

Child with a Disability and Family Loss

Purpose of Presentation

- Leave with and share feelings, reactions, and experiences of families who have children with disabilities
- Leave with the ability to present programs, etc. that promote a more positive attitude toward people with disabilities

DISABILITY AND THE FAMILY

- No one ever plans on having a disability
- When an individual is severely affected by injury, accident or illness it has an enormous effect on not only their own life, but on those closest to them—which almost invariably involves the family

Children with Disabilities

- Approximately 1% of all newborn babies can be identified as having conditions that are disabling
- Another 1% of all disabling conditions are detected during the 2nd year of life
- From 8-11% of the school-age population will show conditions that need special education services (Someday's Child)

Families in Video

- Suzanne and Greg-daughter, Eowind, is mentally retarded
- Lynette and Tom-daughter, Erica, was born deaf, blind and multi-handicapped

Kubler-Ross Five Stages of Grieving

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

- May experience more than one stage at a time
- May not experience stages in order
- May not experience all stages
- May pass through stages more than once
- Parents usually pass through stages in continuous, cyclical manner (Singer, 1999)

Denial and Shock

- Medical condition of child becomes shock and feelings of disbelief-all like to believe we are immortal
- Feelings of shock and disbelief are followed by grief, helplessness, anger, guilt

Stages of Reaction From Parents (Callahan, 1990)

- Shock, grief and/or denial
 - Grieve much the same way if the child had died
 - May shop around for a second or third opinion

Anger

- Helplessness leads to anger toward fate or God for choosing their child
- Certain changes in life have to be made-stressful
- Resentment toward lack of available resources and support
- Tormented feelings of not being able to help your child or “make it all better”

“If only” and “Why us?”

- Initial numbness fades
- Come to grips with realities of new life
- Wonder what they did wrong
- Feelings of guilt
- “If only I had not smoked, the baby might be OK”, “If only”, “If only”, “If only”
- “Why me?”
- Anger

Bargaining

- Philosophical or religious crisis for parents
- Bargain with God or professionals to make child better

Bargaining Stage (“wait till stage”)

- Begins with parent’s refusal to accept reality of situation
- Hope if particular action taken things will suddenly be alright

Depression

- Parents responsible for child’s well-being
- Sick child may elicit guilty feelings from parents
- Feel could have prevented child’s disability- they are somehow to blame for child’s condition-feelings lead to depression

Acceptance

- Accepting that one’s child has a disability is the final stage of coping
- May feel guilty or depressed but better able to cope with feelings
- Now the question is “OK, what now?”

Acceptance Stage

- Can mean final, irrevocable end of dreams for child and family

Successful Grieving

- Involves letting go of old dreams and generating new ones
- If old dreams linger than each day can only be viewed as a disappointment or failure
- New dreams means child can be accepted and loved for who she or he is

Chronic Sorrow

- Some parents never experience a final acceptance and live in a world of sorrow where there is not laughter or hope
- Loss of self-esteem, depression, and guilt
- Need professional help at this point from social workers, counselors, etc.

Family Relations

- Felt neglected other children
- Marriages suffered
- Resented relatives failure to understand and accept child with a disability

Fears

- Fear of failure of child to grow mentally and physically

Parenting May Differ

- Feel they cannot scold, lose temper, make sacrifices-guilt
- Feel resentment due to forfeiting own pleasures
- Likely to feel more guilt if disability is hereditary or due to an accident
- May do too much for child-guilt related
- May deny disability exists

Effects of Disability on Family Life

- Financial

Siblings of Children with Disabilities

- In the United States, over 5.8 million children have disabilities. Most have brothers and sisters
- Throughout their lives, these brothers and sisters will share many—if not most—of the same concerns that parents of children with special needs experience, as well as issues that are uniquely theirs

Sibs

- Caught between 2 worlds
 - Outside world
 - World at home
 - Different demands form both
 - Want to be liked in both and do well in both
 - Outside-premium placed on normalcy-want to be like other children
 - At home they want to be different-stand out to parents-have to compete with “special child”-jealous and resentful

Siblings

- Do not neglect other children-sibs can feel deprived of love and attention because of disabled child-may act out to get attention
- Need one-to-one time
- Share responsibility of child with disability-father and mother take turns
- May not want to bring other children home-interfere with social life
- May not want other children-fear of another child with a disability
- Disability should be explained to sibs
- May have guilty feelings as they are "normal"
- May feel guilt about being angry with disabled sib
- Confused by conflicting feelings-love and affection-anger, jealousy (Dodd, 2004)
- Studies indicate that sibs of ewd or more anxious, withdrawn and depressed than sibs of cwod Prabucki, 1987; Cadman & Offord, 1988)

Grandparents, In-Laws, and Family Friends

- May have no real understanding of disability
- Common misconceptions
- May be critical of "other side of family" and say genetic or hereditary
- May want to have child institutionalized

Grandparents

- Double grief-grieve over grandchild and grieve over child's pain
- Loss of hoped for dreams for grandchild leaves them with grief, anger and anxiety
- Accepting reality is harder for grandparents-see less than parents

Affects of Disability of Family

- Parent Burn-Out-no respite
- Family Imbalance-parents spend enormous amount of time with disabled child

Feelings of Isolation

- Feel parents of children without disabilities could not understand them
- Resentment toward professionals

Services

- Support groups
- Respite care
- Professional counseling

Parent Groups

- Recognize how similar concerns are
- Felt less isolated
- Gained something from each other
- Made for happier relationships with children

How Parents Can Help Themselves (Thompson, 1986)

- Trade-off responsibility-take turns
- Weekly date-simple activities can refresh you

Helpful to Parents (Someday's Child)

- Someone to listen to families' concerns and accomplishments
- Someone to acknowledge their feelings
- Answers to questions about their children
- Info on where to get help outside the family
- Info on child and family development
- New ideas on how to manage their children
- Specific skills in handling difficult problems

Helpfulness (cont.)

- Support of families' self-confidence and esteem, recognizing their ability as parents
- Assistance in developing new ways to solve problems
- Support and acknowledgement for the many things they do that help their children every day
- Skills and support to plan independently for their children's future

Attitudes
are the Real
Disability

Attitudes

- Public attitudes toward disability are often the greatest barrier for people and children with disabilities
- Attitudes are learned through direct and indirect experiences and interactions with people, objects, and events and are highly influenced by the child's primary social group
- attitudes are manifested behaviorally by a predisposition to act in a positive or negative way when the person encounters the attitude referent

Origins of Attitudes Toward Children with Disabilities

- Societal response
- "body beautiful"/"body whole"
- "sick role"-person exempt from school activities or responsibilities
- Status of degradation
- Sin and punishment
- Victims-causality-just world hypothesis-deserve what they get
- Medical model-person dependent
- Death anxiety
- Media

Attitude Change

- Teaching Techniques
 - Information-lack of creates prejudice
 - Direct/indirect (media) contact
 - Group discussion/cooperative learning
 - Experiential-”I hear and I forget, I see, and I remember, I do and I understand” (Chinese Proverb)

Disability Simulations

- A simulation creates a representation of elements of reality to develop a learning activity so participants develop skills, gain knowledge or change their attitude about that reality
- Simulations, as often used in disability awareness training, involve "trying on" a physical, sensory, or cognitive impairment for a limited amount of time, and are sometimes followed by a discussion to explore what is learned (French, 1992; Scullion, 1999)
- Disability simulations are models or imitations of the disabling condition
- Able-bodied experiment with "alternate" ways of seeing, hearing, moving can effect positive changes in non-disabled attitudes toward disabled
- Involves awareness of emotional and functional problems that go along with a disability
- Know what one is feeling, feel what the other is feeling, and respond with compassion to another's distress
- Pros and cons-may trivialize disabilities-may create more negative atts.

Wheelchair Simulation

- Role playing activities appropriate among groups of orthopedically disabled and non-disabled children involve allowing non-orthopedically disabled children to experiment moving with crutches or wheelchairs. Use of wheelchairs and crutches by able-bodied preschoolers could be done in the play area, or in an outdoor setting depending on the able-bodied child's level of comfort. Discussion of the difficulties experienced when rolling in a wheelchair or navigating on crutches presents orthopedic, mobility disabilities as a surmountable challenge, not an impediment

Blind Walk



Kids on the Block - Vermont

- educates young audiences about differences, disabilities and social issues
- The Kids on the Block puppetry program was a successful method for instilling positive attitudes toward the handicapped in non-handicapped students
- The Kids on the Block had a positive effect that was maintained over time

Educating Children Through the Magic of Puppets

ADA Checklist

- <http://www.usdoj.gov/crt/ada/checkweb.htm>
- Google ADA CHECKLIST



ADA Guide for Small Businesses

- www.sba.gov/ada/smbusgd.pdf or Google
ada guide for small businesses



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