

Rebuilding Dreams and Transition

Birthdays, transitions, and other milestones can be packed full of awkward feelings, especially when a family has a child with special needs. Early childhood educators and professionals typically have an awareness of and sensitivity to these strong, shifting feelings in parents. These professionals often are trained to understand the grief and coping process prominent during the initial diagnosis and early phase, when parents are raw to the unexpected news about their child. As a result, early childhood professionals typically address the emotions in skillful ways with families, giving parents opportunities to talk about their thoughts, worries, and concerns. This focused listening supports parents in their efforts to cope, adapt, and find their strengths as they rebuild their dreams. As the child moves on into middle and high school, however, professionals seem to be less cognizant of these normal, yet troubling, emotions which parents may re-experience during periods of transitions throughout the life cycle. It's not that these professionals are less sensitive, but perhaps less aware and more focused on other educational issues and demands.

I am gaining a whole new perspective about transition as my 17 year-old son, who has developmental disabilities, approaches his senior and final year in high school (gulp!). This BIG transition seems to give rise to almost every feeling in the universe, sometime all at the same time. I find myself shoved back into that rocketing rollercoaster of feeling so dominant in our lives when he was a toddler and we were just beginning our ride into the world of disabilities. Ordinary moments now will re-awaken strong feelings: a flyer announcing "College Info Night at the High School," moms chatting about the rewards of having teenage sons who drive cars and run errands, seeing a group of young guys hanging out at the basketball court. Unexpected events like these can cause me to sink into sadness, reel into rage, and whirl into worry. Humbly, I whisper, "I want those ordinary things for my son too." I don't stay stuck in those tender moments forever but they do hit me and my family, often with no warning and little public recognition of the universality of these feelings for families with children with special needs.

My son has a rich life. He is on the high school track team. He is the very proud Board member of a national group called Kids as Self Advocates (KASA) and has recently traveled to St. Louis for his first Board meeting. He does volunteer work, is a member of People First, and loves being a teenager. But my husband and I have had to work extra hard and long to ensure that he has meaningful experiences and rewarding relationships. We've had to be vigilant to counteract attitudes that unintentionally limit what people see as possible for him. We have had to work hard to ensure that folks focus on his abilities and not his disabilities. With the help of many caring people, we are "dreaming and living *new* dreams." Most importantly, our son is finding his own dreams.

Still, there are those moments when we fight back the tears and fears. It is not uncommon for parents to feel moments of grief, sadness, loss, fear, anger, guilt, worry, exhaustion, and even despair. It helps if we have the opportunity to sit with someone who can acknowledge the troubling emotions. Someone to remind us that grieving is a normal part of the parenting experience. Great comfort and strength come from being in the company of caring people who are not afraid of feelings. Feelings are at the core of our humanity. To bury them is to bury our potential to connect with others.

Marsha Forest, a brilliant educator and leader in the inclusion movement, observed that, "Martin Luther King said 'I have a dream' He did not say, 'I have goals and objectives.'" Indeed dreams are what propel us forward, drive us to work harder. Of course we need clearly articulated goals, but ultimately it is our dreams that breathe life into our actions. Parents appreciate it when they have the opportunity to work through their original dreams and move into the new ones. Rebuilding dreams is a lifelong journey, extending into every new phase and new milestone of our child's life.

Adapted from an article by Janice Fialka (Mom, wife, social worker, national presenter, and author of several books).