

# Empowering Students with Hidden Disabilities

## A Path to Pride and Success

by

**Margo Vreeburg Izzo, Ph.D.**

Program Director, Special Education and Transition Services  
The Ohio State University Nisonger Center  
Columbus

and

**LeDerick Horne**

Poet, Speaker, Advocate, Entrepreneur

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## About the Authors

**Margo Vreeburg Izzo, Ph.D.**, is Program Director for Transition Services at The Ohio State University Nisonger Center. She has extensive experience designing and directing projects that improve the transition from high school to college and careers with funding from the U.S. Department of Education, National Science Foundation, and numerous state and local agencies. Dr. Vreeburg Izzo has developed educational curricula for students with disabilities; conducted numerous trainings, focus groups, and interviews with teachers and students; managed the development of web sites, videos, and other dissemination products; and published more than 35 peer-reviewed articles, books, or book chapters on disability and transition issues. She received the Mary E. Switzer Fellow from the National Institute of Disability Rehabilitation Research in 1996. As Past President of the Division of Career Development and Transition, she provided leadership to national, state, and regional committees to improve the quality of education and transition services. She also is a mother, wife, grant writer, and a person with attention-deficit/hyperactivity disorder (ADHD). She believes that people with hidden disabilities are more likely to succeed when they can exercise self-determination in choosing their path to college and careers. In the pages to come, learn more about Margo's life with ADHD and her personal and professional mission to help all people with hidden disabilities lead meaningful lives. For more information on how to contact Margo, visit [www.MargoIzzoPhD.com](http://www.MargoIzzoPhD.com).

**LeDerick Horne**, labeled as neurologically impaired in third grade, defies any and all labels. He is a dynamic spoken-word poet, a tireless advocate for all people with disabilities, an inspiring motivational speaker, a bridge builder between learners and leaders across the United States and around the world, and an African American husband and father who serves as a role model for all races, genders, and generations. LeDerick is the grandson of one of New Jersey's most prominent civil rights leaders and uses his gift for spoken-word poetry as the gateway to larger discussions on equal opportunity, pride, self-determination, and hope for people with disabilities. His workshops, keynote speeches, and performances reach thousands of students, teachers, legislators, policy makers, business leaders, and service providers each year. He regularly addresses an array of academic, government, social, and business groups and has had appearances at the White House, the United Nations, Harvard University, the National Association of State Directors of Special Education, and the Pennsylvania, Wisconsin, Nevada, and Alabama State Departments of Education. His work addresses the challenges of all disabilities, uniting the efforts of diverse groups in order to achieve substantive, systemic change. Go to [www.lederick.com](http://www.lederick.com) to learn more about LeDerick and his work.

## About the Contributor

**Bill Bauer, Ph.D.**, is Professor of Education at Marietta College, a small rural liberal arts school located in the rolling hills of southern Appalachian, Ohio. Bill has a sensorineural bilateral hearing loss, yet a severe hearing impairment has not held him back. He was a former elementary school teacher, school principal, and superintendent. His doctoral degree is in rehabilitation counseling, and he has a private practice at a local hospital and serves as a consultant to many disability-related organizations regarding transition and life span development. He completed postdoctoral work at the Ohio State University Nisonger Center and received the Lifetime Achievement Award from the People First Association. Bill contributed greatly to this book's final chapter, which incorporates his many years of experience in working with youth, adults, and families with hidden disabilities as well as physical disabilities, sensory impairments, and mental health conditions.

# Foreword

## **“EMPOWERING STUDENTS WITH HIDDEN DISABILITIES: A PATH TO PRIDE AND SUCCESS”**

In 2003, I sat at my son Samuel’s hospital bedside in the intensive care unit as he lay in a medically induced coma. He was three years old and had developed pneumonia from complications following surgery. Samuel’s neurologist, Dr. James Filiano, encouraged me to be a photojournalist in the midst of my fear. “You should document this,” he said.

I began working on my first film, *Including Samuel*, and Samuel’s life is the central thread through the film. Making this film helped me face my fears and biases head-on, both as a director and as a father. I wanted to show the general public why I felt so strongly that inclusive education is the most important factor in giving Samuel and other children with disabilities the opportunity for a happy and fulfilling life. As a journalist, I didn’t want to sugarcoat the issue. I wanted the film to be as complex as the reality of successful inclusion.

As I took the *Including Samuel* documentary nationwide I started to understand how our experience parenting a child with a very visible disability—cerebral palsy—differed from parenting a child with a hidden disability. At almost every screening, someone would pose this question in some form: “What about kids with hidden disabilities? Can they be fully included like Samuel?” These hidden disabilities can include depression, learning disabilities, anxiety, ADHD, bipolar disorder, autism spectrum disorder, eating disorders, PTSD and a host of other mental health challenges.

At a screening in Buffalo, a mom spoke up and told the story of her son, who had autism, one of the hidden disabilities that LeDerick Horne and Margo Izzo discuss so powerfully in this book. She explained that his routine had to be carefully managed every morning—just the right food, just the right clothes, just the right type of communication. If anything was off, he’d have a ‘melt-down’ once he got to school. And then, she said through tears, she’d be judged as a ‘bad mom’ because of her son’s challenging behavior.

That experience was one of many that led to create the film *Who Cares About Kelsey?* which focuses on Somersworth High School student Kelsey Carroll. When Kelsey entered high school, she was a more likely candidate for the juvenile justice system than graduation. She had a diagnosis of ADHD and carried the emotional scars of homelessness and substance abuse, along with actual scars of self-mutilation. As a freshman, she didn’t earn a single academic credit and was suspended for dealing drugs. Many wrote her off as a “problem kid”—destined for drug addiction and jail.

The resulting film, *Who Cares About Kelsey?*, shows what successful school transformation looks like on the ground, in a real school, through the eyes of a student. The film follows Kelsey's transformation into a motivated and self-confident young woman. Along the way, critical figures in her personal and educational life shape her coming of age and play important roles in an education revolution that's about empowering—not overpowering—youth with hidden disabilities.

LeDerick and Margo write about the “Kelseys” of the world through their powerful lens of decades of personal and professional experience. I got to know LeDerick first as a passionate poet and masterful facilitator. In 2010 at a youth inclusion summit inspired by *Including Samuel*, he led a group of 20 students with and without disabilities through the process of designing a national campaign called: “I am Norm,” which to this day continues to “Redefine Normal and Promote Inclusion,” as the campaign tag line states.

I met Margo at an AUCD conference when I presented the *Who Cares About Kelsey?* film along with Kelsey. Her support for the film meant the world to me, since Margo has worked at Ohio State University for 32 years and has been directing projects related to the transition from school to college and careers since 1985. That alone would be enough to spark this book. But perhaps her greatest motivation for this book is her daughter Anna, who you will get to know starting on page 16.

LeDerick and Margo understand intimately that youth with hidden disabilities are often misperceived as being troublemakers instead of as complex children who need supports from the adults in their homes, schools and communities.

They understand that effective support and interventions can ease the pain of these students, raise graduation rates and help students connect with their community through mentors and peer groups. They also know that students with emotional and behavioral disabilities are more likely to be victims of violent crime than perpetrators, and that without appropriate interventions, they are at increased risk for dropping out of school, for incarceration, homelessness, and for long-term reliance on government assistance.

Here are a few things to consider while reading this book.

1. **Hidden disabilities are extremely prevalent.** Over three million students in the United States have diagnosed hidden disabilities such as learning disabilities, ADHD or emotional/behavioral disability (EBD). One in every 10 youth in the United States experiences a mental health disorder severe enough to limit daily functioning in the family, school, and community setting.
2. **Hidden disabilities can wreak havoc on learning.** Students with hidden disabilities receive below average scores on reading and math assessments, compared to students in the general population. For example, one-third of students with LD have been held back (retained) in a grade at least once.

3. **Punitive approaches are disastrous.** Punitive discipline policies, like “zero-tolerance,” which emphasize the use of suspension and expulsion in addressing problem behavior, don’t get at the root causes of behavior. Studies also show that these policies do little to improve school safety and disproportionately impact students with disabilities and students of color. What they can result in is traumatic experiences for students and adults, as you can see in another one of my film, *Restraint and Seclusion: Hear Our Stories* ([www.stophurtingkids.com](http://www.stophurtingkids.com)).
4. **Post-school outcomes for students with EBD are dismal.** National studies show that students who are suspended or expelled often drop out of school, which frequently leads to juvenile delinquency, arrests, and prison. Students with EBD are twice as likely as other students with disabilities to live in a correctional facility, halfway house, drug treatment center, or on the street after leaving school.

Ok, now that I’ve provided four major downers on this topic, let me offer four hopeful things:

5. **Psst, here’s a too-well-kept secret: behavior is a form of communication.** When a child is ‘acting out,’ it is generally NOT because they just want to be ‘bad,’ but because they are trying to tell us something and don’t have the language or communication tools to express themselves in a more effective way.
6. **Sometimes simpler is better.** Parents and educators can take crucial, relatively simple actions to help children with hidden disabilities. Parents: Spend 15 minute a day listening unconditionally to your child; do person-centered planning; have a discussion with your child about their needs and their strengths; refuse to allow others to underestimate your child. Educators: meet with a child 1:1 to brainstorm positive solutions to behavior challenges; calling a family member at home to tell them things are going well; share one new resource related to mental health each month with colleagues; create space at a staff meeting to share success stories.
7. **No need to reinvent the wheel.** There are MANY longstanding, evidence-based educational approaches that your school should implement to dramatically improve the outcomes for students with hidden disabilities. Parents should ask their schools about approaches like differentiated instruction, extended learning opportunities, universal design for learning, functional behavioral assessments and transition planning. Like most successful educational practices, these approaches were incubated in the field of special education, but can be crucial for the success of every child—label or not.
8. **Having students with disabilities in general education enriches the school.** 30 years of research is clear that inclusive education will result

in better academic, social, behavioral and post-secondary outcomes for students with disabilities. But just as important, I've never seen a study that shows that inclusive education diminishes the experience of students without disabilities in any way. In fact, studies show that 'typical' students often improve their academic achievement in inclusive settings when they learn alongside students with disabilities. And as I discuss in my TEDx talk, "Disabling Segregation," the social and emotional benefits of learning in a school which represents the true diversity and different-abilities of the world is profound, even if it can't be easily measured on a standardized test.

By working together on this book, LeDerick and Margo stay true to the inclusive values they hold dear, and exemplify the "Nothing about us, without us" theme from the disability rights movement. The book is full of examples from people who have lived the experience of having a disability. They write about the importance of helping students to feel disability pride and accept who they are as people and students. They understand that without that acceptance, these students will find it hard to disclose, use supports, and develop the skills needed to become affective self-advocates.

I agree with LeDerick and Margo that educators, families and community members need to help students with hidden disabilities feel proud of how their minds and bodies work, learn to embrace their challenges, give them the supports and accommodations needed for them to reach their full potential, and provide ways for these students to connect with the disability community. My family has been fortunate in that Samuel, now 16 and a sophomore in high school, has experienced inclusive education with educators who had high expectations for him, and created classrooms rich with innovative, universally designed instruction. It's no coincidence that he is consistently on the honor roll, involved in a host of extra-curricular activities and now has his eyes on college.

Transitioning to college and career is a particularly difficult time for all students and it can be particularly challenging for students with disabilities, so it's wise that LeDerick and Margo spend part of this book discussing how educators can focus on their student's strengths during transition.

Above all else LeDerick and Margo's work centers on helping students connect with their strengths and interest in order to achieve their goals for the future.

This book is based on a clear, essential premise: despite many societal forces working against them, people with hidden disabilities contribute a great deal to the world. Educators and others have the unique opportunity to help the next generation of people with hidden disabilities realize their potential.

*Dan Habib*  
*Filmmaker and Project Director*  
*University of New Hampshire Institute on Disability*



# Preface

## SOME WORDS FROM LEDERICK

Since graduating from New Jersey City University in 2003, I have been fortunate to work with a number of organizations and agencies dedicated to improving the lives of people with disabilities on the national, state, and local level. The New Jersey State Department of Education's Office of Special Education was the first agency to offer me the opportunity to share my story, poetry, and advice to help improve the transition outcomes and self-advocacy skills of high school students with individual education plans (IEPs). Through my work with the New Jersey Department of Education, I was introduced to the IDEA Partnership that is housed within the National Association of State Directors of Special Education. The youth leadership and development work I did with the IDEA Partnership centered on promoting and supporting groups throughout the nation that believed youth and young adults with disabilities need to have a meaningful role in governing the organizations that provided support for people with disabilities. Then, in 2005, I was asked to chair the governing board of a new nonprofit, which is now known as Eye to Eye. The head of this organization had the novel idea of using the power of art, mentoring, and storytelling to empower young people with learning disabilities/ADHD. Over the years, I have been invited into some of our nation's best schools and learned from advocates with and without disabilities, and I have been able to take part in cutting edge initiatives in the field of education. Beyond my poetry, this book is my first attempt at writing down what I have learned about disability culture, education reform, self-advocacy, and what is needed to help young people with disabilities develop their fullest potential.

A college professor with attention-deficit/hyperactivity disorder (ADHD) and a poet with a learning disability decide to write a book. This may sound like the beginning of a really bad joke, but if there is any power within the pages that follow, that power comes directly from the unlikely partnership described in this playful line. Margo and I met in Washington, D.C. at the 2010 Office of Special Education Programs project director's conference. I was invited to deliver an opening keynote for this annual gathering of approximately 1,000 researchers who were working on innovative ways to improve the quality of education and transition outcomes for students with disabilities. I spent an hour sharing my personal story as an individual with a learning disability who had survived a myriad of challenges faced by many young people as they utilize special education services and make the transition to adult life. I also provided suggestions on reforms that I felt were needed to ensure that all students

receive a quality education. Margo was one of the first people to walk up to me after my presentation. Our first conversation together would be one of many, and it began a deep alliance and shared commitment to improving the lives of people with disabilities.

Margo and I began to work together regularly over the next several years. She invited me to The Ohio State University, where she was directing a number of projects to increase academic and transition outcomes for students and young adults with disabilities. I became more and more impressed with her work each time I returned. She was a project director who was able to create and manage teams of diverse professionals who were doing groundbreaking work in the field of transition at both the high school and college level. For example, one of Margo's projects developed transition curricula to assist high school students in researching and developing their own transition plans for college and careers. Another one of her projects facilitated student learning communities to assist students with disabilities who were majoring in science, technology, engineering, and mathematics (STEM) fields to develop self-determination skills so they could advocate for needed accommodations and supports. In addition, Margo directed a project that created Ohio's Statewide Consortia of five college programs that provided comprehensive transition services to enhance employment outcomes for students with intellectual disabilities. These college students with intellectual disabilities benefit from the educational and social aspects of college life while preparing for employment. Another project used online mentoring to help high school students with IEPs develop their transition plans.

Outside of working together, Margo and I also began to build a friendship that was based, in part, on our shared experiences as people with hidden disabilities. Her diagnosis of ADHD and my diagnosis of a learning disability made for interesting conversations as we frequently talked about the benefits and challenges that came with the ways our minds worked. It was during one of these conversations when Margo first suggested that we collaborate on a book that would capture our ideas, stories, and advice. We both realized that in the field of disability studies, and specifically within education, there was not enough advice for educators that comes directly from the people who have lived with a disability. We both believed that the combination of our professional experiences with our respective passion for research and writing would give us the ability to create a book that would have the potential to make a lasting affect on how students with hidden disabilities perceive themselves as they prepare for the adult world.

## MARGO'S MOTIVATION

I went to school before the Education for All Handicapped Children Act of 1975 (PL 94-142) was passed and before students with ADHD were diagnosed and provided with IEPs to ensure that they received a free appropriate public education. My mom and my teachers had high expectations, and I went on

to college, majoring in psychology and special education. I started my career teaching high school students with emotional and behavior disorders. My passion for transition was fueled when I was teaching these high school students. I felt a tremendous responsibility to teach them the skills they needed to work and live in their communities. So, I pursued a master's degree and a doctoral degree to discover how to deliver quality education and transition services.

I realized that the school climate for my daughters was much different than when I had gone to school. Schools had shifted to a high-stakes testing environment in which students had to pass state graduation tests to receive their diploma. I recognized that my daughter, Anna, had many of the same characteristics that I had as an elementary student, but her grades were good, so I did not worry. I also knew that postschool outcomes for students with disabilities were significantly poorer than for students who were not identified, so I did not want Anna to be served by special education. I spoke with her middle school teacher, who pointed out that my daughter may need some additional supports, such as medication and extended time, as the curriculum got tougher and the stakes got higher. We visited our pediatrician and completed the diagnostic surveys to qualify Anna as a child with ADHD who could receive medication—but from the school's perspective, Anna did not need specialized services and did not qualify for special education.

I noticed that Anna's self-esteem was dropping during this time. As she approached the rigors of high school, she resisted taking her medication, and her grades dropped further. The school counselor recommended special education services to gain the additional supports Anna needed to become proficient in more challenging subjects. Anna's self-esteem lowered even more. Once she qualified for special education, the system recommended the easiest subjects, and her teachers' expectations dropped. I felt that we were in an unending downward spiral that was drowning out Anna's potential. Although Anna and I had very similar learning styles, our high school experiences were totally different, in part because the levels of expectations were not the same. The system stopped believing that Anna could learn.

I kept thinking that Anna and I had such similar academic struggles. Memories of my challenges with organization, impulsivity, and focusing on one task made me begin to wonder: Was it possible that I also had ADHD? I started to become more and more convinced. It was at this point that I decided to undergo the psychiatric testing, and, to no surprise, I exhibited many ADHD characteristics and received a prescription for medication. With the receipt of this news, I became determined to be a positive role model for Anna. I was not going to let Anna stop believing in her abilities. She is now completing her master's degree at The Ohio State University while she works full time and is planning her wedding.

As I interact with high school students with disabilities, I see so many who have similar experiences to Anna's high school journey. Students give up their dreams, in large part, because teachers have given up or maybe are just afraid to expect too much. How are students going to believe they can learn if teach-

ers do not believe in them? It may be tougher for students with disabilities to learn, but those students and their teachers cannot give up just because it is hard. This is where LeDerick's story and my story intersect. We both believe that students with disabilities, and especially those with hidden disabilities, deserve to dream about a future in which they make the transition to colleges and careers that capitalize on their strengths, preferences, and talents. This book is dedicated to those students and adults with hidden disabilities and hidden potential who have disability pride and who dare to dream.

## OVERVIEW OF CHAPTERS

The goal of this book is to broaden educators' understanding of disability from an asset-based approach in order to assist students with hidden disabilities in accepting their disability, reaching their goals, and gaining disability pride. Each chapter provides guidance to help students strive to stay in the game—the game of learning, working, and living to their potential. We provide many stories from our own lives as well as others who have walked the journey from struggling student to self-determined self-advocate. Some highlights from the upcoming chapters follow.

Chapter 1 provides the current state of students with hidden disabilities. A number of disability categories are described, and Tips for Teaching are suggested to address some of the challenges that students experience.

Chapter 2 introduces the Path to Disability Pride and demonstrates, through a series of case studies, how people with hidden disabilities come to incorporate disability into their self-concept. Find out how LeDerick, after many years of feeling shame, eventually learned to embrace his disability and why Margo's daughter, Anna, became a strong advocate once she got to college.

Chapter 3 defines and describes various models of mentoring, including Eye to Eye, a national organization that matches college and high school students with dyslexia, ADHD, and other learning disabilities with younger students who have similar learning differences. The chapter also covers other organizations run by people with disabilities who strive to increase disability awareness and pride. The authors share both research results and personal testimonials that demonstrate the impact of mentoring. These testimonials show how self-determination and a positive self-concept are fostered and reinforced by mentors. Mentoring helps students who often feel alone in connecting to a larger community of people who lend support to students through critical junctures and transitions.

Chapter 4 provides an overview of self-directed transition planning so educators and parents can empower students to take charge of their own transition to college and careers by engaging in activities that promote disability pride and positive transition outcomes. Read success stories of how these state and local events changed the course of kids' lives. Finally, gain many free resources and curricula to teach students to plan their own transition to college and careers.

Chapter 5 explores the rights and responsibilities of college students with hidden disabilities. Strategies for preparing for tests, writing research papers, and advocating on campus are provided. Learn how students with hidden disabilities majoring in STEM learned about the effects of their disability and developed disability pride.

Chapter 6 discusses strategies to help students explore their own interests, passions, and abilities and learn how to explore career opportunities that turn a job into a career. Studies have shown that more than 35% of America's entrepreneurs are people with hidden disabilities. Read about how Adam, a graphic designer with learning disabilities, uses his writing/spelling software to label his designs after advocating for technology on the job, and discover how LeDerick started his own consulting business, delegating the tasks that he finds challenging.

The final chapter explores the skills needed to negotiate personal relationships, such as knowing and valuing yourself and communicating needs and wants with spouses and children. Tips on how to navigate relationships are shared through case studies and discussion. Readers also learn how to use the Path to Disability Pride framework to help students build a better understanding of their disability's role in their self-concept.