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## **Finding a Balance Between the Joy and the Sorrow: Parenting Children with Special Needs.**

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There is an old sitcom MASH that replays fairly regularly on cable television these days. MASH stands for Mobile Army Surgical Hospital and is based on an original movie that depicted the general insanity of trying to live within and survive the Korean War. Hawkeye is the lead character in the show. He is a reluctant but brilliant surgeon who when on duty saves the lives of many of the wounded soldiers; and regularly when off-duty, jokes and drinks and fools around with women. He deals with the pain of his everyday serious experience by profoundly refusing to take anything else seriously. In one episode, Hawkeye shows signs of cracking; he has trouble with sleepwalking in the middle of the night and plays imaginary basketball with old childhood friends in his sleep. Sidney, the Psychiatrist, pays a visit and with skill and speed cures Hawkeye of his stress based symptoms. At the end of the half hour (definitely a record cure for the field of psychiatry!), Hawkeye asks Sidney if he is going crazy. Sidney reassures Hawkeye that Hawkeye's troubles with sleep walking and playing imaginary basketball in the middle of the night are not a sign of insanity but instead represent a sane response to the insane experience of war.

I have often thought that this moment captures the essence of what I do for a living. My job is to help parents understand that their difficult and overwhelming feelings often represent a normal response to an insane experience. When I meet with parents at the talks that I have given or work with them in my office, parents tell me how rarely they get the opportunity to focus on their experience of the trauma of their child's disability. In my talks or in my office, I bear witness to their emotional process; I articulate for them the feelings that they have not said before; and I provide a forum for them to begin to find their own words for their inner experiences as parents. As a professional, I can validate the import of their feelings and lend credence to the view that their feelings are neither insane nor "bad" but instead a normal expression of a difficult and often traumatizing experience.

I have more recently come to realize that this episode of MASH works so well for more than one reason. The liberal pacifist in me has always focused on the powerful acknowledgment of the insanity of war; and the psychologist in me has always resonated with the profound permission given in this moment to express one's darkest feelings in the face of trauma and tragedy. However, I now also realize that this moment in this imaginary drama works because the primary, temporarily insane, main character, Hawkeye, is normally profoundly functional in

the face of the demands of patching up wounded and dying soldiers. It is the balance between his functionality and his insanity that makes the moment in this episode work so well! So too, it is finding balance that works in parenting children with special needs.

In my work and in my own personal life, I have found that there is much in life over which we have little control, which leaves us with the task of focusing on how we cope with what happens to us. My life and my work have taught me about the balance between joy and sorrow that is a regular and consistent element of all of our lives. I have been impressed in my office and in talks with groups such as these at how balanced the discussions become once the full range of emotions is acknowledged and integrated. Whether to the parents of a child with an illness or to the child or adult living with the disability, I have found that children and adults find a better way to cope and live with their disabilities when we allow and encourage them to speak to the negative emotions they experience. Repeatedly, I have seen children and adults more willing to struggle to learn a skill or to take an onerous medication when they are given permission to speak of the fact that they may not be able to conquer the skill or that they may die before their time.

Those of you who have heard me speak before on “normalizing the emotional experience of parenting a child with special needs” know that I generally focus on the profound importance of expressing the negative emotions that can accompany the job of parenting special needs children. It is my experience that people coping with disability within themselves or their families add to the burden of the trauma by judging themselves for the negative reactions that they have. And we as professionals often multiply the problem by adding weight to the judgment. Individuals struggling with illnesses and parents with children with disabilities experience a wide range of emotions such as anger, rage, mourning, frustration, sadness and depression. Parents don't dream of having a child who struggles with blindness or cystic fibrosis or autism or learning disabilities. Parents dream of healthy children, and they mourn the loss of the expected healthy child.

Mourning is not a feeling that goes through prescribed stages and disappears. Instead I have learned that it is a feeling that has different expression for each parent. The meaning of the mourning is woven in the history of the individual parent, as is the meaning of having a child for them. The mourning and anger and fear and frustration come and go in response to the struggles that their children will have throughout their lives. If given room for expression, the feelings will go through different stages of expression but will most likely come and go over and over again throughout the life of the child and the parent. Rachel Reman in her book “Kitchen Table Wisdom” says that we all have stories to tell and that we are empowered in the midst of pain by the opportunity of telling our individual stories. Our stories only empower us if they are true to the range of feelings and experiences that we have.

Most of you are here tonight because you have been touched in your life by both joy and sorrow. There is the joy of giving birth to or adopting a child, and there is the pain of knowing that your child has a disability that will make his and your life more difficult. Life is full of moments that are unplanned, unexpected and unfair. People's lives are disrupted by illness and trauma and disabilities. Children are born with problems that rob them of the relative ease of childhood and create a heavy burden for their families. Adults and children are stricken with illnesses that are painful and may impose limitations on the quality and/or quantity of life, robbing them of the experience of living the length of their lives. We act as if life and emotional events will be ordered and come in their proper and expected time and sequence. In reality, life happens, good and bad within its own rhythm, and we must cope and learn to grab the joy and deal with the pain when it happens.

Grabbing the joy when it happens and dealing with the pain when we feel it sounds like a simple prescription. In reality, creating balance between joy and pain is extraordinarily complex. Emotions are not simple and often have a life of their own. They do not occur in an orderly fashion coming at our beck and call. Parenting children is a full time profession, and parenting children with special needs often feels more than full time. There are constant, everyday demands to monitor your child and attend to his medical, educational and emotional needs. There is the constant need to educate oneself about your child's disability and about all the possible professional opinions on how best to treat your child. Then there is the question of how to impart and apply the understanding and wisdom you have acquired to the benefit of your child without interfering with your child's independence and without alienating the professionals involved in your child's life. Most people feel that juggling these responsibilities leaves little time for indulging oneself by steeping oneself in one's negative emotional feelings.

The problem is that acknowledging one's feelings is not an indulgence. It is a necessity that allows us to function more fully. The issue is the need to find a balance between the negative emotions and the need to function in the world. That is the message of the MASH episode. It is Hawkeye's inimitable ability to touch the tragedy of his situation with humor, with pathos, and even with moments of insanity that make him open to being totally present and functional with his patients. This for me defines the complexity of the juggling act of parenting a child with special needs. Finding the balance between the joy and the sorrow, between the pain and the functioning is a constantly changing, complex balancing act.

When I have spoken in the past about working with families with children with special needs, I have addressed three overlapping but separate areas of functioning. I have talked first about the struggles of the individual parent within the family, second about the nature of the relationship between each parent and the child, and third about the issues that arise in the parent couple and the family system. Tonight I would like to readdress each of these areas from the

perspective of the need to establish balance. The concept of finding balance is central to understanding the complexity of coping with the problems that arise individually, interpersonally and systemically within families that have children with special needs.

When Donna Minnick first asked me to give this keynote talk, I asked her what it was she would like me to speak about. She was clear that I had carte blanche to write about any topic I chose. At the time, we engaged in some wonderful conversations about her interest in the topic of advocacy, and it was clear to me that advocacy would be a welcome and appropriate topic. I sat down to write about the importance of advocating for your child. After many hours spent staring at the computer, I realized that I could only understand the role of advocacy from the perspective of the development of psychological balance within the individual parent and the family system.

I have always recommended that an excellent way to cope with having a child with special needs is to become your child's advocate. I have suggested that advocacy is both good for your child and empowering and healthy for you as a parent. Putting energy into self education and becoming a knowledgeable and forceful advocate for your child can be an important and positive mechanism for channeling the intense feelings brought on by your child's disability and for feeling some sense of power and efficacy in being able to help your child. The reality is that the squeaky wheel is the one that gets greased, and no one knows your child as well as you do and no one is going to fight for your child quite the way you will. Furthermore, there is an added advantage to advocacy--the best cure for the powerless feelings of depression and the angry, frustrated feelings of watching your child struggle, or struggling with your child, is winning a battle with THE SYSTEM. Not only is advocacy a necessary parenting skill for parents with children with special needs, advocacy is a positive coping mechanism for healing the parent. In other words, to talk about advocacy, it is necessary to talk about it as a balancing force for the difficult feelings within the individual parent that are an integral part of raising a child with a disability or illness.

Obviously, it is not difficult for me to talk about or recommend the benefits of advocating for one's child. What made it hard for me to write tonight's talk solely on the subject of advocacy is that I kept getting stuck on the fact that the benefits of advocacy are best understood in terms of balance. Sometimes advocating for a child can become the sole focus of a parent's daily experience. When a parent becomes obsessed with advocacy, I get concerned that they are using this all consuming activity to service denial of the anxious and depressive and frustrating feelings that they have about their child's disability. I am equally concerned that the parent who cannot advocate for their child may be either overwhelmed by or in denial of their child's disability.

The fact is that balance is a difficult tight rope to walk, and finding the right balance for anyone individual is not an easy formula to write. It is critical to find

the space and time and setting within which to experience and acknowledge the difficult aspects of parenting a child with special needs. It is equally important to create the space and opportunity to advocate positively for the rights of your child. Recognition of one's internal emotional state and recognition of the child's special needs are not mutually exclusive activities. They are both necessary aspects of creating a balanced solution to the task of raising a child with special needs while taking care of the individual parent as well.

Advocating for a child with special needs is not just about the internal psychology of the individual parent. It is a topic whose dimensions are woven into the complex dynamic of the parent-child relationship. Advocating for your child requires carefully made decisions about when and how to step in and fight the system. Most parents have a long list of conditions they would like to change within their child's educational, social and medical programs. Children with special needs are especially dependent upon their parents to help them navigate these systems. The cost of under involvement on the part of the parent is often paid in lost potential for the child. The problem is that there is an equally important cost of over involvement. There can be a cost to the child and a cost to the parent. There is a cost to the parent-child relationship, and there is an additional cost in terms of one's relationship to the systems you are trying to change. I encourage parents to get in there and fight for their child, to represent their child's needs to schools and doctors and social programs. It is often true that if you don't speak up, who is going to do it for your child. If you don't push, your child may suffer. But it is also true that one can cross the line and push so often and so indiscriminately that both the system and your child stop listening. Furthermore, it is also true that as one's child gets older and closer to adolescence, it is possible that advocacy by the parent will interfere with the independent psychological development of the child.

The difficulty becomes knowing when to intervene and when not to intervene. The issue is to find balance between advocacy and the development of independence in your child, to find balance between fighting the system and stepping back and trusting the professionals to make some of the decisions, and to find balance between helping your child experience success and letting your child sometimes experience a difficult dose of failure. The whole parental task between infancy and adolescence of slowly but surely separating from your child and granting them increasing autonomy, initiative and identity is totally contrary to the need with many children with special needs to be vigilant, intrusive, controlling, limit setting parents. Observing minute details of speech development, hovering over your child when playing with peers to ensure safety of all, translating for deaf or speech impaired children, supervising every homework assignment with learning disabled and ADD children, fervently hanging on to a hyperactive child by hand or leash in public places to avoid kidnapping or embarrassment, sitting in on extra curricula activities to ensure that your child can fit in and survive--are all necessary and intrusive parts of parenting

certain children with special needs. However these behaviors interfere with the development for the parent of the ability to let go.

Vigilance is a necessary, normal and useful part of parenting a child with special needs, but it interferes both with the child's sense of independence and the parents chance to step back and experience their child as separate. It interferes too with the parents chance to go on with their own separate lives. It is important for you as parents to be aware both for your child and for your own sanity that the task of parenting a child with special needs interferes with the normal developmental stages of parenting and, thus, often leaves parents vulnerable to feeling like they have failed at their task. It is not a matter of failure--but instead a matter of recognizing how your child's needs have skewed your parental tasks -- so that you can make judgments that let you move on despite the conflicts. For example, there comes a time, often in early adolescence, when vigilant attention to special needs must be tempered by letting your child separate and handle things on his own. However, this decision comes at the cost of some failure for your child and at the cost for you of sleepless nights spent worrying about your impulsive child's capacity for judgment in the face of peer pressure. The balance is a tricky one--but again knowing what balls you are juggling can help you juggle better. If a parent is unwilling to face the anxieties and fears of letting a child fail, then the decisions about when to advocate and when to let go are based on protecting oneself from the difficult feelings not on your child's needs.

The hardest part of establishing balance within the parent-child relationship is finding your way through the complex maze of decision making about when to become involved and support your child and when to step back. It is my experience that people who deny or ignore the complex array of difficult emotions involved in parenting children with disabilities have a much harder time navigating this complex maze of parent-child decision making. If you don't acknowledge the difficult emotions, then advocacy is used in the service of denial and any potential for thoughtful decision-making or prioritizing is lost.

The opposite is also profoundly true. As much as I personally recommend that we must normalize the difficult array of emotions that are part and parcel of the experience of parenting children with special needs, I am also aware on a daily basis in my work that one can become lost in the darker feelings. Depression and anger and anxiety do have the power to paralyze us in daily life and make it impossible to function for oneself or one's child. Equally concerning is the fact that being steeped in advocacy and positivism burns us out and cuts us off from knowledge and experience of ourselves. Balance between emotionality and functionality should make each side work better. It is critical to understand that neither denial of nor absorption in the darker side of one's feelings allows one to function optimally. The task of finding an optimal balance is to create a life that allows one to acknowledge the more difficult feelings within a safe and bounded forum while allowing time and space for the energy to function and cope in the world. This is not an easy task. It is a complex maze in which one tends to get

lost at times. Recognizing and tracking the potential swings of the pendulum between the moments of dark emotions and the spurts of advocacy is the only path I know to create balance.

I have thus far talked about finding balance within the individual parent and balance within the parent-child relationship. However, balance is an equally important concept in examining the function of the world of the parenting couple or the family system. Having a child with special needs is an overwhelming event in the life of a family. For some members of the family, meeting the needs of the child with the illness or the disability becomes their defining function. At the same time, other members of the family and other relationships seem to fade into the background, losing the importance and role they once played in family life. It is impossible to meet the needs of a child with special needs and totally avoid this pattern. It is difficult work to shift this pattern to make room for all the members of the family. However, it is important to remember that a family focused only on meeting the needs of the child with a disability is making a clear statement that life has become defined by the disability--both for the child with special needs and for all the members of the family. Finding a semblance of balance in the family preserves the individuality and sanity of all concerned.

There is a primary risk to the couple of a child with special needs. Not only can an individual struggle to find balance between focuses on the needs of the child versus the needs of the self, the couple too can become polarized around these issues. In my practice, I have often noted polarity between parents of children with special needs. Because parents are individuals who bring different styles and capacity for dealing with trauma, it is common to see them coping with the difficulties inherent in parenting these special children in totally opposite and polarized ways. What began as individual temperamental differences between parents can turn into seriously polarized positions about the child.

Often one parent becomes absorbed in the issues of parenting the special needs of the child while the other parent focuses solely on the child as a normal member of the family. Thus the parents are stuck arguing over what is essentially different perceptions of their child and different perspectives on the family. One parent sees the needs of the child and struggles between overwhelming difficult feelings and long hours of fighting with the system for the child. The other parent struggles to maintain or create a sense of normality in the family. At its best, a moderate polarity between parents may serve the child. The child has one parent to advocate and acknowledge his special needs and another parent who treats the child as a normal member of the family perhaps encouraging the child to participate in a normal range of activities in the world at large. However, there are times when the polarity between parents becomes so intense that the parent's live separate lives. The family is split in two; one parent lives solely in relationship to the child with special needs and the other parent creates a family with the remaining children. At its worst, a polarized parent can become isolated from the family altogether. Each parent feels a sense of self-

righteousness that they represent the better perspective on what is needed. No one member of the family can thrive in this atmosphere.

What is needed in the family is balance. Balance within the individuals and balance between the members of the family. It is difficult to talk about achieving balance between members of the family without first helping the individual members of the family find a sense of self that is balanced. When disability comes to represent everything about the child, then the identities of the other members of the family are restricted to roles in reaction to the disability. Although it is exaggerated to describe the mother of a child with special needs as a martyred advocate and the father as a denying, uninvolved parent and the sibling as isolated and neglected, these stereotypes are rooted in the reactions of the members of a family that has defined one member of the family entirely by the presence of his or her disability. The critical task is to find a sense of balance both for the child and the family. The child must have a life balanced between care and attention to special needs and focus on normal life cycle expectations; the family needs a balance between attention to the child's needs and attention to couple, sibling and family needs; or else the child or the family feels that life is defined only by illness or disability. Neither child nor family can survive on a focus on damage.

Thus far, I have spoken about the balance that needs to be found within the individual, within the parent-child relationship and within the couple and family systems. I have suggested that each individual parent needs to find balance between emotionality and functionality, between the difficult and at times dark emotions of watching one's child struggle with special needs and positively advocating and supporting your child in dealing with his world. I have described the problems inherent in finding a balance within the parent-child relationship, the inherent struggle between vigilant attention to special needs and age appropriate attention to the development of initiative and independence. I have talked about the difficulties of defining one's child and one's family solely by the presence of a disability, of the need to find a balance within the family between attention to special needs in one child and attention to the needs of all the members of the family.

The title of this talk is "Finding the Balance Between the Joy and the Sorrow". However, in all this discussion of the psychological pitfalls of creating balance within a family with a child with special needs, I have not adequately addressed a word that is central to the title of this talk: Joy. As I read over what I had written for tonight, it seemed to me that I had adequately defined the sorrow and the struggles in parenting children with special needs, and I had tried to talk about how to avoid the pitfalls; however, it seemed to me that describing how to avoid problems and successfully function was not managing to talk about joy. If I go back to the lesson of MASH, it becomes clear that one must acknowledge that Hawkeye has at least three critical states of being. There are the temporary moments of insanity and the moments of outstanding professional functionality in

the operating room, but there are also the moments of pure silliness and joy. He knows how to let go, how to seize the moment and break into song, play poker, play golf in a minefield, flirt with a woman, laugh with his friends and write heartfelt letters to his father. In our current day lingo, he knows how to be mindful of the moments and grasp what he can from them. In creating this delicate thing called balance, it is not enough to manage to function well and find the time to acknowledge the harder feelings. It is necessary that we find individual ways to enjoy our lives and the rare moments when stress does not rule us.

I cannot begin to define joy for any of you. I struggle myself with knowing how to make time to create or appreciate moments of joy within my own life. It is not my intent to describe the experience of joy, but instead to point out that it is easy to get lost in the pain and the demands of parenting your child. Perhaps it is the loss of sufficient experiences of joyful moments that can most define the life of a parent with a child with special needs. One can feel separated and deprived of the normal experience of raising a child and creating a family, perhaps separated and deprived of the normal share of joy. It is understandable that the demands and worries of raising a child with special needs lessen the experience of joy, but the problem is that the very absence of joy intensifies the loss that is created by your child's disability. I cannot provide a formula for finding joy. I can only remind us all to stay mindful of the tiny moments and grab the little opportunities for laughter and celebration that can be a part of any day. I am so used to encouraging parents to be mindful of their sadness and their pain, that it is very different for me to talk about being mindful of the happy moments. Again it is the balance that defines the task of parenting children with special needs. In actuality, I believe that it is balance that defines the task of raising any child. It is just harder to achieve and therefore even more important when your child is special.

What is a reasonable definition of balance? For the purpose of tonight's discussion, achieving balance is best defined as any movement closer to what is missing in your repertoire. If much of your day is consumed in advocating for your child, you need to create moments in the day that are about you. If you are a parent who has yet to meet your child's teachers, you need to find a moment to stop by your child's school. If all your conversations as a couple focus on child issues, how about an evening when discussion of your children is off limits? If you and your spouse are polarized, take one small step towards your spouse's point of view. Take a moment and see if you can imagine or articulate their view. Check with your spouse. See if you are right. It is likely that your polarized roles in the family are more destructive to your child than either of your views in isolation. If your life is all consumed in the serious task of parenting, you probably need to play "hooky" with or without your child. If your life is all about having fun, you probably aren't in this audience listening to me tonight! The point is that a song with one note is tedious and not conducive to growth and healing for anyone in the family.

Much of what I have spoken of tonight is similar to the themes and material that I have presented many times before to this group. However, my intent is to convey a slightly different perspective on the issue of the emotional reactions of parents to the presence of a disability in the child. There is a play called Rashaman that is an old Japanese story of an attempt to solve a murder. In the play, each scene is a replay of the actual murder as seen through the eyes of different eyewitnesses. As I recall the play, the solution to the murder is left to the audience to decide. The obvious point of the play is to provide insight into the fact that there are different ways to understand the same event. If we stand in a different place, we see an issue with new eyes. I started tonight by describing to you the scene from an episode of MASH. I had always felt that the Psychiatrist's view that Hawkeye's emotional struggles represented a "sane response to the insane experience of war" presented a perfect example of my efforts to normalize the dark emotional responses of parents. But recently, I looked at this episode with new eyes. I had a Rashaman experience. I saw from a different perspective that it was the balance in Hawkeye, and Sidney's capacity to appreciate that balance, that made this moment a profoundly meaningful scene. It was the balance in Hawkeye between his capacity for insane moments filled with pathos and pain, his capacity for superb functionality, and his capacity for joy that filled me with respect. It is that kind of balance for which we all strive when faced with pain and loss in life. It is striving to achieve that kind of balance that makes parenting a child with a disability a profoundly complex task. I can only define the task. I wish I could define more clearly the path to achieving such balance in the absence of a large team of great scriptwriters. Hopefully defining the goal makes it a little easier to work towards it for all of us.