Making Memories

Revolutionary Common Sense by Kathie Snow, www.disabilityisnatural.com

Every single day we make memories. Holidays, birthdays, and other special occasions are in our memory banks, as are ordinary experiences at home, school, play, work, and more—like a look, a touch, a conversation. But our memories aren't only recollections of good days, bad days, important days, and such. Memories—the culmination of daily experiences—also weave the fabric of a person's life, shaping the person's character, ethics, attitudes, behaviors, and much more.

Other people contribute to our memories, including parents, other family members, teachers, neighbors, classmates, coworkers, acquaintances, and maybe even strangers. As we grow up and take more control of our lives, we also make more of our own decisions that create new memories: how and where we celebrate holidays and special occasions, who our friends are, where we go to college, what job we choose, where we live, who we marry, and more events, big and small.

But the same may not be true for many children and adults with disabilities. For a variety of reasons, they may not have as much control over their own lives as compared to people *without* disabilities, so others make decisions for them, "do" for them, and/or exert control over them. Thus, their experiences—and the memories that are created—*may be determined by the actions of others:* parents, educators, therapists, service providers, etc.

To understand a man, you must know his memories.
Anthony Quayle

Do we recognize our responsibilities in this area? In the hustle and bustle of our relationships with children and adults with disabilities—that may be primarily in the form of "helping"—do we realize that our actions are creating memories for the person, manufacturing the reality of the person's life, shaping the person's character, and laying a foundation for the person's future?

What memories are created for a young child who receives massive doses of therapy? What about recollections of being segregated in special ed classrooms, being pulled out of class for special services, riding the special ed bus, or attending a different school than your brothers/sisters? What about never being invited to birthday parties, and the only people at *your* party are family members and maybe professionals who are paid to be in your life?

What about the memories of a child who spends more time *watching* other children play, instead of playing with her pals? Or perhaps a child's memories will be about "playing" with adults (therapists and/or service providers). What memories are generated when a child's sense of safety, comfort, and privacy in his own home is violated by the presence of strangers who come to "help" the child?

What about memories of not being able to communicate effectively with others? Or of being treated like an infant because you're not able to walk or talk? What impact do these childhood experiences have on the person when she becomes an adult?

What if the highlight of your adult memory bank is being taken on an "outing" to bowl on Wednesday nights? What if you had no memories of romantic love, and all the joys and angst that go with same? Or no memories of a career you chose, job promotions, coworkers who became friends, or quitting a job you hated?

Can we see things through the eyes of a child or adult with a disability? But maybe we don't have to imagine—let's simply look at what's staring us in the face and/or talk to the person with a disability! We may be so wrapped up in helping, doing for, focusing on "fixing" someone's "problems," and so on, that we fail to recognize how our efforts really impact a person's life.

My son, Benjamin, has cerebral palsy, and when he was very young, I was fortunate to be able to learn from adults with disabilities. I listened to the stories of their lives—good and bad—and learned that the unspoken message of therapies, services, segregation, and other "routine practices" can send devastating messages (and create powerful, traumatic memories) of "You're not okay," "You don't belong," and more.

I recognized the importance of Benjamin having normal childhood experiences, just like his older sister, Emily.

But before I was wiser, I had taken a photo that—at the time—I thought was so cute: two-year-old Emily holding one of her dolls on the top of a small beach ball, as she rolled the doll and the ball back and forth, like she'd seen therapists do to her baby brother. After I "wised up," I was mortified. I realized how Emily saw her brother and the impact of her brother's therapy on *her!* We later replaced the traditional "therapy routine," with more natural ways to help Benjamin master what was important to him without "doing therapy." I wanted to destroy that photo *and* that memory in my daughter's mind. But I kept the photo as a painful reminder, and we took steps to ensure *both* of our children would have more ordinary experiences and more positive memories.

When Emily was a toddler, she let us know she wanted to help decorate the Christmas tree. And she did so: all the ornaments she hung on the tree were on the lowest branches, all bunched together. They were perfect; we left them just the way she placed them. It was a very normal childhood activity—and a very precious one, not only for her, but for her dad and me, too. A couple of years later, Benjamin wanted to do like his sister, but he couldn't stand or walk. So we sat him in a little chair by the tree and he was able to hang some ornaments, just like his sister, with the same precious results.

Memories are the key not to the past, but to the future.
Corrie Ten Boom

The next Christmas, after the kids had plowed through their gifts from Santa, my husband and I were handing out the wrapped family presents, and Emily said she wanted to help. So we read the tags for her and she proudly distributed gifts all around. Again, Benjamin wanted to do what his sister did. But sitting in his wheelchair that year, he couldn't reach the presents on the floor under the tree (and he wanted to do it by himself). So the following year, we bought a smaller tree, and placed it, along with the presents, on a table. It was great: both children could more easily help decorate the tree, and both could reach the gifts and joyfully hand them out.

Benjamin was able to store the same wonderful memories as his sister. Equally important were Emily's memories about her brother: he was more like her than different and despite his disability, he was able to contribute just like her. (Why, I wondered later, did it take our kids' actions to move us in the right direction? Because, it seems, we don't take the time or make the effort to think ahead and be proactive; we're usually reactive, missing out on many wonderful opportunities in the process.)

Let's recognize the importance of experiences and memories not only for children and adults with disabilities, but also for their brothers and sisters. Once children become adults, what will their memories of childhood be—about themselves and their brother/sister with a disability?

What about parents? For many, a generalized feeling of sadness, loss, or disappointment seems to permeate their lives because they don't have many positive, normal memories of their child with a disability. But this can all change when we do what it takes to ensure the child has opportunities to experience the ordinary activities of childhood. Those experiences—not therapies, services, or interventions—are what will really make a difference, today and in the future, not only for the child, but also for *mom and dad and others in the child's life.*

Whether you're a family member, therapist, teacher, service provider, or have some other role, how are your actions impacting the life of a child or adult with a disability? Will his memories consist of exclusion or inclusion? Feeling valued for her strengths or devalued (and "worked on") because of her perceived "deficits"? Living a wonderful, ordinary life or being shuffled from one set of services to another? Keep thinking . . .

Memories are more than recollections of yesterday: they can perpetuate a dismal status quo or pave the way for a successful tomorrow. What kind of memories will you help create?