

# A Flawed National Policy Concerning Early Intervention?

Part II of Talbot Black's Keynote Address at the 1st AAHBEI International Conference

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**N**ow, at some point, intervention is no longer "early." The critical period of early childhood eventually comes to an end and so must early intervention. Our field's current mental models of early intervention may differ about when early intervention should end and how the end time should be determined, but our national policy concerning when it should end is very clear and very wrong.

The policy I am referring to says, early intervention should end for every child with a disability when the child reaches three years of age, regardless of how long the child and family have been receiving early intervention. You know the rest of the policy. If the child is eligible, at age three he or she may begin receiving special education and related services through the public schools, and the early intervention program and the school program are to work together so the transition from one program to the other is smooth.

This national policy exists because of the structure of Part C and Part B, Section 619 of the IDEA. It has been our national policy for more than a decade now. The state programs that have developed in each state have been guided by this policy. Many individuals have devoted a significant portion of their professional work to

refining and improving the way the transition between the two programs occurs. We all have come to accept this policy as "the way things are" and to work within its boundaries.

But, right now, I want you to think with me for a few minutes about this policy, and whether it makes any sense. First, ask

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yourself, "What is the seminal piece of research or collection of research studies from which one could draw the unmistakable conclusion that early intervention should end for all children with disabilities at three years of age?" Is there a research base of any kind that supports such a policy? Given that it is a major feature of our national policy for young children with or at risk of disabilities, shouldn't there be? Think about it.

On the other hand, is there any research that identifies difficulties connected with this policy? Well, as a matter of fact there is some. The Early Childhood Research Institute on Service Utilization at the Frank Porter Graham Child Development Center has found that families often face difficulties as a

consequence of this policy, even when the transition out of early intervention at age three has been smooth from an administrative perspective. Among the difficulties families face is coping with an acute sense of loss upon having to leave an early intervention program. For many families transition means the unwilling severing of a therapeutic relationship with their service provider or providers.

We tend to think of the early intervention program for infants and toddlers under Part C of IDEA as a three-year program, birth to age three, but that is not the way children and families experience it. The vast majority of families participate in the early intervention program for less than two years. Of those families a substantial number participate for less than 18 months, and of those a significant number participate for less than 12 months. Nevertheless, the policy requires that the early intervention partnership between families and early intervention professionals be dissolved when the child reaches three years of age, and a new partnership be formed, either with personnel in the public schools or personnel from some other program. No wonder many families endure a sharp sense of loss in spite of everyone's best efforts to make the transition smooth. The loss is felt because the families weren't able to finish

what they had begun together with the early intervention professionals.

It was late in the summer of 1986, the final weeks of the 99<sup>th</sup> Congress. The Education of the Handicapped Act, the law we now call IDEA, was being re-authorized. A bill had been passed by the Senate and sent to the House, along with 200 million dollars in new money earmarked to fund new early childhood provisions in the Senate bill. But, there were problems and disagreements concerning the new provisions. The house committee staff worked closely with a diverse group of stakeholders in resolving the problems and disagreements.

One major hurdle was who should receive the new federal money and oversee the development of the new early childhood program. On one side there were those who supported the funds going to the state education agency in each state. After all, this was a piece of education legislation. All of the children would eventually end up in the public schools. Why not let the schools be responsible from the beginning? The other side said, no. The money should go where it can be used to build upon what is already there. Plus, schools are not really prepared to serve families in the way called for in this proposed legislation. Let the schools become involved when the child is of school age, just like other children.

In searching for a compromise between these two positions that everyone could support, allowing the legislation to move forward, the stakeholders turned to what was the current structure of the Education of the Handicapped Act. In the original legislation, that is P.L. 94-142, the age ranges for FAPE had

always been from 3 to 21. P.L. 94-142 had a sort of escape clause that said, a state did not have to serve 3 through 5 year olds or 18 through 21 year olds if it was contrary to their state law or practice. In 1986, about half the states had already committed to providing FAPE to children with disabilities beginning at age three. With that in mind, a compromise was proposed and accepted by the key stakeholders. It was that state education agencies would receive some of the money and serve children three through five years old under Part B, Section 619. Below three years of age each state could determine for itself which agency should receive money and serve as "lead agency" for what became the Part C program of early intervention.

It was a good compromise. Without it the final legislation that became P.L. 99-457, creating the Part C and Section 619 programs might never have made it out of the Congress in late September to the President's desk. President Reagan signed it on October 8<sup>th</sup>, after Congress had adjourned. We owe a huge debt to those who labored long and hard to bring that legislation to pass, and I would never presume to second-guess the judgments made during that process.

I am simply saying that that was then and this is now. I am suggesting that the national policy that emerged from that compromise needs to be examined, even though it has been in effect all these years. And if the policy doesn't prove itself to be in the best interests of children and families, then it's time to think about what needs to be changed.

In September of 2000 the Office of Special Education Pro-

grams published new proposed rules for the Part C program. In the preamble to the new proposed rules it states that "a basic theme inherent in the Part C program is the individualization of decisions, through the IFSP process." Doesn't the current policy seem incongruent with that theme? To terminate early intervention for every child and family without exception regardless of how long they have been receiving services, solely on the basis of a birth date and ignoring every other relevant factor that ought to be considered, is hardly "individualization of decisions."

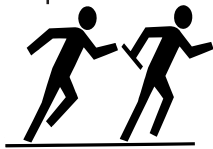
I wonder if our discomfort, or lack of discomfort, with this policy isn't connected to which mental model we bring to the issue. If we follow the first mental model of early intervention, or the healthcare mental model, or the special education mental model, the issues of termination of services and transition become largely administrative. Then transition, like every other early intervention service becomes something we do for the child and family, and if we do our jobs well then everything will be all right. But, if you follow the second mental model for early intervention, then decisions concerning ending early intervention support and transition would be guided by very different factors, and the family would not simply be on the receiving end of our service, but partners in making the decisions. From the perspective of the second mental model this arbitrary and ridged national policy quickly becomes "the emperor who has no clothes." It is not defensible. How could it ever be in the best interests of children and families to end early intervention without regard to what has, or has not yet been accomplished by early intervention?

Perhaps what is needed in order to face such policy questions and meet the challenges of the future is for all of us, early interventionists, special educators, health-care providers, to embrace a shared vision for what we are striving to accomplish for individuals with disabilities and their families during their formative years, that is birth to adulthood. Perhaps under a shared vision of that scope our differing mental models can come together and compliment one another. Early intervention would be only a part of such a vision, but a critical part simply because it comes first.

Not long ago a colleague of mine pointed out to me how helpful metaphors are in understanding and explaining a concept or idea. So, I want to describe to you two metaphors that, hopefully, can illuminate how we all can relate to each other in supporting an individual with disabilities during her or his formative years. The first is ***the metaphor of a cross-country relay race***. Our work together is like a cross-country relay race. It's a long race, and each of us has a section of the race that we are responsible for running. We must train and prepare well for our part of the race, and we must be prepared to receive and pass the baton from one runner to the next smoothly, so that the race may continue without disruption. We can take pride in the way we run our leg of the race, and we can cheer on those who come before and after us. The cross-country relay race can be a good metaphor for how we seem to see our roles and the way we relate to each other, but there is another that I think is better.

The other metaphor for how we can relate to each other in support-

ing an individual with disabilities during her or his formative years is ***the metaphor of building custom designed homes***. I thought this was particularly appropriate for an organization of "home-based" early interventionists. When you build a custom designed home many different craftsmen must be involved. Some aspects of the construction must precede others, but there is an overall plan that all seek to follow, a plan developed with and approved by the owner. When footings are dug and the foundation is laid, it is done so with an understanding of where walls and key support beams are to be



placed. When rough plumbing is laid, it is with an understanding of where the sinks, and tubs, and toilets are to be installed. Different craftsmen must work side by side and coordinate with each other if the construction of the home is to proceed according to the plan. And each craftsman can take pride in his or her work, and together they can share in the satisfaction of seeing a home being well built. But everyone involved understands from the beginning that the home belongs to the family, not the builders.

I think we need to view our work together like the building of custom designed homes. See, in the metaphor of the relay race the focus is on us, the runners, and on the race. The child and family is the baton being passed from one runner to the next. In the metaphor of building custom designed homes, the child and family is the home.

Well, those are *my thoughts* on where early intervention is as a field, and what it is that challenges its future. And



that's all they are really, my thoughts. But, the really important thing is: ***WHAT DO YOU THINK?***

