Inclusion Works! *Inspiration and Information to Counter Arguments against Inclusive Education for Students with Down Syndrome*

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In the late 1980s, Tory Madison's[1] son Charlie was in third grade when she enrolled in a yearlong leadership institute for parents of children with significant disabilities in New Hampshire. The institute's goal was to support parents to re-capture their dreams for their children, learn about best educational practices, and develop advocacy and community organizing skills. Tory soon decided to do everything she could to assure Charlie was a fully participating member of a general education class in his home school, learning academics alongside his classmates without disabilities. Tory asked Charlie's educational team to capitalize on natural opportunities to teach functional skills. During high school, Charlie had summer jobs alongside a typical classmate. He marched at graduation with his class. Between the ages of 18 and 21, the school district provided staff and support for Charlie to learn independent living skills in his own home and city, and to explore a variety of jobs through internships and volunteer activities. Today, Charlie lives in his own apartment with his brother and another roommate, just celebrated 10 years of working at Sam's Club and has a full life in the community.

Despite the lessons that have been learned over the past 20 years from successfully including thousands of other students like Charlie, parents and professionals still face roadblocks based on outdated arguments about inclusion for students with Down syndrome. Here are three common arguments against inclusion and rationale for why they are weak or unfounded.

Argument #1: Some students are just "too disabled."
Some argue that students with DS and other developmental disabilities are "too disabled" to learn in a general education classroom. IQ and other tests given to people with significant disabilities are significantly flawed in their ability to identify people's gifts and talents and the supports they need in order to be successful; so how do we decide if a student is capable enough to benefit from inclusion and instruction in general education academics?

In 1984, University of Wisconsin researcher Anne Donnellan, described a principle called "the least dangerous assumption." She said:

"The criterion of least dangerous assumption holds, that in the absence of conclusive data, educational decisions ought to be based on assumptions which, *if incorrect*, will have the least dangerous effect on the likelihood that students will be able to function independently as adults." Furthermore, "we should assume that poor performance is due to instructional inadequacy rather than to student deficits." Pretty powerful words!

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[1] "Tory" and "Charlie" are pseudonyms.

Let's apply this principle to Charlie, whose mom insisted he be included with his typical peers in every classroom lesson and activity. With the presumption that Charlie could and would learn, his educational team developed instructional, communication, sensory and behavioral supports. Now imagine if a new brain scan was developed that could determine conclusively that, in fact, Charlie didn't learn very much academics? Was harm done? Charlie was taught both academic and functional skills and seems to have a pretty good life as a happy, healthy, employed adult. Therefore, we might judge that no harm was done.

If Charlie's mom had believed he *couldn't* learn academics, *shouldn't* be included, and should only be taught functional skills, he might have been placed in a self-contained class with other students with significant disabilities. The goal of his education might have been to live in a group home and work in a sheltered workshop with few opportunities to develop relationships with his typical classmates. Now, what if the new brain scan showed Charlie was smarter than anyone expected, *could* have learned academics and moved on to life and work in the community?

Most people say that not presuming Charlie as competent did cause him harm. They say:

- We lost an opportunity to teach Charlie things he could have learned.
- We didn't include him as much as we could have and he did not develop a wide network of typical social relationships.
- He missed out on the typical high school experience.
- We might have negatively influenced his self-esteem by treating him as if he were not smart.
- We narrowed the possibilities for his future career or postsecondary education.
- We wasted a lot of money pursuing the wrong educational program.

Attitudes about students' competence are at the heart of many arguments against inclusive education. To presume incompetence could result in harm to our students if we are wrong and is not the least dangerous assumption.

Argument #2: Functional skills are more important that academics to students' futures.
Parents of children with DS are sometimes told it is more important to learn functional skills than academics. To weigh the merits of this argument, consider the functional skills students with developmental disabilities are usually taught.

- Telling time and using money
- Brushing teeth and other personal hygiene
- Recognizing safety signs
- Cooking
- Making beds
- Crossing streets
- Job skills like stocking shelves or assembling widgets

Each of us does most of them every day, so they do seem like important things to learn. (But we do them to participate in the important things that make up our *real lives* – having satisfying relationships, earning a living, enjoying our leisure time and giving back to our communities. Functional skills do not, in and of themselves, make our lives interesting and productive, yet they form the core of many self-contained educational programs.

Functional skills are important, but acquiring knowledge and passion for lifelong learning makes our lives interesting! A student with DS may not learn the whole Periodic Table of the Elements but enjoying experimentation and discovery may mean a future job in a chemistry lab. A love of Shakespeare might inspire an actor or writer. There are literally hundreds of opportunities to learn functional skills that make life interesting and rewarding now and in the future: texting a friend, creating a Facebook page, knowing how to throw a great party, being part of a sports team and taking pride in victory while being gracious in defeat.

The goal of an American education is not simply to produce "worker bees." It is to educate people to participate in our democracy by understanding the lessons of history, the logic and magic of science and math, the joys of art and music, and the power of words to inspire and communicate. Do students with DS deserve less?

Argument #3: There is no harm in *not* including students.
In the 2004 reauthorization of the Individuals with Disabilities Education Act, Congress found: "Almost 30 years of research and experience has demonstrated that the education of children with disabilities can be made more effective by having high expectations for such children and ensuring their access to the general education curriculum in the regular classroom, to the maximum extent possible, in order to…be prepared to lead productive and independent adult lives… "

Several large long term studies have also found – even when controlling for factors such as students' socio-economic status, age, gender, and severity of disability – that there is a positive relationship between the amount of time students with disabilities spend in general education classrooms and a variety of positive outcomes, including (a) higher scores on standardized measures of reading and mathematics; (b) fewer absences from school; (c) fewer disciplinary referrals; and (d) improved post-school outcomes such as enrollment in post-secondary education, independent living, and gainful employment (Blackorby, Chorost, Garza, & Guzman, 2003; McGregor & Vogelsberg, 1998; Wagner & Blackorby, 2004). Leading researchers have postulated that the general education classroom is the optimal place where access to the general education curriculum occurs (Wehmeyer & Agran, 2006). Furthermore, *no* research studies conducted since the late 1970s have shown an academic advantage for students with intellectual and developmental disabilities educated in separate settings (Falvey, 2004).

Bolstering these positive outcomes of inclusive education are studies that show segregated education has negative consequences including: poorer quality instruction in academic skills (Wheelock, 1992); poorer quality IEPs (Hunt & Farron-Davis, 1992); lack of generalization of learning to regular environments (Stokes & Baer, 1977); disruption of sustained opportunities

for social relationships (Strully & Strully, 2003); a decrease in confidence by general education class teachers for teaching diverse learners (Giangreco et al., 1993); and disruption of Maslow's theory that all human beings need to belong before they can achieve (Kunc, 1992).

Conclusion

Arguments against inclusive education are often rooted in firmly held attitudes and information that is prejudicial and inaccurate. Parents and professionals who find themselves in the position of having to justify inclusive education might engage in the following activities to educate themselves and develop supportive allies:

- Know and be able to express your own deeply held values
- Emphasize that children with DS are more alike than different
- Understand the law and be able to cite research
- Visit inclusive schools and help connect professionals from your school with them
- Engage outside experts for professional development and consultation
- Start an inclusive education task force in your school that includes other like-minded parents and professionals, as well as people who are not supportive of inclusion
- Involve adults with disabilities in all your efforts so that they can share the wisdom of their experiences

Remember, the least dangerous assumption is to presume competence, and we must make decisions now that give students the best chance in the future for a typical life in the community.

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Inclusion Works! *Inspiration and Information to Counter Arguments Against Inclusive Education for Students with Down Syndrome: Part II*
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Sam's Club recently presented employee Nate Archambeau[2] with an award for 12 years of exemplary service. When he graduated from Concord High School in 2001, after being included in general education classes, Nate was one of the first students with developmental disabilities in New Hampshire to march across the stage with his classmates. Two years ago, Nate moved into the townhouse he shares with his brother. Nate was ready years ago, but he had to wait for his dad to be ready to take a chance for Nate to live on his own. Nate belongs to a self-advocacy group and contributes countless hours each year giving speeches and mentoring other young people with disabilities. Nate still is looking for the love of his life.

When Nate was born, his parents were told the same thing that many parents of children with Down syndrome were told 30 years ago: "He'll need constant care. He may never go past the developmental age of three. He'll need special schooling. Don't set yourself up for disappointment — don't expect too much. Maybe he'll surprise you." Nate and his parents proved them all wrong and their experience ought to inspire other parents of children with DS to hold high expectations and strive for an "ordinary life" in the community.

Despite 30 years of research and the personal experiences of thousands of children that support inclusive education, parents and professionals still face roadblocks based on outdated arguments against inclusion for students with DS. In the first part of this article (*DSN*, Vol. 32, #2, 2009), I addressed the arguments "some students are just too disabled," "students need to learn functional skills outside the general education classroom," and "there is no harm in *not* including children." In this article, I'll provide a rationale for why two other common arguments against inclusion are weak or unfounded.

Argument #1: Students need special instruction in a special place delivered by special staff.
Some argue students with DS and other developmental disabilities — those who are labeled as intellectually disabled, who have autism or experience multiple physical disabilities — can't

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[2] Pseudonyms are used for the students and teachers in this article.

benefit from instruction in a general education classroom and need a special curriculum taught by special staff in a special education classroom. Wehmeyer and Agran (2006) propose the *best* place for students to access the general education curriculum may be the general education classroom. Research bears this out by showing a variety of important educational outcomes are positively correlated with the amount of time students with disabilities (regardless of the "severity" of their disability or label) spend in general education classrooms. These include: higher scores on standardized reading and math tests, fewer behavior referrals, better attendance and a greater likelihood of achieving post-high school independent living and employment (Blackorby, Chorost, Garza, & Guzman, 2003).

Certainly placement in general education classrooms is not enough. Effective curriculum, instruction, and supports for students with disabilities who are in general education classes are defined by the following characteristics (Jorgensen, McSheehan, & Sonnenmeier, 2009):

Curriculum is...
- Based on common content standards for all students.
- Presented in a variety of accessible formats including written information at appropriate reading levels, and in formats as indicated on a student support plan (e.g., video, picture/symbols, actual objects, demonstrations, orally, etc.).
- Individualized by developing personalized performance demonstrations for some students.

Instruction...
- Reflects the learning styles of all students in the class by using visual, tactile and kinesthetic materials and experiences.
- Prioritizes the use of research-based strategies for increasing student achievement, such as:
    - Identifying similarities and differences
    - Summarizing and note taking
    - Reinforcing effort and providing recognition
    - Homework and practice
    - Nonlinguistic representations
    - Cooperative learning
    - Setting objectives and providing feedback
    - Generating and testing hypotheses
    - Questions, cues and advance organizers
- Is provided in multiple formats such as individual, pairs, small groups and whole class.

Supports…
- Are provided within the general education class and other typical environments to enable the student to participate in and benefit from the general education curriculum and other inclusive learning opportunities and activities.
- Are defined by an individualized student support plan, and may include: physical, emotional, and sensory supports; adapted materials; assistive technology and AAC; personalized performance demonstrations; personalized instruction; and individualized grading and evaluation plans.

- Take into consideration the student's sensory needs.

What does this look like in the classroom? Brianna was a ninth grader with DS enrolled in a general science class. Once a week Brianna's special education teacher met with Mr. Barclay, the science teacher, to find out what he was teaching the following week. During this 15-minute meeting, they discussed: science standards; instructional materials he would use; assessments that would be given; and general instructional routines (e.g., whole class lecture, small group work, individual seatwork, using the Internet for reference) that would occur. The special education teacher took this information back to the other members of Brianna's team, including her speech-language pathologist and occupational therapist. They planned the supports Brianna would need to fully participate in and learn from the general education teacher's instruction.

During a Periodic Table of the Elements unit, Brianna's team asked themselves two questions: "What supports does Brianna need to fully participate in and learn the general education curriculum?" "What are naturally occurring opportunities for Brianna to work on functional and IEP skills within the classroom and other inclusive school and community environments?" Brianna used balloons and a graphic organizer to depict the structure of the helium atom. She used a variety of supports during instruction and assessment including: enlarged text; animated clips from the Internet showing protons, neutrons, and electrons in the helium atom; fill-in-the-blank worksheets (created with Worksheet Magic®) along with a word bank of scientific terms taken directly from the textbook, and word prediction software (Write Out Loud® that helped her compose her lab report). What did she learn? Brianna worked towards achieving the state science standard of "use models for illustration and understanding," she had multiple opportunities to solidify her membership and relationships in the class and she improved her communication and organizational skills. Will Brianna eventually become a scientist? We don't know the answer for her or for the other students in the class. But all students have learned valuable knowledge and skills that will serve them well in their adult lives.

Argument #2: Students will never make "real friends" in general education classrooms.
I recently did a Google search for friendship programs for students with disabilities. One site described a friendship between a student with a disability (Christine) and a young woman who volunteered to hang around with her to get community service credit towards fulfilling her high school graduate requirements (Lesley). Here is what the website reported:

> '**November Buddy Pair of the Month: Christine and Lesley.**' Christine and Lesley have been friends for three years now. They share a beautiful relationship that truly illustrates the true meaning of friendship and serves as an example to all of us about the power of the 'Friends for Life' program. When we saw the two of them at this year's Meet and Greet, it brought tears to our eyes as the two of them gave each other a real hug and asked how each other was after a summer apart. Every time I saw Lesley in the summer, all she could talk about was her 'best buddy' Christine and how excited she would be to see her in the fall. It is times like this that we are able to really realize the importance of true friendship and the impact it has on both the student buddy and the buddy.

After reading a few such anecdotes, I had to ask myself:
- Who are Lesley's friends when the buddies program is not having a special, organized event?
- Do typical kids get awards for being one another's friends?
- Do real friends see each other once a year at a "Meet and Greet?"
- Should we feel good when students with disabilities get "real hugs?"

I think, perhaps, that students with DS deserve more. Carol Tashie, Susan Shapiro-Barnard, and Zach Rossetti (2006) wrote a book called *Seeing the Charade: What We Need to Do and Undo to Make Friendships Happen*. These authors suggest that if we want our children to have authentic, reciprocal friendships, the first thing to do is address barriers we have, perhaps unwittingly, created to naturally developing social relationships, including:
- Students being "partially included"
- Not presuming competence
- Over-reliance on 1:1 assistants
- Mistaking peer support for friendship
- Creating "friendship programs"
- Seeing disability as "deficiency"
- Parents and educators not working together
- Thinking that friendship isn't a school's responsibility
- Inaccessible transportation and public spaces
- Implementing strategies before eliminating barriers

These barriers must be addressed before creating strategies for supporting students to fully participate in the social activities and environments in which friendships develop (Kennedy & Itkonen, 1994).

Conclusion
In part one of this article, I suggested that parents and professionals who find they have to justify inclusive education might engage in the following activities to educate themselves and develop supportive allies:
- Know and be able to express your own deeply held values
- Emphasize that children with DS are more like students with disabilities than they are different
- Understand the law and be able to cite research
- Visit inclusive schools and help connect professionals from your school with them
- Engage outside experts for professional development and consultation
- Start an inclusive education task force in your school that includes other like-minded parents and professionals as well as people who are not supportive of inclusion
- Involve adults with disabilities in all your efforts so that they can share the wisdom of their experiences

I would suggest the following additional strategies for parents or professionals who are facing these or other arguments against inclusive education.

- Join your school's "School Improvement Team" or "Response to Intervention Task Force." RtI is based on the idea that all students benefit from universally designed instruction that accommodates students with different learning styles. It's important for parents and professionals who are concerned about students with disabilities to be part of all school improvement conversations.

- Identify a school in your area that successfully includes students with DS in general education classes and schedule a visit for a team from your school. Arrange for your principal to talk to their principal, for your speech pathologist to spend time with their speech pathologist and for your classroom teacher to shadow a general education colleague for a day. The ride to and from your visit can provide valuable time for discussion and shared reflection.

- Attend a national conference with others from your school to learn about best practices in inclusive education. Three wonderful events, to name just a few, are the annual PEAK Parent Center Conference on Inclusive Education (http://www.peakparent.org), the annual TASH Conference (http://www.tash.org), and the University of New Hampshire's Autism Summer Institute (http://www.iod.unh.edu). Parent-teacher organizations or state Developmental Disabilities Councils might be willing to partially fund attendance for your school's team if you commit to sharing information you learn with other parents and professionals upon your return.

In conclusion, if working to include students with DS seems an uphill battle against old prejudices and myths and you are tempted to give up the struggle, remember the wisdom of an old Japanese proverb: "Fall seven times, stand up eight."

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