saint mary's press

A Place for All Ministry for YOUTH with Special Needs



John E. Barone and The Monarch School

A Place for All

The publishing team included Steven C. McGlaun, development editor; Lorraine Kilmartin, reviewer; prepress and manufacturing coordinated by the production departments of Saint Mary's Press.

Copyright © 2008 by John Barone. All rights reserved. Permission is granted to reproduce only materials intended for distribution. No other parts of this book may be reproduced by any means without the written permission of the publisher, Saint Mary's Press, Christian Brothers Publications, 702 Terrace Heights, Winona, MN 55987-1320, www.smp.org.

Printed in the United States of America

2305

ISBN 978-0-88489-972-3

Library of Congress Cataloging-in-Publication Data

Barone, John, 1961–

A place for all : ministry for youth with special needs / John Barone.

p. cm.

ISBN 978-0-88489-972-3 (pbk.)

1. Children with mental disabilities—Education. 2. Christian education of children with mental disabilities. 3. Monarch School (Houston, Tex.) I. Title. LC4601.B328 2008 268'.432087—dc22

2008003816

A Place for All

Ministry for Youth with Special Needs

John Barone, M.A. The Monarch School Houston, Texas



Dedication

To Marty, mentor and friend, who sees the beautiful butterfly in all of us, even before it emerges, and gently coaxes us to take flight.

Author Acknowledgments

One person did not write this book. It is a rich and varied collection of the ideas, beliefs, and practices of many, both at The Monarch School and in Catholic education and youth ministry.

Thanks to all the Monarch faculty, parents, and students for their support and contributions to this work, especially to the leadership team of The Monarch School, as follows:

- Dr. Marty Webb, for outstanding leadership in her role as head of The Monarch School, guiding us all in our mission to provide an innovative, therapeutic education for children with neurological differences.
- Dr. Neal Sarahan, Monarch Challenger Program director, whose curiosity and love of learning permeate all the work we do, transforming the lives of the children we serve.
- Dr. Debrah Hall, Monarch Apprentice Program director, whose passion for helping children reach their full potential keeps us all focused on the most important priority: our students.

Much gratitude also to Eugene Webb, author, psychotherapist, and cofounder of The Monarch School, for his wise counsel, humorous support, and caring friendship. Unbelievable!

Special thanks to Laurie Delgatto for her important role in the development of this book. Thank you for your advocacy, guidance, and care.

Finally, a big thank you to my family: my wife, Susie; my parents, Alice and Richard; and all the members of the Barone clan for their encouragement and support.

Contents

Foreword	. 7
Chapter 1 Such Is the Reign	. 9
Chapter 2 The Father Knows Best	. 17
Chapter 3 A Different Take	. 27
Chapter 4 Learning How to Farm	. 35
Chapter 5 Preparing the Soil: Hearts and Minds	. 44
Chapter 6 Preparing the Soil: The Learning Environment .	. 59
Chapter 7 Preparing the Soil: The Curriculum	. 69
Chapter 8 Gathering and Training the Workers	. 77
Chapter 9 Sowing the Seeds: Dynamic Lesson Plans	. 93
Chapter 10 Nourishing the Crops: Classroom Management	. 104
Chapter 11 Crop Report	. 117
Chapter 12 Reaping the Harvest	. 124
Acknowledgments	. 130

About The Monarch School and the Author

The Monarch School, in Houston, Texas, is dedicated to providing an innovative, therapeutic education for children with neurological differences. The school is committed to serving the special education needs of children in the community by offering a unique, therapeutic learning environment where active minds are challenged, all are treated with respect and dignity, learning is a joy, and wisdom is the outcome.

The school's unique blend of psychology and education provides a highly individualized program to meet the emotional, social, and academic needs of each child. Monarch has outreach services for the larger community through its Learning Center and its Diagnostic Clinic. The Monarch School also has a Life Academy, teaching students about the business of life through entrepreneurship and student-based businesses.

John Barone received his bachelor of arts degree in religious education from the University of St. Thomas in Houston, and his master of arts degree in private school administration from the Institute for Catholic Educational Leadership at the University of San Francisco. John has extensive background in adolescent development, Catholic education and youth ministry, workshop facilitation, and teaching students with neurological differences. He serves as the director of The Monarch Learning Center, which is The Monarch School's response to the urgent call of parents, teachers, administrators, medical professionals, and mental health professionals hungry for the skills and knowledge to empower them to transform the lives of students with special needs.



Foreword

In a recent family counseling session with the parents and twin sisters of Kurt, a fourteen-year-old boy, I asked who his favorite teacher was at school. He replied without hesitation, "Mr. Jennings, my math teacher."

"Because he really knows his math?" Kurt's dad asked provocatively.

"No," smiled Kurt, "because he knows me."

"Oh," offered his mom, "he knows you remember to do your homework."

"No," stated Kurt, "he remembers that I can't do math unless I repeat the numbers in my head."

That was a golden moment for everyone in the room, not just because Kurt's response was so revealing but also more because of his delightful paradigm shift: a sudden change in focus from what he does to who he is. It was a shift from how math is performed to an appreciation by his teacher of who Kurt is. That moment awakened Kurt's whole family to appreciate how important it is that he be "found out" by teachers dedicated not just to teaching but also to how students with special needs learn.

My grandma used to say we all live with two fears: the fear we will be found out, and the fear we won't. She meant we all live with the terror that our unique personalities, our atypical looks, our imperfect bodies, our origins, our quirky ways, and our interests, tastes, and learning styles will disqualify us from inclusion in and acceptance by the group. At the same time, we live with the hope that those same unique qualities will be discovered, honored, and welcomed into the group. We want to be like others in the group, and we want to be different from them—both as invitations to be part of the group.

How do we accomplish being the same and different, simultaneously, in a learning experience? Kurt tells us the secret:

"I want to learn what everyone else here is learning, but I need to experience it my way, the way that makes sense to me, so I can make sense of it. And if our teacher can catch on to how each of us learns differently by creating experiences that invite our differences, then we can have a group experience that includes all of us."

I am in awe of this kid! Just as I am in awe of the staff of The Monarch School, who have provided in this book a bridge between Kurt's wish and the wish of religious educators who are challenged by challenged kids. These educators have brought together four major themes crucial to working with young people in religious contexts, as follows:

- Education is not about reciting information and then testing for regurgitation skills.
- Teaching is about creating vivid, personal, and dramatic opportunities for all in the classroom—teachers included—to have personally unique responses relevant to their current lives.
- Learning is about doing, comparing, experiencing emotional drama, discusing, asking, wondering, and differing about life in the context of faith.
- Answers and outcomes are not nearly as important or riveting as the process of personal awakening to one's own relevance in the group and confirmation of oneself before God.

The experts at The Monarch School approach these issues with brilliance, humor, and candor, speaking as learners as much as they do as teachers. That is the genius of this book: the work of dealing with our challenged youth combines being a constant learner of "who" with the ever-changing crafting of "what."

Thank you, Kurt, for your incisive, adolescent wisdom: "Because you know me, I can learn it."

Respectfully,

Eugene Webb, LPC, psychotherapist, cofounder of The Monarch School Houston, Texas Fall 2007



Such Is the Reign

1

Great crowds had been following the Master, Jesus, for some time, and on one occasion, parents began to bring their children to him to be blessed. As the parents pressed around him, their eyes were filled with joy and hope, believing that the Master's touch could transform the lives of their children.

The Apostles, seeing the great crush of people surrounding Jesus, began to criticize the parents harshly, but Jesus stopped them:

"No! 'Suffer little children, and forbid them not, to come unto me' (Matthew 19:14; King James Version); don't stop them. Don't you know that the Reign of God belongs to such as these?"

And so the children gathered around him. He touched them, blessed them, and prayed over them. The parents were overjoyed, and the children beamed when he looked at them.

Except for Sarah. When it was her turn to see Jesus, Sarah didn't return his loving gaze. She kept looking at a shiny green stone in her hand, turning it over and over. "What do you have there, Sarah?" Jesus gently asked, as he reached out to touch the stone. "Don't!" She pulled her hand sharply away.

"Sarah," the Master said compassionately, "If you want me to bless you, you're going to have to look me in the eye, and put that stone down."

"No!" Sarah refused.

Jesus shook his head in disappointment and called for the parents. "I'm sorry, but I can't bless her if she won't even look at me. She's disobedient and refuses to follow my instructions. And she's obviously not gaining anything by being here with me. All she cares about is that green stone. Please take her home." The parents sighed and sadly made their way through the crowd with their little girl.

The next child, Joshua, smiled at Jesus, looked him right in the eye, and wrapped his arms around Jesus' neck. Jesus was pleased with this little boy and began to bless him. But while the Master was blessing him, Joshua began to make hooting noises. Jesus said, "Please stop that, Joshua; you're a little boy, not an owl!" All the other children began to laugh except Joshua, but at least he stopped hooting for a little while. Then Joshua's head began to twitch. Then he hooted again. Jesus called for the parents. "I'm sorry, but Joshua's noises and twitches are disrupting the blessings. It's obvious that he can control it, because he stopped when I asked him to. But then a few minutes later he started hooting again. Joshua is making the other children uncomfortable with all these strange noises and twitches. I'm really sorry, but I don't think he can stay." Joshua and his family looked humiliated as they walked away.

Martha was next, but just as she was walking up, Benjamin was so excited to see Jesus that he pushed his way past her and knocked her down. Martha was so upset that she began to scream uncontrollably. She threw herself down on the ground, yelling, "It's not fair! I was next! It's not his turn! I hate that boy! Wahhhh!"

Jesus signaled to both sets of parents, who picked up their children and took them away, avoiding the accusing eyes of the other parents. Martha's screams could still be heard in the distance as Jesus smiled and welcomed the next appropriately behaving child.

Does this story ring true to you? Does this sound like the Jesus you know? When Jesus said, ". . . for it is to such as these that the kingdom of heaven belongs" (Matthew 19:14), do you suppose there was an unrecorded qualifier like the following: ". . . except those with attention differences, social development problems, self-regulation issues, physical and verbal tics, mood disorders, and any other neurological difference that would affect their functioning."

Probably not. Jesus clearly made every effort to reach out to those who were different, marginalized, or troubled. Jesus would not have turned these young people away. You may be familiar with the words from the King James Version of the Bible, "Suffer little children . . . to come unto me" (Mat-thew 19:14). Jesus used the word *suffer* in the sense of "to permit." He was asking the Apostles to give the children permission to approach him.

Then why do young people with special needs so frequently find it difficult to approach our religious education and youth ministry programs? Why do some of us find it difficult to welcome them? This book is about challenged youth, but it is also about challenged teachers and challenged parents.

Our Hearts Are in the Right Place, but Our Children Aren't

Some faith communities work hard at including all God's children. But sadly you often won't find young people with autism, Tourette's syndrome, or severe attention problems in religious education classrooms. If these young people are present, they are too often gathered in one special room where they may be supervised but may not be catechized. It's not because faith communities don't want to include these young people. I trust that the spirit of our pastors, directors of religious education (DREs), youth ministry coordinators, and catechists is one of welcoming and inclusion. Then why isn't it happening? Following are some possible reasons:

"It's Too Hard"

I've done some hard work in my life. At my first job at a fast-food restaurant, I was lucky enough to be assigned the task of emptying and scrubbing the grease bins. I later worked in a non-air-conditioned sheet metal factory, where I fashioned and assembled ductwork. Then as an electrician's apprentice, I crawled through hot attics to install and repair wiring.

I'm no stranger to hard work, but I didn't really know what hard work was until I came to The Monarch School. It's been the hardest and the best job I've ever had. The Monarch School was founded in 1997 on a dream, with no money, no space, no classrooms, no faculty, and no students. The school was a response to a critical need in the community to provide an innovative, therapeutic education for children with neurological differences. The community responded with tremendous support!

In the first year, there were six teachers, one part-time psychologist, two consultants, and twenty-three students with various neurological disorders, such as autism, bipolar disorder, severe language learning disabilities, and Tourette's syndrome. But we knew even then that at Monarch, working with kids wasn't about labels. It was about knowing and working with each child as an individual, unique in the universe.

The neurological differences of our students have affected their learning, as well as their social and emotional development. It is common for them to come to us having been subjected to daily ridicule and rejection. Many are seriously at risk for school dropout, unemployment, and even suicide. For those who are autistic, research suggests they have little chance of falling in love, marrying, or having a family. Our desire is to help young people achieve goals that others thought they would never be able to achieve.

We are now in our eleventh year and are getting ready to move into our permanent home, a beautiful complex on 10 acres. We have established a unique therapeutic program that is a coordinated blend of educational and psychological services. We have outreach services to the greater Houston community through our Learning Center and our Diagnostic Clinic. We have a Life Academy, teaching students about the business of life through entrepreneurship and student-based businesses.

The Monarch program is not modeled on any other program. It is original, innovative, and constantly improving. Monarch exists today because we believe every child deserves to learn, be respected, and experience joy. Monarch will exist tomorrow for the same reasons. It will exist because we constantly strive to better meet the needs of the students who physically find their way to our school and emotionally find their way to our hearts.

I began my Monarch adventure in a self-contained classroom with six boys. Some had autism, some had Tourette's syndrome, and all had difficulty controlling their emotions and following directions. Meltdowns were a daily occurrence, with lots of crying and screaming. Sometimes the students would all melt at the same time. It was . . . challenging.

On his first day, a new student I will call Michael refused to come into the classroom. For several days he stood outside the room, ignoring my attempts to communicate with him. So I just spent quiet time near him, trying periodically to connect. Finally after several days, we had a breakthrough. When I asked him, "How are you today, Michael?" he finally spoke to me. He looked me right in the eye and said, "Why don't you just go to hell?"

I was delighted that he engaged me, and from that point on, things got better. We communicated. He joined us in the classroom and began the long, hard work of learning how to be a student in a classroom, how to connect with others socially, and how to regulate his emotions. From day one we chose not to focus on Michael's obscenities or other provocative behaviors, instead paying attention to times when he chose to engage us and coaching him as he slowly developed his relationship skills. In the same way, Jesus chose not to focus on the weaknesses of the people the community rejected but instead accepted them as they were and encouraged them to take ownership of their struggles.

I've kept up with Michael and have been delighted to see him continue to grow in the expert care of my colleagues. Awhile ago I saw him at a Monarch dance. Throughout our work together, Michael had never been comfortable with physical affection. But when I saw him at this dance, I thought I'd take a chance. I told him it was great to see him, and I asked him for permission to give him a hug. He looked up at me cautiously, thought about it for a moment, and then said, "Yeah, I guess that would be all right." I couldn't have been prouder.

The concern about the difficulty of working with young people with special needs is valid. Sometimes it's hard. But when we step out of our comfort zones and connect with young people in a spirit of love, miracles can happen.

"I'm Not Trained for This"

Each summer I direct the DeBusk Enrichment Center for Academically Talented Scholars (DECATS), a three-week enrichment program for gifted kids. The mission of the program is to influence the leaders of tomorrow to develop a commitment to use their gifts to serve others in a spirit of humility. Our motto is "'Better at' does not mean 'better than.'" In DECATS we deliberately seek out "twice exceptional" young people: kids who are very bright and who also have special challenges. One such scholar, a fourth grader I will call Carlos, had significant attention differences that were resulting in some problems.

While observing in one of his classes, I watched as Carlos left his seat, ran over to a globe in the back of the room, and began spinning it. He smiled from ear to ear as he watched the globe whirl.

"Carlos, where do you need to be?" The teacher's tone was respectful. Carlos complied with the indirect request by returning to his seat, but then two minutes later, he was back at the globe. The teacher sighed and raised her voice a bit. "Carlos! What is your responsibility right now?" He sheepishly returned to his seat.

When Carlos got up for the third time, we realized that the good classroom management the teacher employed was not working. The teacher and I decided to run an experiment. I asked Carlos to tell me what his teacher wanted.

"For me to pay attention and not spin the globe."

"Do you want to do what she wants?"

He nodded vigorously. He knew what his teacher wanted, and he seemed to want the same but was thus far unsuccessful. I then gave Carlos a stress ball, with instructions to try to pay attention and to squeeze the ball instead of running across the room to the globe. I gave the rest of the class the job of observing Carlos to see if he was successful at the following two things:

- staying with the class
- paying attention to the teacher

The teacher continued the lesson, a detailed profile of President Franklin D. Roosevelt. The teacher spoke for about 10 minutes. Carlos's squeezing was intense. He stayed in his chair but seemed to focus all his attention on the stress ball. He never looked up at the teacher and didn't seem to be aware of anything but the ball.

After 10 minutes I interrupted the experiment and asked the class what they saw. "Did Carlos stay with the class?"

They all responded yes.

"Did he pay attention to the teacher?"

In chorus: "Noooo!"

I said, "Let's check that out with Carlos." I asked him if he was successful at his goal to stay with the class.

"Yep." He grinned, never taking his eyes off the ball.

"Were you successful at paying attention to the teacher?"

"Yep." He was beaming. "She was teaching us about President Franklin Roosevelt, and how he brought hope to the people who had gone through the Great Depression. And how he said, 'The only thing we have to fear is fear itself.'" Carlos went on with more details of the lesson. Although he hadn't looked focused, he could recount almost word for word the content of the lesson. I congratulated him and asked the class again if he was successful at paying attention. They had a different answer that time.

Using a stress ball was a simple modification to help Carlos maintain his focus. That modification restored peace to the classroom and brought joy to the students and teacher alike. Teachers deserve and need training and tips like this to help them interpret and appropriately respond to student behaviors. The exclusive use of traditional methods to enforce compliance typically results only in confusion for the child, disruption of the class, and a frustrating sense of failure for the teacher.

"It's Not Fair to the Rest of the Kids"

Some folks believe fairness is treating everyone the same. At Monarch we believe this definition of fairness is unfair! Real fairness occurs when people get what they need.

Typically siblings of a young person with special needs struggle with their brother's or sister's getting more attention, time, and effort from the parents. Siblings have a hard time accepting that this happens because their brother or sister has greater needs. That principle of serving the greater need is an adult concept that is difficult for some children to understand and must be translated for them.

In a scene from *Star Trek II: The Wrath of Khan* (1982, 113 minutes, rated PG), Mr. Spock chooses to sacrifice his own life by entering a radiation-filled chamber to get the engines back online and save the rest of the crew. As he slowly dies, Spock whispers through the glass to Captain Kirk: "It is logical. The needs of the many outweigh . . . "

"... the needs of the few," Kirk replies sadly.

Often young people with special needs are "sacrificed" from classrooms because it is believed their presence will detract from the learning of the other students. This too is logical. If teachers spend all their time dealing with one student, then learning is compromised for the rest of the class.

In situations like this, though, all the time being spent is usually more about the teacher trying to enforce compliance instead of trying to understand how the young people learn best. Ironically a classroom that emphasizes sameness and neglects individualization often ends up with more problems in the long run. It is not the presence of young people with special needs that detracts from the learning of the other students. Instead it is treating everyone the same way that creates chaos. The goals of organization, order, and progress are best reached when teachers allow the students to learn flexibly in the ways that complement their strengths and supplement their weaknesses. We can all agree that no one needs to be sacrificed for the good of the other learners. With teacher training, modification of the environment, and changes to the curriculum, young people with special needs can thrive where they once were unsuccessful. The great news is that this training and modification will benefit all the students in the classroom.

Ultimately fairness demands we do everything we can to suffer all the children to come, regardless of their differences.

"We Don't Have Any Young People like That in Our Community"

Yes, you do. You have youth with diagnoses and others who have not been diagnosed.

The ones in your program are probably the undiagnosed students with special challenges. In any given group of young people, you are going to find variances in development. Students differ in their readiness to work with a teacher, their ability to pay attention, their emotional maturity, and their skills at relating socially. The diagnosed young people in your community are probably not attending your religious education classes.

If you observe a group of young people in your community, you will see them. You'll see the girl whose head turns at every little noise. You'll see the boy who can't seem to keep his papers organized. There's one who seems sad all the time. And another who doesn't seem to have any friends. They are with you, and the normal religious education classroom structure does not work well for them.

"It's too hard," shared a Monarch parent whose son has autism. "We can't go to church. We tried it for a few weeks, and he would go crawling under the pews, and we'd have to go searching for him in the middle of the service. People didn't understand what we were dealing with. They just thought we were bad parents."

Another parent shared the following about their son, who has Tourette's syndrome: "He went [to church] for a while, but not anymore. We encouraged him and pushed him to go. But his tics got bad, and he was worried he was bothering people. He was uncomfortable, didn't have any friends, and got teased all the time. He felt everybody was being mean to him. Finally he would have a meltdown and refuse to go. I would love for him to be able to go and have a good experience at church."

One of the Monarch fathers commented about his son's Confirmation program: "It's not a good program even for normal kids. It's too disruptive. It's bad because it's too unstructured. Kids are out of control, and that makes it really hard to follow. The lessons go too quickly to follow. It's way too stimulating, with kids yelling out answers to the questions before my son even understands the questions. When I talked to the leaders of the program, they gave me books and workbooks. They suggested that I teach him individually at home."

In response this boy asked his father: "Why is God punishing me? I've been praying and praying, and I don't think there is a God. Why do I have to wake up and be me each day?"

Likely, families in your community have attempted to participate in church programs but, because of difficulties, have opted out. This can occur outside the awareness of youth leaders, giving the false impression that no youth in the community have special needs. But in fact they are out there, and if you build a welcoming, inclusive program, you will see them return.

For the Good of the Community

When young people struggle with these challenges, the last thing in the world they need is rejection from their communities of faith. These young people are not the only ones hurt by this. Exclusion deprives all youth of the challenges and benefits of learning to accept others regardless of their differences and to learn from different perspectives. When the one is sacrificed, the many are also deprived!



2 The Father Knows Best

A Real-Life Experience

It is not altogether clear whether his neurological differences were genetically based or a result of his traumatic experiences in early childhood. Perhaps it was a combination of both. He was born into abject poverty in a rough, overpopulated neighborhood on the outskirts of Memphis, where beatings and murders were common. His mother abandoned him in a rich neighborhood when he was just an infant. She was powerless to protect him and hoped someone would find him and care for him. Thankfully a wealthy family discovered and eventually adopted him.

Throughout his life he exhibited symptoms of impulsivity and aggression, dealing with problems through impulsive acts of violence. This was compounded by severe communication problems. At one point he came upon two men fighting in the street, but instead of calling the police, he jumped into the fight and ended up killing one of the men. When the other ran off, he hauled off the body, buried it, and hoped no one would find out. Later he discovered that a warrant had been issued for his arrest. His fear of the death penalty led him to run away.

While on the run, he continued to act impulsively, but one fight at a local watering hole resulted in a change of luck. One of the women there was impressed by his fighting prowess and asked him to join her for a bite to eat. They hit it off, dated for a while, and ended up getting married. He settled down, had a son, and for a while, it looked like everything was going to be okay.

That's when he started hearing the voices. He was clearly suffering symptoms consistent with schizophrenia. He started hallucinating and developed what could be described as delusions of grandeur. He told his wife that God was speaking to him and had a special mission for him. Struggling to get the words out, he explained that God wanted him to go back to where he had killed the man. God wanted him to threaten the authorities with violence and death.

His wife was overwhelmed by this and feared for his life. She wept as she watched Moses and his brother, Aaron, head out for Egypt.

Examples Throughout the Scriptures

When asked to identify scriptural characters with disabilities, most people will typically mention Job or those cured by Jesus in the New Testament. But if you take a closer look at the main characters in the stories of the Bible, you'll be hard pressed to find a flawless hero.

What you will find is a cast of characters with extraordinary strengths and ordinary human weaknesses. Let's take a look at some of the men and women of the Scriptures who had special needs:

- Noah is diligent and righteous, but one of the first things he does when he gets off the ark is to get drunk (see Genesis 9:21).
- Jacob's role as patriarch continues in spite of a serious hip injury that causes him unrelenting pain (see Genesis 32:25–33).
- Samson is dedicated to God from the day he is born, is blessed with extraordinary strength, and serves as one of the judges (rulers of Israel before the monarchies of Saul, David, Solomon, and the other kings of the Old Testament). Throughout his life Samson has a difficult time regulating his emotions and is prone to impulsive, angry meltdowns (see Judges, chapters 14–16).
- Jesus chooses Simon Peter as his "rock," yet at the same time, Peter is impulsive in his words and actions (see Matthew 16:16–18, 26:33, and 26:69–75).
- Mary Magdalene is stricken with seven demons, yet Christ chooses her to be the first witness to his Resurrection (see Mark 16:9).
- Paul is instrumental in spreading the Good News to the entire known world but has a "thorn of the flesh" (see 2 Corinthians 12:7), a mental and moral struggle he lives with throughout his life.

None of these important figures considered themselves worthy of the significant roles God had in mind for them, and their weaknesses made it hard for them to recognize the value of their contributions. In a way they were right. Alone they could never have fulfilled their important roles. Only through working in community, relying on the help of God and others, could they achieve their goals.

Moses's Story

Moses felt unworthy when God called him. He tried to opt out of his special role in the community. He couldn't imagine having the ability to express himself and influence others in the way God deserved. Certainly an understandable response considering the mission Moses was being asked to fulfill! This is similar to the opting out that occurs with so many of our families who have youth with special needs. It is equally understandable considering how challenging it can be for these youth to be successful in environments that do not support them. Like Moses these youth feel inadequate to the task. But in the same way God provides support for Moses, we can provide support for our youth with special needs in our religious education and youth ministry programs.

Feeling inadequate and recognizing and owning his weaknesses, Moses humbly asked that God reconsider his request: "O my Lord, I have never been eloquent, neither in the past nor even now that you have spoken to your servant; but I am slow of speech and slow of tongue" (Exodus 4:10).

God promised to give Moses the words to say and to help him with his speech. Moses still insisted that God send someone else. The scriptural account of God's response to Moses is simply delightful. What would you expect from God at this point in the story? gentle encouragement? Possibly something like: "Everything's going this to be okay, Moses. So you're not the best speaker in the world? So what? You're the best you in the world! You can do it, man! Now, come give me a hug . . . "

Maybe a little divine cajoling, like this: "You know I could have picked Aaron for the role. I mean, I think he wanted the gig. But Mo, baby, Aaron lacks your . . . panache. You've got a certain 'Chuck Heston' dramatic quality that recommends you for the job. So come on, whad'ya say?"

Or perhaps a more empathetic approach along these lines: "Moses, you're not the only one who has trouble speaking. Look at me; I talked to you through a burning bush, for crying out loud! One time, I had to give a talk to the heavenly host about the new creatures of the earth, and I looked down and realized I'd left my notes back at the ranch. (Heaven, of course, is somewhere in the Texas Hill Country!) I was sweating, and my hands were shaking, and I just started making stuff up, and that's why we now have the platypus, seahorses, giraffes, and armadillos"

No, the author of the Book of Exodus describes God's response not as one of sympathy, coaxing, or understanding. It is characterized by anger (see Exodus 4:14). It is the deepest of rumbling frustration that is so often attributed to God when we show a lack of trust in providential care. Remember these classic scriptural moments of human doubt: "I heard the sound of you in the garden, and I was afraid, because I was naked; and I hid myself" (Genesis 3:10). *rumble*

"Why did you bring us out of Egypt, to kill us and our children and livestock with thirst?" (Genesis 17:3). *grrr*

"Lord, if you had been here, my brother would not have died" (John 11:21). *snort*

This divine anger is a reaction to the dismissal of the covenantal character of God's relationship with humans. When Moses and others in the Scriptures communicate doubt in response to God's call, they are saying: "You know that part of the Covenant: 'I will be your God'? Well, God, I just don't trust it."

In anger God reminds Moses that God is the architect of all creation, which includes the creation of Moses—just as he is, communication problems and all. Moses is called not in spite of his weaknesses but as a whole person, complete with weaknesses and strengths. In the same way, people of faith are called wholly to full participation in their faith communities. The part so often missed is that individuals don't respond to God's call alone. "Yes, we will do it," is much easier to say than, "Yes, I will do it." If you read the stories of those in the Scriptures whom God calls, you will discover that God not only provides direct support but also supplies a cast of supporting actors who help God's Chosen People achieve their goals.

In the story of Moses, that support is both figurative and literal. When facing the Pharaoh, Aaron speaks for Moses, providing an accommodation for Moses's communication difficulties. God inspires Moses, then Moses tells Aaron what to say, and then Aaron acts as Moses's spokesman in public. It's clearly a team effort. (see Exodus 7:1–2).

The literal support is illustrated in the following account of the battle with the Amalekites:

Then Amalek came and fought with Israel at Rephidim. Moses said to Joshua, "Choose some men for us and go out; fight with Amalek. Tomorrow I will stand on the top of the hill with the staff of God in my hand." So Joshua did as Moses told him, and fought with Amalek, while Moses, Aaron, and Hur went up to the top of the hill. Whenever Moses held up his hand, Israel prevailed; and whenever he lowered his hand, Amalek prevailed. But Moses' hands grew weary; so they took a stone and put it under him, and he sat on it. Aaron and Hur held up his hands, one on one side, and the other on the other side; so his hands were steady until the sun set. (Exodus 17:8–12) Who are the Aarons and Hurs in your life? Who supports you when you are tired? Whom do you support in this way? Think about how your story would be different without these relationships. When fear and doubt lead us to say no to God's call, consider how we are isolating ourselves from the potential support of family, friends, and community. Separation and isolation rob us of our ability and our hope. Joining with family and community, as Moses did with Aaron and Hur, gives us strength and courage.

This is a wonderful scriptural story for many reasons. One life lesson it teaches is that all of us, no matter how great, need support sometimes. None of us is immune from one day acquiring, through illness or accident, a special need similar to those of people who are excluded.

We Are All Vulnerable

In one of the Jewish commentaries of Exodus is a delightful story in which Moses, as a toddler, grabs the crown from the Pharaoh's head and places it on his own. The Pharaoh's advisors worry that Moses may have done it deliberately and knowingly, as a sign of his desire to usurp the throne.

Pharaoh sends for all the wise men of Egypt to advise him in this matter. The Angel Gabriel, disguised as a wise man, proposes that an onyx stone and a coal of fire be placed before Moses. If the boy chooses the onyx stone, then the Pharaoh will know Moses has wisdom enough to have deliberately taken the crown, and that he should be killed. If Moses chooses the hot coal, then Pharaoh will know the boy is blameless in his taking of the crown. Pharaoh agrees to this test, and when the onyx stone and coal of fire are placed before Moses, his hand is secretly guided by the angel to the coal. Moses grabs the coal and places it in his mouth, and his lips and tongue are burned. This results not only in the Pharaoh's sparing of Moses's life but also in Moses's thereafter stuttering and speaking slowly (adapted from Rabbi Ephraim Buchwald, "The Making of a Concerned Jewish Leader").

This story is a good reminder that we are all vulnerable to events that may disable us in some way, but also that in some mysterious way, God may use these disabilities for the greater good. It is not reasonable to believe God deliberately inflicts suffering, but many believe and have witnessed God's hand in bringing much good from affliction or disability. In supporting Moses, Aaron and Hur also benefit, as do all the Israelites.

Our Experiences at The Monarch School

In the same way as Moses, Aaron, Hur, and the Israelites, we at The Monarch School support our students, and we also learn from and grow with them. It's

important to point out, though, that Monarch students retain ownership of their growth and learning. Aaron and Hur do not replace Moses, nor do they carry him. Moses still owns the role of leader in the battle.

Sadly youth with special needs are often robbed of the ownership of their own development. The desire to help can lead adults to provide too much replacement help ("I'll do it for you"). The result is that the youth are carried instead of supported. They then get stuck and become overly dependent on the adults around them.

Lives are changed at The Monarch School, not through the efforts of any one individual but rather through the combined work of a team of Aarons and Hurs committed to working together to support the youth in their struggles to grow. The youth at Monarch, to the degree they are able, retain ownership of their development. They set goals, reflect on their progress, and build plans for success. Like Aaron and Hur, Monarch staff members support the youth when they need it, but we do not carry them. In the same way, all youth in religious education and youth ministry programs, to the degree they are able, should maintain ownership of their religious understandings and spiritual growth.

One of the saddest scenes is when families of youth with special needs opt out of participating in faith communities because they don't feel enough support for their young people to be successful. For example, those who have Tourette's syndrome are often not welcome in worship gatherings due to the disruption their verbalizations cause. They may hoot or call out words, and many people find this distracting. But consider all the ambient noises that are just as loud as a Tourette's vocalization but that are perfectly acceptable to the community. A hearty cough or sneeze is often the same volume or more than a Tourette's verbalization, and there is a veritable chorus of coughs throughout most congregational gatherings. The only reason Tourette's vocalizations disrupt is because they are unusual.

If the members of the community have the compassion to open their arms to embrace those with this syndrome, they will notice that the vocalizations soon become ambient and blend in with the cacophony of coughs, throat clearing, sneezes, and other noises always present in large gatherings of people.

When there is no acceptance in the community, the families of these people withdraw, and the community is silent in response. We at The Monarch School have heard the same story from many different parents—they tried it, it didn't work, they stopped attending. End of story.

When parents tell us their youth are no longer involved in religious education programs, we always ask them, "When you stopped attending, did anyone call to ask why or to invite you back?"

We Are Called to Respond Differently

You are encouraged to respond to the Great Commission (see Matthew 28:18–20) by creating that yes in your community. Please respond passionately when community members are marginalized. When a youth with special needs stops participating, and the teacher or ministry leader is relieved because the "disruption" or her or his own anxiety has ended, please say: "No. She is one of us. Let's invite her back, and let's provide the support she needs to be successfully present."

The last clause is crucial. If the community is not prepared to modify its environment, curriculum, and hearts to accommodate a young person with special needs, then it just isn't going to work. Welcoming someone into a setting in which she or he will fail is not welcoming at all. The Aarons and Hurs need to be in place, ready to support a youth with special needs in her or his struggles.

Transforming Hearts

The good news is that the modifications to the environment and the curriculum are not difficult to implement. Much harder is the work of transforming hearts to accept and undertake the efforts.

You may encounter people in your community who reject, either philosophically or practically, your efforts to transform religious education programs to be more inclusive. Following are a few fictitious examples of people you might encounter:

The Host of the Book

Readers, I'd like to introduce you to David Dubious.

David

Hello. How are you doing?

The Host

Just great, David, and welcome to chapter 2 of A Place for All: Ministry for Youth with Special Needs.

David

So you're writing a book about mythology?

The Host

No, why would you say that?

David

Because I heard you say "special needs."

The Host

So, you don't believe some children have special needs?

David

Well, if a kid's in a wheelchair, I'll be the first one up here on a Saturday to build him a ramp. But if you start talking about attention deficit disorder (ADD), obsessive-compulsive disorder (OCD), and other psychobabble, then no, I don't believe it.

The Host

But David, research shows that these children's neurological differences cause significant difficulties when they try to function in ordinary classrooms. They have trouble focusing, staying on task, regulating their emotions . . .

David

Yes, and that neurological research is flawed. ADD is society's new label for what we used to call lazy or undisciplined.

The Host

Thanks for sharing your perspective, David. Ladies and gentlemen, please give a warm welcome to our next guest, Polly Pragmatic.

Polly

Thank you for inviting me into your book. I think what you're advocating is fantastic!

The Host

That's wonderful, Polly. So you don't agree with David's assessment of special needs youth?

Polly

Oh, heavens, no. Our family has several children with attention deficit-hyperactivity disorder (ADHD). I know it's real, and I know meds and modifications are necessary for our kids. We have a neighbor boy with Tourette's syndrome too. I know he can't help it when he has those tics.

The Host

Well, it's nice to hear you have a good understanding of these neurological differences. So will you be using the book to make some changes in your parish's religious education and youth ministry programs?

Polly

I'm afraid not. It just wouldn't be possible in our community.

The Host

Why not?

Polly

Well, first of all, our church budget is tight, so we don't have a lot of money to spend on teacher training and classroom modifications. Second, all our Sunday school teachers are volunteers, not professional teachers. They haven't been trained to deal with normal young people, much less youth with special needs. And even if we got somebody to train the teachers and volunteers, half of them would quit rather than spend extra time attending the training classes. We have a hard time finding enough volunteers as it is. I know

it's important, and it breaks my heart to have those poor kids left out, but . . .

The Host

So you understand the need, but you're not willing to work to make it happen?

Polly

I care about these kids; really I do . . . but at our church, it just wouldn't work.

The Host

If others at your church also believe as you do, Polly, then you're probably right.

Why do so many in ministry have such a fear of working with and for young people with special needs? What in our culture leads us to choose not to be inviting to children with disabilities, differences, and quirks?

Based on our experiences at The Monarch School, we have found that some people are afraid. They may be afraid of contagion—that somehow other students will begin acquiring these characteristics. They may be afraid of the unusual in favor of "normality." Unfortunately this fear can result in the loss of the opportunity to gain a broader appreciation of the richness of our lives by including those who have not only special needs for themselves but also special gifts of perspective for all of us.