses on family strengths and resources.
- Family competencies and capabilities are stressed, we look at families from a strengths-based perspective.
- The role of professionals has shifted to support rather than control over family decisions (Dunst, Trivette and Deal, 1994)

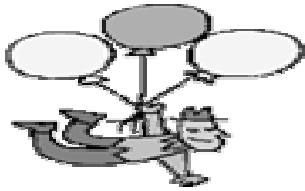
What we've learned

- The experiences of families and the options that are available to them in rearing and supporting a family member with special needs is embedded in the values and culture of the society within which the family resides.
- Also the way that families interact with various systems in which they are nested, neighborhood, community, education, social services, play pivotal roles in how they adapt

What a lovely bunch of balloons?



How many balloons can you hold?



**Principles of Collaboration
Families --- Service Providers**

- Promotes a relationship in which family members and professionals work together to ensure the best service for the child and the family
- Recognizes and respects the knowledge, skills and experiences that families and professionals bring to the relationship
- Facilitates open communication so families and professionals feel free to express themselves

More on Collaboration

- Acknowledges that the development of trust is an integral part of the collaborative relationship
- Creates an atmosphere in which cultural traditions, values and diversity of families are acknowledged and honored
- Recognizes that negotiation is essential in a collaborative relationship
- Brings to the relationship the mutual commitment of families, professionals, and communities to meet the needs of children and their families

Source: Family/Professional Collaboration for Children with Special Health Needs and their Families by Kathleen Bishop

What families and professionals need in this collaboration

- Respect, Trust
- Information, Resources
- Safety, closeness and appreciation
- Expressions of opinion and emotion
- Acceptance of their diversity
- Access, voice, ownership

So much of it comes back to communication



A Communication Framework

Mary Claire Heffron from Children's Hospital in Oakland, California, is one of the developers of the Social-Emotional project for the Illinois Early Intervention System. She has developed a communication model that focuses on three categories.

Communication Framework

- How to Be
- How to Understand
- How to Influence



**What do you feel
these terms mean**

How to Be

- Be aware of your feelings
- Be respectful and follow the parent's lead
- Be empathetic (do not label or judge)
- Be aware there are many ways to see and experience one's reality

How to Understand

- Listen carefully, restate or rephrase when appropriate. Body language is just as important
- Ask open-ended questions. Don't move too quickly
- Try to understand before you try to influence
- Ask about something you are concerned about. "I notice that"

How to Influence

- Give specific feedback
- Encourage an experimental attitude
- Encourage self-reflection and observation skills
 - "How did he do this week," "How can you tell when...."

How to Influence

- Voice anticipated concern and caring – with suggestions
 - "I know you want Paul to graduate. You can help him if you set a time for him to do his homework and maybe sat near by in case he needs help."

How to Influence

- Ask, don't tell and ask questions with information
 - "Did you know the grocery store down the street has a sign up looking of help?"
 - "I've tried some different strategies with children like Mary, can I show you what I mean?"

How to Influence

- Use your own worries about the parents' concern.....
 - "I know this is a difficult subject for you, but I am concerned that John is still not....."

Putting it all together

- Avoid making assumptions
- Avoid jargon and acronym and explain what technical terms that are used
- Share complete, honest and unbiased information
- Offer opinions and specify that these are only suggestions, or options

Putting it all together

- Ask the parent for their opinion
- Respond to questions directly, but acknowledge when the answer is not known
- Avoid patronizing, language and tone
- Recognize individuals' different abilities to understand

Putting it all together

- Clarify mutual expectations
- Identify next steps
- Realign the power
- Respect restraints in family's time and resources
- Note and respond to nonverbal cues
- Create opportunities for open communication

When conflicts happen

- Separate the person from the problem
- Establish interests, goals and priorities
- Generate options that can achieve a win-win position
- Strive for agreement

Thank You

Joan Debelak, MSW
Early Intervention Training Program
708.444.8460, ext. 12
jplondike@aol.com

The Ending

- A family who has a child with special needs is a family first
- A child with special needs is a child first
