

# Setting High Expectations

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How to Navigate the System to Support  
Your Child's Needs

Michael J. Hynes





*Expect the Unexpected...*

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*all life is precious*  
INTERNATIONAL DOWN SYNDROME COALITION  
[www.idscforlife.org](http://www.idscforlife.org)

See me  
as a person.

See my  
potential.

See my  
personality.

See  
that I am able.

*See ME.*



# Learning About Sadie

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*Need an  
advocate  
in the  
home*

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# Exposure to Everything

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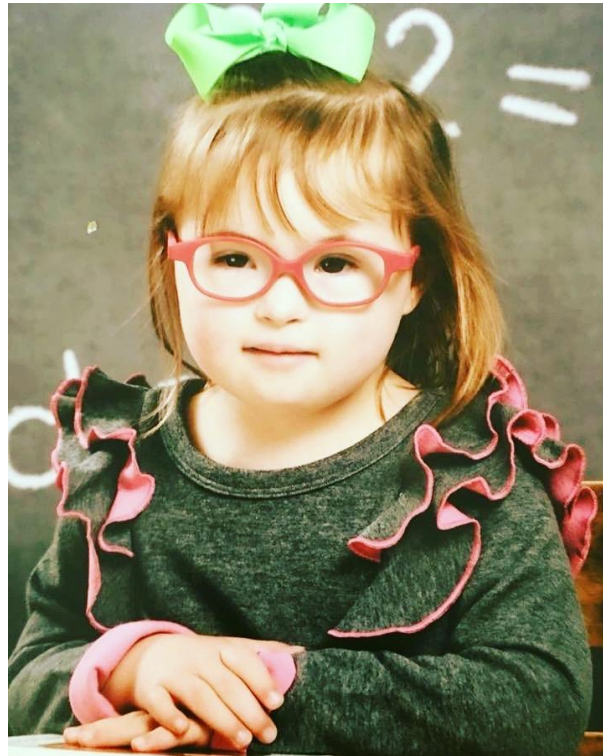






# The System

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## What My Child With Down Syndrome Taught Me

**MY DAUGHTER SADIE** has taught me more in her nine years of life than I have learned in my past 52 years of existence. My wife Erin and I had no idea that our daughter had Down Syndrome when she was born.

Sadie had to stay in the newborn intensive care unit for a few weeks, and we met some of the most compassionate and amazing professionals in the world. Unfortunately, we also met others who were much better off keeping their thoughts to themselves.

I remember a doctor at the hospital telling me he was “sorry” after Sadie was born. On another occasion, a family member shared with my wife and I that “Mongoloids can be nice people.” She didn’t mean to upset us. It was her mental model about Down Syndrome. Initially, as parents, we were surprised with the multitude of closed-minded comments we came across. As Sadie grew and we brought her to restaurants, stores or in public, people would stare at her longer than one should.

I’m sharing this with you not to

complain but to share the insights our journey has given us. We began to learn how the world can perceive others without knowing anything about them whatsoever, except through the lenses of their biases and assumptions. Little did they know our little Sadie has the best sense of humor and can read on grade level like her peers. She enjoys music and hanging out with her best friends as all children do. As parents, we began to advocate for more programs in her school and for the school districts we served in.

### Professional Applications

I perhaps should have started this commentary by sharing both Erin and I are school district administrators. She is an assistant superintendent for curriculum and instruction, and I have served as a superintendent for the past 11 years. Here are the lessons we learned from our personal lives that now transcend to our professional ones.

You never know what others are going through. I have a much deeper

respect for parents who have children with autism, Down Syndrome, ADHD or “Other Health Impairment,” which is one of the 14 categories of disability listed in our nation’s Individuals with Disabilities Education Act. They have incredible stories to share, and we need to support them as much as their children.

Never place limits on your child or students. Don’t always accept what professionals say at face value. If Erin and I listened to what some professionals believed Sadie would never be able to do, her life would be so much more unfulfilled. She is flourishing.

We need to remove the word “special” from education. This word places a label on a child that never leaves them and carries a negative connotation with it. Yes, the children are special, but they certainly are not less than “typical children.” Yes, I loathe that phrase as well.

Inclusion is important, but integration is critical. It’s great to be included but to be fully integrated is where the secret sauce is. Separating and segregating children is not the answer. Teach them to become independent and watch them soar!

### A Reality for All

Sadie is now in 4th grade. She continues to surprise people with her intelligence, humor and, at times, stubbornness. We are so fortunate to have her in our lives.

There are other “Sadies” in every school in America. Are we as school leaders doing everything, in our power to make our school system more inclusive and integrated? That’s for you to answer and my hope is that you strive to make that a reality. Every child will benefit from it.

**MICHAEL HYNES** is superintendent of the Port Washington School District in Port Washington, N.Y. E-mail: [mhynes@portnet.org](mailto:mhynes@portnet.org). Twitter: @MikeHynes5

Loving the Leading  
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# Understand the Arena you are playing in

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# Blueprint from NYSED

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## Key Principles

### BLUEPRINT FOR IMPROVED RESULTS FOR STUDENTS WITH DISABILITIES

- Students engage in self-advocacy and are involved in determining their own educational goals and plan.*
- Parents, and other family members, are engaged as meaningful partners in the special education process and the education of their child.*
- Teachers design, provide, and assess the effectiveness of specially designed instruction to provide students with disabilities with access to participate and progress in the general education curriculum.*
- Teachers provide research-based instructional teaching and learning strategies and supports for students with disabilities.*
- Schools provide multi-tiered systems of behavioral and academic support.*
- Schools provide high quality inclusive programs and activities.*
- Schools provide appropriate instruction for students with disabilities in career development and opportunities to participate in work-based learning.*

# Pupil Support Services

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- Oversee the implementation of Individualized Education Programs (IEPs) and Section 504 Accommodation Plans.
  - CSE: Committee on Special Education
  - CPSE: Committee on Preschool Special Education
- Oversee the provision of services provided to our classified students through various agencies. These services include OT, PT, Behavioral Consultation, Parent Training, Job Coaching, Assistive Technology Consultation, and Vision services
- Oversee the implementation of home instruction services and IHIPs for students who are home schooled by their parents

# Special Education Programs and Services

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- We have developed comprehensive in-district programs for our Students with Disabilities
  - Related services
  - Consultant teacher services
  - Resource Room programs
  - Integrated Co-Teaching services
  - Special classes (8:1:2, 12:1:1, 15:1)
  - Transition Services
  - Extended School Year Services



# When does Transition Planning begin?

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- Beginning at the age of 12, and for any student referred to the CSE for the first time after age 12, students and parents complete transition interviews to determine vocational skills, aptitudes, and interests
  - These are conducted annually
- Beginning at age 15, the transition section of the IEP needs to be completed.
  - This is updated annually
  - This includes PLEP, appropriate postsecondary goals, statement of transition service(s) needed activities needed to facilitate the student's transition to post-secondary activities, and the responsibilities of the district in regards to helping with this transition.



# Set high but not impossible expectations

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- We need to remove the word "special" from education. This word places a label on a child that never leaves them and carries a negative connotation with it. Yes, the children are special, but they certainly are not less than "typical children." Yes, I loathe that phrase as well. Inclusion is important, but integration is critical.
- It's great to be included but to be fully integrated is where the secret sauce is. Separating and segregating children is not the answer. Teach them to become independent and watch them soar!