THE PARENTAL EXPERIENCE OF RAISING A CHILD WITH SPECIAL NEEDS AND THE NECESSITY OF A FAMILY-CENTERED APPROACH TO EDUCATION: A PROFESSIONAL DEVELOPMENT FOR EDUCATORS

A Project

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Allison Jean Rudig

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Department of Special Education, Rehabilitation,
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Abstract

of

THE PARENTAL EXPERIENCE OF RAISING A CHILD WITH SPECIAL NEEDS AND THE NECESSITY OF A FAMILY-CENTERED APPROACH TO EDUCATION: A PROFESSIONAL DEVELOPENT FOR EDUCATORS

by

Allison Jean Rudig

The purpose of this project was to create a professional development for school personal which would increase their understanding of chronic sorrow, the parental experience of raising a child with special needs and family-centered practice. To gather information for the training, research literature was reviewed which explored the educational partnerships between school staff and families, looking specifically at families who have children with special needs and the roles that these partnerships may play in creating stressors that trigger states of chronic sorrow. Findings from the research showed that educators' current perceptions of the chronic sorrow process and understanding of the parental experience, as it relates to raising a child with special needs, were extremely limited (Bringham & Abernathy, 2007; Mandell & Murray, 2009). The research further suggested that a family-centered model of practice serves as the best model for parents, children and staff. However, educators' understanding (including those of teachers and administrators) of this model of service is often limited or incorrect

(Bringham & Abernathy, 2007; Dunst, Boyd, Trivette & Hamby, 2002; Espe-Sherwindt, 2008; Mandell & Murray, 2009). Clearly, the finding from the research strongly supported the need for a professional development which would increase educators awareness of both the parental experience and family-centered practice. The content of the two day professional development program includes discussion and information about the loss of the "dream/ideal child;" a look at the variety of family systems and the way in which one members response to a child's disability influences the other members of the family; the chronic sorrow and coping process that is associated with raising a child with special needs; the idea of "acceptance" of a child with special needs is explored; the role the school system plays in the sorrow process; parental experiences in working with the schools; how schools and parents can form a positive partnership; the need for a family-centered approach to education; the current professional centered model that is found in many schools; the role the law plays in the parent advocacy role; and what educators can do to help alleviate some of the grief experienced by parents of children with special needs.

_______________________________, Committee Chair
Jean Gonsier-Gerdin, Ph.D.

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Date

DEDICATION

This project is dedicated to my son Blake Rudig. He inspires me in ways no one will ever fully understand. I am a better person for having been blessed to be his mother. Often life hands us many of things for which we cannot plan. When life handed me him, I became awakened, driven and I found the true meaning of joy. He has been my greatest teacher thus far.

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Chapter 1

INTRODUCTION

When planning to have a family, there are many hopes and dreams that begin to fill the minds and hearts of the parents to be. Dreams, perhaps, of what sports the child will play, what they will be when they grow up and whose personality traits they will inherit. It is often a time of joy and laughter that is shared with the family's closest friends. It is not very often that the expecting parents consider the possibility that something could go differently from what they have planned or dreamed. Yet, it is a truth that some parents will face. For some, it is at the birth of the child that they learn that their life has taken another course than planned, and for others it may be at a later date that they come to find they must take a different path. Regardless of how it comes to be and regardless of the diagnosis of the child, these parents share a commonality that is not widely discussed, but is seen in many parents with a child who has special needs; a loss of the ideal child (Bruce & Schultz, 2002; Gordon, 2009; Macgregor, 1994; Moses, 1999).

While parents of a child with special needs will often come to accept their child's diagnosis, they still must face the reality that the dreams they have created for their child must now be altered to fit the child they have been given. They face societal opinions and prejudice (Kearney & Griffin. 2001), and the schooling of the child now becomes a situation where they may be forced to not only act as the parent, but also an advocate for their child (Drolet, Paquin, & Soutyrine, 2007).

In an effort to deal with this newfound situation, for which many of the parents are unprepared, the parents develop coping strategies (Drolet, Paquin, & Soutyrine, 2007; Hobdell, 2004; Roll-Pettersson, 2001). As a result of the loss of the ideal child, many parents of children with special needs experience what has been termed “chronic sorrow,” as they struggle to deal with the living loss of the child of whom they have dreamed (Bruce & Schultz, 2002; Gordon, 2009; Hastings, Krovshoff, Brown, Espinosa & Remington, 2005; Macgregor, 1994; Moses 1999).

Background of the Problem

Often, parents of children with special needs are placed into the role of advocate for their child, adding an additional stressor to their lives and forcing them to find a way to cope with the new found role (Drolet, Paquin & Soutyrine, 2007). Additionally, these same parents may encounter within the education system (and their day to day lives) people who view their child as less than capable, set low limits for their child, and see the parent’s acceptance of the child as a denial of the actual limitations that the child has due to their unique needs and/or the diagnosis (Kearney & Griffin, 2001). This lack of understanding of the parents’ experience in raising, coping with and grieving for the child with special needs may actually hinder the educator’s ability to understand and foster the relationship that is needed to alleviate the stressors and relieve some of the sorrow felt by the parents (Bruce & Schultz, 2002). It can also bring forth the possibility of the educators being unable to see the parents’ input as valuable and worthy of being heard, as the educators may view the parents as idealistic and unable to cope with and accept the child's diagnosis (Blue-Banning, Summers, Frankland, Nelson & Beegle, 2004; Stone, 1999).

By fostering understanding of the parents' experience and raising awareness to the best practices in working with parents of children with special needs, many of the stressors and sorrow that is felt when dealing with the child's educational system might be eliminated. Raising awareness and moving toward the family-centered model of practice has been shown to foster parent-professional collaboration and overall family functioning (Blue-Banning, Summers, Frankland, Nelson & Beagle, 2004; Droplet, Piquing, & Soutine, 2007; Duns, Boyd, Trivets & Hamby, 2002).

The family-centered model of practice has received national support from legislative actions which include the Education of Handicapped Children Act Amendments of 1986, reauthorizations of the Individuals with Disabilities Education Act of 1990 and the Families of Children with Disabilities Support Act of 1994 (AAP, Committee on Children with Disabilities as cited in Conception, Murphy, & Canham, 2007). Benefits of the family-centered model of practice include significant improvements in the child's physical and psychosocial health (Bruce et al., as cited in Conception, Murphy& Canham, 2007) that leads to enhanced learning, higher literacy performance and a reduction in missed school days (Conception, Murphy & Canham, 2007). Parental involvement, which is supported and encouraged in the family-centered model, has also been shown to foster an increase in the child's skills (Bringam & Abernathy, 2007). Yet, even with all the known benefits and support of utilizing a family-centered model, the amount of actual family-centered practice has been "shown to decrease at each level from early intervention to preschool to elementary to secondary school programs" (Murphy & Canham, 2007, p. 316). Additionally, administrators admit that parental involvement, which is critical to the success of family-centered practice, is limited in the field of education (Mandell & Murray, 2009).

Research has found one reason for the decrease in the family-centered model of practice as the child progresses in grade level is due to the professionals' lack of understanding and comfort level in working with families, especially those families of children with special needs (Bingham & Abernathy, 2007; Mandell & Murray, 2009). Furthermore, resources that provide information on the best practices on the parental experience, as well as the family-centered approach to education are not readily available to those in the field of education (Bingham & Abernathy, 2007; Mandell & Murray, 2009). Much of what is available appears in the form of brief journal articles (many which are written for those in the field of social work or nursing), or a few large books and webpages with limited information. Nevertheless, this information is critical to developing the educators' understanding of the value of the parent/school partnership and the significant role that family-centered practice plays in improving student outcomes (Mandell, & Murray, 2009). Professional development on these topics for educators appears to be virtually non-existent in the greater Sacramento area, as the author of this project was unable to locate any school districts (of the nineteen contacted) that offered this type of professional development to their staff. This lack of resources leaves many current teachers without the knowledge of how to best serve their students, and finds many administrators with a limited understanding of the value and importance of family-centered practice (Mandell & Murray, 2009). Further, while training on family-centered practice may be offered in the teacher preparation programs, it has been found that much of what is taken away from these trainings are the legal aspects of the special education process rather than the need for a family-centered model of practice (Bringham & Abernathy, 2007). When schools are not grounded with an understanding of family-centered practices, they often "present families with a 'one-size-fits-all' model of activities or events, with only limited attention given to creating a respectful relationship with families" (Mandell & Murray, 2009, p. 32).

Currently, there is a clear divide between the research supported family-centered practice and the skills and understanding needed to implement this practice in the educational setting. Research has shown that needed skills are lacking across the field of education, as many preparation courses are focused specifically on special education law (Mandell & Murray, 2009). The lack of understanding regarding family-centered practice is evident in pre-service, entry level teachers, and even experienced teachers (Bringham & Abernathy, 2007), as well as administrators (Mandell & Murray, 2009). It is the objective of the professional development created by the current project to move teachers and administrators away from the law-focused thought process to a more methodical, family-centered approach to educating children.

Purpose of the Project

The goal of this project is to create a professional development program for administrators and teachers, in an effort to help foster a better understanding of the loss and cycle of grief that many parents of children with special needs experience. The professional development provides a look at the parental experience, the role that the school system plays in this experience and how movement to a family-centered model of practice would be of benefit to the students, the families and the schools. The current project ends with discussion of how to begin to implement such a model, asking those involved in the professional development to begin with a single course of action toward a more family-centered approach.

Significance of the Project

Many pre-service teacher and administrators do not naturally have the needed skills to effectively include families in their day to day practice (Morris & Taylor, 1997, as cited in Bringham & Abernathy1997, Mandell & Murray, 2009). In fact, in a study by Bingham & Abernathy (1997), it was found that many pre-service teachers “were more focused on the system rather than the child” (p.55). In other words, they tended to be more focused on the legal mandates than the people that the laws were designed to protect. Bingham & Abernathy (1997) went on to state, “it is possible that our students are sending messages to the families they encounter that completing the IEP is more important than the people involved in the process,” (p.55).

It is the goal of the project to help educators understand the ways they can help to alleviate some of the stressors and sorrow that is felt by parents when dealing with the current education system. In particular, the professional development strives to open the doors to awareness and understanding; thereby alleviating some of the grief and avoidance coping used by parents and paving the path for a better educational environment for the educators, student and family as a whole. The project has the potential to benefit not just the parents of children with special needs, but also educators and administrators who work with the students and their parents.

The professional development will provide a way for teachers to understand the lived experiences of raising a child with special needs and the sense of both loss and hope that comes with it. It is the hope that, by developing this understanding, teachers and administrators will begin to question the current practices that are being used in many schools. This questioning could lead to a change in the individual teacher’s response to parents as well as an overall change in schools’ and districts’ responses to parents. These changes could lead to the more effective use of family-centered approaches, understanding of both the parent and child and hopefully, a better understanding of the need for inclusive educational practices.

The benefits of a positive parent teacher partnership are limitless and will have a lifelong impact on the child and their family. The ideas contained in this project can be altered to develop a professional development or handbook for parents on how to form successful school partnerships, but for the purpose of the project, the focus will be on the educator’s ability to understand and engage with parents using the family-centered approach.

Limitations of the Project

This project serves as a professional development tool for educators using the best practices of serving children with special needs and their families. As the research literature is limited on the needs of parents specific to their child’s disability, this professional development provides a general overview of the coping and chronic sorrow that is seen in most parents of children with special needs and is non-diagnosis specific. Additionally, the professional development is currently designed to be a two-day program and as a result the follow-up with participants may be limited. The professional development is in no way intended to represent the views of all parents with special needs, as each individual parent and family deals with the stressors of having a child with special needs in a deeply personal and individualized manner. However, research has indicated that there are commonalities among parents of special needs, including the sorrow that they experience and the manners in which they cope (Bruce & Schultz, 2002; Mallow & Bechtel, 1999; Gordon 2009; Kearney & Griffin, 2001; MacGregor, 1994; Moses, 1991; Roll-Pettersson, 2001; Teel, 1991; Yan, Li-Tsang, 1998). It has also been found that there are common triggers for the sorrow and coping, and that a family-centered model of practice could help alleviate the triggers. This project will address those commonalities and family-centered practices (Blue-Banning, Summers, Frankland, Nelson & Beegle, 2004; Drolet, Paquin, & Soutyrine, 2007; Dunst, Boyd, Trivette & Hamby, 2002).

Definition of Terms

Active Coping

This is the process of taking active steps to try and deal with, remove or alleviate the stressors associated with raising a child with special needs. Types of active coping include learning about and understanding the child's disability and seeking social support (Hastings, Kovshoff, Brown, Ward, Espinosa & Remington, 2005).

Avoidance Coping

This refers to avoidance of the stressors associated with raising a child with special needs. Common avoidance techniques include the use of alcohol or drugs, unwillingness to talk about the situation or feelings and an inability to move through the grief process by acknowledging and talking about the feelings the parent is experiencing (Hastings, Kovshoff, Brown, Ward, Espinosa & Remington, 2005).

Chronic Sorrow

Olshansky (1962) first coined the term, chronic sorrow, as a normal pervasive psychological response in the suffering of parents of children with special needs. Chronic sorrow is a natural response to a tragic event that manifests itself through the life of the parent-child relationship (as cited in Gordon, 2009).

Family Allied Model of Care

This is a type of professionally centered model of practice which views the families as capable of caring for and dealing with the child with special needs so long as they listen to and follow professional recommendations and implement suggestions for care under the guidance of the professional. In this model of care, it is believed that the families need professional assistance in order to be capable (Dunst, Boyd, Trivette & Hamby, 2002).

Family-Centered Model of Care

The family-centered model views the families as partners who are capable of making informed choices regarding the care of their child. This approach has been shown to support and strengthen the family and improve the family’s ability to function (Dunst, Boyd, Trivette & Hamby, 2002).

Family Focused Model of Care

This model begins to view the family as capable of making choices, but the choices are limited to what is considered to be resources, support and other services that are necessary to improve family functioning (Dunst, Boyd, Trivette & Hamby, 2002).

Grief

This term refers to a complex process that encompasses a range of emotional responses. These responses include denial, anxiety, fear, guilt, depression and anger. According to Dr. Ken Moses (1999), grieving is an unlearned, spontaneous, self-sufficient process. Moses states that the emotions and feelings associated with grief do not follow a set order and the feelings of grief must be shared if the parents of a child with special needs are to begin to strengthen and grow from the experience of the loss of the ideal child.

Nonfinite Loss

This term is often used interchangeably with chronic sorrow in the research and trainings on grief and sorrow for the medical field. Nonfinite loss is used to refer to feelings of one of the states of grief that are often associated with raising a child with special needs (Bruce & Schultz, 2002).

Professionally Centered Model of Care

This model views the professionals as experts in the care of the child. Little to no concern or value is given to the family’s input and views of what would be best for the child. In this model, the families are seen as less knowledgeable and capable then the professionals. For this reason, the professionals make the decisions and then inform the parents of the decisions that have been made (Dunst, Boyd, Trivette & Hamby, 2002).

Strengths-Based Approach

This is an approach to working with families which explores the best way to support the child by making use of the child's personal and family strengths, skills, reactions, community ties, and resources available in the child's social and cultural environments (Drolet, Paquin & Soutyrine, 2007).

Student with Special Needs

IDEA 2004 defines a child with special needs as a child evaluated in accordance with Sec. 300.304 through 300.311 and found to have an intellectual disability, a hearing impairment, a speech or language impairment, a visual impairment, a serious emotional disturbance, an orthopedic impairment, autism, traumatic brain injury, another health impairment, a specific learning disability, deaf-blindness, or multiple disabilities.

Organization of the Remainder of the Project

Chapter 1 serves as an introduction to the project and explains the purpose, background, significance and limitations of the project. Chapter 2 provides a review of the literature, specifically examining the following: the history of chronic sorrow; coping strategies used by parents of children with special needs; the school's role in the coping process, which includes best practices in working with parents of children with special needs; the family-centered approach to education; the role that educators play in a parents' experience of chronic sorrow; and the need for a professional development in these areas. Chapter 3 describes the methods that were used to gather information for the project and how the final project was developed. Chapter 4 is a detailed description of the completed project, including a discussion, implications for practice and recommendations for further research. The appendix contains the final project and the project ends with a list of references.

Chapter 2

REVIEW OF THE LITERATURE

When a person or a couple gives birth to a child with a disability all that she or he had hoped and dreamed of may shatter, forcing the couple into a new world for which they are not fully prepared. Parents must learn to raise the child they have, letting go of their old dreams and creating new ones for their child that has the disability. Although this re-creation of new dreams is different for every family, the parents will often experience a type of grieving which is referred to as chronic sorrow or nonfinite loss (Moses, 1999). Factored into the grief are the various ways which the parents of children with disabilities cope with their feelings and while studies indicate that no two people experience the grief cycle in exactly the same way, commonalities have been found in events that can send a person into a cycle of grieving (Bruce & Schultz; Mallow & Bechtel, 1999; Kearney & Griffin, 2001; Roll-Pettersson, 2001). Such an event may occur during the parents' interactions with the school and school personnel. These interactions can create situations where the parents may be viewed as being unrealistic, non-cooperative or radical (Drolet, Paquin & Soutyrine, 2007). Parents of children with special needs have expressed concern with not being heard or respected, and not being seen as an equal player in the decision making processes regarding their child's educational needs and services (Burden & Thomas, 1986; Park & Turnbull, 2002). This lack of partnership between the parents and the schools can send parents into cycles of grief that may leave them experiencing feelings of isolation, rejection, anger, hurt or fear, as well as feeling as if they have failed their child (Kearney & Griffin, 2001).

While these issues of sorrow and coping are widely discussed in the literature, there does not appear to be any available research that specifically explored the issue of chronic sorrow and the role that the education system plays in the process. Additionally, very little attention or professional development has been given to the matter of chronic sorrow and how teachers and parents can form better partnerships to aid in decreasing the grief cycles.

This literature review will focus on the issue of chronic sorrow and coping in the parents of children with special needs as they related to the school setting. As the literature is extremely limited in this area, the research reviewed includes the current coping mechanisms used by parents of children with special needs; particularly examining what common events and situations cause parents to experience a state of chronic sorrow, as well as the parents' experiences in working with the school system. The literature reviewed also explores research on the best practices in working with parents of children of special needs in the hope of developing a professional development for educators that will work towards the building of more collaborative partnerships and thereby, aid in decreasing the parents' negative feelings.

Parental Chronic Sorrow and Coping

Much of the literature surrounding parental chronic sorrow and coping examines the relationship specific to certain disabilities and/or behavioral issues (e.g. coping with a child with autism). Limited research was located on parental coping and chronic sorrow in the generalized population of parents with special needs children. However, reviews of the more specifically focused work found great commonality across disability, severity of the child’s disability, and the socioeconomic status of the parent in terms of coping mechanisms (Burden & Thomas, 1986; Drolet, Paquin & Soutyrine, 2007; Hastings, Kovshoff, Brown, Ward, Espinosa & Remington, 2005; Hobdell, 2004). It is important to mention that differences were noted based on the gender of the parent in relation to the specific triggers for the grief cycle and the coping methods used by the parent (Mallow & Bechtel, 1999; Hastings, et al., 2005). Research also showed that family structures are not the same for all families and while chronic sorrow is permanent (i.e. the cycle of grief may reoccur), there are also times of happiness (Hastings, et al., 2005; Teel, 1991). In fact, it is clear from the research that many families of children with special needs are able to adapt to the stressors associated with raising the child with special needs through their development of individualized coping skills/strategies. The coping strategies were developed as a means of dealing with stressful situations and studies have shown a correlation between the intensity of the feelings of grief for a parent and the likelihood of the parent to report the use of a coping strategy. In other words, the more intense the feelings of grief, the more likely the parent reported the employment of a coping strategy (Hobdell, Grant, Valencia, Mare, Kothari, Legion & Khorana, 2007).

Concept of Chronic Sorrow

The first discussions about chronic sorrow began in 1962 when Olshansky developed the term as a means of describing the “normal” pervasive psychological response of parents with children who have cognitive delays. It was Olshansky’s belief that this sorrow experienced by parents was a natural response to a traumatic event. Olshansky asserted that the feelings of sorrow would reoccur throughout the life of the child in varying intensities. It was also his belief that most parents with a child with a disability would eventually reach a comfort level in living with the child who has a disability (as cited in Teel, 1991). Since this identification of the core concept, a variety of different terms and theories have been used to describe the sequence of feelings that parents go through when experiencing a state of “adjustment” or “mourning.” The labels of these stages range from grief to acceptance, depending on the literature and researcher. Stone (1989) recognized five states that parents go through 1) shock; 2) disbelief with varying stages of denial; 3) sadness, anger and anxiety; 4) adaptation; and 5) reorganization with the possibility of long term acceptance. The differentiating representations of states serve as examples of the many views researchers have regarding the grief cycle. Regardless, of the number of states in the grieving cycle, it is an individual process with some commonality in feelings and needs. Each person will experience the states in their own time and manner (Teel, 1991).

While there is a variation in the beliefs surrounding the duration and intensity of a stage in the parental coping process (Roll-Pettersson, 2001), it is generally observed that the adjustment to the disability is not an isolated process, but rather a lifelong period of adjustment as the child proceeds through his/her varying stages of development (MacGregor, 1994). Parents who grieve the loss of their “ideal” child may experience symptoms similar to depression; yet, chronic sorrow is not clinical depression, and labeling parents who are experiencing chronic sorrow as depressed can lead to mismanagement of their care and steer the parent toward ineffective coping strategies (Gordon, 2009). Further, it is imperative that we understand that a parent’s acceptance of their child’s diagnosis and/or disability does not mean that the parents will no longer experience feelings of grief and sadness and will no longer need to cope with the stressors associated with raising a child with special needs (Yau & Li-Tsang, 1999).

Expanding on the ideas of Olshansky, psychologist Ken Moses (1987) suggested that the pain that the parents of a child with a disability experience serves as part of their growth/healing and is not a problem in and of itself. The core of Moses’ theory is that when parents are expecting a child, they begin to develop hopes and dreams for that child while they are still pregnant. When the child is born with a disability (or becomes disabled somewhere along the course of his or her life), the parents must begin to form new hopes and dreams that fit the child they now have been given. Nevertheless, they may continue to grieve at various times for the loss of the child they expected to have. Moses (1987) maintained that grieving is an unlearned and natural response of the parent and is a way for the parents of the child to deal with the “unthinkable.” Moses also suggested that parents of children with special needs either become more or less able to acknowledge their child’s needs based on their ability to accept and experience the grieving process. If parents do not allow themselves to grieve the loss, they may become stuck in a state of grief, and attempt to cope using strategies that some of the studies in the literature reviewed have defined as active avoidance (e.g. turning to work, alcohol, or becoming depressed) (Hastings, et al., 2005).

Relationship Between Chronic Sorrow, Parent Gender and Other Variables

The relationship between chronic sorrow and a parent’s gender was explored in a qualitative survey by Mallow & Bechtel (1999). The authors examined the patterns and feelings of parents who have children with special needs and who were residing in the same house. Findings from the study showed that sixty-one percent of the parents at the time of the survey had emotions consistent with chronic sorrow. Sixty-eight percent of the mothers reported a greater reoccurrence of feelings of chronic sorrow, while forty-four percent of fathers reported feelings of chronic sorrow related to their child's need. The results indicated that after a diagnosis, mothers of a child with special needs were more likely to express feelings of chronic sorrow, whereas fathers expressed feelings more closely related to frustration. Additionally, the study found that there was a difference in the trigger events for chronic sorrow based on the gender of the parents. For example, mothers were more likely to experience feelings associated with chronic sorrow for events related to the care of the child, while fathers often experienced chronic sorrow when faced with social issues and norms. When asked what caused reoccurrence of feelings of grief, many mothers responded that it was when they were asked to think about the first time they found out about their child's diagnosis. In addition to exploring gender differences in the triggers for chronic sorrow, the study also explored differences in coping skills between genders and discovered that fathers may direct their energy toward planning and providing, while mothers may direct their energy toward seeking out information about the child's diagnosis and other caregiving tasks (Mallow & Bechtel, 1999). In the study, both genders discussed ways that providers and educators had intentionally or unintentionally made them feel. Feelings created by the actions and words of the resource providers and educators included the feeling of being punished for their child's diagnosis, being made to feel as if they were less than they were, feelings of guilt for having a child with a disability, or feelings of blame for their child's condition (Mallow & Bechtel, 1999).

The finding of differences in triggers for chronic sorrow based on the parent's gender was also supported by Hobdell (2004). This author studied chronic sorrow and depression in parents of children with neural tube defects. Hobdell's study measured the parent's current level of chronic sorrow, the initial level of chronic sorrow experienced by the parents at the time of the child's diagnosis, and the level of parent depression using Burke's Brief System Inventory (as cited in Hobdell, 2004). Findings from the study indicated that both mothers and fathers experienced the state of grief more frequently and at a higher intensity, than any other state within the chronic sorrow cycle (e.g. anger, shock, etc.). Mothers and fathers also had high intensities of sadness with a difference being that mothers noted feeling the same intensity of fear as sadness. Overall, mothers in the study consistently reported more chronic sorrow than fathers. Finally, the findings supported the data and personal narratives from other studies that suggested no two people experience chronic sorrow, grief and coping in quite the same manner (Drolet, et al., 2007; Hastings, et al., 2005; Kearney & Griffin, 2001; Moses, 1999; Roll-Pettersson, 2001).

In a study that investigated the coping strategies of parents of children with autism, Hastings et al. (2005) also illustrated a relationship between the parent's gender and the coping strategy used. The authors used the brief situational format of the COPE Inventory (Carver, Scheier, & Weintraub, 1989) to explore the coping methods used by parents in their study. This inventory looked in detail at two types of coping strategies that are commonly used by parents: 1) active avoidance coping which includes: the use alcohol or drugs to get through, giving up on the attempt to cope, self-blame for things that happen and criticizing oneself; and 2) problem focused coping includes, coming up with a strategy about what to do, obtaining help and advice from others, getting emotional support from others and the ability to see the situation in a different, more positive light. Hastings et al. (2005) found that parents who use active avoidance strategies to cope with their child having autism reported more stress and mental health problems. In contrast, when parents used problem focused coping, less stress was reported. The study also found that a relationship existed between the type of coping strategy used and the parent's ability to deal successfully with the child's needs. Findings from the study showed that mothers reported a more frequent use of problem focused coping than fathers. In short, the study supported the theory that active avoidance coping strategies, regardless of parent gender, was associated with stress, anxiety and depression; whereas, when parents utilized a more positive coping and reframing strategy, lower levels of depression were found, also regardless of gender.

Complex Nature of Parental Experience of Chronic Sorrow

Burden & Thomas (1986) reviewed literature on parents' coping and grief and suggested that current research approaches have placed an emphasis on negative emotions, guilt and anxiety. The authors contend that this current practice provides little insight into the wide range of parental reactions to a child's disability. The authors identified the stressors in parents as something that was unique to each individual. To support this idea, the authors referenced a study they had done with parents of children with special needs. Burden and Thomas (1986) used the interviews from their study to illustrate the resilience that could be seen in some parents who were facing conditions that the authors felt should overwhelm them, yet the parents continued to be able to advocate for their child. On the contrary, the authors spoke of parents interviewed whose children had minor disabilities or who had professional support, but still found themselves depressed or ill due to their own vulnerabilities. The study done by Burden and Thomas (1986) clearly illustrated the complex and individual nature of the chronic sorrow cycle.

This complex nature was further examined in a qualitative study that focused on the feelings and responses that parents of children with a cognitive disability had. In the study, Roll-Pettersson (2001) found that parents referenced their day to day feelings and concerns, rather than specific events when describing what may cause them to enter into a state of chronic sorrow. Some parents in the study described their feelings as being “thrown back in time” and many expressed feelings of sorrow when they thought about their child’s disability and the difficulties associated with it. These parents expressed a worry over and fear about what the future would bring as well as sense of wondering as to why having a child with a disability had happened to them. They also expressed the grief that was brought on from the actions of others and from professional’s beliefs that one intervention or model is best for all children with a particular disability. In this study, Rol1-Pettersson (2001) also looked at parental acceptance of the child’s disability and what acceptance means from the parent’s perspective. Participants in the study described the beginning stages of acceptance as “trying slowly but surely to dig our way out of a hole" (Roll-Pettersson 2001, p. 8). Another form of the parent's acceptance was found in the recognition that there was nothing that could be done about the diagnosis of the child and that life had to continue. Finally, some parents acknowledged the loss of their ideal child and accepted their child as they were:

> There was once a hope that if we did this or that, that he would be like any other child. That is beyond me now. I have accepted Oscar for what he is. He can be just the way he is (Roll-Pettersson, 2001, p. 9).

In another study, Kearney and Griffin (2001) explored the experiences of six parents of children with significant disabilities. Findings from the study indicated that these parents were aware of their sorrow. The parents in the study said that they will always live in a place that is somewhere between joy and sorrow. The parents also stated that a large majority of their sorrow stemmed from or was triggered by other people's projections of negativity and hopelessness onto the situation. These same parents spoke of their joy of raising their child, expressed feelings of being a better person because of their child and shared that their child is what inspired them to keep going when times were hard. In addition, the parents in the study discussed that their assumptions were constantly being challenged. As one mother in the Kearney and Griffin (2001) study stated, "...you're a million times happier because he's done it, because he wasn't supposed to be able to do it," (p.587). This study also indicated that a large amount of the daily feelings of sorrow seemed to be created by the perception and actions of outside sources; something that the authors believed could potentially be prevented.

Variables Related to Current Practices in the Educational System

Burden and Thomas (1986) suggested that one of the main factors in an individual's differential abilities to cope and handle the stress of raising a child with special needs is not only the extent and nature of the disability, but also the tolerance of the community regarding a particular disability. These authors further stated that the professional literature may be created with little attention or concern given to the voice of the parents. They suggested that professionals need to begin to ask the parents what they think and feel if we are to understand why they act in certain ways. Moreover, the authors contended that some professionals can actually produce conditions which limit the families by creating such an enormous gap between the parent's needs and the services that the professionals actually provided to their child (Burden & Thomas, 1986).

Professionals have also been found to view the chronic nature of the grief cycle that is experienced by many parents of children with special needs as a form of denial (Bruce & Shultz, 2002). Yet, what may appear to an outsider to be denial of a child's disability may, in fact, be avoidance of certain situations. Bruce and Shultz (2002) explained that some parents favor avoidance to reliving and working through the memory of the loss of the "ideal child." The authors further discussed that when parents are given information about their child, it may bring up feelings that the parents have not yet had time to process or work through. One parent from the Bruce and Shultz (2002) study expressed her need to avoid discussing her feelings, in order to cope with the situation, when sharing about her experience from a meeting with her child's teacher:

> I heard what she was saying I could do with Sam at home, but I knew I couldn't do anything about it… I wanted to be

> honest to tell her, I couldn't fit it in … but what would she think of me… what sort of mother would she think I was? In the end it was easier to pretend (p.10).

In an effort to reduce the states of grief experienced by many parents of children with special needs, it is important that those who work with the parents understand the mechanisms parents may use to help cope with their child's condition (Hastings et al., 2005). Professionals also need to understand that the birth of a child with special needs may cause a sense of sorrow for some parents; yet, this sorrow does not always mean that the parents have failed to acknowledge or accept their child's needs. Further, professionals working with the parent should not expect all parents to "accept'' their child's disability (Roll-Pettersson, 2001). As one parent offered:

> Professionals could help parents more-and they would be more realistic if they discarded their ideas about stages and progress. They could then begin to understand something about the deep lasting changes that life with a retarded son or daughter brings to parents… Most parents, I believe, never fully resolve the complexity of feelings about their child's retardation. They don't just 'adjust to it' or 'accept it' that fact, at least not in the way psychology books describe it (Roll-Pettersson, 2001, p. 12).

Regardless of the educator's belief as to the parental acceptance of the disability, there are many strategies for working with the parent of children who have special needs. When implemented, these strategies could serve to reduce unnecessary pain and stress in these children's parents (Blue-Banning, Summers, Frankland, Nelson & Beegle, 2004; Drolet, Paquin, & Soutyrine, 2007; Dunst, Boyd, Trivette & Hamby, 2002). Despite the fact that the research indicates that some of the sorrow experienced by parents of children with special needs could be eliminated in the school setting, there continues to be a lack of parental support in the educational system (Drolet et al., 2007; Dunst et al., 2002; Kearmey & Griffin, 2001). This lack of support may be due to the professionals not understanding the parent experience.

However, this lack of parental support cannot continue to occur. IDEA 2004 stresses the need for schools to give attention to the parent's voice by establishing federal policy which places families in the role of holding the system (e.g. school) accountable for the follow through on the Individualized Education Plan process (Wang, Mannan, Poston, Turnbull & Summers, 2004). This policy instantly forces many parents to serve as their child's advocate; a role which some parents were unprepared for and one which some parents may not want (Droplet, Paquin, Soutyrine, 2007). For the parents who do not desire the role of the advocate, it can become an additional stressor in their lives.

Interestingly, studies have demonstrated that when parents use their role as advocate as a way to cope with their child's disability, their stress is actually reduced and thus, their quality of life may be improved (Drolet et al., 2007, Hatings et al., 2005). In focus group discussions (Wang et al., 2004), parents stated that they believed that their role as an advocate enhanced their ability to cope with their child's disability, since they were required to learn skills and become knowledgeable of their child's needs in order to be an effective advocate. In contrast, the parents who deemed their role as an advocate to be a forced role, felt that the role only increased their stress. These parents felt that the schools should provide services to their child without "forcing" them to fight for them. Parents also stated that they wished for some aspect of the child's education that was positive, noting that the system seemed to take most things that they perceived about their child as positive and turn them around into a negative. It was the overall belief of the parents in the study (Wang et al., 2004) that the schools were more concerned with process then with the quality of the programs and services being offered. The general feeling that was given by many parents in the study was that the schools did not really educate and properly serve their children, but rather babysat them. Not all discussion regarding the school was negative, as some parents did praise specific service providers and teachers for the level of partnership and compassion that they showed. Findings from the study also indicated that parents need more collaborative partnerships within the school system and professionals to help them to advocate for the best possible services for their child, instead of advocating against them (Wang, et al., 2004).

In a qualitative research study regarding the coping strategies of sixty parents of children with violent behaviors conducted by Drolet et al. (2007), similar views on parental coping and lack of support from the educational system was found. This study was unique because it explored the way in which the parent’s perceptions of their involvement with their child’s school lead them to develop coping techniques so that they could play a more active role in the decision making process. Findings reported a desire from parents to be involved in their child’s educational process. Eighty percent of the sample used coping strategies to allow them to interact and participate with the school, yet only a slight majority of the parents (55%) stated that they had ever been invited by the school to participate and help find a solution to the problems their child was exhibiting. Almost the same amount (53%) stated that they were involved in the decision making process for their child. Nevertheless, over half of the parents did not feel that they had any power of influence at the school. The study also found that while almost half of the parents felt they had been involved in the decision making process for their child, over half interviewed were opposed to the measures that the school chose to take (Drolet et al., 2007).

Components and Outcomes of Family-Centered Practice

Research indicates that moving to a family-centered practice in the education system could result in more effective partnerships between schools and families; thereby reducing the feeling of sorrow experienced by the parents (Bingham, A. & Abernathy T., 2007; Bruce, E., & Schultz, C., 2002; Drolet, M., Paquin, M., & Soutyrine, M., 2007; Dunst, C. J., Boyd, K., Trivette, C. M., Hamby, D., 2002; Espe-Sherwindt, M., 2008; Gordon, J., 2009). This partnership could be created by 1) treating parents with dignity and respect; 2) honoring parental values and choices; and 3) support is provided that enhances the functioning of the family (Pretti-Frontcazk, Giallourakis, Janas & Hayes, 2002).

The previously mentioned Drolet et al. (2007) study reviewed the strength based (family-centered) approach to educational collaboration. The authors of this study defined this approach as one where parents are seen as active partners and their strengths are utilized to help make the best decisions for the child. The strength based approach to education is also supported by Feinstein et al., (2009) who emphasized the need to consider the larger social system in which the professional/parent relationships are embedded. Feinstein et al. (2009) pointed out that for each participant involved in the child’s care, there is a social system that must be considered. For the parents, the family system must be considered. A therapist brings with them the clinical system and the teacher brings the educational system. Each of these systems offer a unique prospective, which needs to be considered when beginning to put together an educational plan for the child and fostering the professional/parent relationship.

In addition, during their review of the research, Feinstein et al. (2009) found a study by Horvah & Symonds (1991) which suggested that the quality of the parent teacher relationship can have a strong influence on the child's treatment outcome. This finding is similar to the research findings that positive parent-teacher relationships lead to improved student performance (Dunst et al., 2002). When Feinstein et al. (2009) looked specifically at the research regarding the parent-teacher relationship, they found that a collaborative role between parents and professionals was necessary for the student to have supportive academic and social environments (Henderson & Map, 2002 as cited in Feinstein, et al., 2009). These authors also stated that in spite of these findings which speak to the value of family-centered education, "parental opinions, desires, and knowledge about their own children are discounted, ignored or even resisted by school personnel," (Feinstein, et al., 2004, p.331).

The disconnect between what parents need and what they are actually receiving exist, in part, due to the fact that not all of the professionals who work with parents of children with special needs see the value in the family-centered approach (Dunst et al., 2002). In the readings of approaches to working with families of children with special needs, it is common to find different models of intervention that the child receives and the role that the family plays in the intervention. The models range from being professionally centered models to the strengths based/family-centered model. Dunst et al. (2002) examined the relationship between the four different models that are commonly found. The models that they examined were the following: 1) The professionally centered model, in which the professionals are seen to be the ones with all of the knowledge regarding what would be best for the child. There is little, if any, attention paid to the needs, wants and desires of the family. The family is not seen as an active member in the decision making process; 2) The family allied model, in which the professionals are viewed as experts, but the families are expected to be the “agents” for the expert, by helping the professionals to implement the services the professionals have determined to be of need for their child; 3) The family focused model, which allows and views families as cable of making choices, but limits those choices to the resources and supports that will improve family functioning; and 4) The family-centered model, in which the parents are viewed as equal partners in the decision making process regarding their child (Dunst et. al., 2002).

For each model, Dunst et al. (2002) looked at the relational and participatory help giving practices of the professionals involved in that model type. Authors of the study defined relational practices as those practices that involved, “active and reflective listening, empathy, warmth, trustworthiness, etc. (Dunst et. al.,2002, p.222). Participatory helping giving practices were defined as practices, “that emphasize helpseeker responsibility for finding solutions to their problems and for acquiring knowledge and skills to improve life circumstances” (Dunst et. al., p.222). The level of professional help giving was determined based on the results from a Help Giving

Practices Scale which was administered to 214 mothers and 7 fathers who had children at risk for developmental delays. Findings from the scale indicated that both relational and participatory help giving practices were rated poorly in professional centered models. In the family allied models, relational scores were rated better than participatory scores. Both of these scores were rated highest in family-centered models. These findings indicate that both relational and participatory practices are what distinguish the family-centered model from all other models of practice (including other family oriented models), as family-centered models were the only model type to have high score ratings in both areas. Results also indicated that among family oriented models, the participatory not the relational aspects, of the family-centered model of service are what set it apart. While all family oriented models scored high in relational help giving practices, the family-centered model was the only model type to score high in participatory help giving practices. Thus, as the authors of this study pointed out, "the importance of participatory helping practices should not be overshadowed by claims about the benefits of good relational practice" (Dunst et. al., 2002, p. 227). This study clearly addressed the needs of the parents of children with special needs and the manner in which the schools should work to meet those needs.

A study by Bruce and Shultz (2002) looked at the implications that the communication, between parent and professional, can have on parental feelings of grief, as well as the ability to form a collaborative relationship with their child's school professionals. To form a true participatory partnership, which is a component of family-centered pratice, the authors stressed the need for clear lines of communication which is delivered in a conscientious manner. Further, Bruce and Schultz (2002) suggested that any information be provided to the parents when they can both be present together as each parent hears the information in their own manner and some of what is said may be lost if one parent is expected to relay a message to the other. The authors also offered the suggestion of delivering information to the parents in written form prior to the meeting, with careful attention given to the selection of the verbal and written word choice, so that they will have the chance to review and process more carefully. Of note, the study pointed out that it is important that professionals not assume that parents will always be happy with the delivery of good news. Many of the parents of children with special needs have faced a variety of circumstances and when news is delivered, regardless of how good it may seem to the professional, it may remind the parent of the loss of the “ideal” child. Bruce and Schultz (2002) concluded that a partnership between parents and professionals needs to be established so that parents feel that their opinions are a respected and necessary component.

In order to move toward this partnership between professionals and parents, a more collaborative relationship between the two parties must be formed. In a study by Blue-Banning, et al., (2004), focus groups of thirty-three adult family members of children with and without disabilities were conducted to gain an understanding of the behavioral factors that may serve as indicators of a family-centered collaborative relationship between educators and parents. Findings were reviewed and six themes emerged which were consistent with the characteristics of the family-centered model of practice: 1) communication, 2) commitment, 3) equality, 4) skills, 5) trust, and 6) respect.

In terms of commitment, parents in the study said that communication should be honest and open and should go both ways. They expressed that did not wish for information to be sugar coated and that they would like to hear some positive with the negative. The parents also asked that the professional jargon be removed so that they could better understand what is being said and that communication between the parent and teacher occur frequently in a high quality manner. With regard to commitment, the parents in the focus groups stated that they wanted professionals to work with their child only when they were invested and treated the job as more than just a paycheck. Many of the parents in the study felt that commitment was shown through home visits and the professional’s understanding that they were working with the whole family and not just the child. The parents defined equality as having an equal voice in their child’s education and being seen as an equal player whose contributions of ideas and resources were valued. In relation to skills, parents sought professionals who would look at their child’s unique needs and discover what worked for the child. They wanted a teacher that was willing to continue their education in order to keep up with the latest teaching and technology and who they felt could make changes happen for their child. Parents in the focus groups defined trust in terms of a professional’s follow through on commitments, discretion with information provided and ability to create an environment in which the parents felt safe leaving their children. Finally, it was important for the parents in these focus groups to have the professional respect their child and see him/her as a person first and not a diagnosis (Blue-Banning, et al., 2004).

Similarly, Park & Turnbull (2004) conducted sixteen focus groups consisting of sixty-nine families of children with disabilities. These focus groups looked at what these families perceived as quality indicators in the professionals that worked with their children. The findings from the study coincided with the Banning et al. (2004) study regarding the indicators of what makes a collaborative relationship. In the Park and Turnbull (2004) study, there were three themes that emerged as indicators of quality: 1) respect for the child, 2) having skills required to meet the child's special needs, and 3) being committed. Parents in the study said that they felt that a professional's show of respect toward their child was the initial step in building a positive relationship. According to these parents, respect for their child was shown by the use of language with their child, their child being treated with dignity, and the professional displaying a positive attitude toward the child. This positive attitude was defined by the parents as the professional's ability to see the positive aspects of their child and to value the things that make the child different. The parents also wanted professionals who believed in the abilities of their child and who would set goals for their child's future.

The attributes defined in the focus groups as being necessary to meet the needs of the child, were in agreement with the characteristics of family-centered practice and consisted of a commitment to life-long learning, an ability to provide positive behavior support, and help the parents develop skills to work toward inclusion (Park & Turnbull, 2004). These parents defined working toward inclusion as acting as a facilitator, helping with modification of the activities, and advocating for the child. In the area of commitment, parents of this study viewed professionals as committed when they did not limit their services to time or an outlined set of responsibilities. The participants also indicated that a quality professional is dedicated to the whole family and is someone who understands the importance of getting to know the child's family and home life (Park & Turnbull, 2004).

In addition to the positive parental outcomes highlighted in the afore mentioned research, the family-centered approach to education offers great benefits to the child. Collaborative, family-centered partnerships have been found to be a defining characteristic in the child's overall outcome (Mandell & Murray, 2009).The positive benefits of these partnerships has been extensively explored in by researcher Joyce Epstein (as cited in Turnbull & Turnbull, 2001). Epstein proposed that there are three key stakeholders that must work together to promote outcomes that can successfully affect both the child and the school. These stakeholders are: 1) family, 2) school, and 3) community. Epstein contended that when a positive partnership occurs between the three stakeholders/ "overlapping spheres of influence," students are engaged, energized and motived, leading to the creation of the student's own success (as cited in Turnbull & Turnbull, 2001).

A meta-analysis review of eighteen studies, Espe-Sherwindt (2008) found that family-centered practice was strongly correlated with self-efficacy beliefs, parent satisfaction with the program, parental perceptions of their child's behavior and functioning and their own parental behavior. Additionally, Espe-Sherwindt (2008) found that utilization of a family-centered approach leads to the development of control greater understanding and respect of the family's values and desires by professionals, and subsequently to increased family strength and control. When this understanding occurs, it is more likely that collaborative partnerships will form, strengthening not only the relationship between parent, child and school, but even the family unit.

Need For Professional Development

Although the research clearly shows that a family-centered model of care would offer the greatest benefit to schools, students, families and the community, this type of service delivery is seldom seen in the educational setting (Mandell & Murray, 2009). In a study done by Mandell and Murray (2009), the authors explored the disconnect between educational administrator’s understanding of family-centered practice and what was currently being seen in the school system. The authors shared findings from the 1991 National Education Goals Panel that showed that while school administrators acknowledged the importance and critical nature of parent involvement, it was lacking in implementation throughout schools nationwide. Mandell and Murrary (2009) conducted a study of administrators’ views of family-centered practice using a random sample of eighteen school administrators. The authors found that the lack of family-centered practice implementation was related in large part to a lack of true understanding of the family-centered model. Mandell and Murray (2009) suggested that the limited understanding is due partly to the fact that many leadership preparation programs limit themselves to courses in special education law. Regarding the professional preparation offered, only five of the eighteen administrators interviewed had received any pre-service coursework in regards to family-centered practice. Three of the administrators had a pre-service course, while two had attended a professional development workshop. However, of the five who stated that they had received some level of training, only one had a comprehensive understanding of family-centered practice. The authors contended, based on their research findings, that when a professional does not have a firm understanding of the concept of family-centered practice, they are likely to offer families a "one-size-fits-all" model of care with limited attention given to creating relationships with the families . (Mandell and Murray 2009).

This lack of understanding regarding the family-centered model of service is not only found among administrators. Bingham and Abernathy (2007) looked at the lack of understanding among pre-service teachers. In their study using concept maps to examine pre-service teacher's knowledge of family-centered practice, it was found that communication was seen by pre-service teachers as a verbal means to relay basic information and was not seen as a way to discuss the needs of the family and child. The pre-service teachers viewed their role as one that was responsible for the teaching of lessons, measuring progress and meeting standards. Further, many failed to recognize the true importance of the families' role in the collaborative process. The authors of the study concluded:

> While IDEA may espouse a "person-first perspective, it was evident in the concept maps that pre-service teachers were more focused on the system rather than the "child." It was the legalities if the IEPs, IFSPs and IDEA that captured the attention of the students rather than the human beings that the law and its mandatory documents were designed to protect (Bingham & Abernathy, 2007, p. 55).

While the current author was unable to locate any studies that explored current teachers' understanding of family-centered practice, based on the research reviewed, it is her conclusion that most all teachers regardless of level of service could benefit from professional development on the family-centered model.

Research in this literature review has shown that many parents of children with special needs experience intense feelings of grief that is related to their child’s disability. These feelings are typical and are experienced differently by each individual. The research has also shown that some parents will develop the means to cope with the feelings and stressors associated with raising a child with special needs. Studies have indicated that some of these feelings, stressors and the necessity to cope could be reduced when professionals form collaborative family-centered partnerships with the parents (Bingham & Abernathy, 2007; Bruce & Schultz, 2002; Drolet, Paquin & Soutyrine, M., 2007; Dunst, Boyd, Trivette, Hamby, 2002; Espe-Sherwindt, 2008; Gordon, 2009).

The research also indicated that when administrators have a limited understanding of family-centered practice, they are less likely to provide parents with opportunities to participate in the child’s education (Mandell & Murray, 2009); thereby creating conditions that may lead to the creation of unnecessary parental coping and grief and the decrease in the child’s overall ability to succeed. In light of these findings, the current project develops a professional development for school personnel on the parental experience and the importance of the family-centered model of practice in education.

Chapter 3

METHODS

This chapter provides information on the methods used to develop a professional development on chronic sorrow and family-centered practice for professionals in the field of education. Information found in this chapter includes: a) the manner by which information was gathered for the professional development program; b) the criteria for selecting the material used in the professional development program; and c) the process used for writing, editing and developing the professional development for educators.

The Manner by Which Information Was Gathered

In order to gather information for this project, the author began by contacting nineteen school districts in the greater Sacramento area to find out if they currently offered professional development on chronic sorrow, the parental experience and/or best practices in working with families. Of the districts, contacted none reported offering professional development on any of these topics.

The second step that the author took was to look at the literature that surrounded the topic of chronic sorrow. From this initial topic more topics began to emerge, as will be described in the section below (Criteria for Selecting Information…). Literature was located using the author’s college library, via recommendations from professors and through the resource library on the BEACH center website (the BEACH center on disability is based out of the University of Kansas and conducts research, training and projects to help aid families who have members with special needs. Their website contains many of the research reports, guides to policy, related news, trainings, etc.). The author also used the reference section of the articles found to be particularly relevant to identify other articles to review. Once the author had selected what information to be used, she began the process of reviewing each piece and categorizing the selections based on the information found. Each selected source was then used to help the author to write and develop the professional development program.

Criteria for Selecting Information Used in the Professional Development

The first step in deciding what information would be used in the professional development was to review the literature that was available and relevant to: a) the concept of chronic sorrow, and b) the school's role in the sorrow process (i.e. did the schools have an impact on the states of sorrow the parents experienced; and if the schools had an impact on the sorrow for parents, what, if anything, could be done to help alleviate the feelings). The literature on the concept of chronic sorrow was readily available and articles were found that either spoke of the parents' experiences in raising a child with a particular diagnosis (e.g. autism), or that looked at a broad overview of the concept and the stages within the grief cycle.

Obtaining articles that looked at the educator's role in the chronic sorrow cycle proved to be more challenging. While many of the articles related to chronic sorrow and coping experienced by parents of children with disabilities contained interviews with the parents in which feelings associated with a state of sorrow were expressed, there were no articles that directly addressed the schools' role in the chronic sorrow cycle. Further, when attempting to find articles that discussed how educators could best support the parents of a child with special needs, there were not any that addressed the concept of chronic sorrow. Information on how nurses and others in the medical field could support parents in the chronic sorrow cycle were readily available, and thus this literature was used as a foundation for what educators could also do in an effort to support parents and help alleviate some of the feelings of grief.

Many of the articles reviewed, regardless of the main focus of the article, discussed the need for trust and collaboration among parents and professionals. An overarching theme of family-centered practice began to emerge and it became evident through the research that this method of practice had the greatest positive impact on the family, student, school and community. However, it also became clear through the research done (i.e. review of articles on family-centered practice) that while family-centered practice is commonly utilized in social work settings and among medical professionals, it is not often seen utilized in schools.

Knowing that family-centered practice had the greatest potential positive impact, yet was lacking from the educational system, was grounds for further research. Articles were reviewed that examined the lack of understanding of administrators and pre-service teachers as related to the concept of family-centered practice. No articles were located that addressed current educators understanding of this type of practice.

Articles which were selected for the literature review and/or professional development were chosen based on the availability of articles related to the topic, as many of the topics selected for the review had limited articles written that pertained to the field of education. For this reason, most articles used in the review of the literature provide a broad overview of the concept of sorrow and/or coping experienced by parents of children with special needs (regardless of setting), or are geared toward professionals in the medical and social work fields. Additionally, all articles selected were peer-reviewed and had been published in either an educational or medical journal. To help select what information from the articles would be carried over to the professional development program, the author also reviewed two courses that were found during the research process. These courses were found via a database (EBSCO) search for research on professional development programs and educators understanding of the family-centered approach to education. The first was a parent group “intervention” (Barnett, Clements, Kaplan-Estrin & Fialka, 2003) that was developed to help parents increase their understanding of living loss and chronic sorrow that often stems from having a child with special needs. The second was a course that was developed by Bringham and Abernathy (2007) for pre-service teachers to help deepen their understanding of the parent experience and family-centered practice (see next section for further discussion on how these courses were used in the process).

The Process of Writing and Editing the Professional Development

To begin to create the professional development, the author first reviewed the above mentioned two courses listed above for overall content and desired outcomes (Barnett et al., 2003; Bringham & Abernathy, 2007). From the review of the courses, the author found the order of information delivery of information and some of the activities used with the participants to be a helpful guide for development of her own content. Specifically, the self-reflective nature of the activities seen in the Barnett et al. (2003) course and the necessity of participant’s understanding of the parental experience found in Bringham & Abernathy’s course were deemed most useful to the author’s own creation of a professional development. The current author examined the course layouts and contacted via email the authors, Bringham & Abernathy (2007) to obtain a course syllabus and copies of the articles which were used in their course. From here, the author reviewed all these articles and the syllabus to get an idea of the content delivered. The Bringham & Abernathy (2007), content and course outline was then compared to the content and outline in the Barnett et al. (2003) parent course. The outlines from each of the courses were used to help guide the creation of the professional development. The current author looked specifically at material presented, order of presentation, each of the authors’ rationale for including information and the use of activities to encourage participation.

Once the current author had a rough outline of the course flow, she reviewed the literature deciding what information to include in her presentation. During the process, she considered what information would be essential to an educator in order for him/her to gain a deeper understanding of the lived experience of a parent with a child with special needs and the value of a family-centered approach to education. From here, the current author visited the BEACH center website and the National Resource Center for Family Centered Practice to review professional development that had been created on parent-school collaboration, looking at the structure of the presentations and the depth of the information presented. A book by Ann Turnbull and Rutherford Turnbull entitled *Families, Professional and Exceptionality: Collaborating for Empowerment* (2001) was also reviewed to ensure that all essential content was covered. From this review, the current author made revisions and additions to the content. These included the addition of the different types of family structures and Joyce Epstein's "overlapping spheres of influence."(Epstein as cited in Turnbull and Turnbull, 2001).

This review of sources, coupled with the writing of the professional development program, led to a change in the target audience for the professional development. The initial thought by the author was to develop professional development for administrators on the parental experience. However, as the review of literature and materials progressed, it became evident that information about family-centered practice needed to be included in the professional development. As the development of the actual professional development began, it was found that all members of an educational team (e.g. pre-service teachers, teachers and administrators) would benefit from this type of professional development so the target audience was also changed to fit a more diverse audience which now included all teachers and administrators.

Once the above described review of the materials was completed, the author began the process of creating the PowerPoint slides which would be used in the professional development. To create the PowerPoint presentation, the author designed slides based on the outline created during the material review. Once the slides were completed, the author began to add her notes to the slide in order to aid in facilitation of the professional development workshop. To add the notes, the author went through the PowerPoint slides and orally reviewed the slides, making notes where needed. During this time, slides were also moved around to help aid in the flow of the presentation. Once the PowerPoint presentation was completed, the author established that the information would take approximately one and one-half to two day to deliver. As the author has not yet piloted the program, the estimate of length was based on the content within the professional development, the activities utilized to engage program participants and the authors desire to have panel of parents with children with special needs speak to their experiences of the loss of the ideal child and grief and coping they have experienced when dealing with their child's school.

The author then had a second reader, a parent of a child with special needs, review the slides and notes for ease of understanding and flow. The professional development was created with the help of a project advisor who is knowledgeable in the area of special education and family centered practice. The project advisor read the work, suggested which information to add and to delete until the final professional development was completed.

Chapter 4

PROJECT DESCRIPTION, CONCLUSIONS, AND RECOMMENDATIONS

The desire to develop this program stemmed from the current author’s personal experience as the mother of a child with special needs. Having a son with Down syndrome, she has experienced many of the states of chronic sorrow, some caused by factors that could have been controlled; specifically, those feelings of grief that were due in large to interactions with the educational system when supporting her son’s education. The current author has been forced to act as an advocate for her child since the early years of his education (i.e. preschool). At this time, her son was in an inclusive preschool and was faced with removal from the preschool program mid-year, when the administration in the district changed. The reason for the possible removal was not academic in nature; rather, the director did not feel that a child with Down syndrome belonged in an inclusive setting. This is just the beginning of a series of events that the author would face when attempting to ensure her child had a right to the education in the least restrictive environment which he was entitled under the law.

Further, the current author began to encounter other parents of children with special needs who were facing similar struggles with their child’s education. Many of the parents she encountered stated that they felt as if the school had no true desire to include them in the educational process and that the family’s desires for their child’s education were given little if any value during IEPs and other school meetings. The current author also noted that many of these parents had feelings of grief that were similar to her own and which they all believed could be reduced if the schools would support them to take a more involved role in their child’s education.

When the current author began the credential program to become a teacher she began to experience, during her fieldwork, the view of both parents and children with special needs through the eyes of the educators. While the view was not always negative, she did observe, as the research literature states that many of the education professionals with whom she worked operated from a professionally-centered model of practice, viewing their opinion as more educated and valuable then the families (Bingham & Abernathy, 2007; Bruce & Schultz, 2002; Drolet, Paquin & Soutyrine, M., 2007; Dunst, Boyd, Trivette, Hamby, 2002; Espe-Sherwindt, 2008; Gordon, 2009).

It was in this setting that the author began to understand that while many educators had the best intentions of the child in mind, they did not have a “true” understanding of the parental experience or the critical nature of parental involvement/family support within the educational system. It is with this insight that the author researched and began to create develop the professional development workshop.

Description of Project

The original purpose of this project was to explore the concept of chronic sorrow and the role that the educational system played in the grief cycle of parents who have children with special needs. The current author also hoped to find ways to alleviate the feelings of grief that many of the parents she had encountered attributed to their dealings with their child’s school. Ultimately, a professional development workshop was developed to heighten awareness among education professionals of the chronic sorrow states experienced by many parents of children with special needs and the role that they as educators can take to help relieve some of those feelings by utilizing family-centered practice.

The professional development workshop is entitled, “Families & Schools: A Look at the Family-Centered Approach to Education & Why it Matters.” The workshop is organized in the following manner: Introduction and program goals; Part 1: You are a complex individual; Part 2: The “ideal” child; Part 3: Family systems; Part 4: Chronic sorrow and grief; Part 5: What about acceptance; Part 6: The school’s role; Part 7: Family-centered practice; Part 8: Current practice; Part 9: The law; Part 10: What families need; Conclusion and references.

The professional development begins by introducing the goals of the workshop, the guidelines for participation and the current author’s reasons for creating the professional development. It is the hope that during this portion of the workshop, the participants will begin to become open to sharing with one another and establish an understanding of the desired goals and objectives. The current author has also chosen at this time to include a brief description of her reason for creating the professional development so that the participants will understand that they are receiving the perspectives of someone who is both a parent of a child with special needs and an educator.

In part one, participants are asked to take a look at all of the components that make them who they are (e.g., gender, education, religion, etc.). The purpose of this component is to remind participants that we are all complex individuals made up of a myriad of different components which come together to create our whole person. Participants are also reminded that these components create our differences; so while one person (or parent) may react to a situation in one manner, another person may react to the situation in a different way. Once this discussion on the complex nature of each individual has been given, the participants will introduce themselves and share their experience in working with families with children who have special needs. This sharing will be done so that the participants can get to know one another and see the variety of prior experiences in the room.

In part two, the participants are prompted to imagine that they are anticipating the birth of their own child. They are asked to consider the hopes and dreams that they have for the child. Next, the participants are asked to write a letter to their child. The purpose of this exercise is to help participants to understand that even before a child is born, parents begin to have hopes and dreams for their child; they begin to create the "ideal" child. Once the participants have completed writing their letters, they will be shown a slide which has a picture of a premature baby who is attached to tubes and is in the neonatal intensive care unit. They will be told to now imagine that their child was born four months early, weighs one pound and is deaf, blind and missing half of his/her brain. Participants are asked to consider what it feels like to have the dreams that they created prior to the birth of the child shattered. They are asked to consider that they now, as parents, must not only learn to cope with their child's disability, but they must also begin to form new dreams. The idea of this activity is to help the participants begin to understand the lived experience of a family who has just been told their child will not be the child of whom they have dreamed.

This portion of the professional development continues to talk further about the loss of the “ideal” child and the formation of new dreams. When possible, a parent panel (containing parents of children with special needs) will be present at the professional development and will share their experiences regarding their child’s birth and the feelings and process associated with it. The panel will also discuss how they began to form the new dreams for their child. It is the hope that by having different panel members share, participants will see the differences as well as similarities in the parental experience.

Part three provides an overview of the different family structures that exist as well as a discussion on the fact that one family member’s experiences influence the experiences of all members of that family. This section is included to remind participants that there are a variety of family structures and while we, individually, may not understand or agree with the makeup of some of the family structures, we must remember that all family members are affected by a child’s special needs and the manner in which an individual family member copes with the child’s needs will affect the other members of the family.

This discussion leads into part four, which looks at chronic sorrow, grief, and coping that is associated with raising a child with special needs. In this section chronic sorrow is defined and the ideas of Dr. Ken Moses are shared, including his discussion about states of sorrow and their definitions. This section serves to educate participants on the states of sorrow, the manner in which they might occur and the potential triggers that may send a parent into a state of sorrow or grief. The current author hopes that participants will develop an understanding that the feelings of grief are not something parents of children with special needs can control and that while there are common triggers, the events that influence someone to feel a state of sorrow may be different from person to person. It is further hoped that participants will see that the sorrow process is on-going throughout the life of the child and that the states of sorrow are not sequential in occurrence, but rather happen in different orders depending on the trigger and the individual. The on-going, natural process of the sorrow is further discussed in part five of the professional development, which addresses the question, "what about acceptance?" This section serves to hone into the fact that the chronic sorrow process is lifelong and while parents may never fully except their loss, they do often learn to cope with the loss and love the child that they have been given.

Section six examines the role that the education system can play in the chronic sorrow process. The research in this area is discussed, as are the practices that have been found to lead to an increase in parent involvement and the benefits of this involvement to the student. This portion of the professional development serves as background building for section seven of the program that speaks to the importance of a family-centered approach to education. During part seven of the program, the panel of parents can again share. This time, the parents will speak to their experiences with their child's school(s) and address the question of what schools can do to help alleviate some of the feelings of sorrow that is experienced by parents of children with special needs. This sets the stage for a discussion on how schools and parents can form a collaborative partnership with one another; looking specifically at the needs of the parents and the students. The section also touches on the necessity of a positive, family-centered partnership by sharing Epstein’s Spheres of Influence (as cited in Turbull & Turnbull, 2001) with those in the professional development program. Epstein says that the school, community and family all play a role in helping a child develop and that the three most form a partnership to allow the best benefit for the child to occur. It is the hope of the current author that by the end of this section of the program, the participants will come to see the value and necessity of the family-centered approach to education. The next section eight, presents briefly on the professional-centered approach to education, allowing participants to see where many schools are at today and contrasting it with the family-centered approach.

Section nine, reviews what the federal law says about family involvement and the role of the parent as an advocate. Sharing the law with the attendees can help them to gain an understanding that parent involvement is an integral, necessary component in the education process. This leads to section ten which shares the current author’s findings from the research on what parents need from the school system in order to feel that they are an integral component in education decisions concerning their child. It is the current author’s hope that this will allow participants to see steps they can take now as individuals to help their schools move toward a more family-centered approach to education. Finally, the participants being are asked to write down and share one thing they can do to move to a more family-centered approach to education at their school site. The professional development concludes with a sharing of resources used to create the program.

This professional development was designed to be used in a variety of settings with the aid of a parent panel. Due to time constraints, the professional development workshop was not piloted prior to the completion of this project. However, it is the intention of the current author to implement the program in various settings where pre-service teachers, current teachers and administrators can be addressed. These settings may include pre-credential college education programs for both pre-service teachers and pre-service administrators, professional conferences that target professionals who educate children with special needs and in schools in districts, in and around the greater Sacramento area. Once the program has been piloted, it has been designed so that it could be disseminated over other parts of California and the country. Since the program has not yet been implemented, the exact program time is uncertain, but the author believes the professional development program should be approximately two days in length. It should be noted that the duration of the program can be altered depending on the needs of the audience.

Recommendations for Research and Practice

One recommendation is that the efficacy of the actual professional development workshop be investigated. Suggestions for measurement include the use of pre and post-test surveys to assess the participant’s knowledge of both the parental experience and family-centered practice. In addition, it recommended that follow-up be done with participants to measure the long term effectiveness of the professional development. These follow-ups could be used to help guide the addition or removal of program components, in effort to create the most effective program.

The curent author recommends that further research be done on the parental experience of chronic sorrow. The research in this area could specifically explore commonalities across parents of children with special needs, regardless of their child’s diagnosis. Much of the current research in this area looked at chronic sorrow as it related to parents of children with specific disabilities (i.e. autism, neural tube defects, etc.). Further research should also be conducted on family-centered practice in the educational setting. The author recommends that this concept be explored across grade levels and at each of the common grade groupings: primary, upper elementary, middle and high school. In this area, it is further suggested that researchers explore the current models of practice that are being used most commonly in each grade grouping, educator’s understanding of the family-centered approach, educator’s perception of the current model being used at their site as compared to the actual model in place at the site, along with the reasons for the apparent decrease in family centred practice as the grade level increases.

It is also suggested that teachers, administrators and others in the field of education be offered initial and continued training on the family-centered model of care and the parental experience of raising a child with special needs. Lastly, the current author recommends the creation of an educational program for parents of children with special needs. This program could help them see and understand the value of the family centred model. Additionally, it could deepen their knowledge of the concept of chronic sorrow and their role in their child’s educational process. A program of this nature could be offered to parents in a variety of settings, such as parent support groups, at schools sites and through organizations that support specific disabilities and/or children with special needs as a whole. It is the current author's belief that there must be an understanding and shared knowledge among both parents and educators for true collaboration to occur.

Conclusion

It is the hope that the professional development will serve as a means for education professionals to begin to open the door to understanding of the parental experience of raising a child with special needs and thereby leading to a change in the values and beliefs around educational practice and the family's role in their child's educational program. As Kearney and Griffin (2001) pointed out, this increased understanding will not be able to eliminate all of the feelings of grief experienced by parents, but could serve as a means to help parents avoid some of the feelings that are created by the beliefs and views of others:

> Wilst sorrow seems self-evident, a great deal of pain drives from societal values and beliefs mirrored in the words and behaviours of friends, family and professionals. In a better world, this pain could be avoided. On the other hand existential pain and grief cannot be avoided, as it cannot be ameliorated by education and attitudinal change. (Kearney & Griffin, 2001, p. 582)

APPENDICES

APPENDIX A: Professional Development PowerPoint

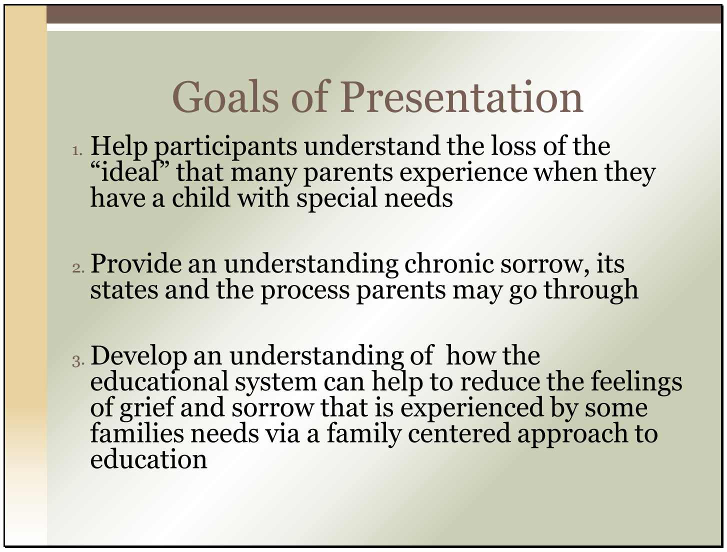
Slide 1

A look at the Family Centered Practice in the School Setting

And Why it Matters…

Allison Rudig, California State University Sacramento

Slide 2



Goals of Presentation

1. Help participants understand the loss of the "ideal" that many parents experience when they have a child with special needs
2. Provide an understanding chronic sorrow, its states and the process parents may go through
3. Develop an understanding of how the educational system can help to reduce the feelings of grief and sorrow that is experienced by some families needs via a family centered approach to education

Slide 3

Guidelines for Participation

- Comfortable, trusting & friendly atmosphere
- Everyone should feel free to participate
- There are no right or wrong questions
- Use this as a learning experience
- Be respectful of other participants and please listen with they talk

Slide 4

My “Why”…

Notes for presenter:

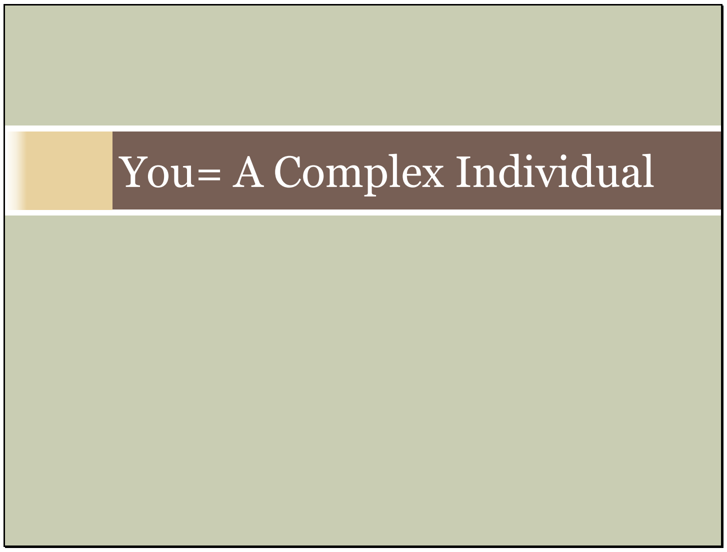
I am both a teacher and the mother of a little boy with Down syndrome.

I designed this training as part of my Master Project. It stemmed from my experience in dealing with my own child’s education and my various experience in schools over the course of the last 3 years.

What I found is that often the schools that I dealt with were apprehensive, if not unwilling, to truly involve the parents in the special education process. This happens for a variety of reasons and leads many parents of children with special needs, myself included, to experience unnecessary feelings of grief & sorrow regarding their child’s disability.

It has been my findings through the course of this project’s development that while we, as educators, cannot alleviate all of the feelings associated with raising a child with special needs we can certainly work together with the families to help alleviate them.

Slide 5

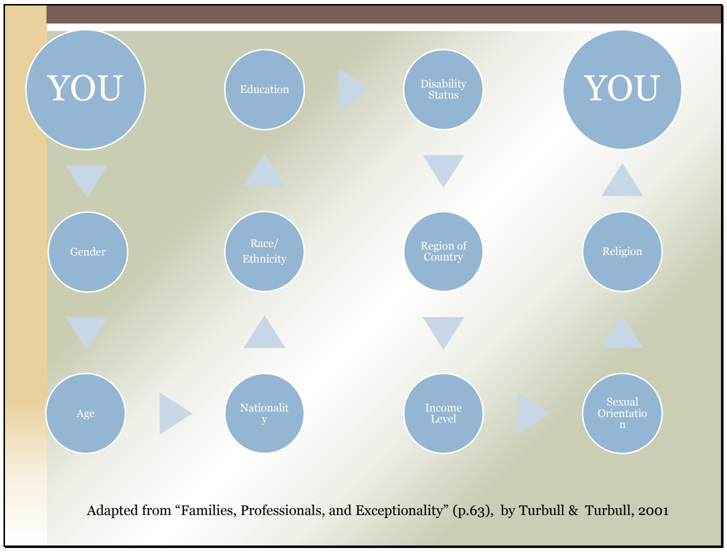


You= A Complex Individual

Notes for presenter:

To begin, I would like you to take a moment to reflect on all of the things that make you who you are. This could be where you grew up, the people who raised you, etc.

Slide 6



YOU

Education

Disability Status

YOU

Gender

Race/ Ethnicity

Region of Country

Religion

Age

Nationality

Income Level

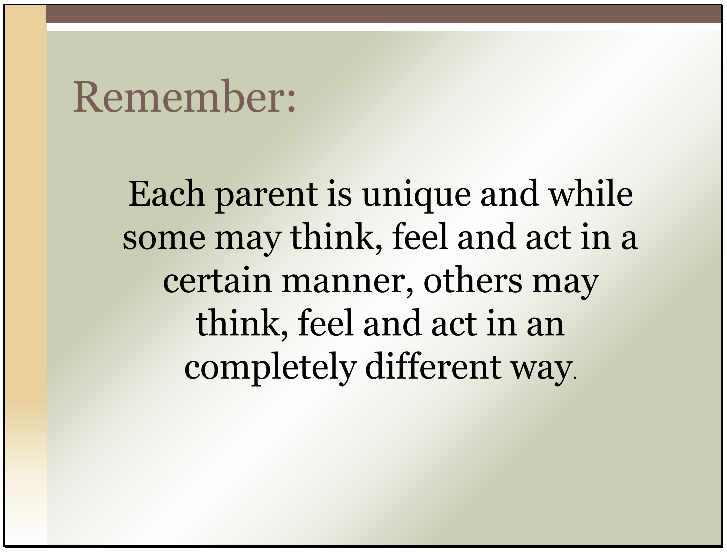
Sexual Orientation

Adapted from "Families, Professionals, and Exceptionality" (p.63), by Turbull & Turbull, 2001

Notes for presenter:

We are all unique and complex individuals with a myriad of components that make us who we are. This is important to remember and understand as each of these individual components combine to make us the person that we are, shaping both our perspectives and reactions.

Slide 7



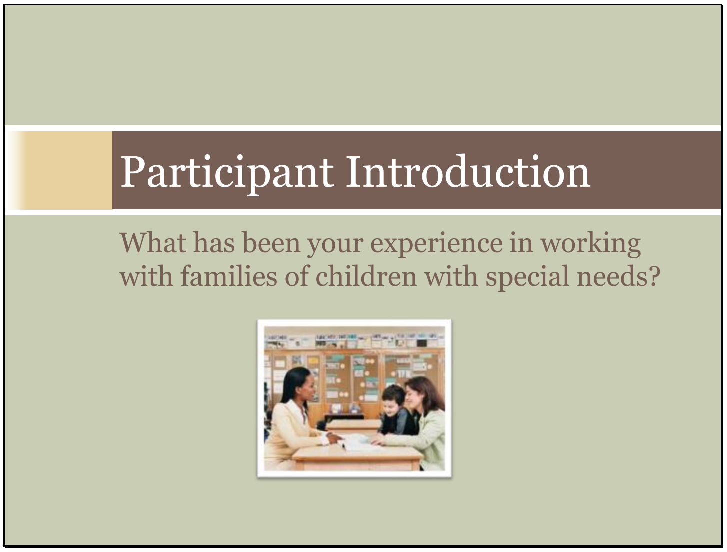
Remember:

Each parent is unique and while some may think, feel and act in a certain manner, others may think, feel and act in an completely different way.

Notes for presenter:

For this reason it is important to remember that the families and children that we deal with are each shaped by their own components. Some which we may be able to understand and others that we may have difficulty relating to.

Slide 8



Participant Introduction

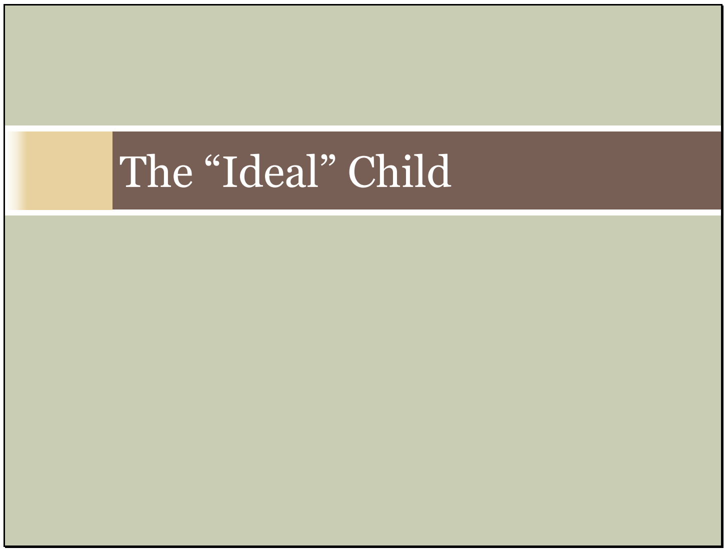
What has been your experience in working with families of children with special needs?

Notes for presenter:

What is your experience in working with families of children with special needs? Has it been largely positive or negative? Why?

**Have participants first share in pairs and then ask for some whole group sharing.*

Slide 9



The “Ideal” Child

Imagine that you are anticipating the birth of your child. Who or what will that child be to you? What hopes and dreams do you have for this child?

Slide 10

Notes for presenter:

**Participants will write a letter about or draw a picture of their "ideal" child.*

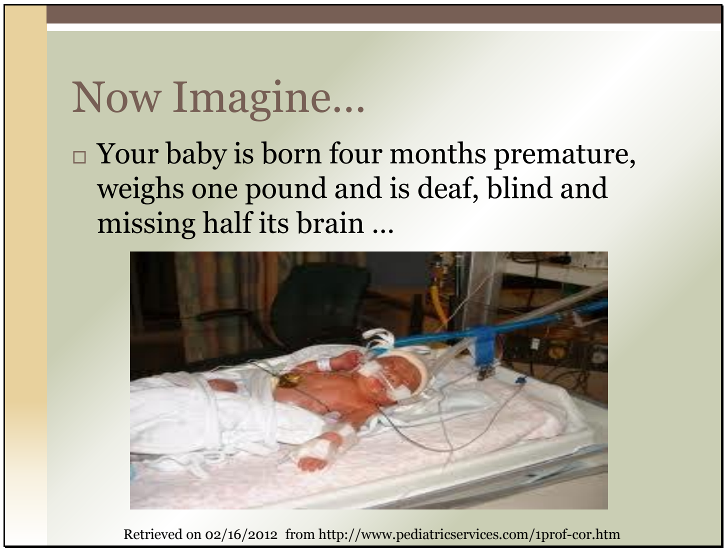
**BEFORE showing the next slide (but after participants have finished with the above) explain:*

Parents attach to their children before they are even born. They do this through dreams, fantasies, illusions and projections into the future (Moses, 1987).

But what happens when those dreams are altered?

Show Next Slide

Slide 11



Now Imagine…

- Your baby is born four months premature, weighs one pound and is deaf, blind and missing half its brain …

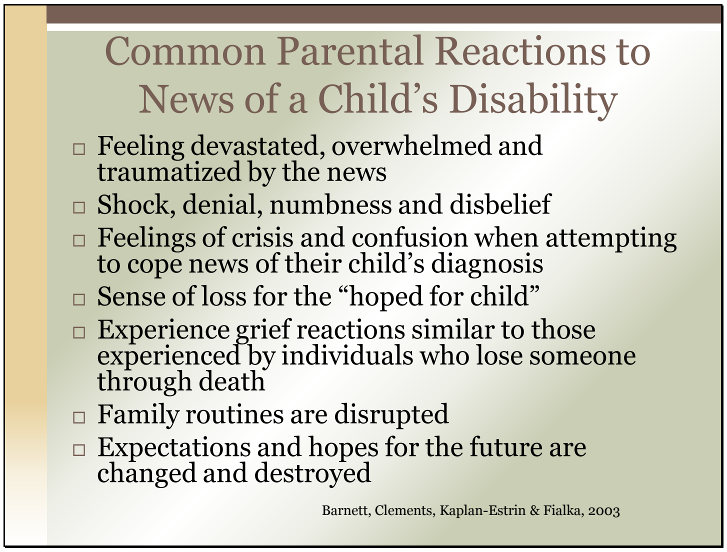
Retrieved on 02/16/2012 from http://www.pediatricservices.com/1prof-cor.htm

Notes for presenter:

Now imagine that you have given birth to your child and the child did not fit into the dreams that you had created prior to the birth. Not only are your dreams shattered by the loss but you must also begin to plan new dreams that may include many items you had not thought of prior. Things such as: frequent medical appointments, additional care for the child and how to cope with the child's needs.

**Participants share their reactions.*

Slide 12

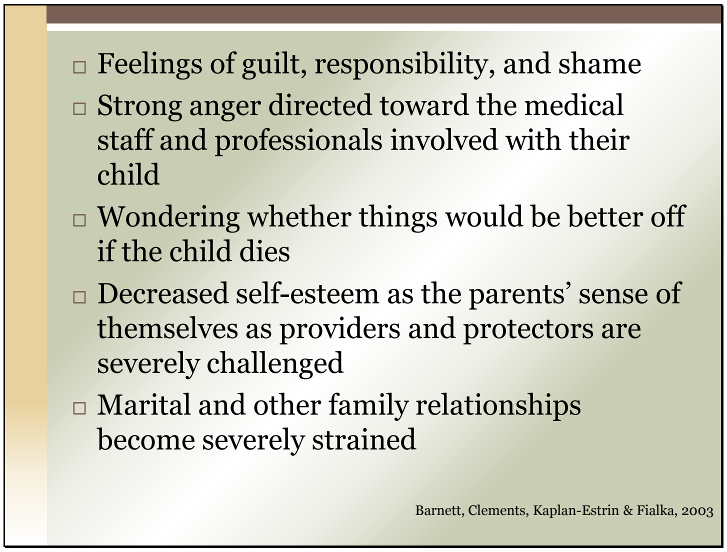


Common Parental Reactions to News of a Child’s Disability

- Feeling devastated, overwhelmed and traumatized by the news
- Shock, denial, numbness and disbelief
- Feelings of crisis and confusion when attempting to cope news of their child’s diagnosis
- Sense of loss for the “hoped for child”
- Experience grief reactions similar to those experienced by individuals who lose someone through death
- Family routines are disrupted
- Expectations and hopes for the future are changed and destroyed

Barnett, Clements, Kaplan-Estrin & Fialka, 2003

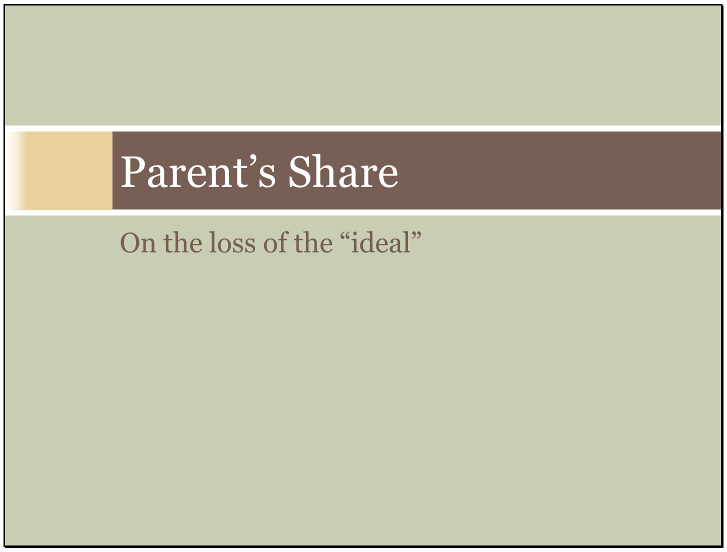
Slide 13



- Feelings of guilt, responsibility, and shame
- Strong anger directed toward the medical staff and professionals involved with their child
- Wondering whether things would be better off if the child dies
- Decreased self-esteem as the parents' sense of themselves as providers and protectors are severely challenged
- Marital and other family relationships become severely strained

Barnett, Clements, Kaplan-Estrin & Fialka, 2003

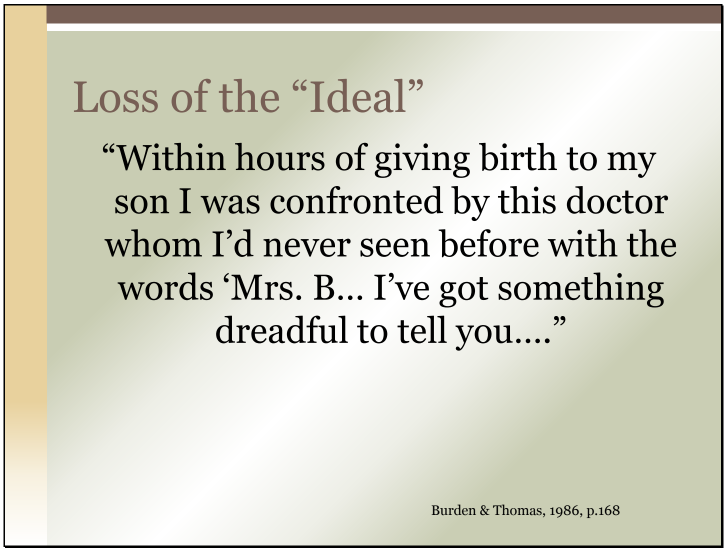
Slide 14



Parent's Share

On the loss of the "ideal"

Slide 15



Loss of the "Ideal"

"Within hours of giving birth to my son I was confronted by this doctor whom I'd never seen before with the words 'Mrs. B… I've got something dreadful to tell you…."

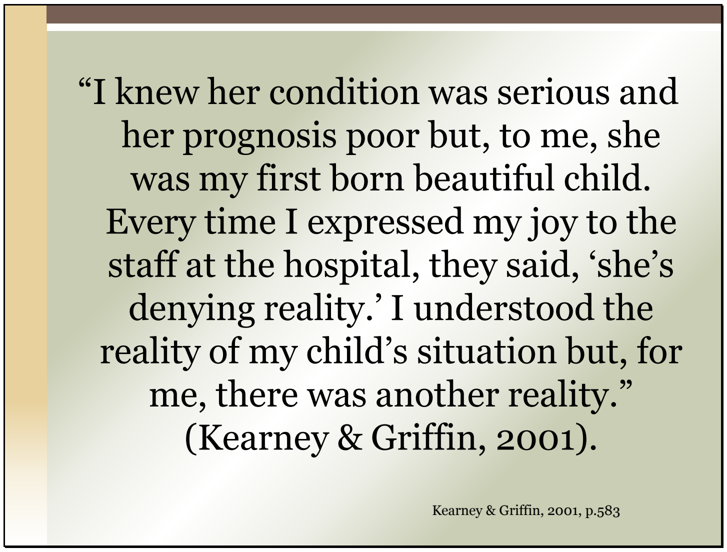
Burden & Thomas, 1986, p.168

Notes for presenter:

The above are actual quotes from parents regarding the loss of the ideal child.

**When possible (if time allows) it would be ideal to have a parent panel at the presentation and during this time they will share their personal experience immediately following the birth of their child with special needs.*

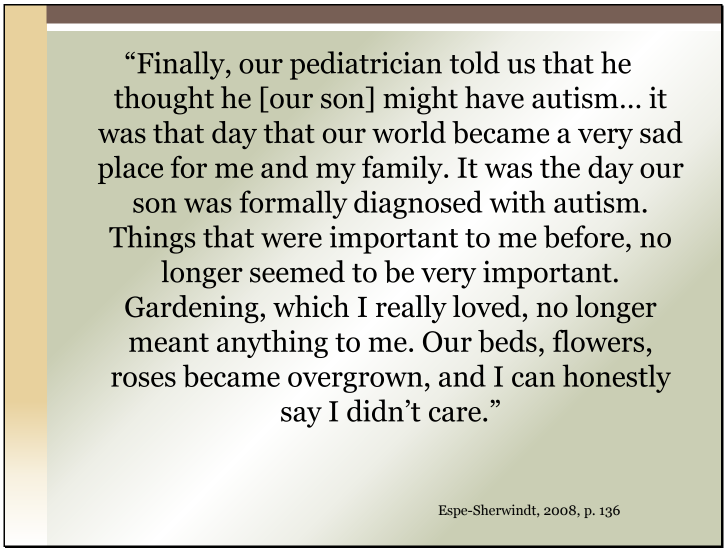
Slide 16



“I knew her condition was serious and her prognosis poor but, to me, she was my first born beautiful child. Every time I expressed my joy to the staff at the hospital, they said, ‘she’s denying reality.’ I understood the reality of my child’s situation but, for me, there was another reality.” (Kearney & Griffin, 2001).

Kearney & Griffin, 2001, p.583

Slide 17



“Finally, our pediatrician told us that he thought he [our son] might have autism… it was that day that our world became a very sad place for me and my family. It was the day our son was formally diagnosed with autism. Things that were important to me before, no longer seemed to be very important. Gardening, which I really loved, no longer meant anything to me. Our beds, flowers, roses became overgrown, and I can honestly say I didn’t care.”

Espe-Sherwindt, 2008, p. 136

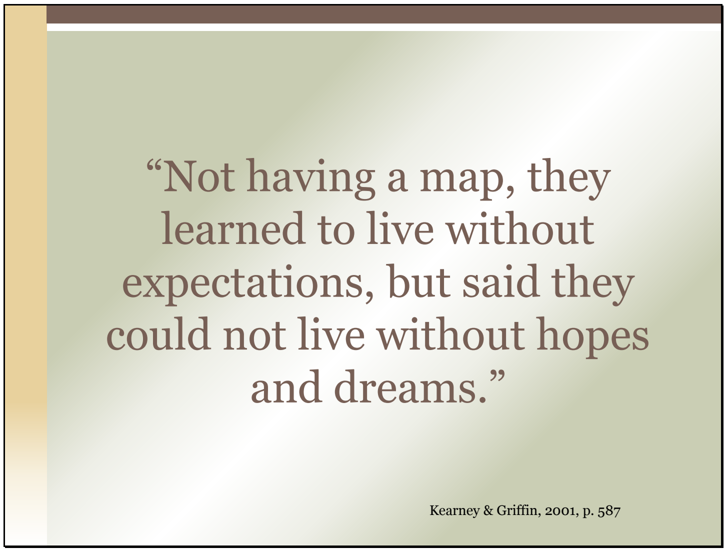
Slide 18

Formation of New Dreams

Notes for the presenter:

Ask participants to read, “*An Open Letter to Educators from a Special Needs Parent Advocate”* and discuss responses to the letter as a group.

Slide 19



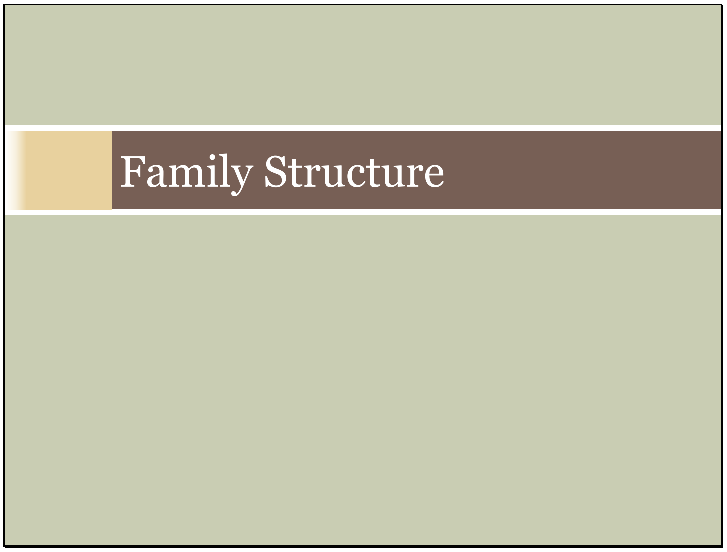
"Not having a map, they learned to live without expectations, but said they could not live without hopes and dreams."

Kearney & Griffin, 2001, p. 587

Notes for the Presenter:

This is one of my favorite quotes from the research. It serves as a reminder that parents of children with special needs enter into a world where they have no experience and no knowledge. A world where there are no maps.

Slide 20

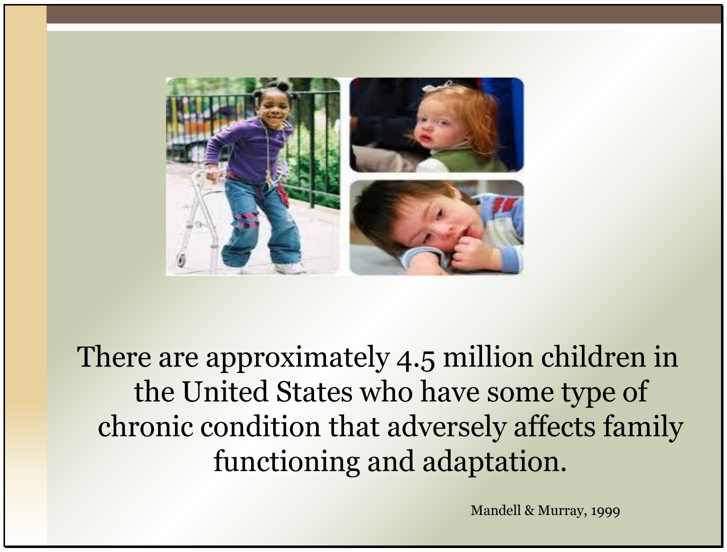


Family Structure

Notes for the Presenter:

Please take a moment to think about your own family growing up. Did you all live together? Where did you live? Was it in a house, apartment, with a grandparent, etc? What kind of work did your parents do? How did these things affect you? How did they shape you as a person?

Slide 21



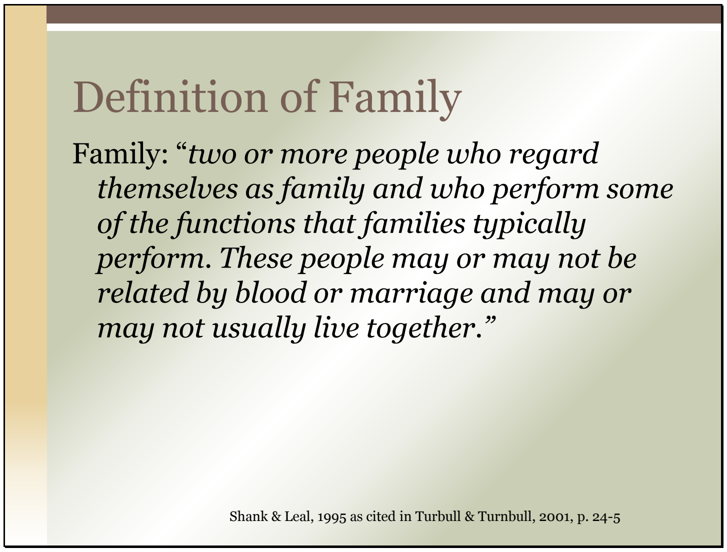
There are approximately 4.5 million children in the United States who have some type of chronic condition that adversely affects family functioning and adaptation.

Mandell & Murray, 1999

Notes for the Presenter:

The family structure of these children will shape the families reaction to and perception of the child’s disability.

Slide 22



Definition of Family

Family: “*two or more people who regard themselves as family and who perform some of the functions that families typically perform. These people may or may not be related by blood or marriage and may or may not usually live together.*”

Shank & Leal, 1995 as cited in Turbull & Turnbull, 2001, p. 24-5

Notes for the Presenter:

Families can vary from culture to culture and even within a culture. Ann Turnbull, a researcher who studies family-centered practice has defined families as (read definition on PowerPoint). In this regard a family could be a mother, father, and child or a mother, grandmother and child. This is important to understand because while we, as educators, may not understand the dynamics of every family or view a family as “typical” the family unit operates together, meaning that what one member experiences will have an impact on all members of the family. For example, if a child has a disability the disability not only affects the child but it also affects all members of the child’s family.

Let’s take a look at some of the different family structures seen today.

Slide 23

Nuclear Families
Approximately half of all families with youngsters under age 18 are composed of two biological parents and their children.

Single-Parent Families
Single-parent families make up 27 percent of households with children under age 18.

Retrieved on 02/18/12 from healthychildren.org

Slide 24

Cross-Generational Families

Approximately 670,000 families with children under age 18 have a family member age 65 or older living with them.

Roughly 2.5 million children under age 18 live with one or both parents in their grandparents' home.

Adoptive/Foster Families

Approximately 120,000 children are adopted each year.

6.3 children per 1,000 live in out-of-home foster care.

Retrieved on 02/18/12 from healthychildren.org

Slide 25

Never-Married Families

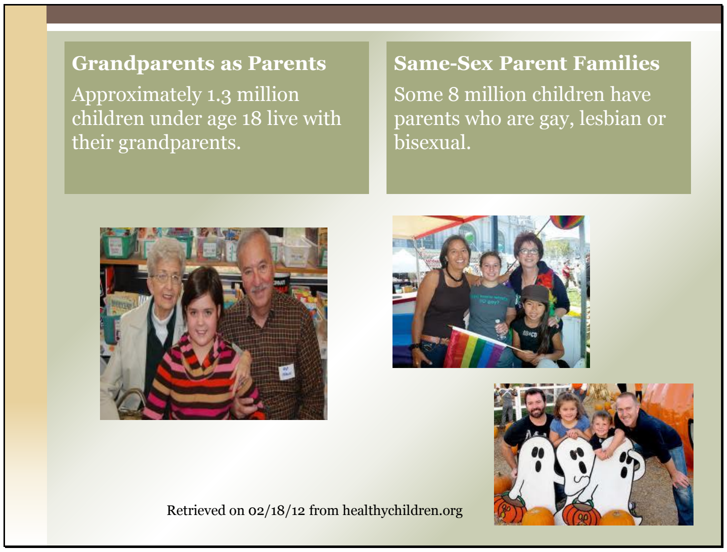
About 1.5 million unmarried couples have at least one child under age 15.

Blended Families

About 20 percent of children in two-parent households live in blended families.

Retrieved on 02/18/12 from healthychildren.org

Slide 26



Grandparents as Parents

Approximately 1.3 million children under age 18 live with their grandparents.

Same-Sex Parent Families

Some 8 million children have parents who are gay, lesbian or bisexual.

Retrieved on 02/18/12 from healthychildren.org

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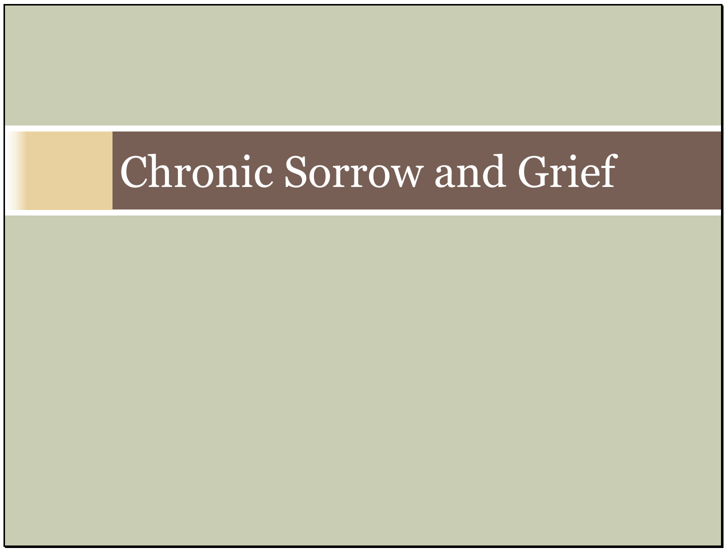
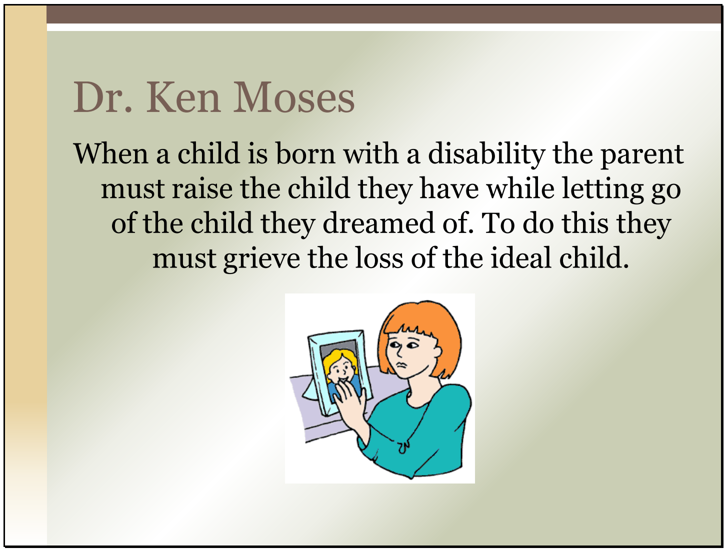


Chronic Sorrow and Grief

Notes for the Presenter:

However, regardless of the family structure many families will experience chronic sorrow and grief related to their child’s disability.

Slide 28



Dr. Ken Moses

When a child is born with a disability the parent must raise the child they have while letting go of the child they dreamed of. To do this they must grieve the loss of the ideal child.

Notes for the Presenter:

Dr. Ken Moses is a psychologist who focuses much of his work on the parents of children with special needs. He is also the father of a child with special needs.

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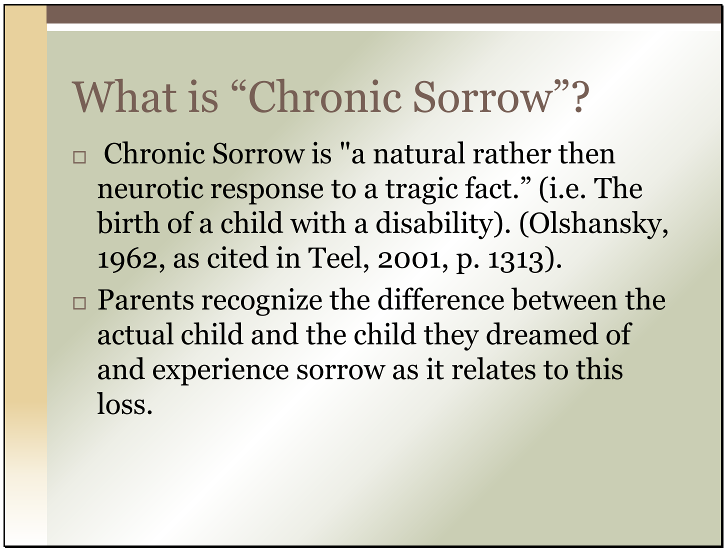


What is “Chronic Sorrow”?

- Chronic Sorrow is "a natural rather then neurotic response to a tragic fact.” (i.e. The birth of a child with a disability). (Olshansky, 1962, as cited in Teel, 2001, p. 1313).
- Parents recognize the difference between the actual child and the child they dreamed of and experience sorrow as it relates to this loss.

Notes for the Presenter:

Chronic Sorrow is both recurring and permanent. It varies in intensity between situations and persons and is interwoven with periods of neutrality, satisfaction and happiness. The intensity of the sorrow is determined by the type and intensity of the relationship between two people.

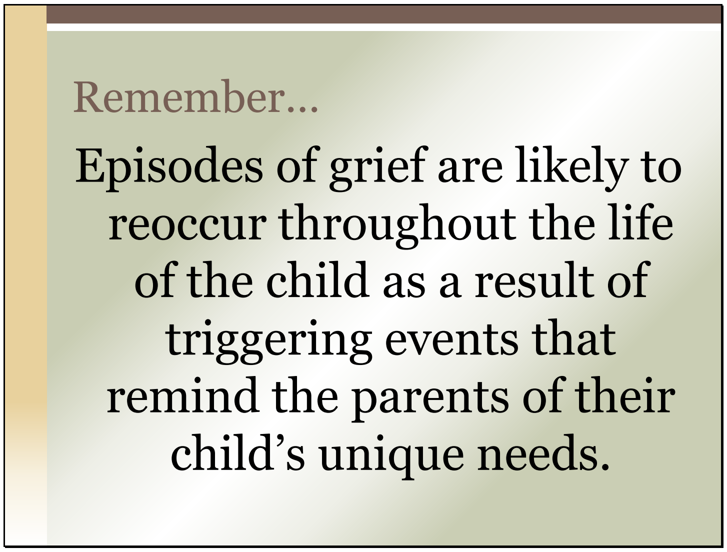
Slide 30

States of grief that facilitate separation from the lost dream

Grieving is an unlearned, spontaneous and self-sufficient response.

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

Slide 31



Remember…

Episodes of grief are likely to reoccur throughout the life of the child as a result of triggering events that remind the parents of their child's unique needs.

Notes for the Presenter:

**Pass out grief cycle handout.*

Denial is always first but the other feelings of grief do not follow an order. These feelings may re-emerge again & again as often as the parents need to experience it

It is not uncommon for two or more states of grief to be experienced at the same time.

Each person who goes through the grieving process experiences each of the feelings, but will experience them in their own unique manner and order.

Triggering events may include, but are not limited to: the child entering a particular grade in school, the age when the child should be able to drive, high school graduation, etc.

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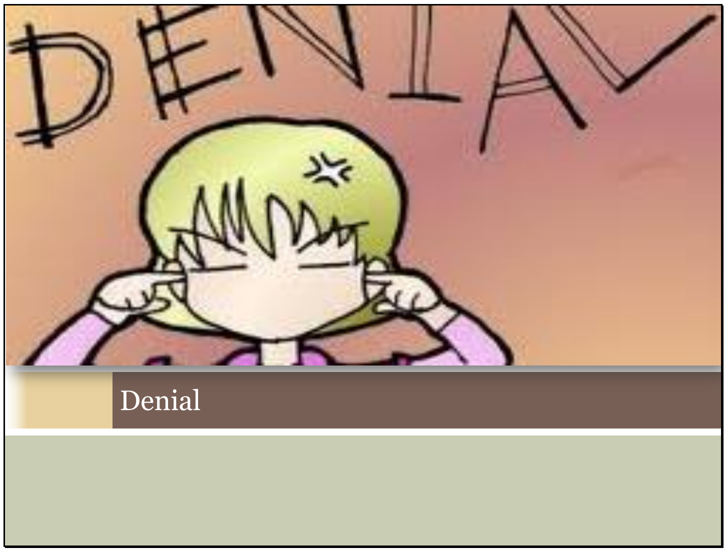

Denial

Notes for the Presenter:

Buys the time that parents need to deal with the loss of the ideal child. During this time parents find their inner strength and begin to find people and resources to help them deal with the loss.

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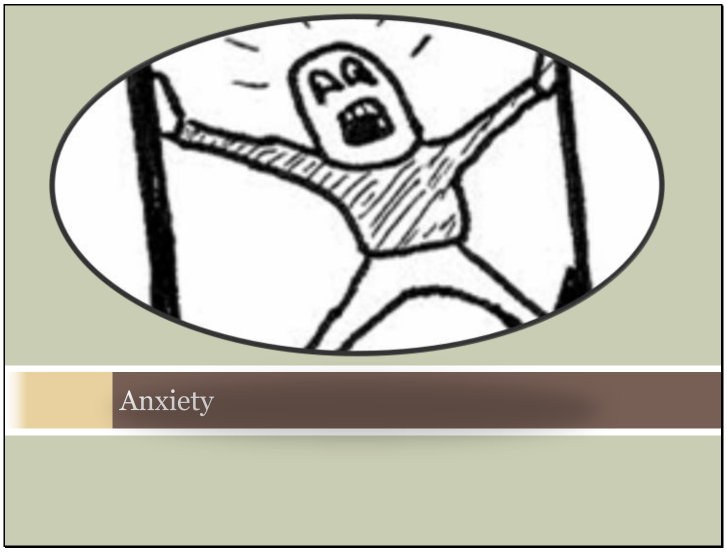


Anxiety

Notes for the Presenter:

Anxiety is usually seen by others as hysteria, inappropriate & unacceptable.

Parents of children with special needs go through dramatic changes that affect their attitudes, beliefs, priorities, values, etc. Anxiety creates the energy needed to mobilize these changes.

Slide 34

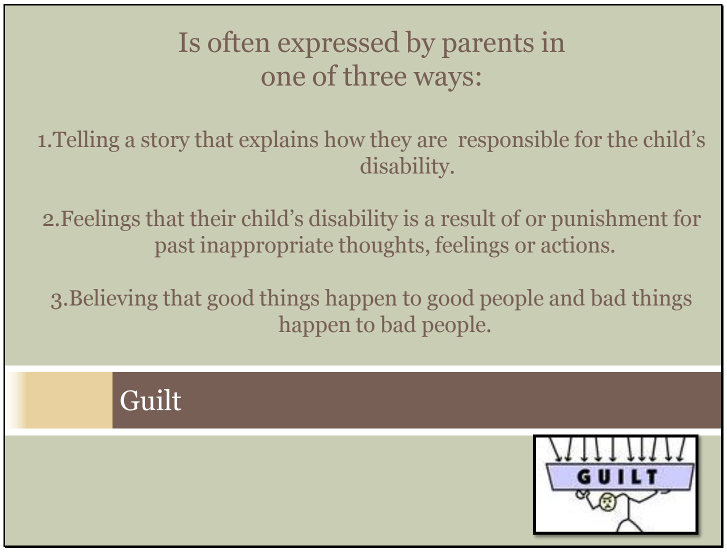
Fear

Notes for the Presenter:

While anxiety mobilizes people to make changes, fear is the warning that allows the parent to know the seriousness of the needed changes.

Parents experience feelings of fear when they realize that they must change at a fundamental level. Parents often experience feelings of being abandoned and vulnerable.

Slide 35



Is often expressed by parents in
one of three ways:

1. Telling a story that explains how they are responsible for the child's disability.
2. Feelings that their child's disability is a result of or punishment for past inappropriate thoughts, feelings or actions.
3. Believing that good things happen to good people and bad things happen to bad people.

Guilt

Notes for the Presenter:

Guilt is often seen as a negative feeling that is not freely talked about in our culture. Sharing feelings of guilt often result in being judged negatively by others.

The current attention that is given to the prevention of birth defects has led many parents to feel as if they are responsible for their child's birth defect.

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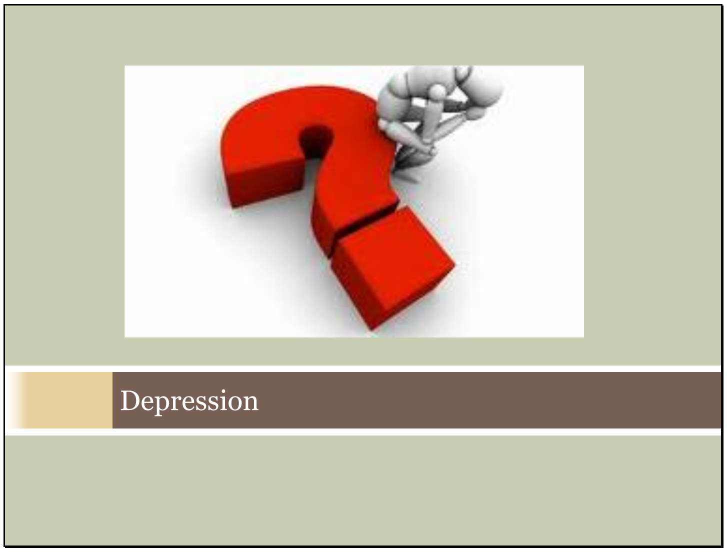
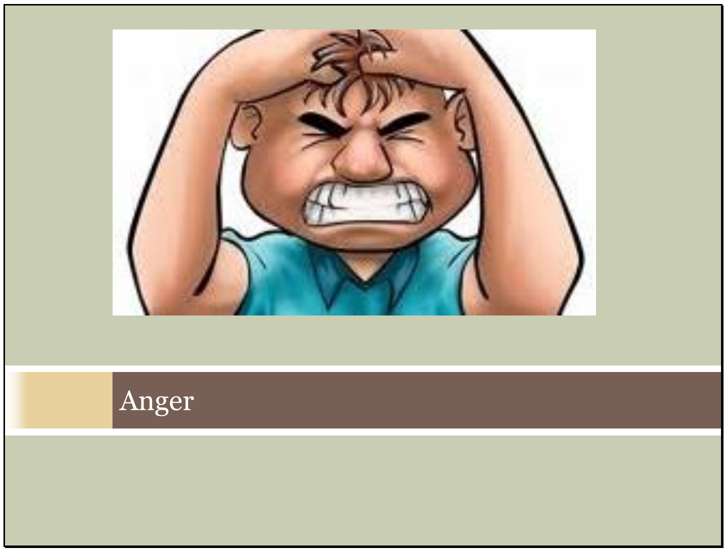


Depression

Notes for the Presenter:

A common response to loss is powerful & painful sobbing. These feelings help lead parents to new definitions of what it means to be a confident and capable parent.

Slide 37

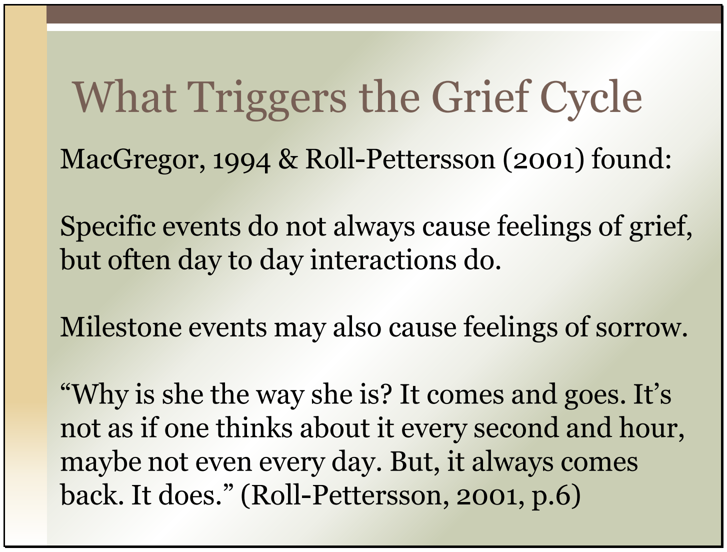


Anger

Notes for the Presenter:

Feelings of “why me not you,” and “What is fair? If this can happen…?” The parents internal sense of justice is violated. Anger is the way the parent redefines fairness and justice.

Slide 38



What Triggers the Grief Cycle

MacGregor, 1994 & Roll-Pettersson (2001) found:

Specific events do not always cause feelings of grief, but often day to day interactions do.

Milestone events may also cause feelings of sorrow.

“Why is she the way she is? It comes and goes. It’s not as if one thinks about it every second and hour, maybe not even every day. But, it always comes back. It does.” (Roll-Pettersson, 2001, p.6)

Notes for the Presenter:

Chronic sorrow and feelings of grief are different for every family and member within the family. For some the cycle could be triggered by comments made by someone about their child or another child with a disability. For others it could be their child’s inability to do a daily task. Additionally, milestone events may trigger the cycle of sorrow, these events can include the age at which a child should be able to drive, graduate from high school, etc.

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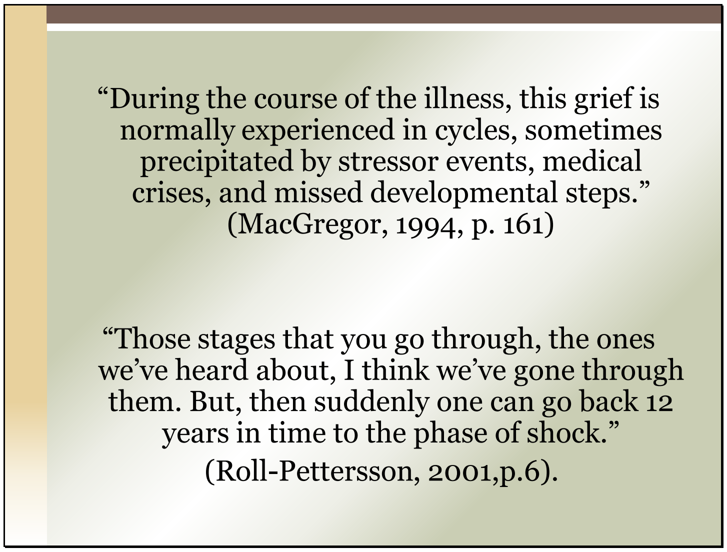

“During the course of the illness, this grief is normally experienced in cycles, sometimes precipitated by stressor events, medical crises, and missed developmental steps.” (MacGregor, 1994, p. 161)

“Those stages that you go through, the ones we’ve heard about, I think we’ve gone through them. But, then suddenly one can go back 12 years in time to the phase of shock.”

(Roll-Pettersson, 2001,p.6).

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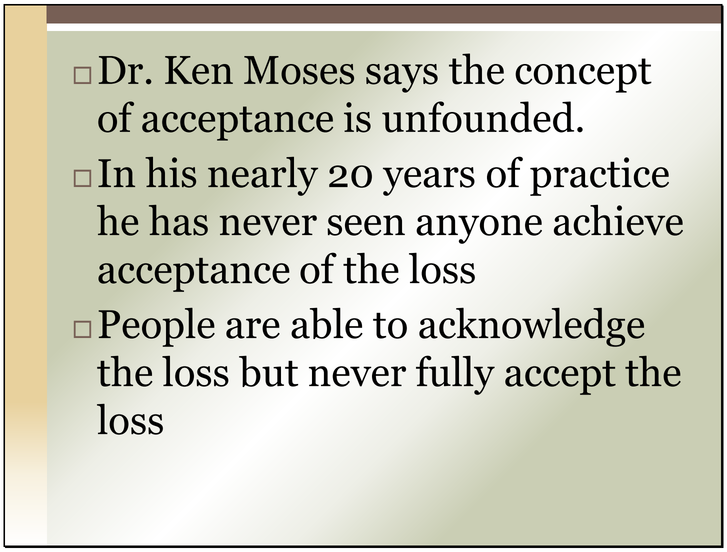
What about Acceptance?

Slide 41

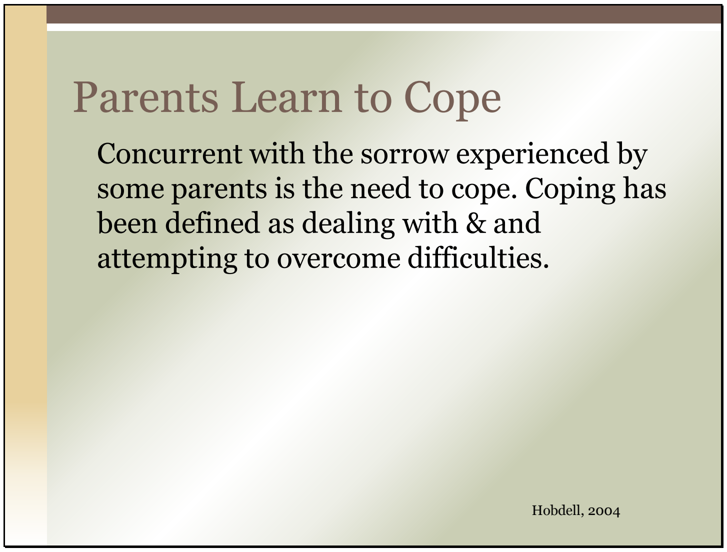


- Dr. Ken Moses says the concept of acceptance is unfounded.
- In his nearly 20 years of practice he has never seen anyone achieve acceptance of the loss
- People are able to acknowledge the loss but never fully accept the loss

Notes for the Presenter:

This acknowledgement of loss is referred to by many in the field as adaptation, where the parents of the child with special needs learn to adapt to the child’s unique needs.
This adjustment is not static or bound by time, it is a lifelong process

Slide 42



Parents Learn to Cope

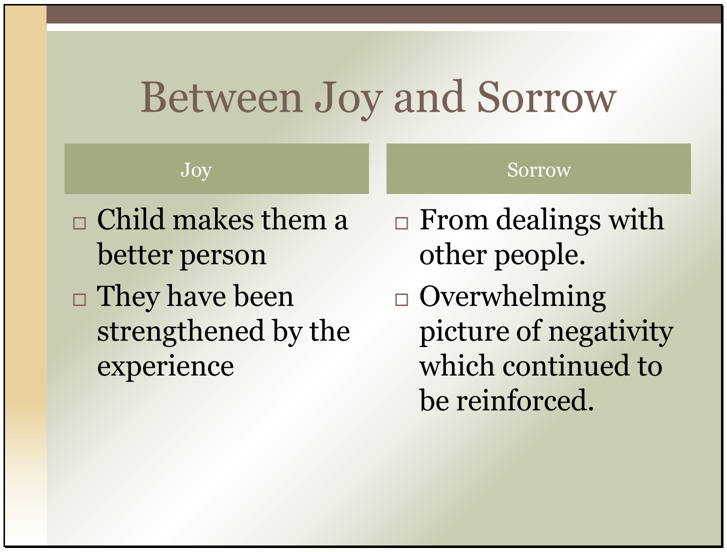
Concurrent with the sorrow experienced by some parents is the need to cope. Coping has been defined as dealing with & and attempting to overcome difficulties.

Hobdell, 2004

Coping for parents comes in a variety of ways and takes on many forms. For some it is through the involvement in support groups or seeking support from others and learning about their child’s disability and the best practices for supporting a child with that disability.

For others it may come in the forms which are known as avoidance coping, Parents who avoid may turn to alcohol, drugs and/or holding feelings related to their child’s disability inside.

Slide 43



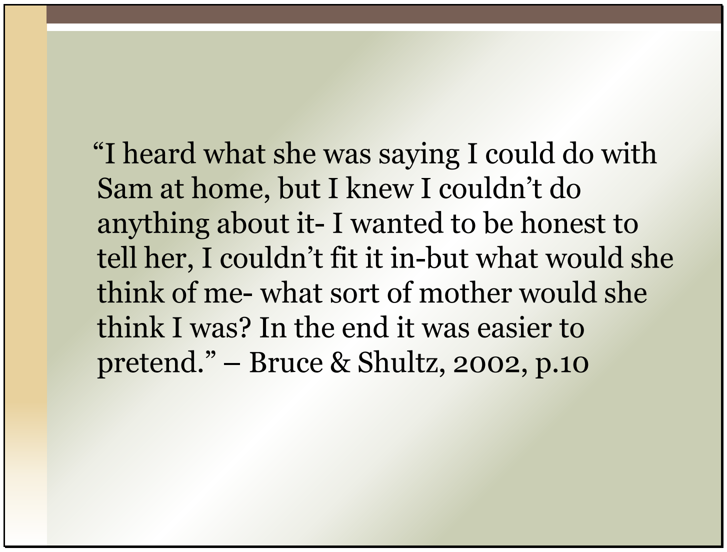
Between Joy and Sorrow

Joy	Sorrow
☐ Child makes them a better person ☐ They have been strengthened by the experience	☐ From dealings with other people. ☐ Overwhelming picture of negativity which continued to be reinforced.

Notes for the Presenter:

Much of the research surrounding the feelings experienced by parents of children with special needs talks about how the sorrow they feel is, in large part, due to other people’s perceptions of their child and/or lack of understanding.

Slide 44



"I heard what she was saying I could do with Sam at home, but I knew I couldn't do anything about it- I wanted to be honest to tell her, I couldn't fit it in-but what would she think of me- what sort of mother would she think I was? In the end it was easier to pretend." – Bruce & Shultz, 2002, p.10

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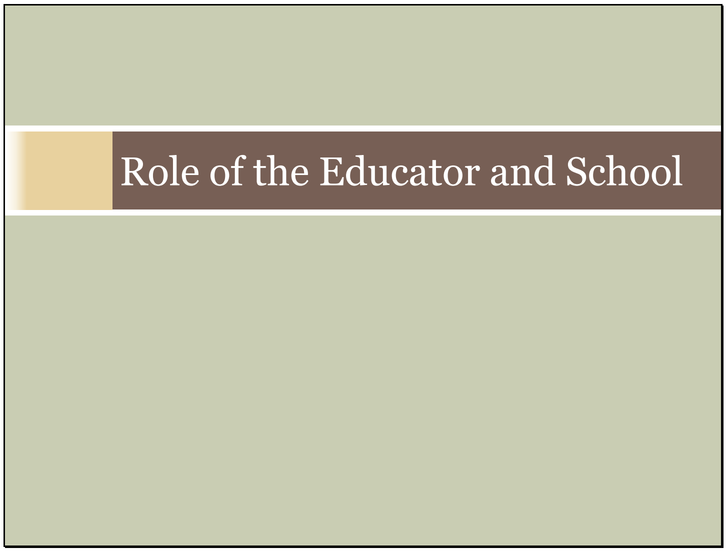


Role of the Educator and School

Notes for the Presenter:

Now, ask yourself what role you as an educator play in this process.

Slide 46

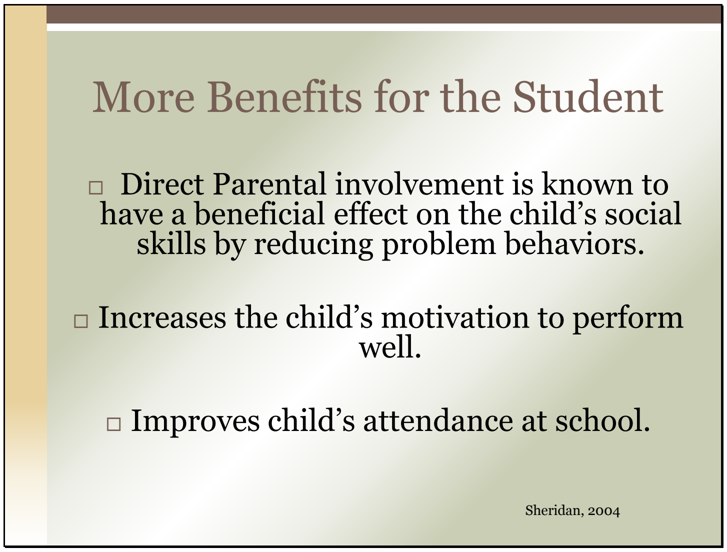
Research shows…

Family involvement is a key element in student achievement.

* This holds true regardless of students culture, socioeconomic status and parent's educational background.

Sheridan, 2004

Slide 47

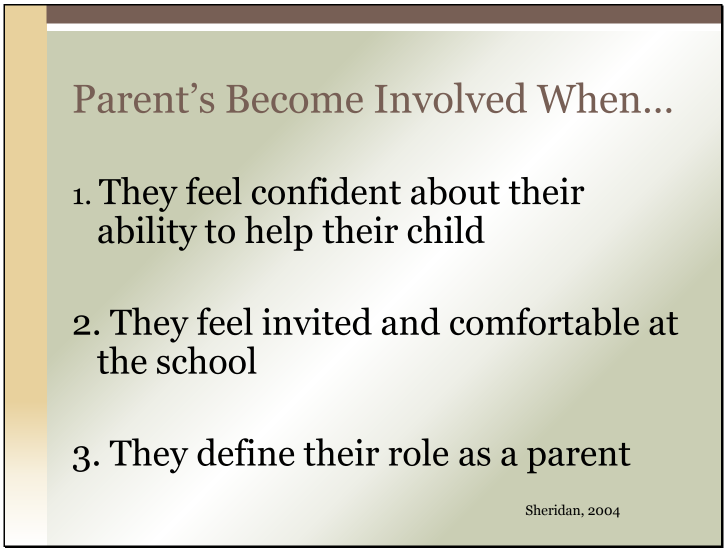


More Benefits for the Student

- Direct Parental involvement is known to have a beneficial effect on the child’s social skills by reducing problem behaviors.
- Increases the child’s motivation to perform well.
- Improves child’s attendance at school.

Sheridan, 2004

Slide 48



Parent’s Become Involved When…

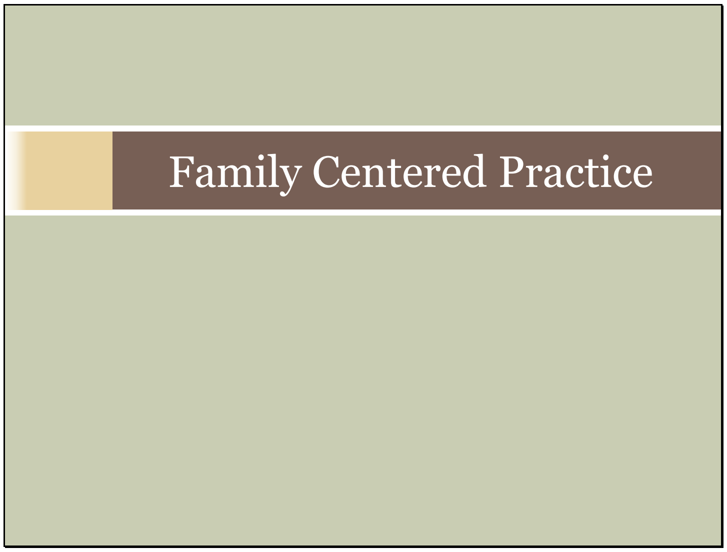
1. They feel confident about their ability to help their child
2. They feel invited and comfortable at the school
3. They define their role as a parent

Sheridan, 2004

Notes for the Presenter:

Parents will become involved when they believe the school gives them an opportunity to act and their actions have a positive effect on the child. They base this decision on the three items above. When these items occur when a positive partnership is formed.

Slide 49



Family Centered Practice

Family-centered practice is the systematic way of creating a partnership with families.

Slide 50

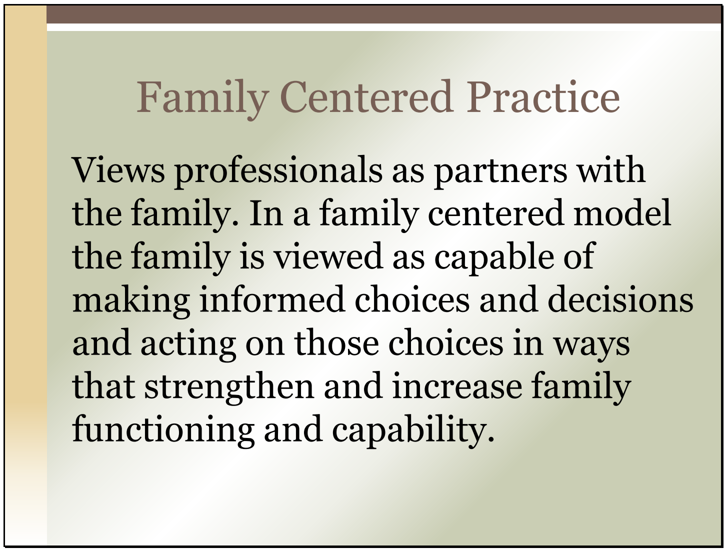
Participants Share

- What do you know about Family Centered Practice?

Notes for the Presenter:

Have participants discuss in small groups what family-centered practice means to them.

Slide 51



Family Centered Practice

Views professionals as partners with the family. In a family centered model the family is viewed as capable of making informed choices and decisions and acting on those choices in ways that strengthen and increase family functioning and capability.

Notes for the Presenter:

Several studies have shown that schools are not as family-centered as they believe and that the degree of family-centeredness decreases as the child increase in grade level.

Slide 52

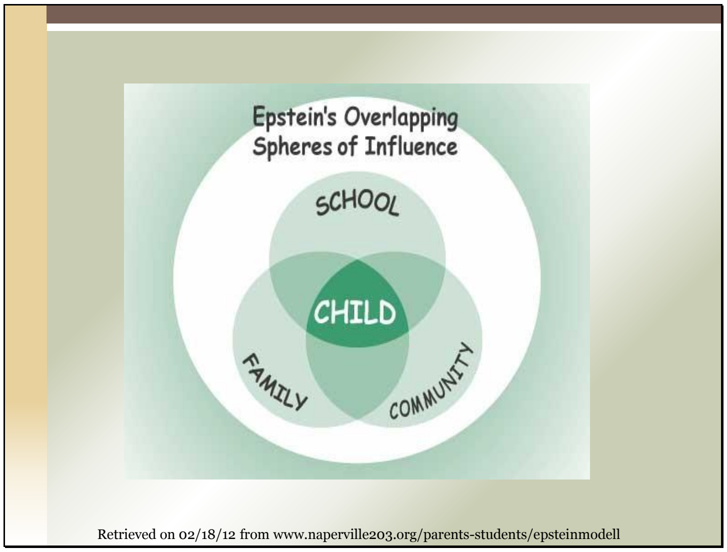
The Partnership is Created by…

1. Involving the families in all aspects of the decision making process
2. Creating partnerships with families
3. Providing families with needed information & support
4. Supporting the cultures, values and traditions of a family. Treating families with dignity and respect
5. Showing honor and value for family input and seeing the family as equal partners

Notes for the Presenter:

In a family-centered partnership the intervention is individualized to meet the needs of the family. It is focused on strengthening and supporting the families and the families are seen as the ultimate decision makers.

Slide 53



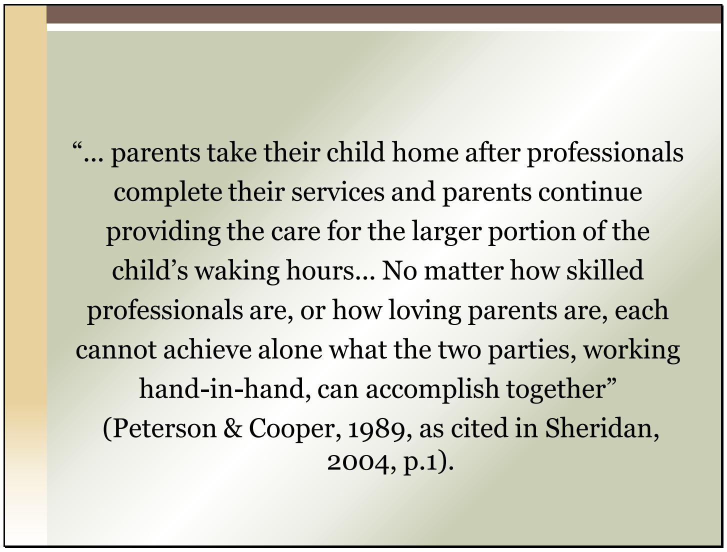
Retrieved on 02/18/12 from www.naperville203.org/parents-students/epsteinmodell

Notes for the Presenter:

Joyce Epstein is a researcher whose studies have shown that there is a “partnership” that occurs between the school, community and family when working together for the students benefit. The size of the spheres may increase or decrease in size depending on 1) The students age and grade level, 2) backgrounds, philosophies and practices that occur within each of the environments and 3) with the recognition that there are some practices that each of the areas will conduct separately.

It is important to note that Epstein is not saying that these partnerships create successful students, but rather that the partnerships guide and motivate the student so that he/she produces their own success. (Turnbull & Turnbull, 2001)

Slide 54



"… parents take their child home after professionals complete their services and parents continue providing the care for the larger portion of the child's waking hours… No matter how skilled professionals are, or how loving parents are, each cannot achieve alone what the two parties, working hand-in-hand, can accomplish together"
(Peterson & Cooper, 1989, as cited in Sheridan, 2004, p.1).

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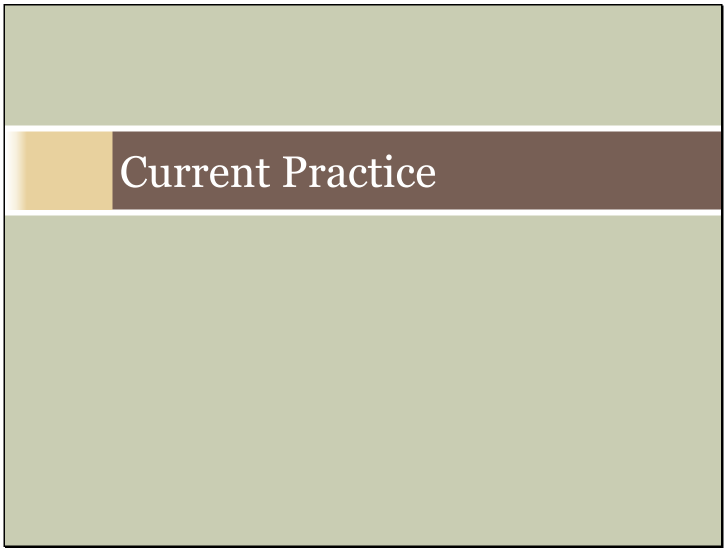

Current Practice

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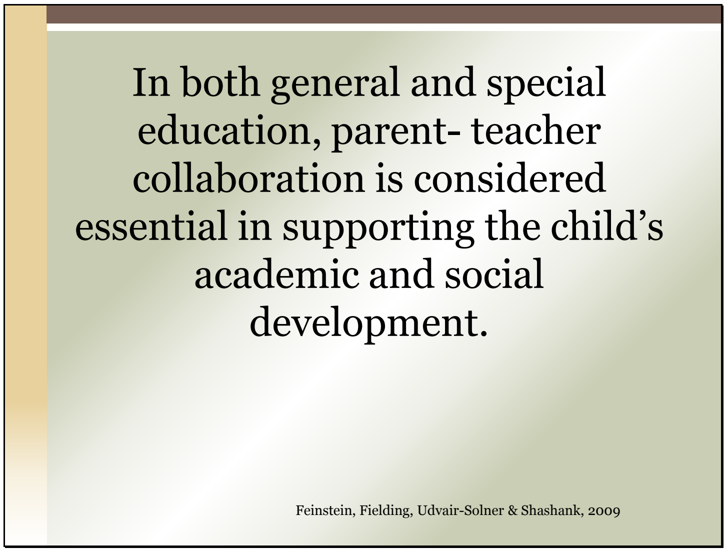


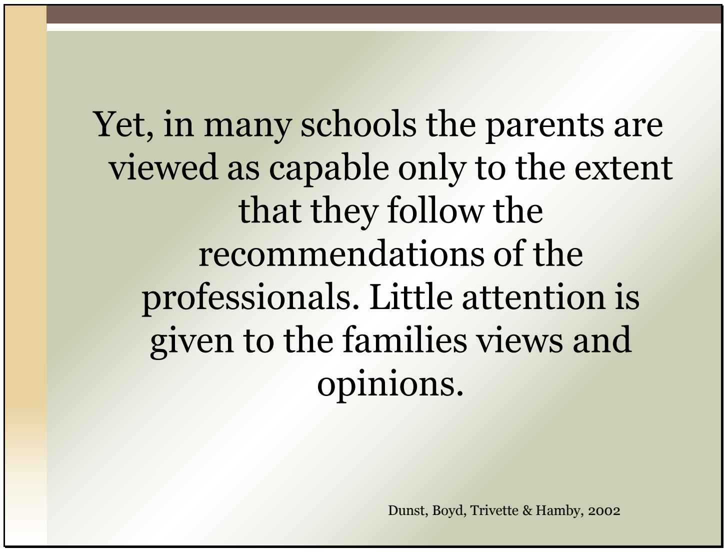
In both general and special education, parent- teacher collaboration is considered essential in supporting the child's academic and social development.

Feinstein, Fielding, Udvair-Solner & Shashank, 2009

Notes for the Presenter:

Aside from the afore mentioned research, failure to include the families into the decision making process can lead the families to experience an unnecessary need to grieve and cope.

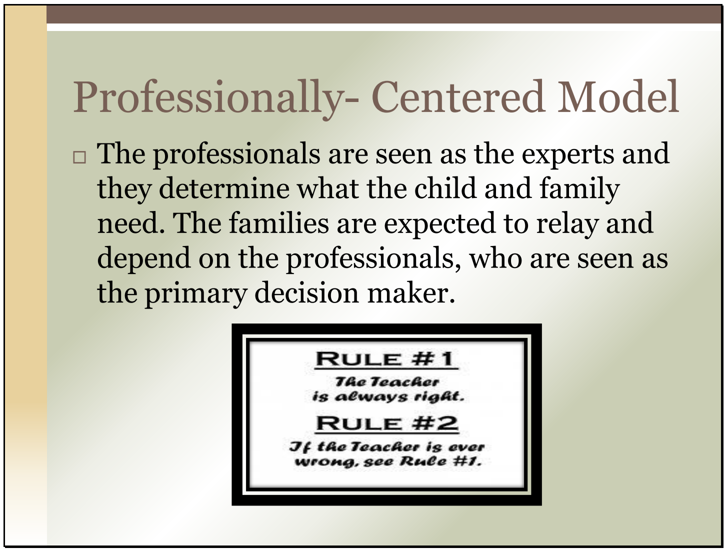
Slide 57



Yet, in many schools the parents are viewed as capable only to the extent that they follow the recommendations of the professionals. Little attention is given to the families views and opinions.

Dunst, Boyd, Trivette & Hamby, 2002

Slide 58



Professionally- Centered Model

- The professionals are seen as the experts and they determine what the child and family need. The families are expected to relay and depend on the professionals, who are seen as the primary decision maker.

RULE #1

The Teacher is always right.

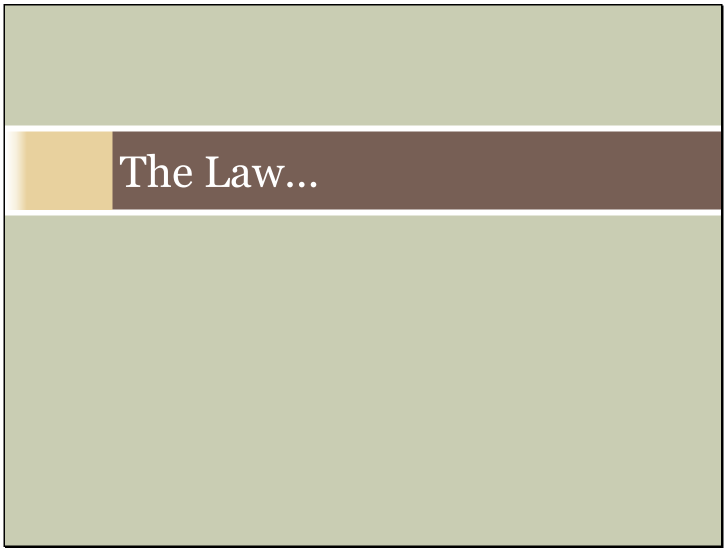
RULE #2

If the Teacher is ever wrong, see Rule #1.

Notes for the Presenter:

While the type of model will vary from site to site or district to district, the research has found that professionally-centered model is most often used in the educational setting. This model has even been shown to be used by professionals who believe they are family-centered due to lack of understanding of the concept.

Slide 59



The Law...

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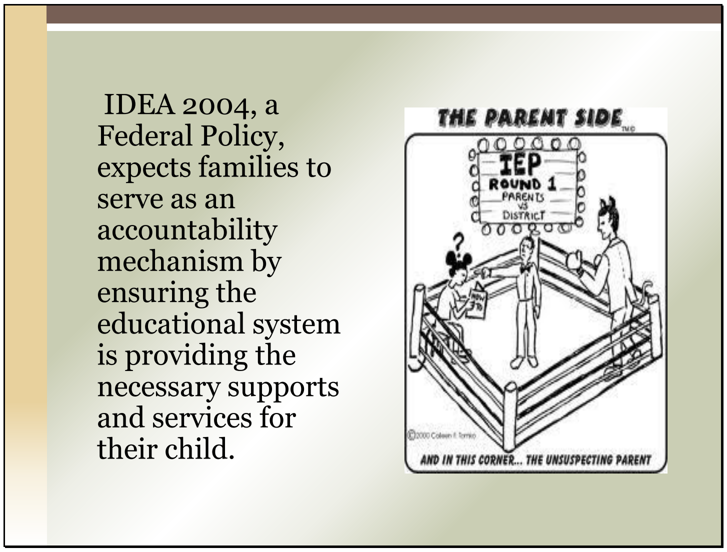
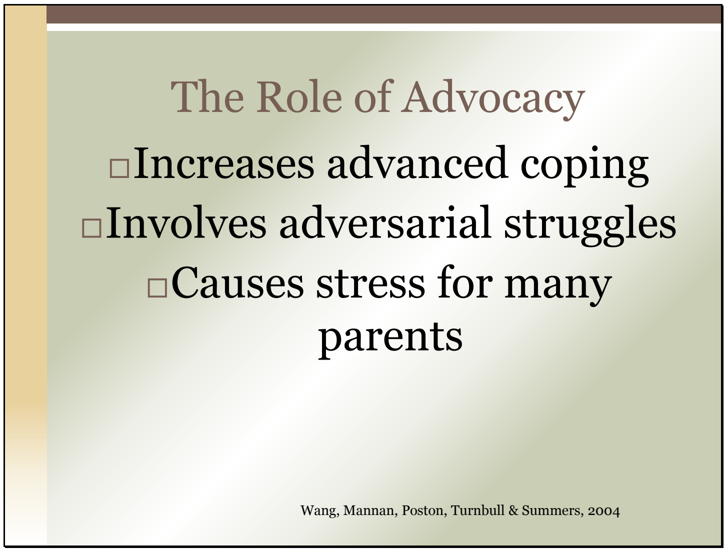


IDEA 2004, a Federal Policy, expects families to serve as an accountability mechanism by ensuring the educational system is providing the necessary supports and services for their child.

Notes for the Presenter:

One area that has been found to cause many parents unnecessary feelings of sorrow and grief is the law. With IDEA 2004 parents have become responsible for ensuring the schools are providing their children with a Free and Appropriate Public Education. This places many parents into the role of advocate, whether they are ready or not.

Slide 61



The Role of Advocacy

- Increases advanced coping
- Involves adversarial struggles
- Causes stress for many parents

Wang, Mannan, Poston, Turnbull & Summers, 2004

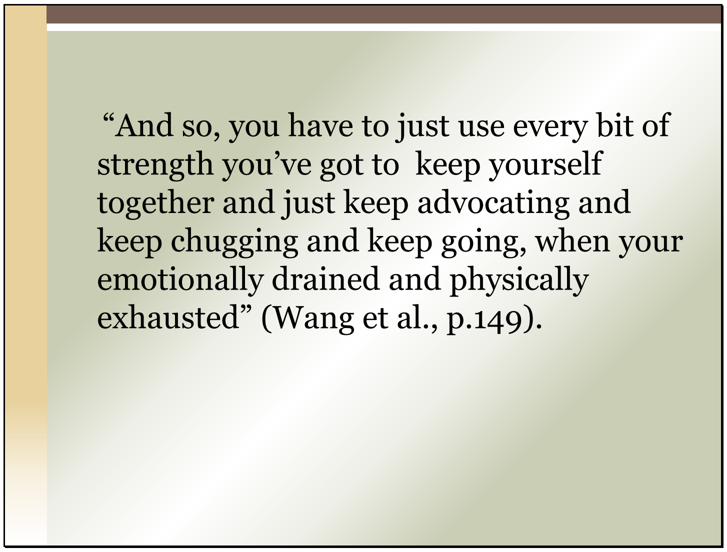
Notes for the Presenter:

Parents must learn new coping skills in order to effectively advocate for their child. This often involves learning more about their child’s disability, thereby increasing coping. Parents in the Wang study also talked about gaining self-confidence as a result of learning the advocacy skills.

Many parents have the idea that advocacy is a life-long battle, and parents wished that they did not have to fight to get their children evaluated and served.

Parents stated that they felt a great amount of stress

Slide 62



"And so, you have to just use every bit of strength you've got to keep yourself together and just keep advocating and keep chugging and keep going, when your emotionally drained and physically exhausted" (Wang et al., p.149).

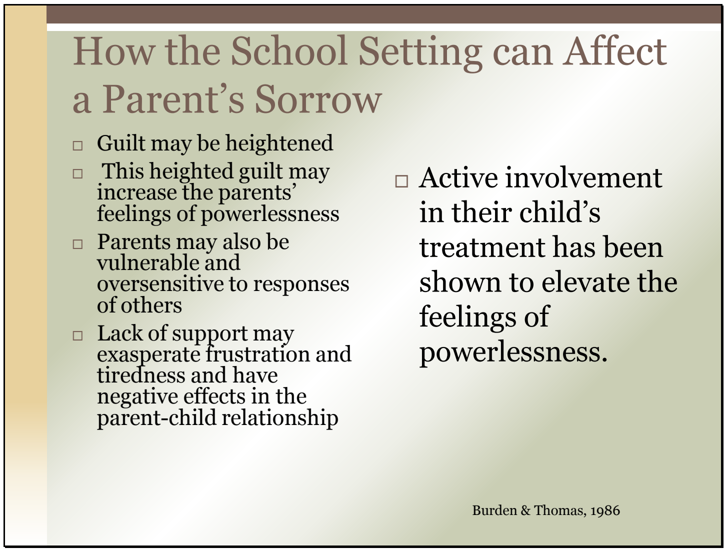
Notes for the Presenter:

With a family-centered approach that includes parents as equal partners and decision makers in their child's education, much of the need to advocate would be alleviated as a trusting and open partnership is formed.

Slide 63

What Families Need from Educators & Schools

Slide 64



How the School Setting can Affect a Parent’s Sorrow

- Guilt may be heightened
- This heighted guilt may increase the parents’ feelings of powerlessness
- Parents may also be vulnerable and oversensitive to responses of others
- Lack of support may exasperate frustration and tiredness and have negative effects in the parent-child relationship

- Active involvement in their child’s treatment has been shown to elevate the feelings of powerlessness.

Burden & Thomas, 1986

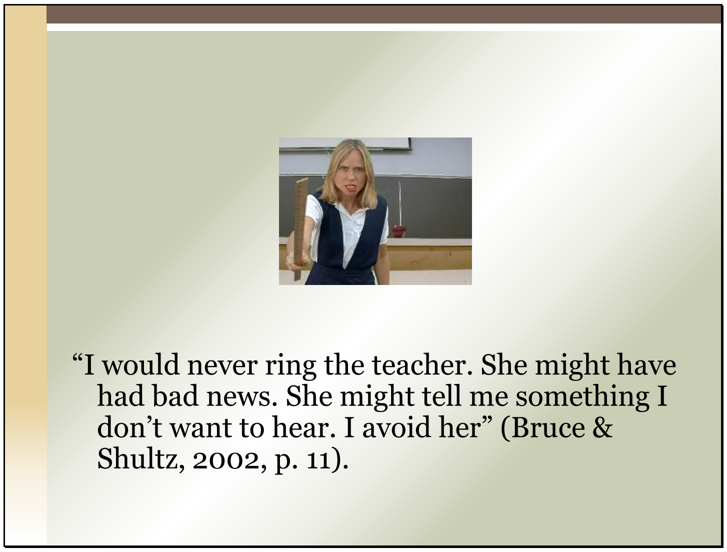
Notes for the Presenter:

Guilt is present in any grief experience but may be heightened in parents of children with special needs due to their sense of responsibility for the child’s well-being.

These feelings of guilt are heightened when a parent feels they have little or no control over their child’s education.

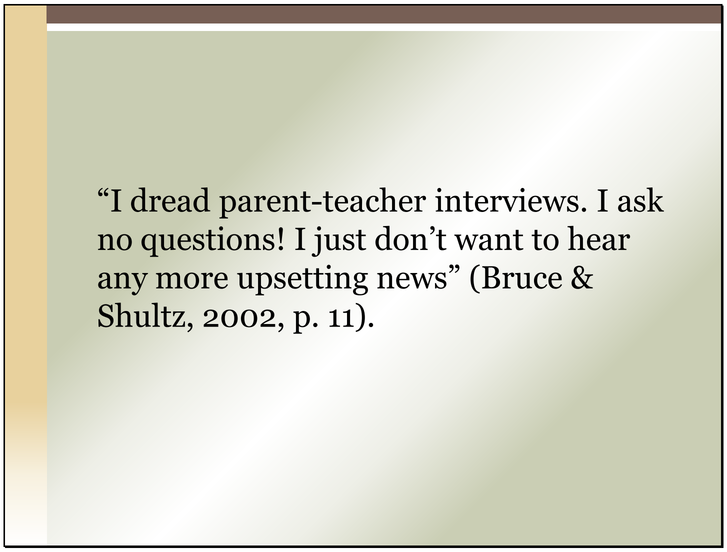
But, active involvement, such as that found in a family-centered practice model, has been show to elevate these feelings in the parents.

Slide 65



“I would never ring the teacher. She might have had bad news. She might tell me something I don’t want to hear. I avoid her” (Bruce & Shultz, 2002, p. 11).

Slide 66

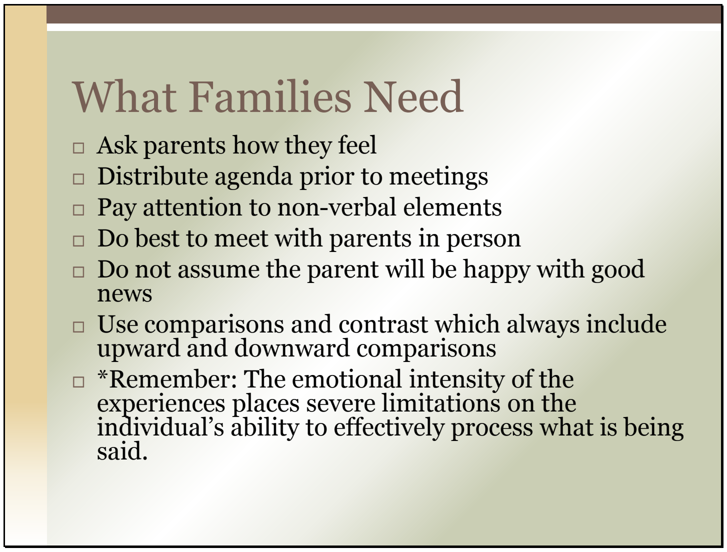


"I dread parent-teacher interviews. I ask no questions! I just don't want to hear any more upsetting news" (Bruce & Shultz, 2002, p. 11).

Notes for the Presenter:

When parents have had prior negative experiences they may fear being traumatized by what other professionals may say about their child. This fear frequently results in avoidant responses from the parent.

Slide 67



What Families Need

- Ask parents how they feel
- Distribute agenda prior to meetings
- Pay attention to non-verbal elements
- Do best to meet with parents in person
- Do not assume the parent will be happy with good news
- Use comparisons and contrast which always include upward and downward comparisons
- *Remember: The emotional intensity of the experiences places severe limitations on the individual’s ability to effectively process what is being said.

Notes for the Presenter:

Do the parents feel overwhelmed, burnt-out? Do they feel reluctant to ask questions?

Agenda: Will allow parents to process their thoughts & feelings on the issue. Allow parents to tell you which items on the agenda feel too emotionally hazardous for them. Distribution of the agenda beforehand also reduces the element of surprise. Remember many of these parents have already been through a lot.

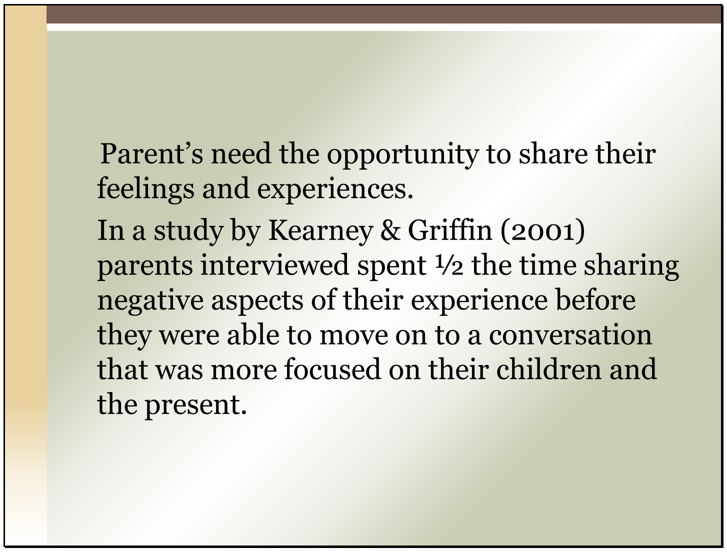
Non- Verbal Elements – body language, seating arrangements (no desk in between parent and teacher) & time: Make sure you allow enough time.

Meeting in person: Is important because communication by phone introduces feelings of abandonment, isolation and helplessness for the parent.

Good news: Remember no matter how good the news may seem to you the parent may process it a different way. They may still be thinking about how far behind their child is.

Comparisons: Some children are more skilled at this; some children are not as skilled as your child. This serves to relieve parents for feelings of helplessness while allowing them to understand their child in comparison to other children.

Slide 68



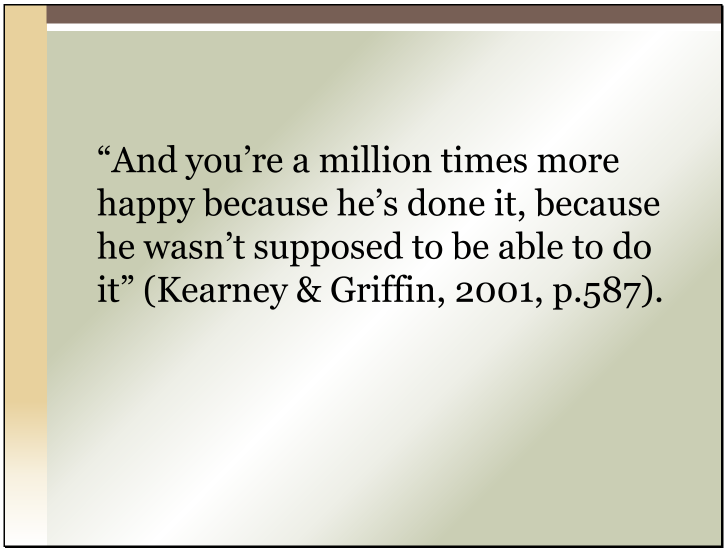
Parent’s need the opportunity to share their feelings and experiences.

In a study by Kearney & Griffin (2001) parents interviewed spent ½ the time sharing negative aspects of their experience before they were able to move on to a conversation that was more focused on their children and the present.

Notes for the Presenter:

Many parents will want to talk about their personal lives, feelings, etc. before they are able to focus on the present. This is a phenomenon that I have observed in many IEPs that I have participated in. I have also seen this in my own meetings of other parents of children with special needs. This sharing seems to serve as a catharsis for the parents.

Slide 69

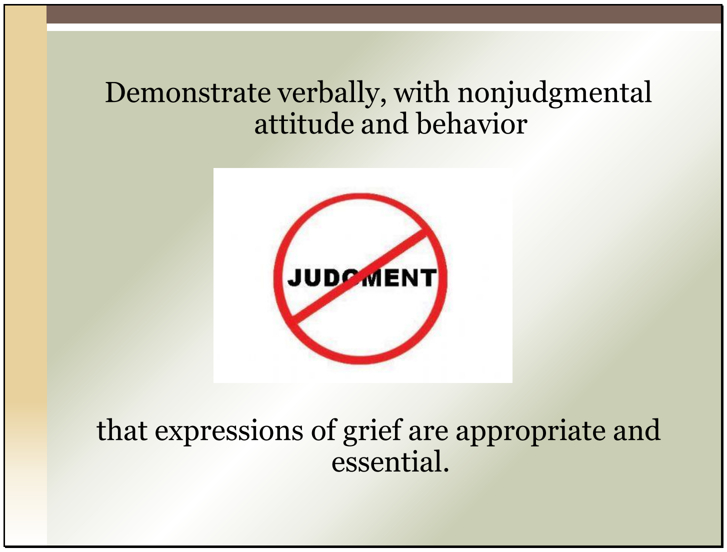


"And you're a million times more happy because he's done it, because he wasn't supposed to be able to do it" (Kearney & Griffin, 2001, p.587).

Notes for the Presenter:

As you saw on the prior slide not all parents will react as you would expect to what you may perceive as good news, parents may experience both joy and sorrow when news of a child's success is delivered. This may be because they are celebrating the success but also grieving where the child should be.

Slide 70



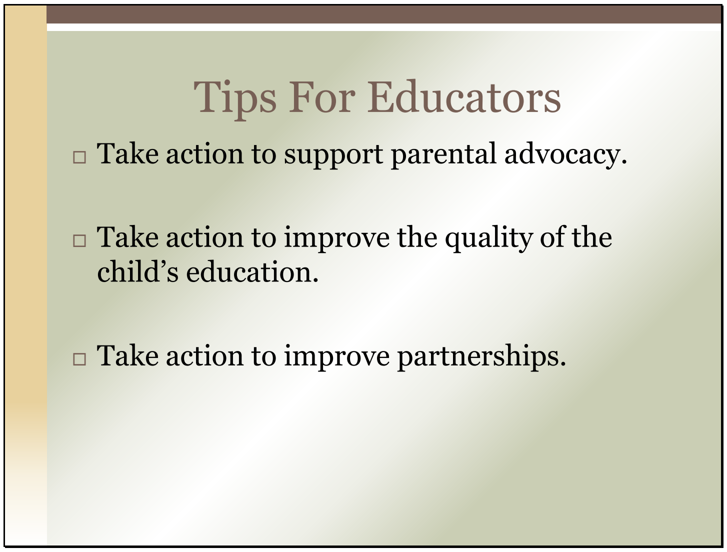
Demonstrate verbally, with nonjudgmental attitude and behavior

that expressions of grief are appropriate and essential.

Slide 71

- "...family members stressed that communication should be honest and open with no hidden information and no "candy-coating" of bad news."

Slide 72



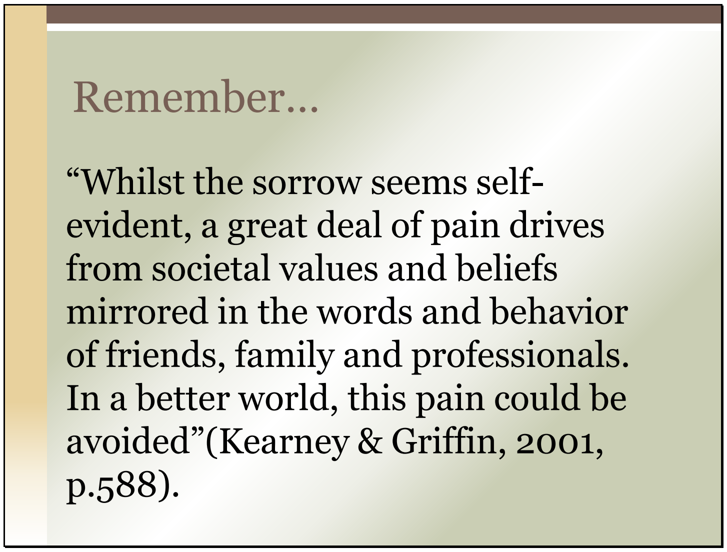
Tips For Educators

- Take action to support parental advocacy.
- Take action to improve the quality of the child's education.
- Take action to improve partnerships.

Notes for Presenter:

*Pass out the Tips for Educators handout.

Slide 73



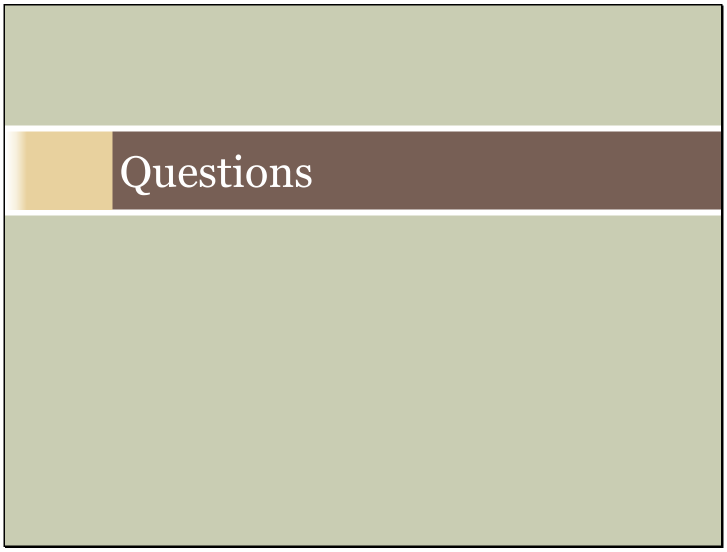
Remember…

“Whilst the sorrow seems self-evident, a great deal of pain drives from societal values and beliefs mirrored in the words and behavior of friends, family and professionals. In a better world, this pain could be avoided”(Kearney & Griffin, 2001, p.588).

Notes for Presenter:

If we, as educators, can do even a small part in elevating the sorrow experienced by a parent we are one step closer to creating a stronger, more successful family and school partnership.

Slide 74

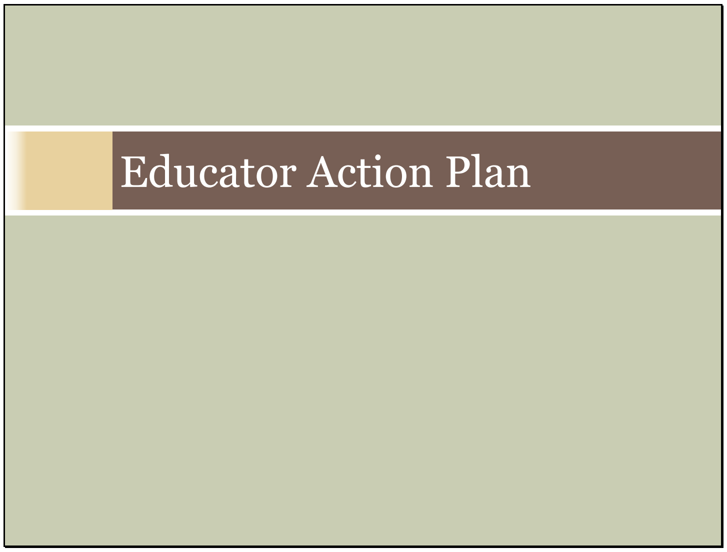


Questions

Notes for Presenter:

Before we wrap up we are going to do one last activity, but first I would like to take some time to answer any questions that you might have.

Slide 75

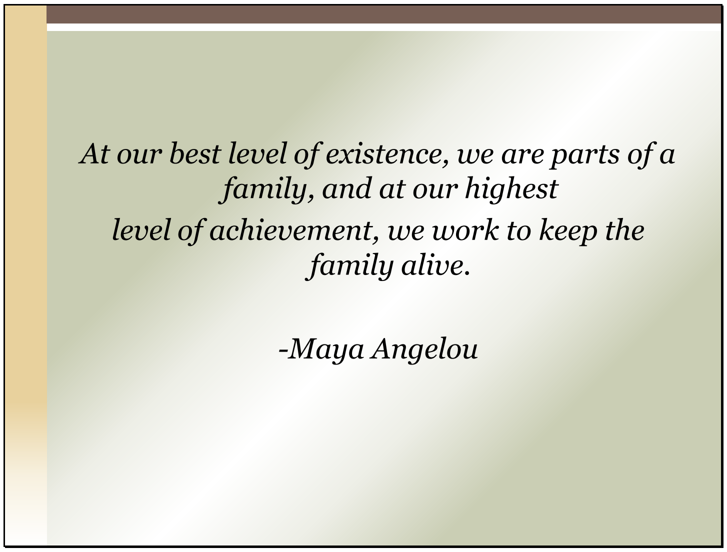


Educator Action Plan

Notes for Presenter:

As a final activity participants will be asked to write down one piece of action that they can do that will help they and/or their school begin to move toward a more family-centered approach to education. Lastly, participants will be asked to share their responses.

Slide 76



At our best level of existence, we are parts of a family, and at our highest

level of achievement, we work to keep the family alive.

-Maya Angelou

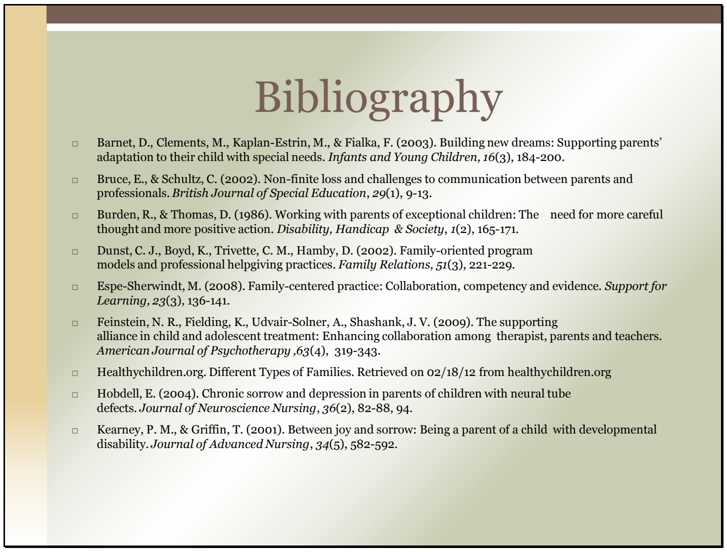
Slide 77

Thank You!

Notes for Presenter:

Allow time for any final questions or thoughts from participants.

Slide 78



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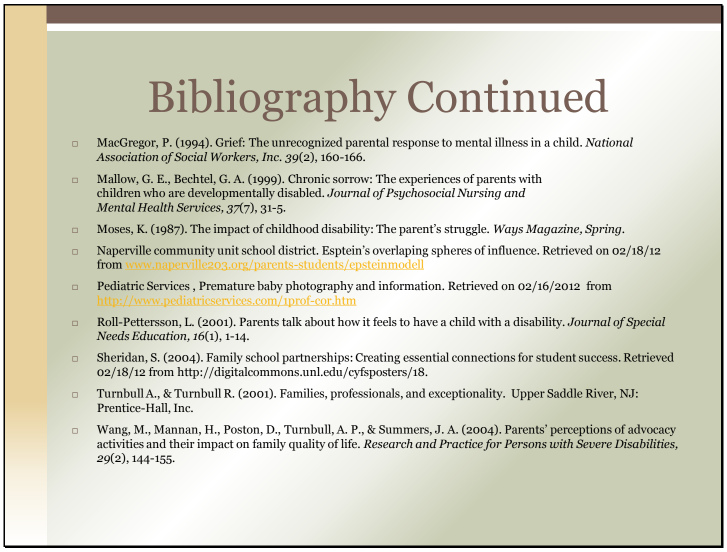
Slide 79



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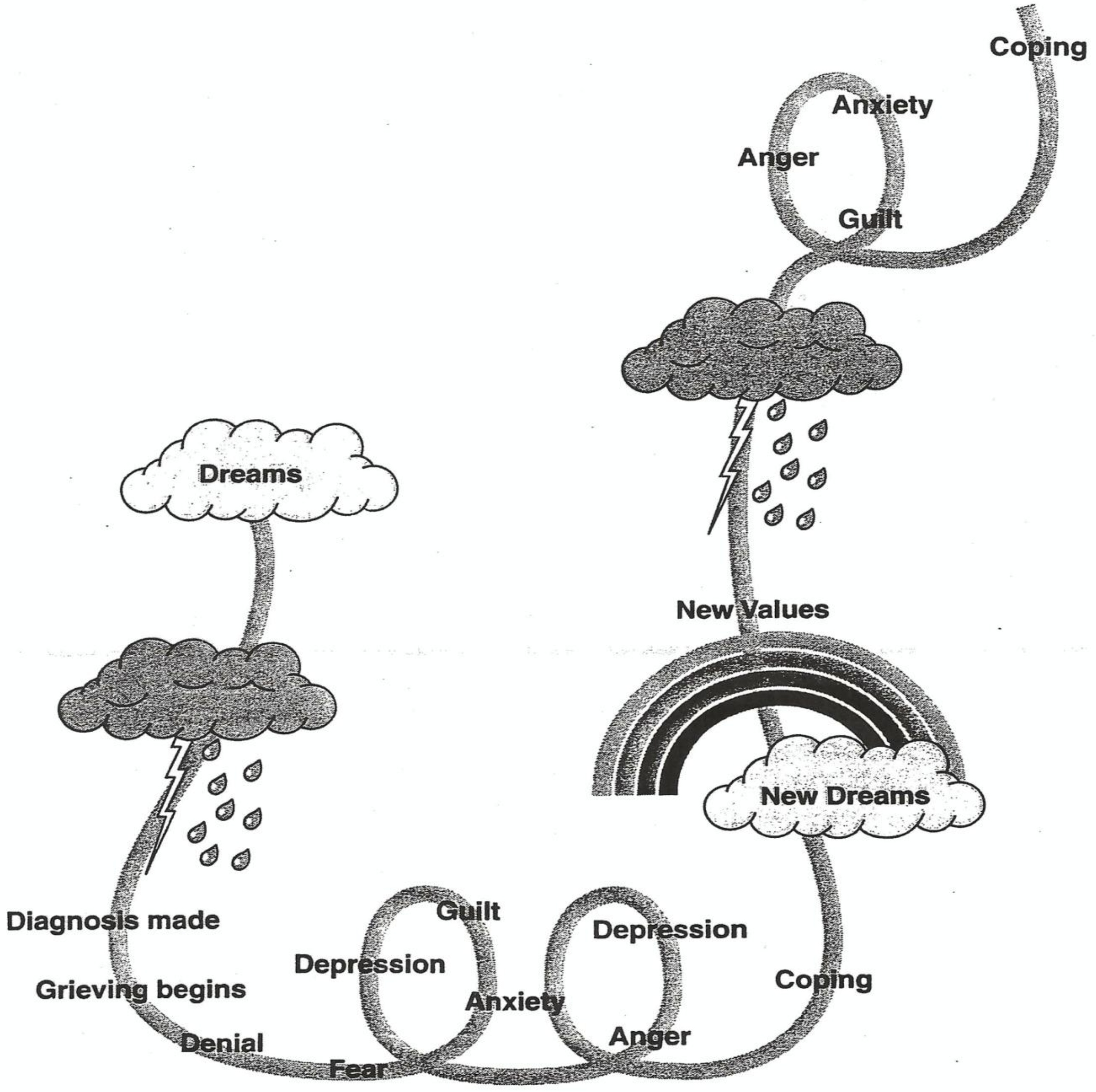
APPENDIX B: Professional Development Handouts


Coping
Anxiety
Anger
Guilt
Dreams
New Values
New Dreams
Diagnosis made
Grieving begins
Denial
Fear
Guilt
Depression
Anxiety
Depression
Anger
Coping

An Open Letter to Educators from a Special Needs Parent Advocate

Look Through the Windows of My World

By Pat Linkhorn

This "open letter" is, of course, not representative of all parents of children with disabilities, but I've tried to make it a fair sampling of the views I've heard expressed from other parents. I know I won't live to see Utopia and my children probably won't either, but the laws that are being passed today providing inclusion of children with handicaps into public schools give educators the opportunity to make this a generation of better people. And that's one step closer!

You can't walk a mile in my shoes, but you can take a short journey with me and I can show you some scenes from my life. I don't ordinarily open up to strangers like this, but you're not really a stranger. You're the person responsible for my child's education - a superintendent, a principal, a teacher, a guidance counselor or a special education director. The object of this is not to make you feel sorry for me. Far from it. It's to try to help you understand me and my child. If you can understand something about the places I've been, you may be able to understand where I'm coming from today.

This first window shows you a death. It's not a typical death. We didn't get flowers or have calling hours. It was a very private affair and not too many people even realized it at the time. This was the death of a dream.

You see, I always thought I'd grow up, marry and have a couple of "normal" children. When this death occurred, and it doesn't matter whether it happened when my child was first born, or as he began to develop. My whole life changed. I hadn't planned to have a child who had to use a wheelchair, or who would never be able to hear or see, or who couldn't "pass" a standard I.Q. test. I was forced to change my whole outlook on the future. It may have taken a while to go through all the stages I had to go through to get to where I am today. There was grief. A lot of that. There was a lot of denial too. I had to get through those two stages before I could accept what had happened and learn to accept my child and the limitations he would put on my dreams. I had to come up with a new dream.

This next window shows me after I've learned to accept my child for who he is. I've learned to take all the backward glances and tasteless remarks in stride. I've seen ignorance from some people I used to think were intelligent and I've met some really wonderful people who I never would have known, had my child been normal. I've had to learn how to make people understand that my child is a child first and handicapped second.

I've seen miracles too. I've seen the first step the doctors said would never happen and

I've seen the light of recognition in my child's eyes when he finally grasped the "meaning of something". And I've seen sunsets you wouldn't believe once I had to really look at them and explain them to my blind child. What may seem ordinary to you has taken on a whole new significance for me.

I've learned a whole new language too. It's called "medicalese". Doctors tend to speak in words you don't hear every day. At first, I thought I'd never be able to keep all the terms and "isms" straight, but I speak it fairly fluently now. I'm beginning to learn "teacherese" now. You use a lot of abbreviations and numbers, but I know I can learn your language too.

Even though I've accepted my child, this next window will show you my fears for my child's future. I realize it's going to take a lot more effort if my child is to lead a fulfilling life. Learning may be difficult for him and in some cases, impossible, but I've really been trying to make his life as normal as possible. I try to focus on the abilities he has and I try to make him feel worthwhile.

I realize there are some things that my child can't do yet and he may never be able to do some things. Sometimes, I tend to focus too much on what he can do and not what he can't do, but it helps me and my family. Some days I seem to be taking three steps backward for every one forward.

You may only see the bad things about my child. It may not seem fair to you to spend more time with him or do things differently for one child, when you have a class room full of children who learn things in standard ways. My child may disrupt your class and may not seem to be learning much. I don't expect you to ignore other students for his sake. I don't want him forgotten in a back class room with all the other "different" kids either, although he may have to spend some time in a smaller class room with more individual attention. My goal is to make his life as normal as I possibly can, and being around regular kids helps. It will take some understanding on both our parts to work this out. Perhaps some of your brighter students could help my child in some areas. You'll be teaching them about responsibility and they'll learn acceptance. They'll view handicapped children as children first and handicapped second. They may learn to accept my child before you do.

As a parent, I know I'm not perfect. I make mistakes every day. I realize teachers are only human too. I also remember the time when some of my teachers were up there with God, in my estimation. They had such an impact on my life! Your lives probably aren't as worry free or stress free as I used to think and my child may only add to a day that's too full and too underpaid. If you at least make the effort to try to treat my child as a person, I know how he will view you. Sit next to God for a while.

My attitude may not be the best you've seen lately. I may already have had some run ins with the "system" before I ever talk to you. I may come on too forcefully and seem too demanding. Maybe I've had to be to get services for my child. Maybe my sister-in-law has excluded my child and I from every family get together she's had since I've had a "disabled" child. Maybe my husband isn't supportive. Or maybe the professionals I've dealt with before have done everything they could to help me. Maybe I'll assume that you will too, and I won't remember all the hard lessons I've learned along the way. Or I may remember each one too vividly. I may be a combination of all these feelings. Whatever the case, I am just a normal person who wants the best for my child.

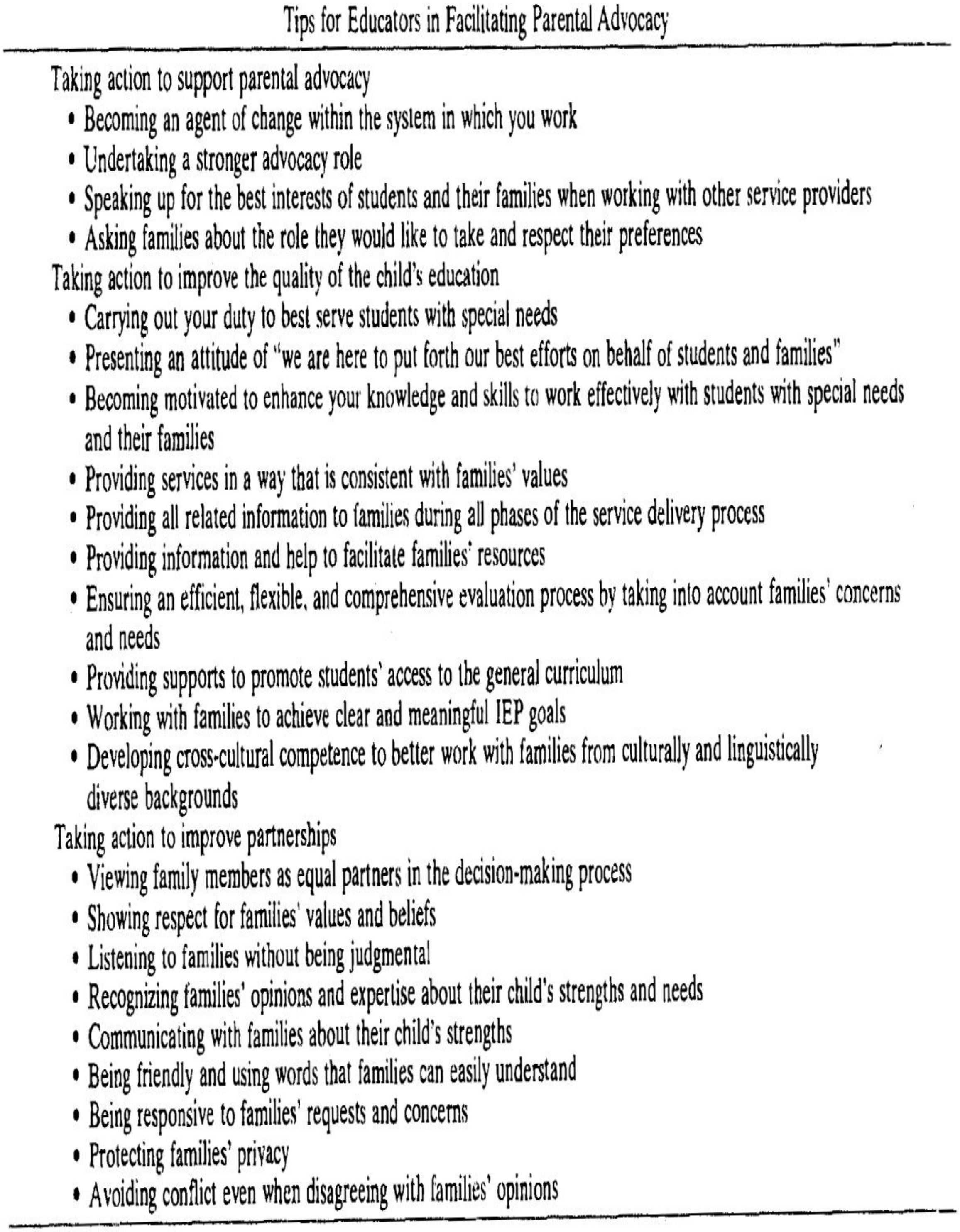
I probably already know that my son won't grow up to be the captain of the foot ball team and my daughter won't be a Home Coming queen, but that doesn't mean that I don't have dreams for them. I've just substituted other dreams for those I've lost. We all harbor some pretty unrealistic expectations for our children and I'm no different than any other parent.

If I seem to want too much from you, I don't mean to. I may have a lot on my mind. I may not have totally accepted the direction my life has taken; it sometimes takes years for a parent to get to that point of acceptance. That's really not too hard to understand when you realize that I lived with that dream for most of my life, whereas I've lived with my "reality" for a lot shorter period. I may even be feeling cheated because my life seems so different from yours. There may be a lot of resentment in me. Or I could just be tired of fighting the battle. You may have a better education than me and you may feel more qualified to make decisions about how and what my child will learn.

In most cases, you are the expert. But if you feel I'm realistic and I've accepted my child's limitations, there will be instances when I will know what will work best. In that case, I am the expert. I've learned some things that you should be thankful you've never had to learn.

If you take all the things you've seen through my windows into consideration, you may understand me and my child better. If we work together, maybe we can do what I pray for each night. That is to give my child as many opportunities as possible to lead a normal life, in a world that isn't fair.

***Pat Linkhorn** is an advocate/trainer/information specialist with the Ohio Coalition for theEducation of Children with Disabilities.. She is also an experienced parent and has two girls with special needs - autism and blindness due to prematurity.*
http://thelinkto.com/laugh



Tips for Educators in Facilitating Parental Advocacy

Taking action to support parental advocacy
- Becoming an agent of change within the system in which you work
- Undertaking a stronger advocacy role
- Speaking up for the best interests of students and their families when working with other service providers
- Asking families about the role they would like to take and respect their preferences

Taking action to improve the quality of the child's education
- Carrying out your duty to best serve students with special needs
- Presenting an attitude of "we are here to put forth our best efforts on behalf of students and families"
- Becoming motivated to enhance your knowledge and skills to work effectively with students with special needs and their families
- Providing services in a way that is consistent with families' values
- Providing all related information to families during all phases of the service delivery process
- Providing information and help to facilitate families' resources
- Ensuring an efficient, flexible, and comprehensive evaluation process by taking into account families' concerns and needs
- Providing supports to promote students' access to the general curriculum
- Working with families to achieve clear and meaningful IEP goals
- Developing cross-cultural competence to better work with families from culturally and linguistically diverse backgrounds

Taking action to improve partnerships
- Viewing family members as equal partners in the decision-making process
- Showing respect for families' values and beliefs
- Listening to families without being judgmental
- Recognizing families' opinions and expertise about their child's strengths and needs
- Communicating with families about their child's strengths
- Being friendly and using words that families can easily understand
- Being responsive to families' requests and concerns
- Protecting families' privacy
- Avoiding conflict even when disagreeing with families' opinions

Wang, et. al. (2004)

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