

Opportunities for Children and Youth with Intellectual Developmental Disabilities: Beyond Genetics^{*}

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Abstract

Research on students with developmental disabilities in Italian schools (Vianello & Lanfranchi, 2009) suggests patterns of greater than expected performance in scholastic and social skills compared to the presumed cognitive abilities of these students based on their genetic profiles. Vianello and Lanfranchi suggest that this may be attributable to the inclusion of almost all Italian students with intellectual disabilities in typical classrooms alongside their peers without disabilities. This article includes considerations for team members working in inclusive schools by: (a) presenting a conceptual framework within which to pursue inclusive education, (b) encouraging us to look beyond students' disability characteristics to examine our own attitudes and practices, and (c) changing our expectations and expanding opportunities available for students with disabilities. This article supports the contention that environmental influences (e.g., inclusive schooling) can be potent contributors to student performance and reminds us that we should not allow disability related information to put limits on what students are capable of learning, what they might be interested in, or what opportunities are available to them – we should continually push the boundaries of these perceived limits – as we seek to do for all students.

Keywords: Attitudes, Inclusive education, Intellectual disabilities

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1. Creating Opportunities for Children and Youth with Intellectual and Development Disabilities: Beyond Genetics

In their review of the cognitive and adaptive profiles of children and youth with four genetic syndromes associated with intellectual disabilities (i.e., Down, Fragile-X, Cornelia deLange, Prader-Willi), Vianello and Lanfranchi (2009) have explored a “deficit/surplus hypothesis”, namely the extent to which children with these conditions have performed below (deficit) or above (surplus) expectations of their presumed cognitive abilities based on assessment of their mental age compared to their functioning in a variety of areas (e.g., reading, writing, math, social adjustment). Vianello and Lanfranchi suggest that implicit in much research on children with genetic syndromes is the assumption that both inter and intra-syndrome differences are mainly due to genetic factors. They challenge this deterministic assumption by continuing a line of research designed to explore the potential impact of environmental influences to produce corresponding variations in cognitive and adaptive profiles among children who have biological/genetic bases for their intellectual disabilities.

A series of studies conducted in Italy on samples of children and youth with the aforementioned genetic syndromes have reported a pattern reflecting an “adaptive surplus”, greater than expected performance in both scholastic and social skills. Vianello and Lanfranchi have posited that this difference may be attributable to the unique fact that almost all students with intellectual disabilities in Italy are educated in typical classrooms alongside their peers without disabilities, rather than in special education classes, as is often the case in many other countries. In the United States placement of students with intellectual disabilities in typical classrooms is not the norm nationally; only 16% of students with intellectual disabilities (identified as “mentally retarded” in U.S. federal statistics) receive 80% or more their education in general education classrooms (U.S. Department of Education, 2007). Yet positive outcomes of educating students with intellectual disabilities in general education classes continue to be reported (Giangreco, Dennis, Cloninger, Edelman, & Schattman, 1993; Hunt & Goetz, 1997; McGregor & Volgelsberg, 1998; Cole, Waldron, & Majd, 2004; Downing & Peckham-Hardin, 2007). Studies comparing special education versus general education classes have found that students with significant intellectual disabilities placed in general education classes: (a) have more access to academic instruction (Logan & Keefe, 1997; Helmstetter, Curry, Brennan, & Sampson-Saul, 1998); (b) made greater gains on both developmental and social competence measures (Fisher & Meyer, 2002); and (c) exhibit higher levels of “happiness behaviors” when interacting with typical peers (Logan, Jacobs, Gast, Murray, Daino, & Skala, 1998).

In the remainder of this paper my aim is to highlight a series of con-

ceptual and practical points intended to aid educational teams supporting students with intellectual disabilities. These points support Vianello and Lanfranchi's premise that the functioning of students with genetically-based, intellectual disabilities can be improved beyond presumed expectations based on how and where they are educated. Given that a student's genetic profile includes factors over which school personnel have no control, I will focus on attitudes and behaviors over which educational teams (e.g., school personnel, students with disabilities, families) can exert control.

2. Framework for Conceptualizing Inclusive Education

Implementing effective education for all children, regardless of their characteristics, depends on "... an inseparable triumvirate: values, logical practices, and research" (Giangreco, 2002, p. 9). Education is first and foremost a *values*-driven enterprise reflected in social policy. Without a clear value orientation upon which to base our educational practices and research, they are at best haphazard, and at worst dangerous. Educating all children and providing necessary supports to those with disabilities in inclusive settings is, at its most elemental, an international matter of civil and human rights (UNESCO, 1994).

As educational team members, our efforts should be directed toward expanding the availability of *logical practices* (e.g., service delivery configurations, inclusive placement options, personnel utilization, meaningful curriculum, effective instruction, necessary supports, assistive technology, self-determination) designed to operationalize values that are consistent with civil and human rights (Giangreco, in press). Values and corresponding logical practices are followed by *research* designed to describe, understand, and determine the effectiveness and impact of our practices to improve the lives of our students with disabilities. Many questions remain about which potentially logical practices are most effective for educating students with disabilities in inclusive settings. This should be the focus of our educational research.

Whether or not students with intellectual disabilities are included in general education settings is not a matter for research to determine – it is a matter of social policy – one that has been implemented on a national scale in Italy since the early 1970s. By approaching education sequentially and cyclically through values, logical practices, and research, we can move beyond genetics by learning what can be learned from it to improve educational effectiveness, while not allowing it to deter us from exploring the boundaries of environmental influences.

3. Examining Our Own Characteristics

Despite trends toward greater school inclusion internationally, too many students, particularly those with intellectual disabilities, remain unnecessarily segregated in special education schools and classes. Some are even segregated *within* general education classes; — isolated from their classmates and the life of the classroom as they are relegated to receive different instruction in the back or side of the classroom, often from an a well-intended, yet inadequately prepared assistants (Giangreco, Edelman, Luiselli, & MacFarland, 1997). Yet, for every student who remains educationally segregated there are other students with virtually identical attributes, abilities, and needs who are successfully included in general education classes alongside their peers without disabilities. This simple fact suggests that whether a student with a disability is meaningfully included may have less to do with his or her disability characteristics, genetic or not, and more to do with the attitudes, skills, structures, and practices of the adults responsible for providing education (Giangreco, Carter, Doyle, & Suter, in press). While acknowledging the valuable, educationally relevant, information that can be gleaned by understanding the traits (e.g., cognitive, sensory, behavioral, health, physical) of genetic syndromes associated with intellectual disabilities, we need to put as much emphasis on examining our own characteristics, attitudes, and behaviors as we do on understanding our students' disability-related characteristics. As disability rights advocate, Dan Wilkins, has printed on one of his advocacy t-shirts: "Your attitude just might be my biggest barrier!" (www.thenthdegree.com/advocacy.asp).

4. Changing Expectations and Opportunities

Changing educational expectations and opportunities over time provides practical evidence consistent with Vianello and Lanfranchi's adaptive surplus hypothesis based on environmental influences. For example, the genetic aspects of Down syndrome have not changed over the past 40 years, but the lives of some people with Down syndrome have changed dramatically during that same period due to environmental influences such as being included in general education classes. When I was an early-career special education teacher in the 1970's, expectations about the presumed capabilities of students with Down syndrome and other students with moderate or severe intellectual disabilities were markedly lower than they are in many places today. Virtually all of these students in the United States were educated in special education schools or classes, — some were institutionalized. Cross-disability textbooks for aspiring special education teachers, written by some of the most respected scholars of that era, gave scant attention to students with this level of intellectual disability because of their

presumed inability to learn certain types of academic content or to learn at all. Such low expectations espoused by experts adversely contributed to limited opportunities.

The lucky few had educational programs designed to acquire rudimentary functional living skills (at least they were learning something potentially useful). If any literacy instruction was attempted at all, it consisted of a few functional sight words (e.g., exit, men, women, danger). Less fortunate students with significant intellectual disabilities were subjected to the monotonous drudgery of completing nonsensical, age-inappropriate, nonfunctional tasks (e.g., assembling and disassembling nuts and bolts, putting pegs in boards, stringing beads, sorting random object, playing with infant/toddler toys) meant to match their presumed mental age and expected capabilities. The culmination of such an inadequate public education typically led to comparably limited post-school opportunities such as placement in segregated day treatment programs, sheltered workshops, or no services at all.

Although the construct of “mental age” may have some normative or comparative utility, it has little value for educators in their daily work and holds the dangerous potential to keep expectations low and inadvertently limit access to chronologically age-appropriate interactions and curricula. Due to the power our society confers on test results, the assignment of a mental age that is substantially lower than a student’s chronological age can lead to harm if a person with an intellectual disability is treated as an “eternal child” (Wolfensberger, 1975). This initial low expectation can be self-perpetuating, whereby the resulting segregated education and inadequate educational programming leads to minimal positive outcomes, stereotypic or problem behaviors, and justification by some school personnel that continued segregation is justified and necessary. In other words, when people with intellectual disabilities are treated like infants or young children regardless of their chronological age, it is not surprising if they behave in accordingly immature ways or exhibit maladaptive behaviors that communicate their discontent.

Now fast forward to the turn of the 21st century. The genetic aspects of Down syndrome have not changed, but for some students with intellectual disabilities (although still too few internationally) the environmental factors have changed substantially (e.g., higher expectations, inclusive placements, access to general education curriculum, differentiated instructional practices, supports). This has resulted in correspondingly positive outcomes that were not even dreamt about just 30 years earlier, yet have become a reality for this group of students and others with genetic conditions associated with intellectual disabilities.

Erin McKenzie, a young woman with Down syndrome, whose parents successfully advocated for her inclusion in general education classes throughout her school career (McKenzie, 2008), is a classic example of what

Vianello and Lanfranchi characterize as adaptive surplus (functioning above expected levels associated with her disabilities). Among many demonstrations of this adaptive surplus, a notable example was when Erin wrote and presented an eloquent speech to the gathering of guests and graduates at her own 2004 high school graduation ceremony. In her speech (video and text online at: <http://library.otterbein.edu/ErinMcKenzie/-video.htm>) she reminisced about what she loved most about high school. Not surprisingly, like many teenagers, Erin told the audience “The best part was being with friends in class, at meetings, at parties, everywhere!” To say the least, it was uncommon that she, as student with Down syndrome, had composed (with some help from her mother) and given a commencement speech in front of hundreds of people, that she was academically skillful enough to read from her prepared text, and even that she displayed normalized social behaviors that she may not have acquired without the benefits of inclusive schooling. These included the composure and stage presence she displayed, the unobtrusive wave of the hand to acknowledge her family in the audience, and the way she tossed back of her long brown hair, with a simultaneous flip of the head and a hand, in a classic maneuver modeled on the behavior of so many of her teenage girlfriends. It is what she shared next that further sets this story apart from the experiences of other students with Down syndrome who preceded her or her contemporaries who still have inadequate access to general education classes and curricula. Reading from her prepared remarks she said: “We learned new things in high school and we discovered what we were good at or liked to do. I learned that I love Shakespeare! And Theatre! And Choir! And Drama Club!”.

Of all the things she that were most important to her during high school, it was her love of great literature – Shakespeare among others – that captured her imagination and interest. As documented by her mother in a letter to her teachers, Erin didn’t just enjoy these pieces of literature and performances, she understood them and made connections between the literature and what she was learning in other classes (e.g., history). We cannot predict which subjects, experiences, teachers, or classmates will be the spark, make the difference, or lead to a personal interest or breakthrough for particular student. It is one of the reasons we expose students to a wide array of classes, teachers, and classmates. Historically most American students with intellectual disabilities have not been sufficiently exposed to or taught appropriately modified, age-appropriate, academic curricular content available to students without disabilities. As Erin’s mother wrote to her teachers: “I doubt very much that Erin would have gotten any Shakespeare or other great literary pieces in the special education classroom for students with cognitive and developmental disabilities. That would have been unfortunate” (McKenzie, 2008, pp. 36-37).

Although it remains important for students with intellectual disabilities to acquire functional living skills and it is logical to select curricular targets based on the student's current level of performance and known learning characteristics, "quality instruction should provide ample opportunities for students to surprise us with their capabilities." (Giangreco, in press). Only within the past few years has access to the general education curriculum been recognized as important for students with the range of intellectual disabilities (Browder & Spooner, 2006; Wehmeyer, 2006; Dymond, Renzaglia, Gilson, & Slagor, 2007; Downing, 2008). In essence this change in social policy reflects an underlying assumption that we have not adequately tapped the adaptive surplus of many of our students – that we expect that environmental influences (e.g., access to general education curriculum, research-based instruction) will result in improved outcomes beyond what has been expected or accepted in the past.

A primary challenge teachers encounter is understanding how students with intellectual disabilities can be successfully included in general education activities when there is a substantial discrepancy between their presumed or assessed level of functioning and those of their classmates without disabilities. Although it is beyond the scope of this article, several widely available approaches provide mechanisms for students representing a wide range of abilities and needs to be successfully included in the same classes and activities, — some of these include: (a) partial participation (Baumgart *et al.*, 1982), (b) differentiated instruction (Tomlinson, 2001; Kronberg, 2007), (c) universal design for learning (Rose, Meyer, & Hitchcock, 2005), (d) multi-level instruction (Peterson & Hittie, 2010), and (e) curriculum overlapping (Giangreco, 2007). These approaches verify that students with intellectual disabilities need not function at the same academic or cognitive level as their peers without disabilities in order to have meaningful participation in shared educational activities because each student may pursue individually determined learning outcomes targeted to his or her respective needs.

While access to inclusive school placements and properly adapted general education curriculum are being sought for more school-aged students with intellectual disabilities, progressive post-school opportunities are providing further evidence that our graduates' futures need not be limited by their genetic traits. Supported competitive employment has become increasingly available for adults with intellectual disabilities (Wehman, Inge, Revell & Brooke, 2007). Recently, inclusive college-based programs and experiences have been developed to provide adult learning opportunities for students with intellectual disabilities (Doyle, 2003; Feldman, Fialka & Rossen, 2006; Grigal & Hart, 2009). Advances in both of these areas also suggest that adaptive surpluses remain untapped for many people with intellectual disabilities.

5. Conclusion

Information garnered about genetic syndromes can be useful to educational teams, but it is unhelpful if it is used to predict the cognitive potential or the upper limits of a student's functional abilities and correspondingly to restrict their opportunities. This is especially problematic if the student has not been sufficiently exposed to a concept or skill or has not received ongoing, competent instruction using research-based interventions. If we must err, it is better for us to err on the side of hope and opportunity. Donnellan's (1984) criterion of the least dangerous assumption, asserts that, "in the absence of conclusive educational data, educational decisions should be based on assumptions which, if incorrect, will have the least dangerous effect on the student" (p. 142).

Although, we do not always succeed in our efforts to teach some children with intellectual disabilities, pushing the limits of our current understanding and practices is what helps our field progress. As Donald Baer (1981) wrote many years ago:

"To the extent that we sometimes finally succeed in teaching a child whom we have consistently failed to teach in many previous efforts, we may learn something about teaching technique. Too often, in my opinion, we teach children who are not only capable of teaching themselves, but eager to do so; in their wisdom, they cheat us of learning completely how the trick is done because they do some of it for us and do it privately. It is when they cannot do much if any of it for us that we get to find out how to do all of it ourselves, as teachers." (p. 94).

As we move forward, it is essential that we increasingly involve not only families, but people with disabilities themselves into the educational decision-making process. For them to be engaged in this process will require an early and ongoing emphasis on self-determination (Wehmeyer, 2005). As many self-advocates are fond of reminding the professionals, "Nothing about me without me!" Vianello and Lanfranchi's hypothesis that inclusive educational placements may contribute to an adaptive surplus in children with genetic syndromes is supported by existing research as well the real life experiences of families around the world who have witnessed their children exceed expectations. As long as genetic syndromes continue to exist, educational teams would be well advised to be informed about the aspects of these syndromes that will help them design a quality education plan, then to set aside the disability label, and move forward by creating opportunities without setting limits — beyond estimates of mental age and beyond genetics.

References

- Baer, D. (1981). A hung jury and a Scottish verdict: "Not proven". *Analysis and Intervention in Developmental Disabilities, 1*(1), 91-98.
- Baumgart, D., Brown, L., Pumpian, I., Nisbet, J., Ford, A., Sweet, M., Messina, R., & Schroeder, J. (1982). Principle of partial participation and individualized adaptations in educational programs for severely handicapped students. *Journal of the Association for the Severely Handicapped, 7*, 17-27.
- Browder, D. M., & Spooner, F. (Eds.). (2006). *Teaching language arts, math, & science to students with significant cognitive disabilities*. Baltimore: Paul H. Brookes.
- Cole, C. M., Waldron, N., & Majd, M. (2004). Academic progress of students across inclusive and traditional settings. *Mental Retardation, 42*, 136-144.
- Donnellan, A. (1984). The criterion of the least dangerous assumption. *Behavior Disorders, 9*, 141-150.
- Downing, J. E. (2008). *Including students with severe and multiple disabilities in typical classrooms: Practical strategies for teachers* (3rd ed.). Baltimore: Paul H. Brookes.
- Downing, J. E., & Peckham-Hardin, K. A. (2007). Inclusive education: What makes a high quality education for students with moderate-severe disabilities? *Research and Practice for Persons with Severe Disabilities, 32*, 16-30.
- Doyle, M. B. (2003). "We want to go to college too": Supporting students with significant disabilities in higher education. In D. L. Ryndak & S. Alper. (Ed.), *Curriculum development for students with disabilities in inclusive settings* (pp. 307-322). Boston: Allyn & Bacon.
- Dymond, S. K., Renzaglia, A., Gilson, C. L., & Slagor, M. T. (2007). Defining access to the general curriculum for high school students with significant cognitive disabilities. *Research and Practice for Persons with Severe Disabilities, 32*, 1-15.
- Feldman, R., Fialka, J., (Producers), & Rossen, P. (Director/Producer). (2006). *Through the same door: Inclusion includes college* [Motion picture]. (Available from Dance of Partnerships Publications www.danceofpartnership.com/index.htm).
- Fisher, M., & Meyer, L. H. (2002). Development and social competence after two years for students enrolled in inclusive and self-contained educational programs. *Research and Practice for Persons with Severe Disabilities, 27*, 165-174.
- Giangreco, M. F. (in press). Educating students with severe disabilities: Foundational concepts and practices. In M.E. Snell & F. Brown (Eds.), *Instruction of students with severe disabilities* (7th ed). Upper Saddle River, NJ: Pearson Education/Prentice-Hall.

Giangreco, M. F. (2002). Values, logical practices, and research: The three musketeers of effective education. In J. Downing (Ed.), *Including students with severe and multiple disabilities in typical classrooms* (2nd ed., pp. 9-13). Baltimore: Paul H. Brookes.

Giangreco, M. F. (2007). Extending inclusive opportunities. *Educational Leadership*, 64 (5), 34-37.

Giangreco, M. F., Carter, E. W., Doyle, M. B., & Suter, J. C. (in press). Supporting students with disabilities in inclusive classrooms: Personnel and peers. In R. Rose (Ed.), *Confronting obstacles to inclusion: International responses to developing inclusive schools*. London: Routledge.

Giangreco, M. F., Dennis, R., Cloninger, C., Edelman, S., & Schattman, R. (1993). "I've counted Jon:" Transformational experiences of teachers educating students with disabilities. *Exceptional Children*, 59, 359-372.

Giangreco, M. F., Edelman, S., Luiselli, T. E., & MacFarland, S. Z. (1997). Helping or hovering? Effects of instructional assistant proximity on students with disabilities. *Exceptional Children*, 64, 7-18.

Grigal, M., & Hart, D. (2009). *Think college: Postsecondary education options for students with intellectual disabilities*. Baltimore: Paul H. Brookes.

Helmstetter, E., Curry, C., Brennan, M., Sampson-Saul, M. (1998). Comparison of general and special education classrooms of students with severe disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 33, 216-227.

Hunt, P., & Goetz, L. (1997). Research on inclusive educational programs, practices, and outcomes for students with severe disabilities. *Journal of Special Education*, 31, 3-29.

Kronberg, R. (2007). Reaching and teaching diverse learners through differentiated instruction. In M. F. Giangreco & M. B. Doyle (Eds.), *Quick-guides to inclusion: Ideas for educating students with disabilities* (2nd ed.) (pp. 137-150). Baltimore: Paul H. Brookes.

Logan, K. R., Jacobs, H.A., Gast, D. L., Murray, A. S., Daino, K., & Skala, C. (1998). The impact of typical peers on the perceived happiness of students with profound multiple disabilities. *Journal of the Association for Persons with Severe Handicaps*, 23, 309-318.

Logan, K., & Keefe, E. (1997). A comparison of instructional context, teacher behavior, and engaged behavior for students with severe disabilities in general education and self-contained elementary classrooms. *Journal of the Association for Persons with Severe Handicaps*, 22, 16-27.

McGregor, G., & Volgelsberg, R. T. (1998). *Inclusive schooling practices: Pedagogi-*

cal and research foundations: A synthesis of the literature that informs best practices about inclusive schooling. Baltimore: Paul H. Brookes.

McKenzie, B. (2008). *Reflections of Erin: The importance of belonging, relationships and learning with each other.* Seaman, OH: Art of Possibility Press.

Peterson, J. M., & Hittie, M. M. (2010). *Inclusive teaching: the journey towards effective schools for all learners.* (2nd edition). Boston: Pearson.

Rose, D. H., Meyer, A., & Hitchcock, C. (2005). *The universally designed classroom: Accessible curriculum and digital technologies.* Cambridge, MA: Harvard Press.

Tomlinson, C. (2001). *How to differentiate instruction in mixed-ability classrooms* (2nd ed.). Alexandria, VA: Association for Supervision and Curriculum Development.

UNESCO (1994). *The Salamanca statement and framework for action on special needs education*, Retrieved on August 20, 2009 from: www.unesco.org/education/pdf/SALAMA_E.PDF .

U.S. Department of Education (2007). Table 2-2. Students ages 6 through 21 served under IDEA, Part B, by disability category, educational environment and state: Fall 2007 [Data file]. Available from Individuals with Disabilities Education Act (IDEA) Web site: <https://www.ideadata.org/PartBdata.asp>

Vianello, R., & Lanfranchi, S. (2009). Genetic syndromes causing mental retardation: Deficit surplus in school performance and social adaptability compared to cognitive capacity. *Life Span and Disability*, 12 (1), 41-52.

Wehman, P., Inge, K. J., Revell, W. G., & Brooke, V. A. (2007). *Real work for real pay: Inclusive employment for people with disabilities.* Baltimore: Paul H. Brookes.

Wehmeyer, M. L. (2005). Self-determination and individuals with severe disabilities: Re-examining meanings and misinterpretations. *Research and Practice for Persons with Severe Disabilities*, 30, 113-120.

Wehmeyer, M. L. (2006). Beyond access: Ensuring progress in the general education curriculum for students with severe disabilities. *Research and Practice for Persons with Severe Disabilities*, 31, 322-326.

Wolfensberger, W. (1975). *The origin and nature of our institutional models.* Syracuse, NY: Human Policy Press.

