

## Education as a Means to Achieve Valued Life Outcomes

By Carolyn Das

Too often our special education system allows IEP goals to supersede and replace academic/curriculum goals rather than support progress within the curriculum. This is almost always the case for children with disabilities that are categorized as “severe” or “multiple.” This reality undercuts the intent of IDEA, which is to support the ability of ALL children to make academic progress. IEP goals are meant to *support* the child’s ability to make academic progress, not to *replace* academic goals.

Doing this properly requires a great deal of work to integrate the “general education” and “special education” systems. Because “special education” has in fact developed in our nation as a place (not a service) and is delivered by a completely separate system of professionals, it has proven to be very difficult to integrate services. School professionals tend to see “special ed” goals as the IEP goals and academic goals as curriculum/report card progress. Contrary to the intent of IDEA, the two systems are too often not mutually supportive; in the worst cases they are in fact mutually exclusive.

I realized the truth of this several years ago. My son, who is now 12 and has “severe” and “multiple” disabilities, is fully included in 5<sup>th</sup> grade; next year he will be moving to middle school and 6<sup>th</sup> grade. It was only in the two years, as I began to investigate middle school, that I realized that the educational paths our children follow increasingly diverge as our children progress through school. In my son’s case, when I evaluated the supportive “special education” options that are typically offered in our district for kids like Stephen, I realized that the increasing emphasis on academic progress was seen by the professional educators as an adequate justification for separation and segregation of kids with disabilities. The older the kids get, the higher the “grade level,” the more kids are relegated to pull-out instruction, resource rooms, self-contained classrooms, and even to segregated center programs.

It seemed that “all roads led back to segregation.” It was a demoralizing and disheartening realization. I began to wonder how I could ever hope for my son to be included in a society—a community—that could not even find a way to include him in the very first community where we as people learn to play, work, and live together: our public schools.

I realized that I had to find a way to bring the two divergent paths—general education and special education—back together. Because I am not an education expert, but only a Mom who seeks to be a good advocate for my son, I decided to look to experts for guidance and began to read. I found philosophical and moral support for my belief in inclusion, and for Stephen’s right to belong in all aspects of the community, in Norman Kunc’s writing. I found practical support and strategies in books like [Including Students with Severe and Multiple Disabilities in Typical Classrooms](#) by June Downing. I found a way to bring the philosophy and the strategies together by using the COACH plan ([Choosing Outcomes and Accommodations for Children: A Guide to Educational Planning for Students with Disabilities](#)) by Michael F. Giancreco.

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When I looked carefully at the writings of these very respected professionals, I realized that it is indeed possible not only for kids with disabilities (even the most significant disabilities) to benefit from inclusion and to make curriculum and social and self-help progress, but that it is possible to do that in a very person-centered, holistic way. In order to do this, you must step back and really think about the life you are preparing your child for. What is the big picture? What will make him happy? Fulfilled? Give his life meaning? How will he develop a sense of belonging in his community—the kind of belonging all human beings desire? How will the community learn to embrace him?

COACH helped me to think through these “life questions” for my son in a structured way. I was able to identify that Stephen’s ability to participate in life is the single most important valued life outcome. I view Stephen’s very ability to participate to be the basic foundation of other valued life outcomes for him. Without participation, Stephen will certainly not have the opportunity to develop relationships, be as independent as possible, choose a lifestyle and possibly a profession, or to live in safety with people of his own choosing. Without participation, it is more likely that Stephen will evolve into a being that is relegated to the sidelines of life, marginalized, whom others see as a pitiable recipient of benevolent charity—the kind of life no one wants to lead.

Beginning with the valued life outcome of participation, and using the COACH model for structure, I realized that Stephen’s IEP goals tended to fall into two distinct categories: either curricular (“Stephen will learn the numbers 1 - 10”) or self-help/activity of daily living (toilet training, shoe tying, appropriate responses, etc.) Frankly, the more “disabled” the child (or the more limiting his disability is perceived to be) the less focus there is on curriculum and the more focus there is on self-help. This is one of the reasons inclusion for kids with significant or multiple disabilities, like Stephen, is so often viewed as a purely “social” exercise.

I was fortunate that as I was going through the COACH process, I landed a job working on the *Everyone Together* project for UCP Michigan/Metro Detroit. In my work on the project with Lauri Stein, we developed a different philosophy, which I believe is supported by IDEA. This philosophy is that “Universal Education,” in which each child learns according to his/her own ability and needs, is the only appropriate educational method. It is supported by the use and practice of authentic multi-level teaching and differentiated instruction *within* the classroom. It seemed obvious to me that Universal Education supports the learning of all students (not just those who have labels) and that, moreover, it provides a framework for understanding how valued life outcomes can impact and shape the educational plan for a child with disabilities.

To help my son's educators understand this I did a lot of work on my own. First, I developed a life plan for Stephen. It is meant to answer the questions of WHY inclusive and universal education is important in Stephen's life.

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Secondly, I combed through the elementary curriculum guides for our school district grades 1 - 5. I noticed that there were common threads in each curricular area and also a great deal of overlap from grade to grade. Using the district's own words as a template, I extracted Summary Objectives for each curricular area. This clearly set Stephen's curriculum up to MATCH the general education curriculum. From each area I then identified key curriculum goals for Stephen. These unique curriculum goals were also taken verbatim from the district's curriculum guides for grades 1 - 5. The difference between Stephen's "Adaptive Curriculum" and a typical 5th grade curriculum is that his unique curriculum goals are specific to HIS learning needs, which tie ultimately to his valued life outcomes.

So, for example:

Curricular area: English Language Arts

Annual Goal: (taken from district's verbiage for ALL elementary students)  
"Stephen will acquire optimal literacy in personal, social, occupational and civic contexts."

Sample Curricular Goals:

Reading Objective: "Stephen will identify central purpose, major ideas, and supporting details contained within informational text."

2. Listening Objective: "Stephen will sustain focused listening through discussion."

3. Writing Objective: "Stephen will create written pieces that reflect unity, order, and completeness."

ALL of the objectives reflect real objectives for elementary students. There are more objectives than the ones listed above...and they are from all grade levels.

I call this complete document "Stephen's Adaptive 5th Grade Curriculum." While it is absolutely consistent with the curriculum for ALL students, it is adapted to his unique learning needs.

Now, the question is how the IEP goals fit into this. I believe IEP goals are misused in our academic system and that they have become entities unto themselves, when their real purpose is to support curricular/academic learning (whatever that level of learning is!).

To help me develop IEP goals that would *support Stephen's progress in his Adaptive 5th Grade Curriculum* I used the COACH process (it is similar to MAPS) to:

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1. Identify "priority learning outcomes" (I lined these up with the main curricular objectives)
2. Identify short-term instructional goals that support each priority learning outcome.
3. Clearly identify each short-term instructional objective's conditions (setting, situation), behavior expected, and criteria for measurement.

So, supporting the English Language Arts curricular area we developed one IEP goal as follows:

Priority Learning Outcome: Stephen will acquire optimal independent literacy skills in personal, social, occupational and civic contexts.

STIO example: In instructional and group settings, Stephen will demonstrate focused listening behaviors. Criteria: Stephen will present as quiet, attentive and receptive and alert (not distracted, disruptive or sleeping) 80% of the time.

The IEP goals are clearly labeled as "Annual IEP Goals Supporting Adaptive 5th Grade Curriculum" for Stephen. I used repetitive verbiage as much as possible, to link the IEP goals to the broader curricular goals.

This technique can be used for ALL curricular areas (including things like physical education) and allows you to dispense with standalone IEP goals and purely therapeutic goals that are more clinical than educational. We have PT and OT and speech clearly written into Stephen's IEP as supporting curriculum...and have had great success with PT, for example, partnering with the gym teacher about how Stephen can participate in gym and using gym time as an opportunity for some things that would have otherwise been done in the "PT room" for example: if the kids are rope jumping (Stephen uses a wheelchair!) he participates by turning the rope. This is participatory, inclusive, AND Stephen gets range-of-motion exercise in his arms/shoulders.

The opportunities are ENDLESS...

This has been a strategy that is working for me, as an advocate, and for Stephen, as a student. By linking Stephen's life *to* school curriculum *to* his individual goals, we have been able to develop a plan that self-justifies inclusion for Stephen and supports the long term valued life outcome of participation. This strategy is a dramatic departure in the way many professionals, no matter how well-intentioned, are taught to teach our children. Yet the benefits of relating education, today, to community life, tomorrow, seem obvious. I cannot stress enough how important it is to develop the links between the life plan, curriculum, and goals.

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As your child's parent and as their primary advocate, it may be that you need to take the lead role in this process. Although my son attends a very progressive and forward-thinking elementary school where inclusion is clearly supported, even those professionals are new to the reality of integrating school goals with life outcomes, and how to develop strategies to directly relate IEP goals to curriculum goals. I found that I was the primary author of the program, although once I was able to show it to the educators I received significant buy-in and support.

I do not know of any model out there for doing this. Although I used the COACH process as a catalyst, I believe you need to look at your district's curriculum and correlate it to YOUR CHILD'S learning needs. To me it made a lot of sense to use the district's own words as substantiation that their curriculum objectives COULD be appropriate for my son! It took me hours of research and work. I don't think it's perfect, but I have seen a huge change in Stephen's school program and I have gotten a ton of support for this from the school personnel. It was frustrating to an extent because I had to lead the way and, truly, do all the "work" to pull this together. But then again, I don't think anyone else COULD have done it because no one else has the same "big picture" that I do for Stephen.

Other reading:

Inclusive Teaching: Creating Effective Schools for All Learners (J. Michael Peterson and Mishael Marie Hittie)

Inclusive Schooling Practices: Pedagogical and Research Foundations (Gail McGregor and R. Timm Vogelsberg)

Inclusion: A Service, Not a Place (Alan Gartner and Dorothy Kerzner Lipsky)

Inclusive Classrooms from A to Z: A Handbook for Educators (Gretchen Goodman)

The author.

Carolyn Das is the mother of two sons, Stephen and Michael. She and Lauri Stein are the Parent Coordinators for *Everyone Together*, a project to build 16 parent networks across Michigan to advocate for Universal Education("All Children, All Together, All the Time"). Click on these links to view the project position paper and concept paper: (insert the link on the WS/NIS website where you have stored the papers). To contact Carolyn Das for more information about *Everyone Together*, please send email to [carolyndas@twmi.rr.com](mailto:carolyndas@twmi.rr.com).

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