

### A Word to Education Professionals about Parents, Transitions, Feelings, and Dreams

A Teacher Reaches Out to Ease a Parent's Transition Worries

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Several years ago, my friend's son, Andrew, who has Down syndrome, was approaching his sixth birthday—the first one celebrated in a regular education setting. Andrew was gleefully excited, as evidenced by his regular declarations that “soon, soon, I am bringing a big, big birthday cake with hundreds of baseball bats decorated on it to school for all my friends!” The teacher was preparing for the big day. She was also mindful that my friend was anticipating this day with delight, but perhaps with some sadness, too. The teacher found a quiet, private moment and offered these words to my friend: “I know how wonderful birthdays can be for families. I have also learned that some parents re-experience some less comfortable feelings, such as grief or sadness. Birthdays and other milestones sometimes call up uninvited feelings. I just wanted you to know that this might happen and that I would be here if you wanted to talk about them.”

Stunned, my friend fought back tears. She wondered how this teacher knew what had been keeping her up nights. How did she know? The teacher had validated her private experience and helped her know that she was not a “terrible mother” for having those feelings of regret, loss, and sadness. Andrew's mom left the teacher's classroom feeling less alone and a bit more normal than when she had entered the school that day. She was not “cured” of her sadness, but she felt lighter, less troubled, more able to move forward. The teacher's insight and words of compassion were as beautiful a gift to my friend as were the 25 red and blue baseball bats my friend lovingly decorated on the cake for her son.

#### A Five-Minute Interaction Can Impact a Lifetime

This interaction took less than five minutes, but its positive impact continues for my friend even today, ten years later. Seemingly simple and sensitive interven-

tions by professionals do not go unnoticed by families who often struggle to make awkward and conflicting feelings fit together.

Transitions, especially for young people with disabilities, seem to give rise to almost every feeling in the universe, sometimes all at the same time. Often there is no warning and very little public recognition of the universality of these strong feelings.

As my 17-year-old son, who has developmental disabilities, approaches his senior and final year in high school (gulp!), I find myself shoved back into that speeding roller coaster of feelings so dominant in our lives when he was a toddler and we were just beginning our ride into the world of disabilities. (See “A Self-Determined Athlete Achieves his Goals with Help from Parents, a Peer Mentor, and an Open-Minded Coach” on [page 18](#)). Ordinary moments now re-awaken strong feelings: a flyer announcing “College Info Night at the High School;” moms chatting about the rewards of having their teenage sons who drive cars run errands for them, seeing a group of young guys hanging out at the basketball court. 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.”

#### Fight Back the Tears and Fears

Early childhood educators should have an awareness of and sensitivity to these strong feelings in parents. These professionals are well trained to understand the grief process during the initial diagnosis phase, when children are babies and toddlers and parents are unprepared for such



unexpected news. As a result, early childhood professionals often address family emotions in skillful ways, giving parents opportunities to talk about their thoughts and concerns. Listening can help families to cope, adapt, and find their strengths. As the children move on into middle and high school, however, professionals may grow less cognizant of the normal, yet still troubling emotions that parents may re-experience during periods of transition with milestones occurring throughout the life cycle. It's not that these professionals are less sensitive, but perhaps they're less aware and more distracted by other educational issues and demands.

#### Empathy from Professionals Can Empower Parents

When school, vocational, and health professionals are empathetic and aware that grief is an expected emotion for most parents at any phase of our children's lives, we feel validated and empowered. It is helpful and tremendously supportive when professionals can reframe our parental feelings of evolving sadness and loss and recognize that, while these feelings come from a deep core of love and passion, they ultimately move us to create the best world possible for our children.

The next time you are working with a family, continue to create strong goals, clear objectives, fruitful action plans, rea-

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in an attempt to carve out a position to match the student's skills and interest areas. Once the student is placed on a job, the autism technician provides job coaching services to assist her/him to master the tasks of the job and to organize and structure its routines. It is during the job coaching phase that the autism technician works to develop natural supports in the workplace to prepare the student to work as independently as possible at the job. Once job coaching has been completed, the student receives ongoing job retention services provided by the case coordinator.

One case example will illustrate the effectiveness of this model. James has transitioned into a work site that requires minimal to moderate supports. Initially, he demonstrated behaviors such as hitting himself and others when exposed to stimuli such as sneezing, sniffing, and coughing. After completing the first two components of the program, he returned to the classroom and received additional supports and training to help him cope with these stimuli more appropriately. Upon James's return to JVS for the third component of the program, the autism technician utilized James's updated work system that included a storyboard with behavioral intervention techniques for inappropriate behaviors. James demonstrated consistent improvement and currently uses his storyboard only at the beginning of his workday to remind him of coping techniques he can use, if needed. Prior to this program, James was very echolalic and tended to wait for prompts in order to interact with people. He now interacts independently with co-workers, staff, and his supervisors. Joyce Wefel, autism teacher at the Oakland Schools program, states, "I think this program was successful because of the cooperation and teamwork among JVS, MDCCD-RS, and Oakland Schools."

According to Jim Stokes, MDCCD-RS counselor, "Ideally, the goal for all participants involved is competitive employment. This program has allowed for an objective and realistic approach toward defining what this goal means. Under the umbrella of this program, we have been able to assemble a team that can assist in the transition process whether it is employment, supported employment, or sheltered work activity. Participation by the parents/legal guardians, school staff, and representation from the local community mental health agency is essential. This program has allowed for services to be provided, goals to be identified, and a team to be ready to implement the outcome, all within a framework of fiscal responsibility."

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sonable time frames, and responsive interventions. They are important ingredients for successful transitions. But don't forget to take time to sit with parents, ask how they are doing, inquire about what might be on their minds, and invite them to share a bit about what they are wishing for or missing. Let them know that it is not uncommon for parents to feel moments of grief, sadness, loss, fear, anger, guilt, worry, and even despair. Allow parents the opportunity to sit with someone who can acknowledge the troubling emotions. Remind parents 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, an educator and leader in the inclusion movement, observed: "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.

If professionals move too quickly into action plans, they lose the opportunity to support parents through the phases of normal grieving, worrying, and wondering.

In Susan Zimmerman's book, *Grief Dances*, she poignantly tells the story of her daughter, Kat, who had Rett Syndrome, and the lessons learned by each member of the family in dealing with Kat. In one passage, Zimmerman's younger daughter, Helen, says "Don't you get it, Mom? Kat keeps us from just living on the surface."

Professionals have that chance, too. When you pause, sit, reflect, inquire, and invite parents to share their darker feelings and worries, when you validate those experiences and value this part of your job as much as the well-defined action plan, then the work you do is not surface work. It is the stuff of which dreams—even new dreams—are made.

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