

**“Was It Worth It? You Bet”:
The Impact of PL 94-142 on Lives and Careers**

Jill M. Leafstedt

California State University, Channel Islands

Tiina Itkonen

California State University, Channel Islands

Fran Arner-Costello

Ventura County SELPA

Amber Hardy

Santa Barbara County Office of Education

Bernard Korenstein

California State University, Channel Islands

Matthew Medina

Taking Care of Business, Owner

Eileen Medina

Santa Barbara County Office of Education

Alan Murray

Ventura County Office of Superintendent of Schools

& April Regester

University of California, Santa Barbara

This article presents a panel discussion held to celebrate the 30th anniversary of the Education for All Handicapped Children Act (EAHCA), commonly referred to as PL 94-142. The panel discussion was one part of a statewide Commemoration in California. A seven member panel,

Jill M. Leafstedt and Tiina Itkonen are professors and Bernard Korenstein is an instructor, all in the School of Education at California State University, Channel Islands; Fran Arner-Costello is with the Ventura County SELPA; Amber Hardy and Eileen Meddina are with the Santa Barbara County Office of Education; Matthew Medina is owner of Taking Care of Business; Alan Murray is with the Ventura County Office of Superintendent of Schools; and April Regester is a doctoral student at the University of California, Santa Barbara.

consisting of families and educators were invited to share their experiences with special education since the passage of PL 94-142 in 1975. After the discussion it became apparent that the panel’s diverse stories could be brought together to demonstrate the wide ranging impact this legislation has had on individuals both personally and professionally.

The stories shared by the panel members provide a picture about where special education began and how far we have come. These stories will remind educators about the importance of their role in the public education of all students. As the field of special education continues to develop, the following stories remind us that at the center of special education—its very purpose and goals—are the students.

People with disabilities have a long history, which for centuries was characterized by exclusion, abandonment, or out-right violence (Smith & Erevelles, 2004). With the passage of PL 94-142, the United States led the world in enacting a statute that guaranteed free appropriate public education for all students with disabilities, regardless of the type or severity of their impairment.

The enacted law was a result of focused disability advocacy. The advocacy movement was critical in the activities leading up to the passage of PL 94-142 and in the lobbying that helped get the legislation passed. Parent groups, such as the Association for Retarded Children (ARC) and United Cerebral Palsy (UCP), worked with professional organizations, such as The Council of Exceptional Children (CEC), to keep the agenda moving forward for people with disabilities (Yell, Rogers & Rogers, 1998). CEC, ARC, and UCP worked closely with members of Congress and their staff in crafting the legislative language of PL 94-142 (Melnick, 1995).

The enactment of PL 94-142 was a major policy victory for individuals with disabilities, their families, and disability advocates. Since the 1970s, special education has evolved from access to outcomes, both due to the evolution within special education itself, and with the accountability movements in general education (McDonnell & McLaughlin, 1997). Today special education as a field has new concerns about implementing policies regarding highly qualified teachers, accountability, and standards.

The purpose of the panel presentation and this article is to re-visit the early years of this life-changing statute. Who are the people who were impacted by the passage of PL 94-142 and how has it changed their lives? By looking at a small sample of personal stories we provide a glimpse at what the legal changes meant for professionals in the field of special education, students with and without disabilities and their parents. As the personal histories below illustrate, special education was not always ideal for those implementing or benefiting from it, but in the end, it was worth it.

Panel Discussion

In planning the panel discussion, invitations to participate were sent to people connected to the field of special education in our local community in Southern California. All invited panel members were included due to their personal and/or professional involvement with special education around the time of the passage of PL 94-142 and continued dedication and involvement in the field. Our aim was to have a sampling of teachers, administrators, parents and students with disabilities who could provide a picture of how changes have impacted lives on a local level. Our search resulted in seven people. All seven are panel members and co-authors on this paper. The first three participants shared their experiences with special education from a students' perspective. The remaining four became involved in special education later in life, either through family members with disabilities or career choices.

The first panel member, *Amber*, participated in special education programs due to learning disabilities throughout her K-12 schooling. She is currently working as a pre-school specialist for young children with disabilities that are included in typical pre-schools. Her specialty is students with behavioral challenges. She has her early childhood credential and recently received a Master of Arts degree.

April graduated from high school in the mid 1990s where she first became involved in special education as a peer tutor. She was a self-described at-risk student, when a counselor suggested she work as a peer tutor in the special education classroom. As a result, she not only graduated from high school, but got a position as a special education instructional assistant and is currently enrolled in a Ph.D. program with an emphasis in special education. While working as a Ph.D. student, April is also working as a supported living vendor. In this position she coordinates supports for friends with disabilities so they can live independently.

Our third participant, *Matthew*, was born shortly after the passage of PL 94-142. Matthew was diagnosed with Down syndrome at birth and went through infant and school services under PL 94-142. Matthew attended local schools and was included in the general education program throughout most of his high school experience. He now owns his own business, "Taking Care of Business." He provides support services to small businesses such as washing and folding towels in a physical therapy office.

Eileen, our first non-student panel member, became involved in special education as an adult and is also Matthew's mother. As a mother of a child with a disability she became very involved in special education and disability advocacy. She is now a well respected special education

professional in the community. Eileen works at a local county educational agency as a special education related services manager. She also teaches special education college courses for teacher education students at a local University. Eileen has years of experience working with and advocating for people with moderate to severe disabilities.

Our next panel member, *Fran*, received her teaching credential in 1976 and began teaching special education immediately. She has continued her career in special education working as a principal in a school for students with special needs and is currently the Assistant Director of the local county Special Education Local Plan Area (SELPA). Fran is also an instructor in the Special Education Program at a local University. In addition to being a professional in the field of special education, Fran is the step mother of an adult with a disability.

Bernie, officially retired, remains active in special education as a consultant and lecturer/supervisor for the local University. During Bernie's career in public education he worked as a teacher, principal and district level administrator. He retired as Director of the local county SELPA.

Our final member of the panel is *Alan*. Alan also became involved in special education as an adult. He is currently working as a principal in a school for students with Emotional Disorders. Prior to this he was a special education teacher and worked at the Camarillo State Hospital and Developmental Center¹ as a hospital administrator prior to its closure in, 1997. Alan also has an adult cousin who has Down syndrome.

Salient Themes

During the panel, participants were asked to describe their experiences in special education and share how the passage of PL 94-142 impacted their lives and careers. For those who were sharing their perspectives as a student they were also asked to share how *special education services* impacted their lives. The panel discussion was originally intended solely as an educational experience for students at our local University. However, while listening to the presentations it became clear that this collection of personal experiences told a cohesive story that could provide a portrayal of the impact PL 94-142 had and continues to have on the lives of people with disabilities and those who live and work with them. The panel discussion was videotaped and later transcribed. The video was reviewed by two viewers for consistent themes across participants. Transcriptions were then reviewed to code for themes (Coffey & Atkinson, 1996). Quotations that exemplify the themes are presented here. Three themes emerged from the coding: Evolution of Special Education, Social Impacts, and Career Impacts.

Evolution of Special Education

The evolution of special education theme described the tremendous changes and growth that has occurred in the field. The participants' description of evolution within special education went well beyond the increased numbers of students or the types of disabilities being served, but rather focused on how complex special education has become since its inception. As an illustration of where special education was prior to PL 94-142, Alan provided a description of what existed educationally for students with disabilities at Camarillo State Hospital:

Prior to PL 94-142, the educational services were almost non-existent at Camarillo State Hospital and Developmental Center..... They didn't really have any formal educational programs because [the state] was not mandated to do that. So what you had was a smattering of maybe voc ed. (vocational education) teachers, maybe a few teachers that they hired, who weren't really teachers, they weren't credentialed or anything. Any type of educational classes that were done before 94-142 were done pretty much by the nursing staff, in this case the psychiatric staff, without really knowing what they were providing, it was all kind of a medical model you might say. *The education* involved mainly psychiatric intervention with children, behavior management... that sort of thing....

Also coded within the theme of evolution were descriptions of what education was like immediately following the passage of PL 94-142. There was now legislation to follow but responses to the legislation came in different forms and at different rates. Below Fran describes the attitude towards special education in her first job as a special education teacher immediately following the passage of PL 94-142:

When I first started, the programs for kids with severe disabilities were more prevalent [than those for mild/moderate disabilities] and they were of course very segregated. The perspective was absolutely not education, it was lets take care of these poor kids, lets nurture them, lets give their parents a rest, that kind of thing. So we were not talking about educational outcomes in those days.

Alan, speaking from his experiences at the Camarillo State Hospital, describes how quickly changes began to happen within the institution after 1975:

With the passage of PL 94-142 everything changed, almost overnight. The California Department of Health and Human services began their own educational division, recruited fully credentialed teachers.... Implemented reading language arts, math, a lot of life skills training and vocational readiness, various work training programs, work activity centers, that sort of thing.

The years following the passage of PL 94-142 began a time of rethinking education for students with disabilities. This rethinking continues and has led to extensive legal changes including participation in statewide exams and access to state standards. As the administrators on our panel explained, the law has continued to evolve since its inception thirty years ago, at a level of complexity that is sometimes daunting. Bernie illustrated this by holding up the composition of regulations from thirty years ago and the current regulations. He explained:

When I first started here as an administrator I could tell you everything in here [holds up book] without ever having to look it up. I guarantee you I could not tell you everything in this book [holds up current composition of laws], these are the current laws *in special education*.

Fran took us further into the evolution of special education by explaining how the writing of Individualized Education Programs (IEP) has become more complex and systematic:

When I was in graduate school, we heard about this new law, this Education for the Handicapped Act, and we knew there was something called an IEP so they said to me, a grad student, Fran, you know these IEPs we are supposed to be writing...and I said oh yeah, and they are supposed to have these goals, so we thought ok, lets write one. And this is a true story, we pulled out that brown school paper with the blue stripes on it, the ones that the elementary school kids learn to write on, and we wrote a couple goals on one sheet of brown paper with the blue stripes on in. That was 1976 and we all know that thirty years later, that form is at times 12 pages for every IEP.

The administrators on the panel brought together stories that remind us of where we have been and how far we have come. Fran closed her talk with the following comment in reference to the field of autism: “The awesome thing is that we really know what to do now. We have tons of strategies, communication systems, and it’s wonderful.” We share these stories in hopes of reminding educators to stay focused on the original purpose of the law and continue making progress for the students as special education despite regulations and policies that have become more cumbersome and time consuming.

Social Impact

The impact of PL 94-142 went beyond the school room doors in unforeseen ways. It profoundly affected individuals’ lives, families and communities. With the passage of PL 94-142 we have witnessed people with disabilities move from institutions to group homes and many back into their family homes or independent living situations. We have

also witnessed support systems being developed that allow for persons with disabilities to participate in all aspects of school and society. The social impact theme begins with descriptions of living situations and social responses to people with disabilities prior to and shortly after the passage of PL 94-142. This is followed by the perceptions that the students shared. They share where we are now and the advances that have taken place. Alan's quote below presents an historical perspective on the difficulty of getting services for people with disabilities prior to PL 94-142. He describes how his Aunt Grace's involvement in parent advocacy helped to develop a system in which her daughter with Down syndrome could get an education prior to PL 94-142:

When Mary (Alan's cousin with Down's syndrome) was born in the 1950s they really didn't have anything, there were no educational programs, nothing at that point. What she had was a mother who was a true advocate for her. They (Mary's family) became involved with legislators in Santa Barbara, the Lanterman Act²...they were really involved in that. When Mary was born they were told to institutionalize her —[they were told] that was all they could do.... That she would need nursing care all of her life. Aunt Grace was a nurse and she decided that this wasn't going to happen so she got involved with some other families with disabled children and they worked through the Association for Retarded Citizens (ARC), to develop a wonderful program at St. Vincent's (private school).

Aunt Grace's advocacy illustrates the passion that continues to define parent advocacy (Itkonen, in press) These struggles have changed since PL 94-42, although the changes have taken time. Fran portrays this through a quote describing how living situations have changed and become more supportive of people with disabilities.

...children with severe disabilities, when they were born thirty years ago, their families were not encouraged to bring them home. We know that in California we had the system of state hospitals... and most folks, in those days had their children put in institutions. When I was a teacher all of my students came from group homes, and children's institutions, foster homes and things like that. So one of the absolutely fabulous *things* over the thirty years that has been changing is that people are now growing up with their families and people with disabilities are staying at home and moving out into their own homes, which is really awesome.

It is evident that the quality of life has improved for those with disabilities based solely on access to support systems, such as independent living and education programming. Eileen's perspective on the social impact of PL 94-142 provides an illustration of the tremendous impact PL 94-142 has had on family systems. Thinking back to when Matthew was

born, Eileen recalls her first experience with people with Down syndrome and how this experience shaped her response to Matthew’s diagnosis.

When I went to high school, I went to an all girls Catholic high school and ...on the other side of the fence there were twin brothers with Down syndrome and every once in awhile they would escape, climb over their fence naked and run through our school. It would be this lock down situation. So imagine, when Matthew was born and I was told he had Down syndrome and I just thought, oh no, this is not going to be a very good experience...

Eileen’s immediate experiences after giving birth did not do much to alleviate her fears, but as she describes, the rights she was given under PL 94-142 provided her with the resources she needed to meet the dreams she had for her family. In the following quote Eileen describes what happened at the hospital shortly after Matthew was born.

A pediatric neurologist came into the hospital to talk to my husband and I about Down syndrome, he gave us a book. This book told us everything [about Down Syndrome]. It was written for parents and at the end it had five stories about children with Down Syndrome. Three of the children at the end of their stories were all institutionalized, one passed away and the other one was still living at home. So the dreams I had for my three children and for my family were on real shaky ground when we were given the diagnosis... I am here to tell you that my dreams that I had for my family are still coming true. One of the big support systems was that we had a law that really guaranteed that things were going to be okay. That there was a team of people that were going to work towards the educational goals for Matthew and that it was also connected with parents and the mandate for parent involvement and parent training really gave me a lot of tools to work as a communicator and understand what I needed to happen in order for Matthew to be successful.

Eileen’s story provides a glimpse at how families must reconcile previous experiences with people with disabilities and their expectations for their own children. As we move into the direct impact PL 94-142 has had on the lives of students, we can see how Eileen’s dreams for her son have come true due in large part to the supports provided through this legislation.

Matthew was born two years after the passage of PL 94-142. Due in large part to parental advocacy, his educational career included many typical activities that his siblings had experienced. In 1980, he attended a typical pre-school and received special education supports there. Matthew was also a member of the local T-Ball league. There he met a friend for life, Ryan, who supports him to this day. Matthew was also mainstreamed in elementary schools, although he never got to go

to school with his siblings. He had to move schools three times, since over-crowding resulted always in moving the special education student population first. Once Matthew reached high school, it was a very special time because for the first time, he got to go to school with his older brother. Matthew was a freshman and his brother a senior. The older brother introduced Matthew to the school and his friends. Matthew got the 'insider's guide' to high school. He reported in the special education class in the mornings, but then took general education classes such as life science, Regional Occupation Program (ROP), computers, creative writing, basic math, art, and family health with peer support.

Matthew was socially very much part of the school. In creative writing he worked hard to write an invitation letter to his potential date for the prom (a very important social activity for anyone in high school, nonetheless for Matthew). He met a few of his IEP goals by completing the writing process, and more importantly, got a date. Eileen recalls how Matthew's first concern was the limo—from his older siblings, he knew how things needed to be. From high school, Matthew went onto the local community college and took PE and health classes. He also received special education services in the community and learned more independent living skills such as using public transportation. Matthew now lives in his own home, with support from his roommates.

Matthew's story is full of love and family support along with strong positive relationships with the public school system. April on the other hand did not have a positive and supportive relationship with the school, and yet her involvement in special education had a tremendous impact on her life. April exemplifies how special education has a far reaching effect and can impact the lives of students without disabilities, by providing exposure to disabilities and providing students opportunities for involvement in school. April, who became a peer tutor in a special education program during high school, shared how special education became a refuge for her despite the fact that she was not identified as having a disability. She found a place that for the first time she felt accepted and could impact others lives positively. April describes herself as an at-risk student in high school:

If I went to school at all, I was an average student, not involved in any extra-curricular activities. I was going less and less [to school], so my counselor asked me to become a peer tutor in an SDC (special day class) class.

April went on to share how she became a peer tutor and how these experiences along with her participation in a leadership camp for students with disabilities and those involved with them called Project Interdependence helped her to transition from having helping relationships

with her peers with disabilities to forming actual friendships. These friendships not only got her through high school but have provided her with a career path in special education. April currently lives within close proximity to her former high school friends, and the group—consisting of former students with and without disabilities—continues to be a tight-knit community of friends, who see each other on a regular basis.

PL 94-142 has had long-term social outcomes for all of our participants. Matthew and April, both of whom met during high school are friends to this day. Eileen’s dream of having all her children be part of the family have been fulfilled as Matthew takes care of his nieces and nephews, and helps out with shopping and organizing. PL 94-142 provided opportunities that were not otherwise available for families to get socially connected with others, to keep their children in local communities and included in family lives.

Career Impact

The final theme that was prevalent in the panel discussion relates to the careers of our participants. This theme exemplifies how work is more than just earning money—it includes developing social relationships and networks with co-workers. Many of the participants have found a community within the field of special education that provides both career and social support. Despite the fact that all of the participants were invited due to their involvement in the field of special education prior to the panel, it was not clear how dedicated all were to the field of special education. All participants were originally drawn to the field due to personal involvement with a person with disabilities, either themselves, a family member, or a friend. All have stayed in the field because they have seen the impact special education can have on the lives of individuals with disabilities and those without. In this section the focus is on the three panel members that became involved in special education as students.

Amber’s story provides a glimpse of both sides of the coin, as her teachers were rewarded for their involvement by her success. Recall that Amber received special education services throughout most of her K-12 schooling. In elementary and junior high school she said that she was largely placed in what was called “self-contained classrooms” with low expectations for academics. Amber describes one experience in her early career planning:

Around this time [high school] I was sent to a vocational assessment. I had to take the bus somewhere and take this intimidating test with strangers. The results deemed that I was not college material. I was told I could get a job at a grocery store bagging groceries.

Amber went on to state that her parents were not involved in her

education, and typically did not attend IEP meetings. Had it not been for the special education teachers who listened to Amber's dream of wanting to become a teacher, and pushing her from self-contained classes to general education and advanced placement classes, she would likely be working at a grocery store bagging groceries rather than educating young children. Amber continued:

College was the hardest thing I ever did. It took me many years and I re-took math and English classes at least twice. But I wanted to be a teacher and I had people who told me I could do it and who tutored me along the way.

April's story also provides a look at how teachers can have a lifelong impact on students. April mentioned that when she was a senior in high school, her father lost his job. It was thanks to the special education teacher whose class April was a peer tutor in, who helped her find a job and mentored her through those difficult times. April stayed in school, and through this teacher's contacts, got a job as an instructional assistant in special education. For ten years, April worked as an instructional assistant in all types of special education programs, and also provided respite care and residential support for families she met along the way. Eventually she became a supported living vendor for one of her peers from high school. While working as an instructional assistant in an inclusive elementary program, she decided to go back to school, and is now a doctoral student with emphases in special education, disabilities and risk studies.

We perhaps sometimes forget the career impact of PL 94-142 for former students receiving special education supports. Matthew is a case in point. He owns his own business called "Taking Care of Business." He works with small businesses as their personal assistant doing various tasks. He has two clients presently, and charges \$11 an hour. Amber, as mentioned before, has a Master's degree and is a successful pre-school specialist, highly-regarded by her peers, superiors, and the parents with whom she works.

The previous discussions on the social and career impacts clearly indicate that labels—whether disabilities, at risk, or others—do not determine who a person is. Individuals have dreams, aspirations, and unique skills. Having teachers who listened to these students and heard them, helped Amber, April, and Matthew to reach their dreams. Strong social support networks that developed were also critical in reaching these dreams and shaping the lives of these individuals and those around them.

Implications for Teacher Education

Why should teachers learn and be concerned about the history and background of special education? As the special education system expands

and becomes more complex, it is important to reflect and remember that special education was developed to better the lives of people with disabilities and that through its history, the policy has impacted a great many lives, both those with disabilities and those without. Understanding how special education has impacted individual lives, can provide educators with a positive view of special education despite what can be tedious regulations and paperwork.

Stories such as Amber’s, April’s, and Matthew’s remind us that teachers must keep their expectations high for all students. When educators second-guess a student’s abilities due to a label, we may be inadvertently dissuading the next great leader in education or our very own child’s preschool teacher. Despite the fact that we are currently living in an era of standards and accountability, teacher education must remember not to lose the focus on students first and foremost as individuals. April’s words remind us of how a teacher can turn school into a positive experience for students.

When I was a peer tutor and buddy [in special education], the teachers treated me differently. I was not an outcast but was treated with respect.

While Eileen provided a perspective of a parent and how important families are to keeping the focus on the student, Fran, Bernie, and Alan’s stories remind educators of how far we have come. It is important to remember how much growth we have made to improve the lives of people with disabilities, specifically their education. The results of the many who had dedicated their careers to special education are evident in the stories of the student perspective participants.

We believe the most salient message across all themes sent by our panelists was to remember that students are the focus of legislation and that they should be involved in their education. Teacher education programs may consider including methods on teaching person-centered planning, student-led conferences, and other processes that promote inclusion of the student’s perspective in educational decisions.

It is important to remind the reader that our panel was limited to seven participants. While it is easy to draw conclusions based on the strength of the themes the panelists shared, it is important to keep in mind that these themes cannot be generalized to all. Despite the small number of perspectives presented, each participant shares an important part of the history of PL 94-142 that can inform educators now and in the future.

In conclusion, special education has grown from a simple booklet of laws to a complicated set of procedural rules and regulations. IEPs are now long and specific, teachers have to be highly qualified, and there are a myriad of other requirements. Despite this evolution, our

panel's stories from the beginning of PL 94-142 to today, share several powerful commonalities on the profound impact behind special education. For our panelists and their extended families, PL 94-142 meant living in the local community. It meant education. It meant actualizing dreams—high school graduations, college, careers. It meant inclusion in the local community. It meant growing up to be contributing adults. The authors invite teachers, teacher candidates, and teacher educators to reflect on these outcomes and re-visit them often. Special education is ultimately not about compliance. It is not about procedures. It is about impacting lives of students with *and* without disabilities. It is about educating the next generation of citizens. Is it worth it? You bet.

Notes

¹Camarillo State Hospital was a residential psychiatric hospital that housed people with mental illness and developmental disabilities.

²The Lanterman Act is a California Law that promises services and support to people with developmental disabilities and their families. The Lanterman Act was signed into law in 1969.

References

- Coffey, A., & Atkinson, P. (1996). *Making sense of qualitative data*. Thousand Oaks, CA: Sage Publications.
- Itkonen, T. (in press). Politics of passion: Collective action from pain and loss. *American Journal of Education*, 113.
- Levine, E. L., & Wexler, E. M. (1981). *PL 94-142: An act of Congress*. New York: Macmillan.
- McDonnell, L., & McLaughlin, M. (1997) *Educating one and all: Students with disabilities and standards based reform*. Washington, DC: National Academy Press.
- Melnick, R. S. (1995). Separation of powers and the strategy of rights: The expansion of special education. In M. K. Landy & M. A. Levin (Eds.), *The new politics of public policy* (pp. 23-46). Baltimore, MA: The John Hopkins University Press.
- Smith, R. M., & Erevelles, N. (2004). Towards an enabling education: The difference that disability makes. *Educational Researcher*, 33(8), 31-36.
- Yell, M.L., Rogers, D., & Rogers, E.L. (1998). The legal history of special education: What a long strange trip it has been! *Remedial and Special Education*, 19(4), 219-228.