

Program Evaluation Proposal:  
Policy Discriminates Against Students with Autism

by

Mary Ann L. Fiedler

Brandman University/Modesto, CA

Dr. Lester Clements/SSCU 494 5301

21 October 2011

## ABSTRACT

Social differentiation is described as “how people vary according to social characteristics” although the social ranking that occurs is typically not based on such differences.<sup>1</sup> However, in the case of the American social class system, there are many different factors, “determined either through ascription or achievement,” that define one’s social placement and “will determine his/her access to America’s valuable resources.”<sup>2</sup>

A unique condition has been present in the Central Valley region of California as it relates to special education resources for a special class of autistic children. In 2005, my son was diagnosed with autism and I began to advocate for his services; I was informed by members of an autism support group about an intensive model of behavioral treatment known as “EIBT,” an acronym for the Central Valley’s intensive autism treatment/program. I was also informed that it would be difficult to obtain this service because the program is tightly controlled by public agencies through a 52-page contract which must be signed by parents whose child gains entrance. My personal struggles as a parent and parent advocate to access this program for my son and other families revealed discriminatory provisions generating from the EIBT contract. These provisions, in my opinion, interfere with the rights of autistic children, and exceed public agencies granted authority. It drives a policy that prefers a class of higher functioning autistic children, setting them apart from other lower functioning ones.

My attendance of hundreds of special education meetings demonstrated the complex machinations of the EIBT policy. It outlines “rules” governing the “entrance,

---

<sup>1</sup> Basirico, L.A., Cashion, B.G., Eshleman, J.R., & Roman, M.R. (2010). *Understanding sociology and social problems, fifth edition*. Horizon Textbook Publishing: California. 191.

<sup>2</sup> Ibid, 193-195.

continuation, or exit” or children.<sup>3</sup> These rules are based on discriminatory “criteria” created by public agencies and their representatives; according to parent Nutt, they are criteria children must meet to stay in the program.<sup>4</sup> In 2005, a regional center representative gave me a copy of the 52-page policy. My examination of the document revealed numerous “criteria” which, for example, sets forth a requirement for children to be able to master spoken language, and has a requirement for children to consistently achieve a 80% acquisition rate every 90-days on the majority of the programs’ intensive lessons.<sup>5</sup> Failure to maintain 80% quarterly triggers a child’s removal from the program.

Contrary to general education in public schools, these kinds of rules are not required of, and not applied to children who do not have disabilities; regular children may remain in public school programs even with failing scores. As such, these criteria are, in my direct experience and observation, inconsistent with federal laws and regulations and are, in fact, arbitrary. Working as a parent advocate since 2005, I have observed and been informed by parents, that their children’s progress is measured by the EIBT criteria, interfering with the access to these services. The purpose of this paper is to propose an evaluation of the EIBT policy and criteria that present barriers to children’s access rights. An examination of this policy may also be linked to past attempts to create California legislation that would authorize its systemic implementation.

As a result of my direct observation of the struggles faced by many parents, and my personal experience of the delay caused by the EIBT policy, an analysis and evaluation of the “Early Intensive Behavioral Treatment 4-Way Agreement” (“EIBT 4-Way”) also

---

<sup>3</sup> Torres, J. (2008). “Parents challenge autism-care rules”. [Web Article]. *San Joaquin County Record*. Retrieved at Record.net on 17 September, 2011  
<http://www.recordnet.com/apps/pbcs.dll/article?AID=/20051224/NEWS01/512240362/1001>

<sup>4</sup> Ibid

<sup>5</sup> “Early Intensive Behavioral Treatment Program Procedures and Guidelines” 3rd publication, May 24, 2006.

known as the “Early Intensive Behavioral Treatment Program, Procedures, & Guidelines” (“EIBT PP&G”) is hereby proposed for funding of pending litigation on behalf of autistic students. In addition, I am recommending the abolishment of this policy in order to protect the rights of California’s class of autistic students to access this valuable educational resource based upon their individualized needs.

## TABLE OF CONTENTS

Abstract . . . . .	i-iii
Table of Contents . . . . .	1
Preface . . . . .	2
Description of the Program/Policy to be Evaluated . . . . .	4
Background of Prejudice and Discrimination in Special Education . . . . .	4
Background of EIBT Program . . . . .	4
Purpose of Evaluation . . . . .	6
Assumptions . . . . .	8
Overview of Methodology . . . . .	9
Organization of Proposed Evaluation . . . . .	10
Literature Review . . . . .	11
Early Intensive Behavioral Treatment (EIBT) Discussion . . . . .	14
Discrimination Through Legislation . . . . .	15
Future Action: International Consequences . . . . .	17
Proposed Recommendations . . . . .	18
Conclusion . . . . .	20
Bibliography . . . . .	21

## PREFACE

For many years, Americans have claimed that the United States is a country committed to the equality of people. Concepts of fairness, liberty, equality, and justice were developed from analyses of temporal conditions, usually those revealing grave inequalities, necessitated or prompted social movement and change. Despite history's quest for an egalitarian society, the stratification of people results in the inequality of opportunities and "life chances."<sup>1</sup>

Newman agrees and in his textbook, he writes that "social identities are always related to unequal access to life chances."<sup>2</sup> His examination of a stereotype, "the over generalized belief that a certain trait, behavior, or attitude characterizes all members of some identifiable group" is relevant to this proposal.<sup>3</sup> Through my direct experience and observations, the EIBT policy promulgates society's acceptance that some children should receive intensive services and others should not. This distinction necessitates change because it affects children's access to the Central Valley's intensive program.

For the purpose of better understanding this policy, I would begin with a review of the practice of disability discrimination in American public schools. My review of literature shows that distinctions based on race, ethnicity, or language results in the unfair treatment of minority special education students. This should provide constructive information related to the systemic social, economic and political implications of the EIBT policy and its harmful consequences. It is my belief that the policy is a product of what Alexis de Tocqueville describes as the "tyranny of the majority." The "tyranny of

---

<sup>1</sup> Basirico, p. 211

<sup>2</sup> Newman, D.M. (2007). *Identities & inequalities: exploring the intersections of race, class, gender, and sexuality*. McGraw-Hill: New York. p. 147

<sup>3</sup> Ibid, p. 151

majority” in this case is the unchecked governmental power of public agencies. The autism policy, in my direct experience, perpetuates prejudice and discrimination by distinguishing services on the grounds of differing levels of an autism disability, age, race, and other factors.

Drawing mostly from public documents and the class action lawsuit, I will outline and clarify the discriminatory criteria to show how it violates special education laws and regulations to support my recommendation for its abolishment. Aside from these two major objectives, my goal is to enlighten readers to the existence of prejudice and discrimination in special education with regards to the stratification of autistic students into strong and weak performing groups reinforced by the policy’s EIBT criteria. This sets a dangerous precedent towards cultural acceptance of a norm that only strong achievers are entitled to intensive behavior treatment; weak ones, the disadvantaged, are offered other services.

## **DESCRIPTION OF THE PROGRAM/POLICY TO BE EVALUATED**

### **Background of Prejudice and Discrimination in Special Education**

There are hundreds of studies documenting the educational discrimination of children with disabilities. Among other types of discrimination, “[r]acial discrimination, according to Assistant Secretary of Education Judy Heumann, Director of the Office for Special Education and Rehabilitative Services in the Clinton administration, exists within the systems of both regular and special education.”<sup>4</sup> Minority special education students “remain segregated and unequal,” their disproportionate identification and overrepresentation in inadequate and inappropriate categories and programs is historically noted “over the last thirty seven years.”<sup>5</sup> From this, an EIBT policy that distinguishes high functioning from low functioning students is not so seemingly terrible. Therefore, it does not seem difficult to understand the rationale behind the Central Valley’s EIBT policy if readers consider this proposal from a conflict theory perspective; the perspective from which a dominant group reserves funding treatment for those who meet the EIBT criteria, thus preventing the access of those resources for children who do not.

### **Background of EIBT Program**

In the 1990’s, parents were “frustrated by obstacles” to special education services specifically, the lack of effective interventions.<sup>6</sup> Strained relations between parents and schools were a source of conflict including litigation.<sup>7</sup> Central Valley representatives suggest that the EIBT “collaboration model” of “shared responsibility” addresses those

---

<sup>4</sup> Losen, D.J., & Welner, K.G. (2001). Disabling discrimination in our public school: comprehensive legal challenges to and inadequate special education services for minority children. Harvard, *Civil-Rights-Civil Liberties Law Review*, 36(2), p. 407

<sup>5</sup> Ibid, p. 408

<sup>6</sup> California Department of Developmental Services, (2008). *Autistic spectrum disorders: best practices in inter-organizational collaboration*. Sacramento, CA. p.25

<sup>7</sup> Ibid, p. 25



parental concerns.<sup>8</sup> Autism Connection confidently asserts that “[i]n this way, parents enjoy treatment options for their child, with smooth transitions at age three, without the need to change programs and/or providers or to pursue due process litigation in order to continue with the EIBT program.”<sup>9</sup> Unfortunately, this is merely an illusion. My advocacy for EIBT services on behalf of my son and other clients, and interviews with a special education attorney and parent advocates since 2005 argue that this is simply not true.

Skyrocketing rates of increase in autism confound the Central Valley special education system. Tuition for an average 30 hour one-to-one Applied Behavior Analysis (ABA) program costs approximately \$60,000 per year.<sup>10</sup> Public education must protect the State’s limited resources regarding the overwhelming burden of attempting to fund every child with an EIBT. Creating a policy designed to ensure services for more deserving students seems economically rational and educationally justifiable. In my opinion, however, it is not. Parents whose children never gained access into EIBT or lost their EIBT placement have complained to me that other non intensive programs were nothing more than “glorified babysitting.” The pervasive attitude of low academic expectations in other settings contributed to their child’s failure to make meaningful gains in all areas of learning. Thus, the dichotomy between EIBT students and others dangerously sets apart two classes of autistic children causing the isolation, segregation, and disadvantage of less-abled students.

---

<sup>8</sup> Ibid, p. 25

<sup>9</sup> Ibid, p. 27

<sup>10</sup> Glazer, S. (2003, June 13). Increase in autism. *CQ Researcher*, 13, 545-568. p. 558

## **Purpose of Evaluation**

The purpose of the evaluation is to examine how the EIBT 4-Way/PP&G policy violates the law and children's rights:

- Designates the age range and disability for those eligible for consideration for treatment contrary to the law; students with disabilities other than autism or whose diagnosis is co-morbid with autism are automatically precluded from eligibility,
- Entrance, continuation, and exit criteria requires children to meet the EIBT program which does not meet the individualized needs of each student; failure to meet policy criteria results in no entry, limited diagnostic placement, and/or premature exit,
- A student must be pre-approved in a variety of areas prior to the IEP process. Diagnosis, source, date of residence, referral list/waiting list, age of the child, geographical residence, English vs. non-English speaking, and other factors must first go through review and be approved by VMRC and its coordinator of autism services before the IEP process; the concept of agencies' collaboration of early identification, assessment, and seamless transition of services is an illusion serving mostly as the mechanism for agencies to weed out the high functioning EIBT candidates from the low functioning non EIBT children,
- Among other provisions, if a child gains entry into the EIBT program, assessments such as IQ testing can be done without parent consent or an Assessment Plan.<sup>11</sup>

If this proposal were to go forward, both the actions and policy of government and representatives must be reviewed. On its face, I believe the policy violates federal and state laws. However, the people implementing this policy must also be made culpable for spreading harmful criteria as it relates to the negative social, educational, economic, and political consequences for students denied evidence-based treatment and left to other services.

## **Audience**

The intended audience for this proposal are the Superintendent and staff of the California Department of Education, the Autism Advisory Committee, the California

---

<sup>11</sup> "Z.F. et al v. Ripon Unified School District, et al." (2007). United States District Court Eastern District.

Legislative Blue Ribbon Commission on Autism, the California Senate Select Committee on Autism, San Joaquin County Office of Education, SELPA, and LEA representatives, Stanislaus Country Office of Education, SELPA and LEA representatives, Autism Connection group, EIBT Committee, Valley Mountain Regional Center staff, and parents of children with disabilities. Other audiences include, Canadian Ministries of Education especially Ontario, all state government officials, Napa/Solano County Office of Education and ACT group, SELPA and representatives, all California SELPAs and LEAs, special education and civil rights attorneys, disability rights advocacy groups/non-profit organizations, and the general public.

### **Limitations**

Parents and educators who spoke to me in confidence regarding their belief that the policy harms children and violates parental rights have expressed their unwillingness or reluctance to speak out against the policy because of a perceived real fear of intimidation, retaliation, discrimination, threat of job loss, or threat of loss of their child's EIBT or other services. For me, advocacy for EIBT services has resulted in intimidation, retaliation, and discrimination by our local education agency. It would be important, then, to protect families who would consider participating anonymously by ensuring confidentiality of their responses.

## Assumptions

A major assumption of this proposed evaluation is that the Central Valley's EIBT program/policy describes the "demanding and intrusive intervention program aimed at giving [children between the ages of 1 and 5] the tools to be independently included in a general education classroom."<sup>12</sup> It is based on the "intensive in-home treatment program for ASD [Autism Spectrum Disorder] designed by O. Ivar Lovaas from [UCLA ]."<sup>13</sup> Early intensive behavioral treatment of the hallmark one-to-one model by Dr. Lovaas has been proven to be effective in treating the symptoms of autism;<sup>14</sup> The Autism Connection which "meets monthly" developed the 4-Way Agreement/PP&G as part of the collaboration to co-fund intensive non public agency services to some children.<sup>15</sup> It is a funding model, a policy designed to pay for evidence-based intervention for certain autistic children—those who meet "criteria". Sandee Kludt, former San Joaquin County Office of Education Superintendent and Special Education Local Plan Area (SELPA) director is cited as having "engineered [the] collaborative with DDS regional center."<sup>16</sup> That collaborative, the EIBT program/policy, is the basis of a class action lawsuit, of which my son, Zachary, is the lead plaintiff.

The EIBT program is described as:

- for children diagnosed as Autistic Spectrum Disorder (ASD), specifically, autistic disorder, PDD-NOS, or Asperger's disorder;

<sup>12</sup> "Early Intensive Behavioral Treatment 4-Way Agreement" 1st Edition, January 1, 2004. Revised September 8, 2005. p. 5 of 53. There are two versions of this document that are substantially similar. The May 24, 2006 version was renamed "Early Intensive Behavioral Treatment Program Procedures and Guidelines."

<sup>13</sup> Ibid

<sup>14</sup> Glazer, S. (2003, June 13). Increase in autism. *CQ Researcher*, 13, 545-568. p. 557

<sup>15</sup> "Early Intensive Behavioral Treatment 4-Way Agreement" 1st Edition, January 1, 2004. Revised September 8, 2005. p. 5 of 53

<sup>16</sup> Brydolf, C. (2004). *Stuck inside*. Retrieved 20 October 2011 from <http://www.csba.org/NewsAndMedia/Publications/CASchoolsMagazine/2004/Summer/InThisIssue/StuckInside.aspx>

- in-home or center based (typically);
- 20-30 hours per week for ASD children under age 3;
- 35-40 hours per week;
- funded for 47 weeks per year through collaborative agreements between Valley Mountain Regional Center (“VMRC”), Special Education Local Plan Areas (SELPA’s), and/or local education agencies (LEA’s).<sup>17</sup>

Parents advocate zealously for this program because there is “compelling evidence that many children with ASD can respond to and improve with intensive behavior modification therapy.”<sup>18</sup>

### Students

The students of EIBT programs span the age range from 1 through 5, although those who meet the continuation and high-functioning criteria may continue to receive intensive services. This observer places special emphasis on the unequal treatment of minority students, specifically Hispanics and African Americans, who, in expressing their complaints to me regarding the EIBT program, feel culturally and/or linguistically discriminated. Moreover, the age range immediately precludes other children from receiving services contrary to the law.

### Overview of Methodology

The research goal here is intended to better understand how the EIBT program/policy interferes with the laws that protect special needs individuals from discrimination that is based on age, race, language, or other category. Four main aspects of the proposed evaluation, the needs assessment, process evaluation, progress evaluation, and summative evaluation, should produce relevant information in support of parents’ claims opposing the EIBT policy.

---

<sup>17</sup> Ibid, p.5-10 of 53

<sup>18</sup> California Legislative Blue Ribbon Commission on Autism (2007). *An opportunity to achieve real change for californians with autism spectrum disorders*. Retrieved 17 October 2011 from <http://senweb03.senate.ca.gov/autism/documents/whatsnew/Commission%27s%20Report%20to%20the%20Governor%20&%20Legislature.pdf>

### Organization of Proposed Evaluation

Table 1.

<b>Evaluation 1: Needs Assessment</b>	<b>Description:</b> Qualitative and quantitative assessment of all EIBT and Non EIBT recipients to assess the perceived needs of families; identify elements of barriers/bias; determine/clarify parental issues/concerns
<b>Evaluation 2: Process Evaluation</b>	<b>Description:</b> Qualitative and quantitative survey and data collection of EIBT recipients and non EIBT recipients
<b>Evaluation 3: Progress Evaluation</b>	<b>Description:</b> Qualitative and quantitative survey and research to identify barriers, parental concerns, complaints, and compliments between intensive EIBT and less intensive other programs
<b>Evaluation 3: Summative Evaluation</b>	<b>Description:</b> Comprehensive analysis of data and findings

## Literature Review

**AB 1872, SB 383, SB 527, SB 1475 (2008, 2009). Retrieved 18 October 2011 from <http://www.leginfo.ca.gov/bilinfo.html>**

These bills are related to the EIBT policy in its desire to create the “seamless” evidence-based collaboration services described by the Autism Connection.<sup>19</sup>

Input for these bills came from members of Autism Connection. Some are members of California’s Autism Advisory Committee, who also gave input to the California Legislative Blue Ribbon Commission on Autism in drafting the language for 2008 and 2009 autism bills. Several members are also named defendants in the class action lawsuit.

**Autism Resolution Ontario (2008). “ABA as needed, where needed.” Retrieved from October 17, 2011 <http://www.autismresolutionontario.com>**

This document was accessed from the information I received from Canadian advocates opposing the “Stockton criteria” which ultimately caused the benchmark policy of Ontario’s autistic services. The author, herself a parent of a child with autism, has been challenging Ontario’s Ministry of Education benchmark policy to show that Stockton criteria violates children’s rights to access evidence-based ABA.

**Basirico, L.A., Cashion, B.G., Eshleman, J.R., & Roman, M.R. (2010). *Understanding sociology and social problems, fifth edition*. Horizon Textbook Publishing: California.**

This university textbook is used to clarify definitions of social stratification. It is used to support my claim that social class and stratification causes unequal access to resources for minority groups.

**Benchmark Developmental Expert Panel (2008). “The Development of Benchmarks for the Delivery of Intensive Behavioral Intervention for Children with Autism Spectrum Disorders in Ontario” (Condensed Version).**

This document was given to me by advocates in Ontario, Canada who argue that, because of the EIBT 4-Way Agreement, the benchmark policy of wait-listing, entrance, continuation, and exit criteria serves as the Canadian model of autism treatment. Parents are opposing the “Stockton criteria” as they call it, because the criteria impedes with autistic children’s rights to access evidence-based treatment.

**Brydolf, C. (2004). *Stuck inside*. Retrieved 20 October 2011 from <http://www.csba.org/NewsAndMedia/Publications/CASchoolsMagazine/2004/Summer/InThisIssue/StuckInside.aspx>**

An article from the California School Boards Association website addressing struggles faced by California communities and its members with regards to autism and autism services. Various school districts and programs are reviewed as well as concerns of public educators and parents. The Central Valley’s EIBT collaboration is described.

---

<sup>19</sup> California Department of Developmental Services, (2008). *Autistic spectrum disorders: best practices in inter-organizational collaboration*. Sacramento, CA. p. 25-27

**California Department of Developmental Services, (2008). Autistic spectrum disorders: best practices in inter-organizational collaboration. Sacramento, CA.**

This manual describes the background history of how the EIBT policy came to be developed. Beginning with a meeting, several leaders of special education and Applied Behavior Analysis research came together to discuss bringing evidence-based autism intervention to the Central Valley. This meeting gave birth to a group known as the Autism Connection from which came the EIBT 4-Way Agreement or EIBT PP&G policy.

**California Legislative Blue Ribbon Commission on Autism (2007). An opportunity to achieve real change for californians with autism spectrum disorders. Retrieved 17 October 2011 from**

**<http://senweb03.senate.ca.gov/autism/documents/whatsnew/Commission%27s%20Report%20to%20the%20Governor%20&%20Legislature.pdf>**

This manual provides comprehensive information regarding the public health crisis of autism in California. It proposes, among many things, creating models of collaborative services, guidance for school personnel in the education of students with autism, conflict and dispute issues, employment, housing, and law enforcement awareness.

**“Early Intensive Behavioral Treatment Program Procedures and Guidelines” 1<sup>st</sup> and 3<sup>rd</sup> Editions.**

These two documents are substantially the same in content. There are the primary source documents which are the basis of the current class action. They contain criteria which essentially define the optimal autistic child for the Central Valley EIBT program. Failure to meet the policy’s criteria will result in negative consequences for children; mainly, less-abled students receive other than intensive EIBT services.

**Glazer, S. (2003, June 13). Increase in autism. *CQ Researcher*, 13, 545-568. Retrieved from <http://library.cqpress.com/cqresearcher/>**

This document is used for factual information pertaining to autism and autism treatment. Applied Behavior Analysis is found to be the one evidence-based proven treatment. One-to-one intervention based on Dr. Lovaas’ University of California Los Angeles autism project has been shown to significantly reduce autism characteristics. Almost half of the students in the study were able to independently transition to regular classrooms with little or no support appearing indistinguishable from their peers. The cost of intensive ABA averages \$60,000.00 per year.



**Losen, D.J. & Welner, K. (2001). Disabling Discrimination in Our Public Schools: Comprehensive Legal Challenges to Inappropriate and Inadequate Special Education Services for Minority Children. *Harvard Civil Rights-Civil Liberties Law Review*, 36(2) 407-460.**

This comprehensive article highlights the years-long battle history of racial discrimination in special education. Although powerful laws protect children with disabilities, barriers preclude parents from accessing special education processes when advocating for their children. Discussions involve the disparate treatment, disproportionate overrepresentation, misdiagnosing and labeling of students as mentally retarded and emotional disturbance related to wealth, education, or poverty levels of communities causing a pattern of systemic discrimination by “systemic forces.”<sup>20</sup>

**Newman, D.M. (2007). *Identities & inequalities: exploring the intersections of race, class, gender, and sexuality*. McGraw-Hill: New York.**

Citing this textbook, supporting material is used to show that unequal life outcomes are, in fact, a problem related to socially constructed ideals pertaining to the unequal distribution and access of social, educational, or economic resources.

**Torres, J. (2008). Parents challenge autism-care rules. [Web Article]. *San Joaquin County Record*. Retrieved at Record.net on 17 September 2011  
<http://www.recordnet.com/apps/pbcs.dll/article?AID=/20051224/NEWS01/512240362/1001>**

Writer Jennifer Torres provides an objective review of the situation between parents opposing the EIBT policy and public school official’s opinion supporting it. Her interview of me and other parents opposing the policy is an accurate reflection of the summary of the class action complaint. Information given by a SELPA official from this article is used to support the fact that children who are not high functioning are not candidates of an EIBT program. In addition, according to this official, parents such as myself who do not agree to sign the EIBT contract are not able to receive EIBT services.

**“Z.F. et al v. Ripon Unified School District, et al.” (2007). United States District Court Eastern District.**

This is the federal class action currently pending. The lawsuit alleges numerous claims against government, regional center, and individuals for their part in creating a systemic policy that violates the Individuals With Disabilities Education Act, Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, and the Unruh Civil Rights Act of California.

---

<sup>20</sup> Losen, D.J., & Welner, K.G. (2001). Disabling discrimination in our public school: comprehensive legal challenges to inappropriate and inadequate special education services for minority children. *Harvard, Civil-Rights-Civil Liberties Law Review*, 36(2), 407-460.

## EARLY INTENSIVE BEHAVIORAL TREATMENT (EIBT)

### Discussion

A consensus between this parent, interviews with parents of children with autism, and interviews with Ms. Loughrey, a civil rights attorney, and Ms. Smith, a parent advocate in Region 6<sup>21</sup> is that the EIBT policy interferes with several laws and regulations. Ms. Smith adds that an agency representative alerted her that the EIBT 4-Way Agreement is “bad for children.”<sup>22</sup> Loughrey, Smith, and this parent agree that parents whose children have benefited from EIBT services have not complained about the EIBT policy. Parents whose children were not allowed into the program, or were in the program but exited prematurely after the brief diagnostic period for failure to meet EIBT criteria, do complain that the EIBT criteria interfered with the rights of their children to receive an effectively proven treatment. Their belief, according to many personal stories, is that the loss of intensive ABA and subsequent change to a lesser intensive program adversely impacted their progress. Public agencies continue to implement the policy disregarding the plight of many families who feel discriminated by it.

Some might argue that, despite pending litigation and protests from parents and advocates, the 8-year old pact is legally sound.<sup>23</sup> Public agencies, including the California Department of Education, have promised that, while from 2003 to 2005, parents were required to sign the 4-way agreement, parents are no longer required to do so.<sup>24</sup> According to Loughrey, Nutt, and this advocate, this is simply not true. In addition, Kludt admits on

---

<sup>21</sup> Ms. Smith is a pseudonym to protect the interviewee’s identity due to her expressed fear of retaliation and discrimination based on her advocacy of special education rights and services for herself and other families.

<sup>22</sup> Interview with Ms. Smith., parent of a child with autism.

<sup>23</sup> Torres, J. (2008). Parents challenge autism-care rules. [Web Article]. *San Joaquin County Record*. Retrieved at Record.net on 17 September, 2011  
<http://www.recordnet.com/apps/pbcs.dll/article?AID=/20051224/NEWS01/512240362/1001>

<sup>24</sup> “Z.F. et al v. Ripon Unified School District, et al.” (2007). United States District Court Eastern District.

behalf of San Joaquin County Office of Education that the intensive EIBT program is "most appropriate with the higher functioning children." For other children, other services are available. Moreover, as was the case of my son, when the IEP team agreed to an EIBT program, my rejection of the EIBT contract prohibited Zachary's entrance. "Because the four-way agreement is tied to the early intensive program, if a parent rejects the agreement, they are rejecting the program, Kludt said."<sup>25</sup> Recent evidence given to me from parents confirmed that government and agencies are requiring parents, again, to sign the EIBT 4-Way/PP&G contract.

This parent and Nutt strongly agree that the policy is discriminatory:

"It tells you these are the exact, specific things that your child has to do to remain in that program, or you're gone," [Nutt] said.

Nutt said the rules discriminate against children who are slow to progress.

Fiedler agreed, adding that special education should be tailored to a child's needs, and not to any agency's criteria.<sup>26</sup>

This is the crux of the complaint and as the legal process continues, it is the hope of many families that intensive ABA services will be available to all those children who need it.

### **Discrimination Through Legislation**

Since the inception and implementation of the EIBT 4-Way/PP&G policy began in 2005, government agencies and members of the Autism Connection began work on expanding the EIBT program into State policy. In 2006, Assembly Bill 2513 authorized State Superintendent Jack O'Connell to organize a 20-member Autism Advisory Committee.<sup>27</sup> Out of this committee came three main proposals; the first was to create

---

<sup>25</sup> Torres, J. (2008). Parents challenge autism-care rules. [Web Article]. *San Joaquin County Record*. Retrieved at Record.net on 17 September, 2011  
<http://www.recordnet.com/apps/pbcs.dll/article?AID=/20051224/NEWS01/512240362/1001>

<sup>26</sup> Ibid

<sup>27</sup> California Department of Education (2007). "Schools chief jack o'connell releases autism committee's

“seamless delivery of services;” the second was to develop a “Statewide clearinghouse...for evidence based interventions;” and the third was for “technical assistance and training to people at schools to implement and disseminate evidence-based ASD information and strategies.”<sup>28</sup> From these recommendations came three major autism bills proposed for 2008:

**Senate Bill 1475: Autism Pilot Project**--a “2-year pilot project” model of “voluntary collaboration between regional centers and school districts” to provide “seamless services to ASD children”<sup>29</sup>

**Assembly Bill 1872: Autism Spectrum Disorders: Clearinghouse**--Adding to Section 56848 of California’s Education Code, this bill would create a clearinghouse to “provide evidence-based and recommended information, and practices regarding the education of pupils with autism spectrum disorders, including, but not limited to...instructional strategies, fiscal management practices, and organizational structures supporting quality service delivery.”<sup>30</sup> It would also “establish, criteria, guidelines, and processes” regarding evidence-based services.<sup>31</sup>

**Senate Bill 527: Autism Spectrum Disorders: Screening**--This bill would “require the State Department of Developmental Services to partner with at least one or more regional centers to implement a two-year pilot program in at least 3 key geographic areas around the state for the purpose of providing...seamless services and systems of care for children with ASD who *are deemed eligible...by regional centers.*”<sup>32</sup>

Together with parents, advocates, and colleagues, I wrote letters to then-Governor Arnold Schwarzenegger and numerous California Assembly and Senate members, opposing each of the three bills. Citing and attaching the class action lawsuit with its accompanying exhibits, the EIBT 4-Way and PP&G agreements, I vehemently claimed that passing these bills would authorize discrimination of autism services. If these bills

---

recommendations to legislature and governor.” Retrieved 18 October 2011 at <http://www.cde.ca.gov/nr/ne/yr07/yr07rel144.asp>

<sup>28</sup> Ibid

<sup>29</sup> SB 1475 (2008). Autism pilot project. Retrieved 18 October 2011 from <http://www.leginfo.ca.gov/bilinfo.html>

<sup>30</sup> AB 1872 (2008). Autism spectrum disorders: clearinghouse. Retrieved 18 October 2011 from <http://www.leginfo.ca.gov/bilinfo.html>

<sup>31</sup> Ibid

<sup>32</sup> SB 527 (2008). Autism Spectrum Disorders: Screening. Retrieved 18 October 2011 <http://www.leginfo.ca.gov/bilinfo.html>

were not rejected, it would legally authorize the California Department of Developmental Services and regional center, specifically, Valley Mountain Regional Center to arbitrarily establish criteria, procedures, and guidelines for alleged “seamless” evidence-based autism intervention services. I emphasized that, upon review of the documents, they would likely find that discrimination is currently systemically practiced through the Central Valley’s EIBT program. It may be that our advocacy effort, in fact, contributed to Governor Schwarzenegger’s decision to veto all three bills that year; that result satisfied many of us in the Central Valley.

In 2009, another autism bill was introduced for 2010’s legislative year resembling SB 527: Autism Spectrum Disorders: Screening. Senate Bill 383: Autism Spectrum Disorders: Screening was substantially equal in language to that of SB 527. It repeated the proposal that seamless evidence-based services will be provided to children “*deemed eligible by regional centers.*”<sup>33</sup> Using the same letter-writing campaign to request the veto of SB 527 in 2008, we requested the Governor’s veto of SB 383 due to the similar language of this bill and citing the potential negative impact it would have on many children. SB 383 was vetoed by the Governor in 2010 and since then, no bills reflecting the dubious language of the aforementioned ones have resurfaced.

### **Future Action: International Consequences**

In 2009, I received an E-Mail from several advocates working together in Ontario, Canada. They requested information regarding my knowledge of “Stockton criteria.” They had many questions regarding the criteria which came to be known in Ontario as “benchmarks.” After several conference calls, we exchanged documents and agreed that,

---

<sup>33</sup> SB 383 (2009). Autism Spectrum Disorders: Screening. Retrieved 18 October 2011 from <http://www.leginfo.ca.gov/bilinfo.html>

after our review of literature, Ontario's government adopted the California's Region 6 EIBT practice of wait lists, entrance, continuation, and exit criteria for the development of its autism intervention program.<sup>34</sup> Of the 80 experts across Ontario, Canada, the United States, the United Kingdom, and Europe, "one set of standardized benchmarks was identified: the Stockton, California, Region 6 Autism Connection Early Intensive Behavioral Treatment Program Procedure and Guidelines (2006)."<sup>35</sup>

Opposing the "Stockton criteria" are numerous advocates and non-profit Ontario groups. In particular, Autism Resolution Ontario (ARO) has lead the way in raising awareness to take down the benchmark criteria born from the Central Valley's 4-Way/PP&G.<sup>36</sup> According to ARO's director, children are on years long waitlists, receive 1 or 2 years of ABA treatment, if any, and are prematurely exited because of the failed benchmarks.<sup>37</sup> The EIBT criteria seem to have made its way to Ontario, severely impacting the rights of children to access this much needed treatment. After on-going communications with ARO's members, we agree that abolishing Canada's autism benchmark policy, adopted from the Central Valley's EIBT policy, must occur there also to protect the rights of Canadian children and their families.

### **Proposed Recommendations**

1. Immediate cessation of the implementation of all parts of the 4-Way/PP&G agreement/policy or any type of policies or actions similar to that agreement/contract;
2. Abolish all parts 4-Way/PP&G agreement/policy in writing and in systemic

---

<sup>34</sup> Benchmark Developmental Expert Panel (2008). "The Development of Benchmarks for the Delivery of Intensive Behavioral Intervention for Children with Autism Spectrum Disorders in Ontario" (Condensed Version). p.9

<sup>35</sup> Ibid

<sup>36</sup> Autism Resolution Ontario (2008). "ABA as needed, where needed." Retrieved October 17, 2011 from [www.autismresolutionontario.com](http://www.autismresolutionontario.com).

<sup>37</sup> Ibid

practice;

3. Autism Advisory Committee, California Senate Select Committee on Autism & Related Disorders, and California Legislative Blue Ribbon Commission on Autism should conduct a reassessment of EIBT policy to claims made in the class action. An assessment must include the part of the community, those families whose voices have not been reflected in past State committees, who believe that they have been harmed. The policy, according to many clients' view, is unfair to the disadvantaged minority who fail to meet agencies' EIBT criteria;
4. Further evaluation of Ontario's and possibly other Canadian states' adoption of the EIBT policy and a call to abolish all related benchmark criteria.

## CONCLUSION

Clearly, students with disabilities experience prejudice and discrimination that negatively impacts their future outcomes. The EIBT 4-Way policy segregates autistic children based on their performance levels determining an offer or refusal of an EIBT program. Contrary to public and private agencies' claim that the decision regarding autism services is made by the IEP team, this parent and many others have experienced the underhanded nature of this policy that occurs outside the IEP process. Parents including myself continue to reject EIBT discriminatory criteria and advocate for equal opportunities for the intensive one-to-one ABA intervention that is based on each students' unique needs. The EIBT policy and those who implement it should not be allowed to flout the law by its imposition of autistic criteria.

Unfortunately, whether or not the EIBT program/policy is legally sound will depend on the decision of twelve members of a jury. The hearing, likely to be scheduled in 2013 or 2014, will not come soon enough for those children in desperate and immediate need of intensive one-to-one behavior treatment who, because of the continuing implementation, will either be denied entry or will be exited prematurely because of the policy's entrance, exit, or continuation criteria. The policy and actions of Central Valley's government, education agencies, and providers are in clear violation of the laws that protect children from discriminatory procedures and criteria. Until this policy is abolished in its entirety, the fundamental rights of children to access intensive evidence-based ABA here and in Canada will continue to be violated.



# BIBLIOGRAPY

## Primary Sources

Benchmark Developmental Expert Panel (2008). "The Development of Benchmarks for the Delivery of Intensive Behavioral Intervention for Children with Autism Spectrum Disorders in Ontario" (Condensed Version).

Brydolf, C. (2004). *Stuck inside*. Retrieved 20 October 2011 from <http://www.csba.org/NewsAndMedia/Publications/CASchoolsMagazine/2004/Summer/InThisIssue/StuckInside.aspx>

California Department of Developmental Services, (2008). *Autistic spectrum disorders: best practices in inter-organizational collaboration*. Sacramento, CA.

"Early Intensive Behavioral Treatment Program Procedures and Guidelines" 1<sup>st</sup> Edition Approved January 1, 2004. Revised September 8, 2005.

"Early Intensive Behavioral Treatment Program Procedures and Guidelines" 3<sup>rd</sup> publication, May 24, 2006.

"Z.F. et al v. Ripon Unified School District, et al." (2007). United States District Court Eastern District.

## Secondary Sources

Basirico, L.A., Cashion, B.G., Eshleman, J.R., & Roman, M.R. (2010). *Understanding sociology and social problems, fifth edition*. Horizon Textbook Publishing: California.

Glazer, S. (2003, June 13). Increase in autism. *CQ Researcher*, 13, 545-568. Retrieved from <http://library.cqpress.com/cqresearcher/>

Losen, D.J., & Welner, K.G. (2001). Disabling discrimination in our public school: comprehensive legal challenges to inappropriate and inadequate special education

services for minority children. Harvard, *Civil-Rights-Civil Liberties Law Review*, 36(2), 407-460.

Newman, D.M. (2007). *Identities & inequalities: exploring the intersections of race, class, gender, and sexuality*. McGraw-Hill: New York.

### Electronic Sources

AB 1872 (2008). Autism spectrum disorders: clearinghouse. Retrieved 18 October 2011 from <http://www.leginfo.ca.gov/bilinfo.html>

Autism Resolution Ontario (2008). "ABA as needed, where needed." Retrieved from October 17, 2011 <http://www.autismresolutionontario.com>

California Legislative Blue Ribbon Commission on Autism (2007). *An opportunity to achieve real change for californians with autism spectrum disorders*. Retrieved 17 October 2011 from <http://senweb03.senate.ca.gov/autism/documents/whatsnew/Commission%27s%20Report%20to%20the%20Governor%20&%20Legislature.pdf>

SB 383 (2009). Autism Spectrum Disorders: Screening. Retrieved 18 October 2011 from <http://www.leginfo.ca.gov/bilinfo.html>

SB 527 (2008). Autism Spectrum Disorders: Screening. Retrieved 18 October 2011 <http://www.leginfo.ca.gov/bilinfo.html>

SB 1475 (2008). Autism pilot project. Retrieved 18 October 2011 from <http://www.leginfo.ca.gov/bilinfo.html>

Torres, J. (2008). Parents challenge autism-care rules. [Web Article]. *San Joaquin County Record*. Retrieved at Record.net on 17 September 2011 <http://www.recordnet.com/apps/pbcs.dll/article?AID=/20051224/NEWS01/512240362/1>