Our Mission

To advance the quality of life, dignity, equality, self-determination, and freedom of choice of persons with disabilities through collaboration, education, advocacy, as well as legal and legislative strategies.

Board of Directors

Ms. Helia Garrido Hull, Esquire, Chair
Mr. Peter Schoemann, Esquire, Vice-Chair
Mr. Jonathan Alpert, Esquire
Ms. Minerva Bailey, Esquire
Mr. Lawrence Forman, Esquire
Mr. Lawrence Fuller, Esquire
Mr. Douglas Jones, Esquire
Mr. John Nelson Kull, III
Ms. Susan McCulloch
Ms. Catherine (Beth) Piecora
Ms. Linda (Lin) Rayner
Dr. Karen Anita Thornton
Ms. Carolyn Wilson
Dr. Elizabeth Holifield, Chair Emeritus

Protection and Advocacy for Individuals with Mental Illness Advisory Council

Ms. Linda (Lin) Rayner, Chair
Ms. Angela Vickers, Esquire, Vice-Chair
Ms. Carolyn Boswell
Mr. Michael Demers
Mr. Phillips Ketchum
Ms. Diann Mayo
Ms. Sandra McQueen-Baker
Ms. Amy Peloquin
Mr. Andrew Straticzuk
Dr. Rajiv Tandon
# Table of Contents

Message from BOD Chair and Interim Executive Director ........................................ 4  
Voter Independence Project ......................................................................................... 6  
Fighting for Due Process ......................................................................................... 7  
Making Home and Community a Reality ................................................................. 8  
Passage of Guardian Advocacy Reform .................................................................. 9  
Rights Training and Facility Monitoring .................................................................. 9  
Peer Initiatives ........................................................................................................ 10  
Mental Health ......................................................................................................... 10  
Reforming Restraint and Seclusion Use Statewide .................................................. 11  
A Close Look at the Mentally Retarded Defendant Program .................................. 11  
30th Anniversary Timeline ...................................................................................... 12  
Community Access .................................................................................................. 14  
Getting to and around Florida .................................................................................. 14  
Securing Direct Notice of Abuse and Neglect .......................................................... 14  
Information Services .............................................................................................. 15  
Stopping the School to Prison Pipeline .................................................................. 17  
Advocating for Youth with Disabilities in the Juvenile Justice System ................... 18  
Making School Safer ............................................................................................... 18  
Better Outcomes at School .................................................................................... 19  
Focusing on Successful Transition for Students ..................................................... 19  
Employment Successes ........................................................................................... 20  
Protecting Rights ..................................................................................................... 20  
Self-Empowerment .................................................................................................. 20  
Jobs and Assistive Technology ................................................................................. 21  
Statistical Overview ................................................................................................. 22  
Financial Information ............................................................................................... 23
2008 was a difficult year for all Floridians, especially Floridians with disabilities. Having just celebrated our 30th Anniversary and being encouraged by the Governor’s declaration of November 29, 2007 as Disabilities Rights Day, we began the year reenergized and ready to tackle the challenges ahead.

The outcome of the 2008 legislative session included two reforms from the Advocacy Center’s platform. The first of these was passage of a bill that required Medicaid eligibility to be suspended rather than terminated for individuals who are inmates in the state’s correctional system, county detention facilities, or municipal detention facilities, and who were eligible and received Medicaid immediately prior to being incarcerated. This change was extremely important to people with disabilities, particularly individuals with psychiatric disabilities. Such individuals must have ready access to ongoing treatment and medications upon discharge to successfully reenter society and have productive lives. The second of these was passage of substantial revisions to guardian advocacy law. The Advocacy Center was heavily involved in developing these revisions, which updated the law and created a new rights restoration process for individuals with developmental disabilities under guardian advocacy.

After the 2008 legislative session came the 2008 hurricane season, which was devastating for our neighbors in the Caribbean as well as for many Florida residents. Tropical Storm Fay caused major flooding and wind damage making a record four landfalls in our state. The major storms that followed Fay required vigilance by Floridians. Mid-way through the hurricane season, Florida’s economic base took a direct hit when the real estate market collapsed and a national and global economic downturn began. Florida had the second highest home foreclosure rate in the nation and unemployment was on the rise. State government began belt-tightening exercises unlike any in recent memory.

In 2008, we fought for the due process rights of people with developmental disabilities facing draconian cuts to service levels. We pushed for reform to the mental health system and for the end of criminalization of psychiatric disability. We launched a multi-faceted Voter Independence Project. These projects and others were possible because our Board of Directors had performed its key role of establishing our annual goals.

To advance these goals and carry out our mission, we used many different strategies. We fielded thousands of calls and provided information and referral. We investigated abuse and neglect allegations. Hundreds of clients for advocacy and legal services were accepted. We supported dispute resolution by helping people self-advocate and/or representing them in negotiations or hearings. Training and technical assistance was provided to a variety of individuals and organizations – including members of the Florida Bar.
A key strategy, which the Advocacy Center used as necessary, was litigation. We filed a series of actions seeking to preserve individuals’ rights to a fair hearing before an Administrative Law Judge to determine their level of Medicaid funding for services provided through the Home and Community Based Services Waiver for people with developmental disabilities.

Most of our work for individuals was linked to our multi-year systemic change advocacy goals. In the area of systems change, we advocated for meaningful and fair due process and dispute resolution. We advocated “nothing about us without us” while working to ensure that people with disabilities and disability rights advocates were involved and heard in policy making at every level. Needed reforms and changes were advanced through policy maker education – locally and at the state level. Education and advocacy efforts were directed at agency officials, the Governor’s office and various executive task forces and committees. Efforts were also directed at elected legislators, members of Congress and the federal government. We collaborated with hundreds of groups and individuals to learn about and sometimes jointly address pressing problems faced by Floridians with disabilities. Community education was provided via workshops and trainings, media and our webpage. We conducted outreach about our services.

As we reflect on the outcome of the 2009 Legislative session and look forward to the problems and opportunities that lay ahead, we remain committed to championing the many yet unanswered urgent causes. On the list are funding for developmental disabilities, mental health and other services, school restraint and seclusion reform, implementation of a Medicaid Buy-In program, mental health parity, changes to state housing law, implementation of reforms to the mental health and juvenile justice systems and others. We will continue to support and assist those in a position to make these changes happen. We will continue to urge more individuals, groups, and especially leaders to join us in the work of protecting and advocating for the rights of people with disabilities.

As we approach another hurricane season, we redouble our efforts to support individuals with disabilities who face barriers to appropriate preparedness, shelter and recovery programs and we remind you to prepare yourself and help your neighbor. As always, we are grateful for our hundreds of partners and reminded that we can do much more together than apart. In this report, you will read about many of our successes, challenges, and the successes and challenges of the people we serve.

Helia Garrido Hull  
Board of Directors Chair

Robert E. Whitney  
Interim Executive Director
Voter Independence Project

In 2008, a priority concern of Floridians with disabilities was access to the electoral process. Our approach was a multi-faceted initiative to support access. We published Voting in Florida: A Guide for Citizens with Disabilities in collaboration with the Florida Developmental Disabilities Council. Voting in Florida covered the who, what, where, when and why of voting in Florida as well as information about rights to accommodations, where to file complaints and how to get help. More than 20,000 copies were distributed by the Advocacy Center, the Florida Developmental Disabilities Council and other organizations.

We promoted Voluntary Guidelines for Accessible Political Campaigns, because access to polling places and voting equipment is not fully meaningful without access to information and the opportunity to participate in all facets of the political process. More than 1,400 Voluntary Guidelines were mailed to candidates running for office and to state and county party committees. We directly contacted several candidate campaigns and both the Democratic and Republican state parties to urge that their campaign websites comply with Section 508 of the Rehabilitation Act standards.

The voting rights of persons living in institutions were included in our efforts. We promoted voter registration and voting rights through mass mailings to over 6,000 residential institutional settings. The mailings to assisted living facilities and nursing homes reminded facility operators of the option to have local elections officials come to the facility to run a “supervised voting” program. This option in Florida law helps individuals who face transportation barriers.

Compliance with the National Voter Registration Act was monitored by surveying various local state agency branch offices, community colleges, universities, and Centers for Independent Living.

We tested (and re-tested) the websites of each county Supervisor of Election for accessibility and Rehabilitation Act compliance as well as disability user friendliness. Problems were noted with two-thirds of the websites.

We also surveyed the 67 Supervisor of Elections offices plus the major political party headquarters for access for voters who are deaf or hearing impaired.

More than a third did not know about telecommunications devices for the deaf or the Florida Relay. We monitored and participated in testing of accessible voting equipment in several counties. Information and assistance was provided to the Hillsborough County Supervisor of Elections to aid in the selection of the AutoMark as the county’s accessible voting system. We also monitored Okaloosa County’s testing and implementation of an internet-voting pilot for military and overseas voters.

Accessibility of early voting locations was a priority. A total of 178 early voting polling sites in 47 of Florida’s 67 counties were surveyed for compliance with accessibility requirements. We monitored 85 early voting sites in 19 counties for the presidential primary in January, and an additional 93 sites in 33 counties for the August primary. The survey addressed parking, path of travel, ramps, elevators, other building features, and features inside the voting area.
Restoration of voting rights of former felons was also a priority. The lack of a meaningful rights restoration process has adversely and disproportionately affected individuals with psychiatric disabilities and traumatic brain injuries. Thus, we were active in the Florida Rights Restoration Coalition working to reform the system for Floridians who have served their sentences and completed terms of probation or parole. The Florida Cabinet was convinced to change the rules of executive clemency thereby “automatically” restoring the rights of approximately 40 percent of former felons. However, thousands of people eligible for automatic restoration were not processed in time to vote in Florida’s presidential and regular primary elections. This work is ongoing.

We met with the Secretary of State and top officials in the Office of the Secretary of State on several occasions to discuss voter accessibility issues and voting rights, offer our assistance, and report on our activities. We exhibited at the Florida State Association of Supervisor of Elections Annual Meeting in Pensacola and distributed packets of voter education material. Lines of communication were established for addressing problems. Poll worker training materials from eleven large urban counties were reviewed.

**Fighting for Due Process - Tiers Litigation**

In 2007, Florida redesigned the Home and Community-Based Services (HCBS) Medicaid Waiver system for people with developmental disabilities and created four new tiers or levels of services.

Prior to the redesign, the system had two waivers or levels. The first waiver, the Family and Supported Living Waiver (FSL waiver), had an annual cost limit of $14,792.00. The second waiver, the Developmental Disability Waiver (DD waiver), had no annual cost limit. A person on the DD waiver generally received all services determined to be medically necessary. While the FSL waiver remained the same and one tier remained uncapped, two of the new waivers had new cost limits. In the fall of 2008, the Agency for Persons with Disabilities (APD) began implementing the four-tiered system and assigning individuals to a tier. The preliminary tier assignments, had none been challenged, would have resulted in approximately $124 million in cuts to services. As this wholesale redesign of the HCBS system for people with developmental disabilities was implemented, the Advocacy Center prioritized serving individuals affected and invoking avenues of litigation and collaboration.

We filed a challenge to APD’s proposed rules implementing the new system. An Administrative Law Judge upheld the rules, but our appeal remains pending before the First District Court of Appeal.

Two other actions were filed to secure hearing rights for all individuals affected by the tiers. Those actions were a Petition for Declaratory and Injunctive Relief filed in State Circuit Court and a Writ of Mandamus filed in the First District Court of Appeal. We based those lawsuits on APD’s responses to nearly 7,000 requests for hearings about tier assignments. APD initially referred approximately 700 individuals to the Division of Administrative Hearings. For the remainder of those challenges, APD sent out a form order titled, Final Order Denying Hearing Request. APD found
that the only challenge in these appeals was to the statute itself, which is not cause for an administrative hearing, and allowed for two further avenues of administrative reconsideration. First, the individuals were given ten days to amend their petitions to state more particular reasons for their tier assignment challenge. Second, if the ten days had passed, the individuals were noticed of their right to challenge the decision by filing an appeal in the District Court of Appeal. Both the Petition for Declaratory and Injunctive Relief and the Writ of Mandamus requested the same relief, an order from a higher court directing APD to provide a fair hearing for those adversely affected by their tier assignment. Regrettably, the courts denied both lawsuits for failure to exhaust administrative remedies (such as amending petitions or seeking an appeal). As the group of individuals affected grows, we will continue to review cases for possible re-filing of the due process challenge should their Amended Petitions be denied a hearing yet again.

We agreed to represent as many affected individuals for litigation as we could. We developed improved form petitions that included a challenge that APD’s Operational Rule and Detail was an unlawful, un-promulgated rule. We assisted hundreds of individuals and successfully resolved many disputes. We collaborated with statewide legal aid organizations and experts at the National Health Law Program to exchange information and develop litigation strategy. Some avenues of legal challenge are not ready for litigation until the new system forces individuals to seek institutional placement.

Through public records requests, we obtained information regarding flaws in the waiver applications for the two new cost-capped tiers. A report was compiled of the flaws in the applications and the problems with implementation. We provided that report to key personnel at the Centers for Medicare & Medicaid Services. We asked that they either revoke approval of the two cost-capped tier waivers or conduct a thorough review of implementation.

Throughout this period and as an ongoing commitment, our goal is to ensure that all individuals who contact us for assistance receive it—whether through the Advocacy Center or through other means.

To this end, we recruited and trained pro-bono attorneys and qualified representatives willing and able to accept tier-challenge cases and we referred individuals to competent legal aid organizations throughout the state that have received grant funding to help these individuals.

**Making Home and Community a Reality**

We were contacted by parents of a 21-year-old who was denied private duty nursing. This young adult was living at home with multiple and significant disabilities. The state agency only authorized two hours of personal care assistance. Her parents’ appeal explained that the family had six other adopted children, each with varying disabilities, and that one of the parents recently experienced a stroke. After we worked with the waiver support coordinator and family to submit documentation, her requested hours of private duty nursing were granted.
Our work also helped maintain supported living services for an adult who has autism and needed 24-hour assistance. When she was threatened with reduced services, her guardian feared she would have to move to a more restrictive environment. We discussed possible supports and shared information with the guardian regarding a Circle of Support. A Circle of Support is a dedicated group of individuals who assist in visualizing, expressing and accomplishing dreams of a focus person. While professional staff are not excluded, the circle participants are selected by the individual from a wider group: families, friends, direct care staff and neighbors. The individual has a controlling voice in all decisions. The guardian reported that the Circle of Support they created allowed the individual to remain in her residence. The guardian also shared that she was more confident about making decisions now, because she had the help of the Circle of Support.

**Passage of Guardian Advocacy Reform**

Guardian Advocacy under Florida law provides alternative surrogate decision-making for individuals with developmental disabilities who need help with certain choices. It purports to be less restrictive than standard guardianship, but was for some individuals, more restrictive and less protective of rights. When lawmakers proposed to amend the law, we expressed concerns, offered assistance and commented on many needed changes. We were asked to assist policy makers by conducting analysis and drafting proposed language. Because of a coalition effort that included judges, lawyers, the Agency for Persons with Disabilities, the Florida Developmental Disabilities Council and the Advocacy Center, the law now includes many new protections and rights – including a new process for rights restoration.

**Rights Training and Facility Monitoring**

We launched a large-scale initiative to provide rights training at Florida’s state mental health treatment facilities. We conducted legal rights training twice at each of nine facilities. A total of 1,780 individuals who have mental illnesses were trained. Individuals were provided information in English, Spanish and Creole. The information addressed legal rights, Advocacy Center services, self-advocacy, and voter registration. Attendees asked about their rights to communicate, recreate, access programming, services and their public defenders. During the same visits, we conducted extensive monitoring at each facility and followed up on various problems with policies, programs and practices.
Peer Initiatives

For a third year, the Advocacy Center collaborated with the Florida Peer Network, Inc. (FPN), a statewide independent organization of and for individuals with psychiatric disabilities and co-occurring disorders. FPN’s mission is to promote recovery, quality of life, advocacy, education, mutual support, peer directed services, and participation in mental health policy design. The Advocacy Center purchased community education and outreach services from FPN to promote leadership development, self-advocacy and peer services for adults who have psychiatric disabilities. FPN’s accomplishments included:

- Publishing and distributing four editions of a newsletter to more than 2,200 individuals and organizations and 60 drop-in-centers and clubhouses
- Maintaining an active website, Forum E-News announcements and toll-free number
- Providing on-line educational materials about advance directives
- Publishing Common Threads, Stories of Survival and Recovery for Mental Illness, containing first person accounts of survival and recovery
- Distributing new standards for Peer Specialist Certification as well as a frequently asked questions fact sheet
- Printing and distributing 2,000 copies of the new FPN brochure
- Continuing to provide leadership training for people with psychiatric disabilities and family members.

Mental Health

Ending the Criminalization of Mental Illnesses and Improving Care

While progress toward systemic change remained slow statewide, progress was made in local communities. We continued to support and advocate for needed changes at every level. We also assisted many individuals caught in the criminal justice system and receiving inadequate care. An example was an adult with a psychiatric disability held in a county jail. The jail was not giving this individual his mental health medications, because they were not on the jail’s medication formulary. The jail was giving him something else and that medication was not working. Using the information and technical assistance we provided, his mother worked closely with his Florida Assertive Community Team (FACT). They resolved the issue by having the FACT Team provide the medication directly to the jail. His mother was so moved that the jail was unaware of such an easy solution, she decided to devote her time to advocacy for better treatment of all individuals with psychiatric disabilities in her community. She was thereafter accepted as a member of her county’s criminal justice coordinating committee.
Reforming Restraint and Seclusion Use Statewide

Part of ongoing restraint and seclusion reform advocacy was addressing rulemaking by the Department of Children and Families (DCF) and the Agency for Persons with Disabilities (APD). DCF and APD both made progress toward fulfilling their 2006 rulemaking mandates. We tracked both agency’s rules, analyzed drafts, submitted written comments, advocated at rulemaking workshops and hearings, and followed implementation as part of our wide-ranging advocacy for reform.

DCF promulgated its revised rule in May of 2008 (F.A.C. 65E-5.180 Right to Quality Treatment). Our input focused heavily on trauma-informed care, training, safety, post event analysis and reporting. APD then promulgated its first revised rule in August of 2008 (F.A.C. 65G-8.001-8.012 Reactive Strategies). APD also immediately initiated an informal process to gather input for use in a refined and improved version. Our input at that stage focused heavily on assessment, dangerous procedures and prohibitions, training, criteria for release, notice to parents and guardians, overall reduction, debriefing, data collection and analysis. At this time, APD has yet to resume formal agency rulemaking or act on our recommendations. We also continued to investigate restraint and seclusion related deaths.

The overall rate of known restraint and seclusion deaths in DCF and APD programs substantially decreased as a result of heightened awareness, legislative policy making, agency rulemaking, increased training and other events in which the Advocacy Center remains an integral part. Our advocacy is ongoing.

A Close Look at the Mentally Retarded Defendant Program

The Mentally Retarded Defendant Program (MRDP) is a secure forensic institution for defendants with developmental disabilities who are incompetent to proceed to trial. The MRDP is operated by the Agency for Persons with Disabilities (APD) on the grounds of Florida State Hospital in Chattahoochee, Florida. In 2007, an incident occurred at the MRDP involving residents and staff that resulted in injuries to both. This incident was the third of its kind in less than eight weeks, and resulted in “extended seclusion” for seven residents. The event and MRDP’s response to it, prompted us to conduct an intensive ongoing review of the program and issue a series of reports, including several in 2008. Our reports addressed several issues including access to rights information, use of seclusion rooms, environment, staffing, admissions, the behavioral wards, and the competency restoration training and other curricula. Our monitoring and advocacy continues, and includes regular dialogue with APD about their progress and plans to address concerns.
The Advocacy Center was established by executive order of Governor Reubin Askew as the Governor’s Commission on Advocacy for Persons with Developmental Disabilities.

The Florida Legislature passed a law transferring the Florida P&A to the Executive Office of the Governor, creating the Governor’s Commission on Advocacy for Persons with Disabilities.

The Florida Legislature passed a law transferring the Florida P&A to the Executive Office of the Governor, creating the Governor’s Commission on Advocacy for Persons with Disabilities.

Jon Rossman became the Advocacy Center’s first Executive Director.

Miller Frank Johnson, et al, v. Martin Von Holden. The Advocacy Center had amicus status in this case, heard in the Middle District Court, which resulted in the closure of the G. Pierce Woods State Hospital (a mental health institution).

Gonzalez v. Martinez, et al. (also known as Sanbourne) The Southern District Court of Florida recognized the rights of individuals receiving mental health services to include improved services, community treatment and individualized treatment plans. The Advocacy Center was the court appointed monitor for the improved services.

By executive order, Governor Bob Martinez designated a non-profit corporation to receive federal funds for the Commission on Advocacy for Persons with Disabilities. The Advocacy Center for Persons with Disabilities, Inc., was established, and was designated in the Laws of Florida Chapter 87–131.

1975

The Protection and Advocacy (P&A) concept was inspired by a series of TV broadcasts by Geraldo Rivera, exposing abuse, neglect and lack of programming at Willowbrook, a state institution for people with mental retardation in New York. These broadcasts galvanized the state’s senior senator to action. He worked to incorporate P&A systems in the renewal of federal developmental disabilities legislation.

1977

The Advocacy Center was established by executive order of Governor Reubin Askew as the Governor’s Commission on Advocacy for Persons with Developmental Disabilities.

1978

Willowbrook State Institution

1979

Florida Association for Retarded Citizens v. Martinez. This was the first case in the United States that resulted in a court directing final closure of an institution for citizens with mental retardation. Southern Legal Counsel of Gainesville represented plaintiffs and was also legal counsel for the Advocacy Center throughout the 1980’s and early 1990’s.

1986


1987
Beginning in 1988, Quality of Life Reviews were conducted on several mental health and developmental disability institutions and state hospitals, which resulted in recommendations, policy changes and litigation in favor of residents.

**1989**

**Shelyndra Brown and Jesse O’Neil, et al., v. Bush, et al.** The Advocacy Center sought appropriate community placement for adults with disabilities residing in the state’s Developmental Services Institutions. The class action lawsuit resulted in the closing of Landmark and the projected closing of Gulf Coast Center in approximately 2010. The Advocacy Center monitored the discharge and placement of individuals to ensure their safe and successful future.

**1988**

**Chris Doe, et al., v. Dr. Charles E. Stincer, et al.** The Southern District Court of Florida granted clients the right to review their mental health records, upholding the Advocacy Center position.


**1996**

**Hunter v. Chiles, et al.** The Southern District Court of Florida supported the Advocacy Center’s position, and held that augmentative communication devices and services prescribed by treating professionals should be covered by Medicaid.

**1997**

**Wolf Prado-Steiman, et al., v. Bush, et al.** This was a class action lawsuit that established a regulatory infrastructure and provided more benefits to individuals with developmental disabilities. A successful settlement agreement was reached on behalf of approximately 12,000 individuals who were on a waiting list for services under the waiver—a number that reached 24,000 within a year.

**1998**

**Esteban v. Cook.** The Southern U.S. District Court agreed with the Advocacy Center and held that the dollar limit for wheelchairs provided to people over 21 years old violated the Medicaid Act and was arbitrary and unreasonable.

**1999**

**London v. Agwunobi, et al.** The Advocacy Center joined three other legal services organizations in filing a class action lawsuit on behalf of people with developmental disabilities protesting a legislative reduction in personal care assistance (PCA). Corrective legislation permitted additional PCA. The case settled and the Advocacy Center monitored rule making and helped individuals receive appropriate PCA.

**2003**

**Advocacy Center v. Butterworth.** The Advocacy Center filed suit in federal court in Tampa on behalf of individuals with mental illnesses who had been declared incompetent to proceed to trial but not transferred in a timely manner or provided appropriate restoration treatment.

**2006**

**2007**

A series of projects were undertaken resulting in publications produced by the Advocacy Center, which gave vital information to the public such as:

- The Medicaid Community Mental Health Project—Blueprint for Reforming & Enriching Florida Services
- Medicaid Substance Abuse Project—Blueprint for Reforming & Enriching Florida Services
- Transition—The Passage from Youth to Adulthood and Freedom to Work 2003—An Update to the Medicaid Buy-In Program.
Community Access
Working at Every Level to Protect Rights

• We monitored dozens of cases filed in federal court on behalf of people with disabilities to determine whether to intervene and/or whether the proposed settlement complied with appropriate laws, such as Title III of the Americans with Disabilities Act.

• We advanced rights protection through our seat, guaranteed by state law, on the Florida Building Commission Accessibility Advisory Council and Technical Advisory Committee. In that capacity, we worked with state agencies and other advocates (including advocates for individuals with physical disabilities, hearing impairments, and paralyzed veterans) to evaluate requests for waivers of accessibility requirements.

• Beginning in 2007 and continuing through 2008, we focused on access to buildings that house the courts and the justice system in Florida. As a member of the Supreme Court of Florida’s Court Accessibility Subcommittee, we helped develop regional trainings and a comprehensive site survey instrument. All 67 counties submitted site surveys and plans for correction. The final report found that the initiative would need to be ongoing, but that it had successfully raised awareness and resulted in immediate improvements (including greater access to the Supreme Court of Florida building).

• Additionally, we were active in the Tampa Bay area as part of the City of St. Petersburg’s Committee to Advocate for Persons with Impairments. In this local arena, we also brought to bear our extensive legal knowledge and expertise in building code compliance and accessibility.

Getting to and around Florida
Our Airport Accessibility Project

As a new and ongoing initiative, we launched our Airport Accessibility Project. Each year many individuals with disabilities are unnecessarily denied access to and use of airport facilities in Florida. The Advocacy Center reviewed the physical facilities of some of Florida’s largest airports and worked with ADA accessibility coordinators to ensure ADA compliance and proper use of assistive technology.

Securing Direct Notice of Abuse and Neglect

The Advocacy Center must be able to investigate deaths in a timely fashion. Delayed access to key information frustrated that ability for years. The Advocacy Center has authority to access records from facilities that treat people with disabilities as well as agencies that investigate alleged incidents of abuse or neglect. However, other states have a cooperative system with state government so their protection and advocacy system can quickly
learn of selected suspicious deaths and injuries. In Florida, there was not a reliable or efficient system in place. For years, the Advocacy Center had unsuccessfully requested access to a system of direct notice of deaths and serious injuries from state agencies. A breakthrough occurred in October of 2008 when the Department of Children and Families finally agreed. The current agreement covers reports of deaths and serious injuries of persons with disabilities in certain settings once received by the Florida Abuse Hotline.

Initial results confirm that this system will substantially increase the Advocacy Center’s efficiency to perform key functions.

However, results also raise concerns that the current system may not be sufficient because it relies solely upon reporting to the Florida Abuse Hotline. Our experience has taught us that unfortunately not all deaths and serious injuries of people with disabilities are reported to the Florida Abuse Hotline despite clear mandates in state law.

Information Services

Information and referral, community education, outreach, media stories and press releases are crucial to our work.

We provided more than 6,500 high quality information and referral services such as the following:

- We assisted a man from north Florida with information about his right to use an emotional support animal. We later heard back that using the information he was able to bring his dog to his new residential placement.

- We assisted a woman from central Florida with multiple sclerosis and the impacts of two strokes. She was unsure of her ability to return to work. We sent her information about Social Security Presumptive Disability, a referral to her local Division of Vocational Rehabilitation office and her local CIL and then heard that, “I wouldn’t have known [my rights] without your mentioning it. I have already called SSI. I have now scheduled a phone interview to apply for both SSI and SSDI on November 3 at 10:30. Not that I have ever wanted to apply for government benefits but this is the first bright spot in my life in sometime. Please go home tonight and know that your job is not only meaningful but that you have surely had a positive impact on my life immediately.”

- We assisted the mother of an adult with a developmental disability in south Florida who asked for help with an APD Tier hearing. We heard back “thank you and everyone in your organization for helping all of us who have loved ones with disabilities. The manual was a tremendous help in writing my daughter’s appeal. It was very concise and easy to follow. I have emailed it to several families and also have encouraged them to call your organization. Everyone that I have spoken with has been so kind and caring. It takes very special people with very big hearts to do what all of you do. I just want everyone to know that your help and kindness is greatly appreciated. Keep up the good work and once again, a great big thank you to everyone.”
We provided 25 trainings on legal rights issues and best practices subjects. For example:

- Hillsborough, Pinellas, Volusia, Putnam and Flagler area foster parents received training about special education rights and responsibilities, including psycho-educational evaluations and how to access our services for children in foster care.
- Attendees at the Dependency Summit sponsored by DCF were trained in transition for youth with disabilities.
- A group of 40 gathered at the Family Council of the Pensacola Cluster and were trained in guardianship and guardianship alternatives.
- Elementary-aged children were taught disability awareness and sensitivity.
- Transition-aged youth with disabilities were taught about their legal rights to transition services.
- Staff and guests at the Palm Beach County Center for Independent Living were trained about workplace accommodations and employee rights and responsibilities.
- New Vocational Rehabilitation counselors were trained to understand VR client rights.
- Families were trained in English and Spanish about special education and advocacy.
- Staff at the Aging and Disability Resource Center of Broward was trained about the Fair Housing Act, the ADA, assistive technology, para-transit and guardianship.
- Cultural Arts Center members and staff were trained in disability sensitivity and assistive technology.
- Attendees at the Governor’s Hurricane Conference were trained about best practices for meeting the needs of people with disabilities before, during and after a disaster.
- Young people in Shriner’s Hospital were trained about their rights to transition services.
- Attendees at the Youth Leadership Forum were trained about employment, advocacy and independent living.
- General education students at the FSU College of Education were trained on students’ rights to education in the least restrictive environment.
- Administrative Law Judges were presented a workshop on parents’ perspectives during due process.
We were out in force at Family Café, volunteering, exhibiting and offering training. The Voter Independence Project (VIP) was the focus of the Advocacy Center’s exhibit and training was provided on self-advocacy and special education rights. As part of the Planning Committee, we also contributed ideas for exhibitors, sponsorships, speakers and other activities.

Additionally, we engaged in outreach about our services to dozens of audiences ranging from the Vision Summit and the Florida Bar to the Florida Disabled Outdoors Association and University of South Florida’s Department of Psychiatry and Behavioral Medicine. We took the opportunity during the legislative session to conduct outreach at several special events at the Capitol including Transportation Disadvantaged Day, Developmental Disabilities Day and Behavioral Health Day. We met with Disability Program Navigators to develop a better referral system to expand employment opportunities for workers with disabilities.

We launched a Recovery Collection library in partnership with the Florida Mental Health Institute. Use of the collection is growing across the state and the available materials can be viewed at http://lib.fmhi.usf.edu/advocacycenter/ and accessed statewide through the Inter-Library Loan Program. Anyone who has a public library card can access the collection. Materials focus on mental health recovery and resiliency.

The Advocacy Center’s work in Leon County to address abusive use of time out and seclusion received local media coverage. We worked to educate the press about the redesign of the developmental disabilities home and community based services waiver system into four tiers. We worked to explain how cost caps and cuts to medically necessary services would be harmful to individuals. Through the media, the public was also kept aware of litigation developments involving the new tier system.

---

**Stopping the School to Prison Pipeline**

**Hillsborough County**

With the support of grant funding from the Southern Poverty Law Center, the Advocacy Center worked to change how Hillsborough County Schools treats special education students. The current system creates a school-to-prison pipeline where children do not get the free and appropriate public education they are entitled to under the law, but instead get fast-tracked into the juvenile justice system after arrests on-campus for behaviors relating to their disabilities.

On October 1, 2008, the Advocacy Center and the Southern Poverty Law Center jointly filed an administrative action against the School District of Hillsborough County. The complaint, filed with the Department of Education, alleged that students were subjected to harsh and illegal disciplinary techniques. The action generated media attention statewide. Local resolution was attempted. Our proposal centered on the use of Positive Behavioral Interventions and Supports in all public schools in the county. This advocacy work is ongoing.
Advocating for Youth with Disabilities in the Juvenile Justice System

Through testimony at several Juvenile Justice Blueprint Commission public hearings and legislative committee meetings as well as submission of written comment and work on Department of Juvenile Justice (DJJ) rules, we advocated for the unmet needs of youth with disabilities. Our recommendations addressed:

- Restraint and seclusion reduction
- Juveniles found incompetent to proceed
- Health care and mental health care
- Community based care and evidence based practices that reduce recidivism
- Education
- Transition back into the community and home school
- Interagency cooperation
- Parental involvement and engagement, and
- Legal process and representation

Many of our concerns were addressed in final DJJ rules. Moreover, several concerns were addressed in the final Juvenile Justice Blueprint Commission report and have been subsequently considered or implemented. The Advocacy Center works in collaboration with the Children’s Campaign and other advocacy groups as part of ongoing advocacy for reform in this area.

Making School Safer

Restraint and Seclusion Reform

Ending abusive use of restraint and seclusion in schools remains a top priority at the Advocacy Center. While more and more groups and policy makers recognized the need for urgent change and stepped up to take a role, we continued to work in a lead capacity. Our work was coordinated closely with the Florida Families against Restraint and Seclusion and the Florida Developmental Disabilities Council. During 2008, that work focused on legislative action and Department of Education proposed rulemaking.

Raising awareness has been key. Successful use of media to educate the public has been a crucial strategy for families, advocates and the Advocacy Center. Raised awareness began to create local changes as well as greater pressures for statewide reform throughout the year. Awareness was also raised nationally through television network and cable news reports and the National Disability Rights Network’s January 2009 report titled School is Not Supposed to Hurt. The report showed an unsettling use of seclusion and restraint tactics resulting in physical and emotional injuries as well as deaths in schools serving students grades K-12 and documented specific situations, including several from Florida.

Advocacy support to families was an area we worked to expand. We assisted several parents end abusive use of restraint and seclusion on their children and put appropriate programs in place. We secured a positive outcome for a 12-year-old student with autism who exhibited behavioral issues on the school bus. Her self-stimulating behavior was controlled by soft-handcuffs. We initially educated the parent about Positive Behavior Supports (PBS) and Behavior Intervention Plans that would teach replacement behaviors. We also addressed the inappropriateness of the restraint use. We assisted the parent in requesting no further use of restraint. When the school obtained additional assistance in PBS, the restraint use ended.
Better Outcomes at School

In addition, dozens of students experienced improved outcomes at school as a result of assistance provided by the Advocacy Center. One example was a 14-year-old with autism who was in segregated classes against his parents’ wishes. The student had minor behavior issues and an I.Q. of 42. The school principal declared that no such student could be successful in a mainstream setting. The Advocacy Center negotiated appropriate classes and convinced the school to look at the student’s achievements, not just the results of one test. The staff and principal then admitted to having little experience with the Autism Spectrum. We arranged training opportunities for them through the Center for Autism and Related Disabilities. We worked to change the principal and staff’s perception of children with autism and their capabilities. We also helped the family develop effective negotiation and advocacy skills. The student was given another chance in general education classes with increased supports and a new functional behavior analysis and behavior intervention plan. The behavior intervention plan was successful and eventually the 1:1 staff support was faded back. The student later reported feeling comfortable without the aide and proud of how things were going - on track for graduation with a standard diploma.

Focusing on Successful Transition for Students

In partnership with Florida's Children First, Inc., we co-published a guide especially for youth transitioning out of foster care. This guide, *Transition: The Passage from Youth to Adulthood*, is about the services and information that can help make transition more successful. The guide provides practical information on the legal rights of students with disabilities as they transition to adulthood. The guide reviews the necessary components of a transition plan, including goals related to education, work, and community integration. The guide has details about:

- Student’s desired postsecondary school outcome
- Adult living arrangement
- Training and services needed to achieve the outcome
- Practical life skills that have yet to be mastered
- Guardianship options for adults who cannot manage their own affairs
- Specific technological devices (supplied by agencies)

The guide also highlights the role of the Department of Vocational Rehabilitation in providing job training, assistive technology, and employment-related assistance. It includes a glossary and a list of state and national transition resources.
Employment Successes

The Advocacy Center also assisted dozens of individuals to better access Division of Vocational Rehabilitation (DVR) services. For example, we assisted an adult with fibromyalgia, mental illness, asthma, and physical and orthopedic impairments who needed full time employment. He was receiving SSDI and working to become a Certified Addictions Professional. DVR had denied training and a home workstation modification request. We contacted DVR to expedite a rehabilitation engineering evaluation of his home office and secure needed training. The training, home office modifications and specialized certification obtained with our support will allow a flexible work environment and increased employment opportunities.

Assistance was provided to a postal clerk who had no health insurance. The individual had applied to DVR seeking a better job. The individual later learned he had cancer and asked DVR to help pay for treatment once all other resources were exhausted. The request was denied. The DVR medical consultant believed that the cancer was terminal and no employment outcome was possible. The Advocacy Center represented the individual in an appeal and provided evidence that with the proper treatment, the prognosis for recovery was good and the individual would be able to return to work. The decision was reversed and treatment for cancer was approved.

Protecting Rights

Major Changes in Vocational Rehabilitation Services

The Division of Vocational Rehabilitation (DVR) reported a budget shortfall in 2008 and implemented two major policy changes: Financial Determination and Order of Selection. The Advocacy Center, along with the Florida Rehabilitation Council and people receiving DVR services, expressed concerns about barriers to work created by these changes. As the changes rolled out, we educated policy makers and engaged in systemic advocacy. Based on federal regulations, we challenged the legality of policies. We also raised arguments about disparate treatment impacts that were likely to result, and we shared insight on other potential problems.

DVR agreed to hold public meetings, make revisions to specify which services would be subjected to changed policies, consider cost of living differences among regions in determining an individual’s cost share for services, and exclude certain disability related expenses.

Self-Empowerment

The Advocacy Center’s work to support individuals in this area is highlighted by several examples. We successfully litigated changes to a number of inappropriate guardianship restrictions placed on an adult who had a mild to moderate intellectual disability. Worthy of special mention was our securing of restoration of voting rights – just in the nick of time for the individual to register to vote.

We assisted a man with a developmental disability who, along with a sibling, inherited a house. While he had a representative payee for Social Security benefits, he was a legally competent adult. His concerns were for the way he was treated by his sibling, and that his sibling was pretending to be his guardian. He was afraid that the sibling would sell the house. Advocacy Center staff explained how guardianship could only be established by a court, with notice, hearing and appointment of counsel.
Regarding the estate issue, we referred him to the Florida Bar with some confidence that he better understood his rights.

In a situation involving end of life issues, the daughters of an elderly adult who was HIV+ contacted the Advocacy Center regarding their father’s care. The callers alleged that their father’s guardian had discontinued critical medications and put a “Do Not Resuscitate” (DNR) order in place. While their father was adjudicated incompetent to make decisions regarding personal care and finances, he was very conscious and aware and had strong desires and opinions about wanting to remain alive.

Advocacy Center staff determined that guardians do not have unfettered discretion to make decisions with such far-reaching consequences against the wishes of the ward.

Medical directives of this type require court approval. We wrote a memorandum of law outlining the issues and sent it to the guardian’s attorney, after which the DNR order was removed and medications restored.

Jobs and Assistive Technology

Advances in technology and science have made it possible for millions of Americans with disabilities to work. Using funding we received from the U.S. Department of Labor, Office of Disability Employment Policy for this Assistive Technology Collaborative Project, we collaborated with Hyatt Corporation to increase the employment of workers with disabilities in the hospitality industry by utilizing assistive technology in the workplace. We developed a DVD video called *Imagine the Possibilities, Innovative Hiring through Assistive Technology*. The video highlights employees with disabilities using assistive technology at Hyatt. Hyatt plans on using the video to educate human resources and hiring managers about assistive technology to recruit and hire more qualified workers with disabilities.

Richard Sabb, a Hyatt employee, was featured in the video. Prior to working for Hyatt, Richard worked for Campbell’s Soup for 20 years. He resigned because of medical complications from a blood clot. After several hospitalizations, Richard began to focus on getting back to work. He had paralysis from the waist down and because most kitchens were inaccessible to his wheelchair, he found it very difficult to get back into his chosen field. Then 9 years ago, Richard entered Hyatt’s Hands-On Educational Services culinary training program. This led to a consultation with a manufacturer that provided Richard with a standing wheelchair with the advanced engineering and technology he needs to maneuver in Hyatt’s four-star restaurant. Richard says, “the standing wheelchair has done amazing things for me.” He is able to reach food seasoning on shelves, use his cutting board for chopping salads, and maneuver around the kitchen just like his co-workers.

For the last 9 years, Richard has worked for the Grand Hyatt Tampa Bay as a Garde Manger Chef. His standing wheelchair has allowed him to work his dream job in the hospitality industry serving guests and being productive.

Mr. Richard Sabb, back at work, with the help of his standing wheelchair.
Statistical Overview

The Advocacy Center provides services to thousands of callers each year. These services are divided into two primary categories – Information and Referral (I&R) and Cases Beyond I&R (such as self-advocacy support, mediation, representation in court or at a hearing).

When we assist an individual with a service beyond information and referral, our success rate is excellent.

Success Rate for Individuals Receiving Services Beyond I&R

- **2008**: 94.77%
- **2007**: 99.32%
- **2006**: 96.46%

We serve diverse callers. This chart shows the latest US Census ethnic percentages for Florida compared to our ethnic distribution of cases for the last 3 years.
Financial Information

Advocacy Center for Persons with Disabilities, Inc.
Statement of Activities
Year ended September 30, 2008

Revenue and Support
Protection & Advocacy of Individual Rights – PAIR $ 786,609
Rehabilitation Services - Client Assistance Program – CAP $ 565,650
Protection & Advocacy for Obtaining Assistive Technology - PAAT $ 217,837
Protection & Advocacy for Individuals with Mental Illness – PAIMI $ 1,449,023
Protection & Advocacy for Persons with Traumatic Brain Injury – TBI $ 51,271
Protection & Advocacy for Persons with Developmental Disabilities - PADD $ 1,808,235
Protection & Advocacy for Voting Access – PAVA $ 477,549
Protection & Advocacy for Beneficiaries of Social Security - PABSS $ 265,536
Donations, Other Grants and Program Income - Non-Federal $ 200,336

Total Revenues $ 5,822,046

Expenses
Program Services $ 5,352,266
General and Administrative $ 828,919

Total Expenses $ 6,181,185
Change in Net Assets $ (359,139)

Revenue and Support FY08

Program vs. General & Administrative

Program Services 87%
General and Administrative 13%