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Advice from Parents of Children with Exceptionalities to Future Teachers

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Each year universities across the nation graduate future educators for children grades preschool through high school. Often their programs include learning how to engage and work with parents in a collaborative nature for the betterment of the educational process. This article will focus on the advice of two parents to future teachers who will teach children with exceptionalities. Although many people traditionally have referred to children who have differences, limitations, or delays as *disabled*, this article will refer to them as *exceptional*. Although my co-authors and I attempt to give advice and direction to future teachers, we acknowledge that this article is limited only to the perspective of two parents.. Many other parents have wonderful advice to share, and we hope that this article encourages dialogues between parents and teachers to promote compassion and understanding about living with exceptionalities.

OUR STORIES

Brandie Martine—a letter from a parent

Let me introduce you to Team Martine. This is the title we give to our family. Why? To make sure that we keep our focus on all members within our family, not just one person. This provides us with balance.

Our first child, Jacob, was born on August 1, 2000. It was during our “roller coaster” ride of a pregnancy that we found out through prenatal testing that Jacob had Down syndrome. My husband, Andrew, and I had decided not to have the AFP (Alpha-fetoprotein) test completed to determine if Jacob was going to have Trisomy 21 (Down syndrome) because this indicator had a high false positive reading for Down syndrome and because, if Jacob was going to have Down syndrome, we would not do anything differently with the

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pregnancy. However, a series of different indicators showed possibilities for various life-threatening diagnoses, so we ended the uncertainty and decided to have the amniocentesis done. Approximately five days later, the call came: “I’m sorry to tell you your son does have Down syndrome.” I analyze the words, “I’m sorry” quite a bit and am disheartened by society’s perception that was placed on my child, even before he was born.

I might have agreed with the sentiments at first, but have “transformed,” if you will, through Jacob’s 11 years of life. Advocacy training such as the Special School District Fred Saigh Leadership Program and Missouri’s Planning Council for Developmental Disabilities’ Partners in Policymaking have opened my eyes toward perceptions of disability and how these perceptions limit individuals in our society. These trainings have given me tools to use as we, Team Martine, move forward in our lives--modeling the sense of respect and kindly educating those we encounter as to how to think outside the box and open the doors of opportunity within our communities for all individuals regardless of their ability levels.

Amy Barnes—a letter from a parent

First and foremost I want to start by thanking you in advance for taking the time to read this and for being open to considering a stranger's advice in the first place. My name is Amy Barnes, and I live in St. Louis County, Missouri. I grew up about 20 miles south of Downtown St. Louis in Imperial, just north of Kimmswick. It was a semirural setting, and my parents raised an army of children as there were eight of us within a 20-year span: 4 girls and 4 boys. Surprisingly, we all got along well despite the fact that we were a very diverse mix of people and personalities. One of the most valuable lessons I carried from my youth was the importance of not just getting along but also the benefits of sharing and working together to keep things moving.

As an adult, it is amazing to me that out of all those kids my parents had, there are only two grandchildren: my 13-year-old nephew, Wesley, and my 11-year-old daughter, Mia. Both are very nice kids, but both very different! Wes is into action-packed video games and *tae kwon do*. Mia likes art projects and watching *Ghost Adventures*. Wes has blond hair and blue eyes and wears glasses to help him see, and Mia has brown hair and blue eyes and wears braces to help her walk. And neither one of them likes to do housework! I think they share the same allergies there!

Mia and I met for the first time about three days after she actually came into the world. At 34 weeks of pregnancy, I developed pre-eclampsia, (toxemia), which also translated to congestive heart failure.

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Upon this last discovery, they had to take my baby immediately! Her dad and I were frantic because everything had been going so smoothly before that! I loved being pregnant and carried the pregnancy manual around with me like a schoolbook. I read that thing front to back. Early on, I declined any kind of prenatal testing, choosing to remain positively surprised about everything. "I will cross that bridge when I come to it" were my exact words to my OB/GYN when asked about the serum screening to search for birth issues.

When I came to after my C-section, the nurses said to me, "You have a beautiful little baby girl! I said "Okay then, let's call her Mia, Mia Claire". They then proceeded to tell me how she had to be taken to the children's hospital for surgery because she had spina bifida and the surgeons had to repair a wound on her back.

Here I was at the bridge, but I knew it would all be okay. I had read about it beforehand, so I remember asking if she would be able to walk. They weren't sure about that. Time would tell. Then I passed out.

Fast forward almost twelve years and here we are. Mia's a fifth grader in a public school and leads a life full of adventure. Her dad and I are divorced, so she lives with me and visits him twice a year in Florida, where he lives. She spends her whole summer there. She's a girl who leads a life full of adventure. I sell real estate for a living and work on an inclusion and diversity project for kids that involves them in social life through the arts and culture. We live life to the fullest and don't let anything hold us back.

ADVICE FOR FUTURE TEACHERS

Have compassion for both the student and his/her parents/guardians.

The first part of compassion is understanding the family's journey.. Research can provide insight. Miller (1994) found that families of children with exceptionalities go through a four-stage process that she called the Family Stages of Adaptations. The stages are surviving, searching, settling in, and separation (Miller, 1994).

Surviving, the first stage, involves reacting to the child's diagnosis, which often involves shock, confusion, grief, confusion, guilt, self-doubt, anger, and denial (Miller, 1994). These are common traits, but not every family will experience these emotions in the same ways. Families in this stage typically learn to recognize that their feelings are normal and acceptable and that they need to make sense of their new situation. Many find that maintaining autonomy as individuals through time to themselves is important. Often in this stage families will start to develop a support system of varying levels.

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The second stage, searching, can be broken down into outer searching and inner searching (Miller, 1994). The outer searching involves empowerment through understanding the diagnosis and networking with other families who have experiences with exceptionalities. Inner searching is self-discovery on various life questions, such as what it means to be a parent of a child with exceptionalities, how all individuals of the family unit are involved, and how one reassesses his or her life goals. This stage is not static but continues through time.

The third stage, settling in, involves a redefinition of normalcy and belonging. Shifts in attitude, balance, and understanding are apparent in this stage (Miller, 2004). Whereas the survival and searching stages are intense and emotional, the settling in stage finds greater balance (Miller, 1994). Many families may not reach this stage because of financial health, or marital issues.

The final stage of separation is both physical and emotional. Ultimately, the parents will separate from the child to allow autonomy in adulthood. Separation requires that the child have self-esteem; self-help skills; and the physical, social/emotional, and cognitive ability to live on his or her own. These needs are all the more important for a child with an exceptionality.

Future teachers should understand these stages so that they can communicate compassionately with the parents/guardians with whom they work. Compassion means acknowledging that all children learn differently and idiosyncratically. Teachers need to display compassion for students both in the general education setting as well as in a “pulled out” setting, with special attention to transferring skills from one setting to the other.

Compassion is not about pity. Be empathetic, not sympathetic. Feeling sorry for a child suggests weakness and frailty—for both the parent and child. A teacher’s pity does more harm than good and mistakenly assumes suffering where, in fact, there may be none. “Normal” is different for everyone.

Focus on what the child can do and not what they cannot.

It is important for future teachers--and all people, for that matter-- to focus on an individual’s strengths more than his or her weaknesses. This fosters the child’s personal development.. As Amy states,

I know there are things my daughter will never do. I also know science progresses very rapidly and that there are changes that will take place over her lifetime that will help her to be more independent. She can't stand unassisted right now, but perhaps she will some day. In the meantime, she has her canes, walker, and wheelchair and can go pretty much anywhere those three devices will take her. There are more

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things that she can do than that she can't, and so that is what we focus on.

Recognize that all children are different and that they develop and learn at their own pace and own way.

We are all individuals with our own strengths. We are all students of life and are continuously learning. Learn from the children. Watch them; study them; and find out what they motivates them. Good teaching requires knowing your students. If a student does not tell you with words, he or she will tell you with actions. Listen and take heed. See the teacher/student relationship as a give and take, a sharing of knowledge between all. Be willing to learn as much as you are willing to teach.

Be advocates for your students and families.

An advocate works for the interests of others. That requires that a teacher know what the student and family wants and needs and can determine what is in their best interests. Teachers should be knowledgeable about services that can empower children to participate in meaningful ways rather than demand that they change to fit into society.

The second part of advocacy is to know when to challenge the status quo--for instance, by advocating for acceptance, inclusion in the least restrictive environment, and quality teaching for all. When selecting classroom books, make sure all children are represented in your selections, and ensure that all children can identify with the books. When selecting any educational materials, think first about the students in the classroom. How will these materials advance and encourage learning? Continuously ask how you can ensure that diverse learners are being accommodated in the classroom. Advocate for good practices in the classroom. Teaching is an ever-changing profession that requires teachers to keep current on new knowledge, methods of instruction, and good practices. Lastly, advocate for good interactions between students, between teachers and students, and between teachers and families. Model good interactions for you're your students. Teachers also can encourage an inclusive classroom with classroom meetings, discussions, and readings of books that discuss inclusive teaching. To advocate is to empower. Advocacy is part of a teacher's job.

Recognize when you need to seek assistance and help.

The classroom setting is ever-changing and teacher responsibilities over the years have increased. The increasing diversity of the student population requires teachers to develop a toolbox and interpersonal skills to work collaboratively with a wide variety of individuals.

Preservice teacher training at the university level is where the toolbox should begin to fill. Through various courses, practica, and

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experiences a future teacher will be exposed to experts in education, teachers who have great content knowledge and resources. The field of education is a community of practice that is a living and breathing resource for teachers. With all these resources being available, the most important part is to recognize when assistance is needed. No single person possesses all the knowledge needed to educate children with exceptionalities. It is important to reach out and seek support when needed. New teachers can find themselves isolated if they do not develop a support network on which they can rely. Develop this support network early on in your career, and continuously add to it.

Also recognize that not all situations will require the same tool. One resource or piece of help and advice may be very useful in one situation, but it may not work in another. Never give up your tools. Be persistent and tenacious in seeking the appropriate help that you need.

Teachers must set aside their personal biases. Everyone has some biases, but we must reflect and work through them. The first step is to acknowledge them. Interpersonal and collaborative skills are imperative to serving the best interests of children with exceptionalities. Often a team is formed of the special education teacher, mainstream classroom, family, and other support staff, in order for this team to function properly. Parents know their children better than anyone. Therefore, empower parents to be part of your team, and put their knowledge to work..

Empower parents and students

People with exceptionalities often feel isolated, sometimes because of a parent's fear and desire to protect. Teachers can encourage parents and attempt to break the barrier of isolation by encouraging interactions and developing friendships. Teachers can host neighborhood events or trips in the community. They can even offer Dine and Learn evenings, offering a potluck dinner in the classroom.

Communication is an important element in empowering parents and students. Have a classroom blog or Facebook page that allows the parents to see what goes on in the classroom daily. In order to visually assist the student in discussing his or her day at home, teachers could design a placemat featuring pictures of all the students and school staff (but remember to get permission to photograph minors). This project encourages community and fosters nightly discussions at the dinner table.

Use Universal Design in your classroom. Oftentimes, certain supports designed for exceptional students can help all students (e.g., a checklist of expectations). Look for materials for students to use at their own ability levels. For example, if a student needs a textbook that is below grade level, then seek assistance from other support staff in accommodating the student's needs.

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Students also need to be empowered by being allowed to take chances, problem solve, and learn by trial and error. Resist the temptation to do things for them just because it is easier and faster. Learning is a process and takes time. Challenge all students, regardless of whether they have an exceptionality. Experiential learning is the most powerful form of learning and helps to build efficacy. Confidence and motivation are essential skills to success in life and this should be fostered daily in all interactions.

Acknowledge and value the many characteristics of a person with an exceptionality

Avoid labels to refer to children with exceptionalities. Jacob is a student, a son, a friend--not "Jacob, the Down syndrome kid." Labeling in this manner harms well-being of the individual. When a student is described first and foremost by their exceptionality, he or she loses the right to be much more. No single characteristic defines a person. Use people-first language instead. Name the person, and then attach the diagnosis. For instance, "Jacob has Down syndrome."

Also consider the context and relevance of the exceptionality before mentioning it in conversation. Ask yourself whether the diagnosis is important to the statement you are about to make. The goal should be to avoid labeling students. Labeling leads to limiting and self-fulfilling prophecies.

CONCLUSION

Future teachers will be working with students with exceptionalities and their families every day. Advice from parents to future teachers is to be resourceful, be respectful, and always remember that the student is someone's child--their world and everything.

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REFERENCE

Miller, N.B. (1994). *Nobody's perfect: Living and growing with children who have special needs*. Baltimore: Paul H. Brookes.

SUGGESTED RESOURCES

The Belle Center: www.bellecenter.com

Disability is Natural: www.disabilityisnatural.com

Keysor Elementary - Project IDEA - <http://project-idea.com/>

Missouri Planning Council for Developmental Disabilities:
<http://www.mpcdd.com>

Museum of History of DisAbility -
<http://www.museumofdisability.org>

NICHCY (National Dissemination Center for Children with Disabilities): <http://nichcy.org/babies>

Partners in Policymaking - <http://www.partnersinpolicymaking.com/>

Special School District: www.ssd.k12.mo.us