

Advocate

The Georgia Advocacy Office...securing protection and advocacy for individuals with disabilities or mental illness throughout the state...now in our 28th year

**THE GEORGIA
ADVOCACY
OFFICE, INC.**

Fall 2005

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THE POWER OF THE PEOPLE

“...HOW MUCH IT MEANS TO HAVE OTHERS JOIN IN”

as told by Laura Royal



Photos of Zachary and his family.

Laura and her entire family, husband Chris and children Sarah and Lee, have been outstanding advocates for Zachary for all of his life.

This advocacy story began shortly after Zach’s birth when the family had to adamantly oppose the idea that Zach should be institutionalized. Last year when flu and pneumonia put Zach in the Intensive Care Unit (ICU), the members of the Parent Leadership Support Project (PLSP)* came to his aid. The following is Laura’s story.

“Last year, as Thanksgiving approached, we found ourselves stuck in the hospital, with Zach in the Pediatric ICU. His pediatrician and the attending doctor agreed that Zach would be able to go home as long as he could get a few days of around the clock home nursing care.”

This request from the doctors was made to Medicaid. The answer came back that Zach needed only 12 hours of nursing care a day (half of what Zach’s pediatrician recommended). Laura says, “Zach’s pediatrician couldn’t believe the doctor at Medicaid made that (*see description of PLSP on pg. 2)

decision having never seen Zach. Especially since the ICU cost about \$3000 per day, and the cost of around the clock nurses to come to our home is only about \$1000 per day.”

There seemed to be no recourse, so Zach went home with just the 12 hours per day of nursing care. “Within 24 hours, Zach stopped breathing,” Laura remembered, “and I had to give him mouth to mouth resuscitation until the ambulance arrived.” Zach was rehospitalized in the ICU for another week. Once again the doctors wrote orders for him to go home with three days of around the clock nursing. Once again the answer from Medicaid was “No.”

“It was then that I spoke to my friend, Jenny Clark, about the dilemma,” said Laura. Jenny, a recent graduate of the Parent Leadership Support Program, drafted a letter (see inset on page 5 for a copy of the letter), put it on the PLSP listserve, and several others, and the phones in the Governor’s office began to ring. Jenny estimates that hundreds of people called the Governor’s office about Zach’s situation.

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HISTORY, ACHIEVEMENTS, AND FUTURE OF THE PARENT LEADERSHIP SUPPORT PROJECT

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"I just wanted to share something we are doing down here. We are empowering everyone! There's a group of us attending everyone's IEP who wants us. It has changed the whole face of IEP's."

*- e-mail from PLSP Graduate
Fall '03*

The Parent Leadership Support Project (PLSP) began as an idea of Leslie Lipson, a GAO attorney. She wanted to give citizens an opportunity to assist families who are advocating for their children by giving them the specific skills and knowledge they need to advocate for students who have disability labels. The goals are for children to be included in regular education and to benefit from the other provisions of the Individuals with Disabilities Education Act (IDEA). IDEA is the federal regulation that guarantees all children a free and appropriate public education.

Participants in PLSP receive over 40 hours of instruction in a challenging, interactive format. The first series of classes was held in the Winter of 2003 and 24 people graduated from the course. The fifth, and most recent course, was held in Macon and the 24 members of that class bring the total number of PLSP graduates in the state to 134. The Fall 2005 session is being held in Athens from August 27 to December 10.

In the planning stage of PLSP the expectation was that graduates would assist families with their individual

education situations. When the Project was evaluated this spring, the consensus was that the graduates have far exceeded those expectations. The graduates, with their skills honed by the course and networked by their listserve, have put their enthusiasm to use in many different ways. The following excerpts from their e-mails and letters represent some of their extra accomplishments:

- o Presented to a college class of future teachers.
- o Became the Parent Teacher Association Chairperson of child's school.
- o Joined the Exceptional Children's Committee in county.
- o Coordinated advocacy training for parent support group.
- o Rallied political support to reinstate funding for Inclusion Specialists in county.
- o Spoke at child's school's teachers' luncheon.
- o Circulated a petition for American Sign Language to be accepted at the state level for foreign language credit.
- o Wrote a newsletter article.
- o Started a charter school.
- o Spoke to Vocational Rehabilitation Counselors.
- o Met with the County Special Education Director about policy.
- o Wrote and filed a complaint of violations of a student's rights to the State Board of Education.

"Today was the IEP meeting for the child whose family I'm assisting. We got an independent evaluation, a change of placement, and all the goals amended, as the Dad requested."

*- e-mail from PLSP Graduate
Spring '04*

PHOTOS FROM GRADUATION DAY FOR PARENT LEADERSHIP SUPPORT PROJECT CLASS V

On Saturday, May 7, 2005, Class V of the Parent Leadership Support Project held their graduation ceremony at the First Christian Church in Macon, Georgia. Of the twenty-four graduates, thirteen were awarded commemorative pins for their perfect attendance in the 40 hour, 12 week course.

“Without question, this course has improved my advocacy skills,” shared one graduate. “It taught me how to organize and prepare [for an IEP meeting]. I have already begun advocating for others!”



Georgia Seabrook (second from right) and her family surround Leslie Lipson (center), PLSP Coordinator.



Elizabeth Pruitt’s family, as well as other families, came to celebrate the accomplishments of the graduates.



Floyd Douglas, Henrietta Bellows, Kat Bartlett and Joszet Johnson have just graduated and are enjoying the reception.



The Parent Leadership Support V class members in their Macon classroom, with Leslie Lipson and guest presenter Daryl Morton in the background.

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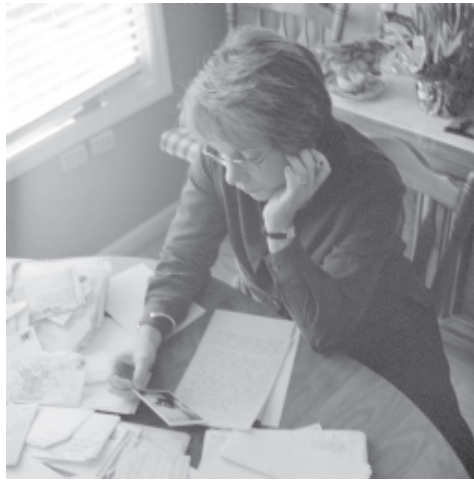
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A 16 YEAR VIGIL

Jessica Howell



In 1989, Susan Earl was working for an organization assisting elderly people in Chatham County when the Coordinator of the Citizen Advocacy office asked her to attend a school meeting in the absence of another advocate. The purpose of the meeting was to discuss a plan the school was proposing to send Benjamin Smith* to Georgia Regional Hospital because of his persistent absence from school.

At the meeting with ten adults and 12-year-old Benjamin, Susan was the only one to ask him why he didn't go to school. The young man simply said, "What I want is to not be in the third grade, and I don't want to be in this school."

This single exchange sparked what has become a 16-year relationship between a citizen advocate and a now grown man. In an effort to find better options for Benjamin, Susan made weekly visits to the Department of Youth Services. She worked with the Citizen Advocacy Coordinator to find a young man to be a role model and advocate and to help draw Benjamin away from the petty

crimes he was committing to fit in with the neighborhood kids. Susan often met with the Smith family, getting to know his sisters and sharing information about Benjamin while he was in a Youth Detention Center.

After five years of serving as his temporary advocate, Susan realized, "I am the advocate." She and Ben had established a solid relationship through visits, letters and phone calls. Benjamin, while having been moved 28 times throughout his years of incarceration, has written nearly 100 letters to Susan. He has spent much of his life in institutions, and he faces several more years in prison.

*Susan realized,
"I am the advocate."*

Both Benjamin and Susan have learned from their relationship. Susan says Benjamin has been comforted by the fact that she always knows where he is. He has counted on her to check on him or to send others to do so in her absence. For her part, Susan has been able to recognize her young friend's resilience and strength, as well as to appreciate his talents. She has learned much about the persistence and patience that are so vital to Citizen Advocacy.

Susan says that the most important lesson was when she learned to step outside her comfort zone. With support from her family, community, and colleagues, she has become a part of something she never could have imagined.

** Name has been changed to honor privacy.*

HOW MUCH IT MEANS (CONTINUED FROM PAGE 1)

Re: Calling All Advocates

I am writing this on behalf of my best friend Laura Royal. Laura and her husband Chris live in south Georgia with their three children. Their youngest son Zachary is medically fragile and requires in home nursing care. Zach has private insurance and Medicaid.

Three weeks ago Zach was ambulated to Macon due to pneumonia. Twice they brought him home and Friday, November 12, Zach coded and Laura and the home nurse had to perform CPR. He was again rushed by ambulance to Macon. With intense therapies, Zach has gotten better and his docs on Thursday, November 18 wrote a letter to Medicaid saying he could go home.

Now here is the reason you all are needed. Medicaid drug their feet until Friday passing the buck as to who could make the decision that would increase the in home nursing hours. The orders stated to increase from 12 hours a day to 24 hours a day for two weeks, then to go down to his normal 12 hours. The reason for the increase is the aggressive treatments he needs around the clock to keep him well. By 2 PM on Friday no one was in the Medicaid office and no decision was made to increase the hours. Due to the care Zach needs, his doctors did not feel comfortable sending him home with just 12 hours. So Laura and Zach were stuck in the hospital all weekend and are praying with the upcoming holiday someone will be in the Medicaid office on Monday morning.

Zach and Laura want to go home. They need everyone's help. We have come up with a plan to bombard the Governor's office with calls and faxes. When you get this letter please send it to everyone you know and ask them to respond. We are asking everyone to call all day on Monday (Nov. 22) and Tuesday (Nov. 23). Also call the Dept. of Community Health and respond. Your response can be simple. The Olmstead Act was passed to keep people out of institutions because it is against their civil rights. An example of something to say is ... Protect Zachary Royal's civil rights, give him the care that is necessary for him to go home. His family wants to be together for the holidays. Thank you.

Laura reports that "The next day, the Friday before Thanksgiving, when I called the Governor's office, the secretary in the Governor's office said, 'So, are you Laura Royal, Zach's mother?'" No one was at the phone numbers the secretary gave me to call." However, the next day, Saturday, the word came to the hospital that if Zach went home, he could have 16 hours (of nursing care per day)

for three days, then 14 hours for two days, then down to 12 hours."

Laura says, "You don't know how much it meant to us to have others join in. We didn't get around the clock nursing, but without the members of PLSP and the others I know we wouldn't have gotten anything."

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AN ALERT TO ADVOCATES: THE OVERUSE OF THE JUVENILE JUSTICE SYSTEM BY THE EDUCATIONAL SYSTEM

excerpted from a paper written by Donna Champion

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The evidence in the literature and the impression of citizens who are advocates and the GAO staff indicate that a significant number of students, especially boys of racial minorities who are labeled with disabilities, are not as safe as they should be within the public schools or the juvenile justice system.

The following key points of the problem stated above are described in detail in a report entitled "An Alert to Advocates," which is available from the Georgia Advocacy Office.

- Students who are Latino, African American or Native American are more than twice as likely to drop out of school as they are to graduate with a diploma.
- A student who is both African American and male is much more likely to be involved in a disciplinary action at school.
- Nationally, approximately 10% of youth in school have a disability, compared to between 30% and 50% of youth who are incarcerated.
- Special education has risen as a percentage of total enrollment every year since the passage of the Individuals with Disabilities Education Act (IDEA) in 1975.
- An "expedited hearing" can occur to unilaterally remove a youth from school.
- Schools can have these same students arrested, regardless of whether or not the offending behavior was related to the student's disability, even though IDEA and other legislation governing the education of students with disabilities provide that students cannot be expelled for disability-related behaviors.
- Special education itself turns out to be a more segregated environment than regular education. Children receive special education services in more congregated, isolated settings than children receiving regular education services. Segregation is often distinguished by similarities in disability label, gender and race.
- Students from minority racial groups receiving special education are more likely than students who are Caucasian to be placed in restrictive educational settings.

- Restrictive settings themselves breed frustration and bad behavior.
- The labels given to children of minority groups in disproportionate* numbers are: mental retardation, emotional/behavior disorders, and specific learning disorders.
- Evaluation and testing for these disabilities listed above are much more subjective than the evaluations of disabilities such as visual impairments and orthopedic impairments.
- Students with labels of disabilities are also overrepresented* in the juvenile justice system.
- The negative social effects and potentially hazardous conditions in juvenile justice settings could possibly be avoided for students with disability labels if accommodations in the schools were pursued and rigorously implemented. This is true especially in the area of behaviors which are challenging and related to a disability with an emotional component.
- A significantly disproportionate percentage of youth with labels of emotional disorders are in correctional facilities. The percentage is three to five times greater than that of youth with similar labels in the general population of public schools.

* **Disproportionate:** more or less of the population than would be expected based on the group's percentage of the population as a whole.

* **Overrepresentation:** more of the population than would be expected based on the group's percentage of the population as a whole.

Conclusion

The labeling of more and more students as having disabilities has caused the special education system to mushroom. Boys from racial minority groups are especially likely to end up in restrictive settings receiving special education services with labels of mental retardation, learning disorders and emotional disabilities. Students labeled with emotional disabilities are more likely to be removed from school and placed in highly restrictive school settings or juvenile justice settings. These settings are much more dangerous than normal settings for youth.

(continued on page 7)

Action Steps

Recommendations for advocates of youth in schools, especially youth who are boys labeled with emotional disorders and from minority racial groups, are as follows.

- Prevent labeling if possible. Seriously weigh the advantages and disadvantages of entering the special education system.
- Refuse segregated settings and insist on services in typical classrooms. Have this written into the IEP.

- Prohibit the placement of the student into any setting that isolates the child from typical students.
- Prohibit the use of restraints and seclusion.
- If the child for whom you are advocating is already in a restrictive setting such as a juvenile justice setting, do not leave the youth there without a written guarantee that restraints and seclusion and force will not be used. Insist that you will be called should a problem with behavior arise. Be present or have friends present while you appeal the treatment plan.

For a copy of the paper “An Alert to Advocates: A report on the disproportionate labeling of minority students, and the overuse of the juvenile justice system by the educational system” contact Donna Champion at 800-537-2329 or dchampion@thegao.org.

EXCERPTS FROM “IN THE NAME OF TREATMENT: A PARENT’S GUIDE TO PROTECTING YOUR CHILD FROM THE USE OF RESTRAINT, AVERSIVE INTERVENTIONS, AND SECLUSION”

... The Problem

Every year, children with disabilities are injured, traumatized, and even die as a result of inappropriate and inhumane interventions.

The purpose of this publication is to help parents and families learn more about the dangers of the use of aversive interventions, restraint, and seclusion, and to assist them in keeping children safe while dealing in a positive way with challenging or inappropriate behaviors.

Know your rights

There are no justifiable reasons for using aversive interventions, restraint, and seclusion. Laws and regulations covering most children’s service delivery systems generally agree that aversive interventions, restraint, and seclusion may not be used for purposes of staff convenience, or as coercion, punishment, or retaliation. . . . The use of aversive interventions, restraint and seclusion under the guise of therapeutic or educational interventions is unethical because these procedures create risk and unnecessarily take away basic rights.

The IDEA supports positive approaches for all students. The Individuals with Disabilities Education Act (IDEA) creates a presumption

in favor of positive methods, requiring an IEP team to consider using positive behavior interventions and strategies when addressing a child’s behavioral concerns.

You have the right to be fully informed and to deny consent. Because of the dangers involved in using aversive techniques, restraint, and seclusion, programs wishing to use them must require children’s parents or guardians to give “informed consent.” You have the right to refuse that consent.

Parents should beware of “stealth consent forms” that some programs try to slip under their radar when their child is admitted. These consent forms are vaguely worded, asking only for the parent or guardian’s permission to use “restrictive procedures” (or some other unclear term).

You have the right to fully informed and appropriately trained teachers and staff. These are some important questions to ask: Have staff been fully trained in positive means of support? Have they been trained in techniques of prevention, de-escalation, and redirection in the face of a challenging situation?

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For a copy of the paper “In the Name of Treatment” contact The Alliance to Prevent Restraint, Aversive Interventions, and Seclusion at www.aprais.org

The Georgia Advocacy Office is Reorganizing to Advocate for the Most Vulnerable Children

The Georgia Advocacy Office's highest priority is preventing abuse and neglect to people, especially children, who have labels of disabilities. The children of greatest concern live in large institutional facilities overseen by the Georgia Department of Human Resources. Most of these young people have little voice in determining their futures and are far removed from attentive families. Also of concern are the several thousand children who are living under the authority of state and county entities, the Department of Community Health, the Department of Juvenile Justice, and the Department of Education. When children are removed from the people, places, and opportunities that characterize life in a loving home and family, the harm done is too great.

The Georgia Advocacy Office is addressing this concern by reorganizing its advocacy on behalf of children in the following ways:

- **Staff Advocacy.** Staff advocates who were providing advocacy to families seeking advocacy assistance for the education of their children who live at home will now advocate for children who have labels of significant disabilities who are living in institutions, nursing homes, and foster care.
- **Resource Advocacy.** Resource Advocates will continue to provide phone consultation to parents calling for advocacy assistance for their children who live at home.
- **The Parent Leadership Support Project.** Members will be recruited who want to advocate for children who are

entitled to extra supports in their educational services due to being labeled with a disability and who have no parent advocate.

- **The Children's Freedom Initiative.** The Georgia Advocacy Office, Governor's Council on Developmental Disabilities, Institute on Human Development and Disability, People First of Georgia, and the Statewide Independent Living Council, continue with a collective systemic advocacy effort to put pressure on the state systems who have custody of children with disabilities to reallocate their efforts from institutionalizing children to providing homes and families.

The facts concerning the risk of great harm facing and being experienced by Georgia's children who have labels of disabilities are not new nor are they secret. However, they are difficult to comprehend and respond to in ways that have the prospect of long term protection of the children. No professional or legal solutions alone that we at the Georgia Advocacy Office can undertake have the positive possibilities that could be provided by local community members acting alone or together.

If you are interested in being a powerful ally to a child who has a disability label who lives in or is from your community, and who currently has no parent advocate, please get in touch with us via e-mail at info@thegao.org or call to speak to one of the resource advocates.

The GAO Advocate

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- US Dept. of Education/Rehabilitation Services (PAIR);
- US Dept. of Education/Nat'l. Instit. on Disability and Rehab. Research (PAAT);
- US Social Security Administration (PABSS);
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