

## **Parenting the Whole Family Considering the Needs of Parents and Siblings of Special Needs Children**

The Millers came to me for counseling for help in coping with the extreme stress in their marriage. A couple in their mid- 30s with two young children — one of whom was developmentally disabled — they talked about being sleep deprived and of not having the energy or the time to meet their needs as individuals or as a couple. Their oldest child, a five-year-old boy with a significant developmental disability, required total care for activities of daily living. They took turns sleeping in his room, subjected to erratic sleeping patterns due to his nighttime seizures. Not only were they sleep deprived, they were also missing the sexual intimacy in their relationship. Adding to their stress, their youngest child — a typically developing four-year old — had started having temper tantrums and was expressing strong negative feelings towards his older brother; “I wish he’d die or just go away!”

The Millers were at a loss for what to do. They were understandably exhausted and distressed. They wanted to cultivate a healthy marriage and they wanted their typical child to develop compassion and love for his sibling. They were concerned about their non-disabled son’s emotional and psychological health.

It’s no simple task to nurture a marital relationship while parenting children with such different yet compelling needs. The circumstances may seem insurmountable. How can parents carve out quality time to be together as a couple in addition to creating quality time for their individual children under such conditions?

As the numbers of children being identified and diagnosed with developmental, behavioral, and emotional disabilities increase, these types of stressors will impact increasing numbers of families. In my private practice as a Marriage and Family Therapist and Behavior Consultant, I have witnessed the effects of these stressors — and my clients’ efforts to seek relief from them.

Many parents — with the benefit of personal resources, social support, and sufficient capacity to manage stress — succeed in taking time for themselves while also providing opportunities for healthy growth and development for their typical children. However, parents like the Millers, who are pushed nearly beyond their limits by the moods and behaviors of their typical children are more the rule than the exception.

How can we support these families who find themselves in such extreme circumstances, helping parents to better understand the needs of their typical children?

First and foremost, parents need to recognize that carving out time to take care of themselves is well worth the investment. Couples need to create opportunities for time alone individually and together by identifying a willing family member, a capable adult or mature teenager with whom they can leave their children, and give themselves this

necessary break and time for recharging their emotional batteries. Time out for parents is an effective stress management strategy that is frequently forgotten. By creating time for themselves, parents are then better equipped to consider their needs and those of their typically developing children.

### **Stressors Affecting Siblings**

A non-disabled sibling's emotional and psychological development can be affected by a variety of stressors, such as witnessing their disabled sibling's severe temper tantrums or being physically victimized by their sibling's assaults. They might see their sibling getting away with behaviors that are unacceptable for them but notice that the same rules do not apply.

Placing unrealistic expectations and age-inappropriate responsibilities on a sibling might trigger resentment and/or embarrassment leading them to act out or withdraw socially from peers. Lack of individual quality time with their parent(s), or lack of access to extra-curricular activities due to limited economic resources or parental support can produce anger and jealousy. The list goes on.

### **Feelings of Ambivalence and Grief**

Parents of recently-diagnosed disabled children often find themselves swept up in the wake of unfamiliar medical jargon and procedures, the advice (and the sometimes intimidating knowledge) of early intervention professionals, and an avalanche of information related to their child's developmental status and special needs. Demands on their time, energy, and economic resources can be physically and emotionally depleting. It can seem impossible to find the time or energy to seek counsel and support from a family member, close friend, or mental health professional to process such deep and challenging emotional reactions. Or these thoughts and feelings may simply feel too painful or embarrassing to reveal.

A typical child needs an outlet for their natural emotional expression. A parent who leaves their own feelings unprocessed may therefore be unable to allow their typical child to express negative feelings in an appropriate manner. An unintended gesture or word from a parent can stifle this necessary outlet, sending a message that, for instance, ambivalent or angry feelings towards their disabled sibling are unacceptable.

Parents who are comfortable with their own range of emotions regarding their disabled child are better able to create an atmosphere for their typical child's emotional expression. The child learns that they have permission to explore and express a wide range of feelings about their disabled sibling without fear of parental rejection or abandonment. They feel secure and loved for who they are — with all of their feelings, positive or negative. Dr. Bryna Siegel and Stuart Silverstein in their book, "What About Me: Growing Up with a Developmentally Disabled Sibling" (Da Camp Press, 1994), write that children can learn to cultivate compassion for others once they feel the safety and security of their parent's unconditional love.

## **Support for the Entire Family**

Support within the community for typical siblings can be found in professionally facilitated support groups for children or in “Sib Shops,” designed by Seattle’s Donald Meyers. These groups can help siblings have fun, reduce their feelings of alienation and express feelings that they may be uncomfortable sharing with their parents. Siblings, depending upon their ages, might also benefit from individual therapy and/or family therapy.

Parent-led support groups, individual therapy, or couple’s counseling are settings where adults are invited to express their innermost thoughts and feelings in an empathic and nonjudgmental environment. Couples are encouraged to talk and listen to one another’s deepest truths and feelings regarding the challenges and rewards of parenting a child with special needs.

Family therapy has the potential to provide an environment where each family member has an opportunity to voice their experiences and feelings; to clarify and understand how the family dynamic impacts them. A skilled therapist creates a setting where the family can experience healthy functioning, open communication and, ideally, cultivate a deeper compassion for each other in the process.

In our couple’s counseling sessions together, the Millers worked on their underlying feelings of grief and loss and a myriad of issues associated with these painful emotions. They addressed their underlying beliefs that no one else could adequately care for their special needs son. They acknowledged that their four-year-old was not getting enough positive attention from either of them. They agreed to find someone they could trust to provide respite services while they spent quality time with their typical son doing things that he found enjoyable and rewarding. They fashioned a realistic daily routine that included age-appropriate tasks and a reward sticker chart for his cooperative behavior. Over time, his acting out behaviors decreased and a caring interest in his special needs sibling emerged.

The Millers also began to see that their relationship as a couple needed tender care and nurturing. They made a commitment to establish a date night every other week where they could talk about the things they wanted together as a couple, not just as parents of their children. By doing so, they creatively found the time to satisfy their needs for the intimacy and closeness they had been missing. This dramatically improved the quality of their relationship — and their capacity to manage the stress of parenting their two children.

Having learned effective strategies for the health of an entire family system, parents of special needs children often report that when they take time for their psychological health, they have more on reserve — physically and emotionally — for themselves, their relationships, and for their children. What might feel at first like an investment in time and energy that is seemingly unavailable, is indeed freeing and supportive and well worth the commitment.

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