



American Association of
Caregiving
Youth

ANNUAL REPORT

July 1, 2014 – June 30, 2015

This fiscal year ended with the AACY Board revisiting, editing and simplifying its vision and mission statements without changing its charge.

The new **Vision of AACY** is that every youth caring for ill, injured, elderly or disabled family members will achieve success in school and life.

And the new **Mission of AACY** is to increase awareness and provide support services for youth caregivers and their families by connecting them with healthcare, education and community resources.

With the simplification of the vision and mission statements, the **Core Values of AACY** remain constant and continue to be those which permeate the organization:

- **Compassion** that inspires a caring nonjudgmental attitude to honor and value the role of caregiving youth and instill a sense of hope in the future.
- **Innovation** as AACY is unique in the country, the organization will evolve as it explores and discovers the most meaningful ways to convey to the public and professionals the issues and solutions to efficaciously support this otherwise hidden population of children.
- **Responsiveness** to the practical and research findings with ongoing process improvement to evaluate and deliver best methods of supporting caregiving youth including those who otherwise lack access to community support systems.
- **Collaboration** with local, county, state and national partnerships with institutions and organizations to rely on their expertise and resources to achieve desired outcomes and possibilities yet unknown.
- **Empowerment** as more and more are educated including caregiving youth, the public, students and professionals in caring and inclusive learning environments, benefits beyond what can be dreamed today will be achieved.

Background

The American Association of Caregiving Youth began in 1998 as Boca Raton Interfaith in Action with a Faith in Action program grant from the Robert Wood Johnson Foundation. Subsequent funding from the Quantum Foundation formed the cornerstone of its family caregiving support services. In 2005, the organization's name was changed to Volunteers for the Homebound and Family Caregivers (VHFC); its primary program was Boca Respite Volunteers.

A skeleton staff and volunteers contributed more than a decade of hard work, perseverance and dedication to meet the growing needs of an older and more diverse population. Research findings led to the establishment of the U.S. pioneering model, the Caregiving Youth Project (CYP). By the end of 2009, VHFC transitioned its Boca Respite services to Aloesea, a non-hospice program of Hospice by the Sea, and began its focus solely on youth caregiving. Effective

January 1, 2010, the organization officially changed and adopted its new name, the American Association of Caregiving Youth (AACY) to continue its work locally and nationally.

AACY Board of Directors

This fiscal year revealed transition and ultimate strengthening among the AACY Board of Directors members. As of June 30, 2015 the officers and members included:

Joseph Kraus – Chair
Daniel Davidowitz – Vice Chair
Lauraleigh Gould, CPA – Treasurer
Abbi Bentz – Secretary
Connie Siskowski, RN, PhD – President
Gail Eagle - Director
Michael Miller - Director
Isabel Parrado – Director
Beverlee Miller Raymond, Director
Tom Tift, PhD – Director



Kadniel comforting His Grandmother

AACY Development

This year the demand for local services continues to increase. Many families, barely making it from paycheck to paycheck, become disadvantaged when confronted by unexpected and complex health conditions and other circumstances. High copays impact the ability of a family to access needed medical and therapeutic services. As AACY evolves and pushes forward, the highlights of the past and this fiscal year include:

- ♥ 2010 – Official “kick-off” of the nonprofit name conversion from Volunteers for the Homebound and Family Caregivers to the American Association of Caregiving Youth so that the organization could focus solely on this other hidden and un-served population
- ♥ 2011 – AACY received the Community Outreach Hero Award from the Palm Beach County Medical Society
- ♥ 2012 - Dr. Siskowski became a 2012 CNN Hero and was selected to be among the Top Ten globally, bringing national attention to the role of caregiving youth
- ♥ 2013 – Diane Sawyer named Chris Miller, a CYP participant, her “Person of the Week”
 - New videos were produced by WUSF and the United Methodist Church
 - The AACY National Advisory Council was established
- ♥ 2014 – AACY became a certified non-profit by Nonprofits First

- Dr. Faraone, Director of Education Services, participated in the Grad Nation Summit in Washington, DC
- Caregiving Youth Project information was included in the Student and Family Handbook of The School District of Palm Beach County
- Dr. Siskowski presented at the Governor's Child and Youth Council in Tallahassee
- The Content Capsule, housed on the home page of the AACY website, was created through pro-bono services of W2O in NY
- The Schmidt Family Foundation provided seed money to establish the Caregiving Youth Institute
- Two medical students from the University of Miami Miller School of Medicine presented their AACY research results at the American Academy of Pediatrics (AAP) national conference in California
- National sportscaster Dick Stockton donated his voice for an educational Vodcast about caregiving youth which is housed on the School District website and within the Content Capsule on the AACY website.

♥ As of June 30, 2015

- Caregiving Youth Institute held its first conference at Safe Schools in Boca Raton with over 150 attendees including those from several states
- The Washington Post and others carried the story of the AAP presentation in CA and an article also appeared in the national AAP newsletter
- Caregiving Youth Research Collaborative was formed with the University of North Carolina with UNC and AACY in leadership roles
- Dr. Siskowski attended the White House Conference on Aging meetings in Tampa and specifically for caregiving in Washington, DC
- Family University of Detroit joined the AACY Affiliate Network
- AACY again received nonprofit certification from NonProfits First and also was certified as a Mentor Center of United Way
- Extraordinary Charities named AACY for the 4th year in a row for inclusion in its publication as did the fundraising publication of Hands on Tzedakah

Major Accomplishments and Local Impact of the Caregiving Youth Project

AACY is located in Palm Beach County while developing its national presence through a growing affiliate network, partnerships, presentations and publications. The economic hardship of families is reflected in the increasing demand for caregiving by children. Now concluding its ninth year of service delivery through the Caregiving Youth Project (CYP), the following reflects the accomplishments of this important work.

The CYP is the beta program of the American Association of Caregiving Youth®. It began at Boca Raton Community Middle School in 2006. The school was selected from the top ten in prevalence of caregiving from 2002 research, its proximity to the organization's headquarters and the willingness of the principal to take a risk to serve a newly identified group of students,

many of whom were struggling academically and personally. The CYP, in partnership with The School District of Palm Beach County, is now fully integrated in seven middle schools and their related high schools located from Boca Raton north to West Palm Beach and west to Wellington. Additional schools are on a waiting list pending expanded funding.



Since its inception, the CYP has directly served more than 990 youth caregivers and their families or nearly 3,000 individuals of all ages. Additional youth and families received services but have either relocated or are no longer caregiving. There are other children, who have been identified as caregivers within the schools, who are in various phases of program processing. Furthermore, this past year, more than ever before, there are referrals from non-CYP affiliated schools and self-referrals from students, family members or agencies.

The CYP has also reached more than 12,000 students plus school staff with community resources through its Lunch and Learn sessions. The local CYP Advisory Council meets quarterly with participation from The School District and various professionals. It meets at the regional offices of the University of Miami, Miller School of Medicine.

The CYP eligibility process is a day in time in sixth grade; family health situations are ongoing and dynamic. Thus, throughout the school year, the CYP receives referrals from school staff and collaborating agencies along with many self-referrals by students in middle and high schools.



Highlights of the CYP in 2014-15

- ♥ Conducted in-home initial assessments by CYP social workers along with multiple needs-driven follow up home visits during the first nine years resulting in referrals for appropriate community, medical access and medical service assistance to strengthen families and reduce the burden on the child;
- ♥ Utilized collaborative relationships and special funding resources for families to improve their safety and home environment such as making a home, including the bathroom and kitchen, accessible; grab bars and ramps to allow for increased independence; medical equipment and others;
- ♥ Provided continued process improvement through participant and family feedback from major activities (skills building group, camp, workshops) evaluations indicating the success of the activity for them personally as well as input for change and what else they want to learn;

- ♥ Held 230 regular Lunch & Learn sessions twice/month (when school is in session) and provided disease specific and general resources to CYP youth, other students and school staff. During these sessions, there were 1,065 individual student contacts with the distribution of resources and/or follow up as appropriate;
- ♥ Evaluated outcomes from 319 students through the End of the Year Feedback process during May – June 2015. Not all students responded to all questions and not all students receive the same services as they are needs-driven. The results are on page 11.
- ♥ Sponsored various meaningful activities including Camp Treasure, Reunion Camp, picnics, fishing trip, family Holiday Celebration, workshops, and more;
- ♥ Supported student academic success by obtaining school supplies for >300 students; continuing the distribution of laptop or refurbished computers (now totaling 178) and provided tutoring and/or mentoring assistance for CYP participants as needed;
- ♥ Sent birthday cards to CYP members – for some it is the only acknowledgment they receive;
- ♥ Obtained multi-media exposure regarding our youth and their challenges in local, national newspapers, magazines and journals as well as television, radio and internet coverage;
- ♥ Continued participation with Bachelor’s and Master’s social work students from Florida Atlantic University;
- ♥ Conducted 583 student session hours for Skills Building IV and V workshops for high schools students at various schools;
- ♥ Celebrated the graduation of 40 of 41 active CYP high school students (96.7%) of which 33 went on to post-secondary education (82.5%) and two entered the military;
- ♥ Became an official Mentor Center Network Program of United Way;
- ♥ Produced a Study Guide for Caregiving Youth and one for Volunteer Tutors;
- ♥ Addressed the unique needs of CYP students who have experienced the death of their care receiver with bereavement support; there were 13 deaths in 2014-15; and
- ♥ Provided a Caregiving Youth Scholarship in partnership with the George Snow Scholarship Foundation and through the generosity of the Jeffrey Firestone family, presented five other students with scholarships at their CYP graduation celebration.



Aereonna with Family

The number of people served is exponential as school staff and family members, in addition to the direct services provided to the student-caregivers, are impacted.



Having a break from caregiving – time for some fun!

It Takes a Community!

The success of this work is based on strong collaboration among healthcare, education and the community services. Alone it could never be as effective as it has been with partners together. Several examples of how these efforts benefit our students and families include:

- ♥ AmeriCorps of Palm Beach County Literacy Coalition members assist at Camp Treasure and reunion camp with activities and tutoring;
- ♥ Back to School Bash – provides school supplies, physicals and hair cuts for the return to school;
- ♥ Boca Helping Hands – provides food, relief and employment resources for local families;
- ♥ Boca Raton’s Promise – assists students who have a mental health diagnosis of their own and is participating in the Alliance for Mental Health to Break the Silence as it raises awareness about mental health issues and services in PBC;
- ♥ Christ Fellowship Church – delivers meals at Thanksgiving to the homes of CYP families;
- ♥ Clinics Can Help – provides free recycled needed medical equipment for families;
- ♥ Families First – assists families in which grandparents have and/or need guardianship;
- ♥ Florida Atlantic University School of Social Work – CYP is a supervised site for BSW and MSW students who learn first-hand about caregiving by youth;
- ♥ Linus Project makes handmade comfort blankets and a quilters group makes comfort quilts for CYP participants who often have challenges sleeping at night;
- ♥ Florida Atlantic University is the host for Reunion Camp Treasure on its Boca Raton campus which includes swimming, high ropes and campus tours; and
- ♥ Spirit of Giving Network shares information among non-profits, performs Live Scan background checks, gathers Holiday gifts and more.

The CYP has had significant impact on student-caregivers, their families, AACY staff and volunteers as well as within the schools. Four students who shared stories with the media were recognized with “Courage Awards” at Cinco de Mayo party at Strikes of Boca. Existing partnerships continue and new national partnerships have been formed with Caring Across Generations and Patients Like Me.



The Caregiving Youth Institute

The establishment of the CYI was in direct response to the growing number of caregiving youth who are unrecognized, invisible and falling through the cracks at school; youth who, with support, will become healthy, educated and productive adults. The public and professionals do not recognize them and their situations out of ignorance, not intent. Unlike other countries

including the United Kingdom, there are no professional or public opportunities which are focused on any of the four dimensions of C.A.R.E. – Connection, Advocacy, Research and Education - as they relate to the issues and solutions of this hidden population.

Thanks to the Schmidt Family Foundation, during the spring of 2014 a generous grant provided seed funding for the establishment of the Caregiving Youth Institute (CYI) as a program of AACY. The CYI's goal is to raise the level of awareness and multi-system needs of caregiving youth along with solutions for their support. It provides the venue and opportunity to create the formal structure for what AACY has been informally providing for several years. The segments identified through C.A.R.E. include:

Connection

National and social media has helped to begin to raise some awareness about youth who are family caregivers. In response, calls have been received through the AACY 800 number as well as by email from different parts of the US requesting support for family or caregiving youth. The AACY team has been responsive to those who do not have access to the support of services of a Caregiving Youth Project by locating local resources and providing electronic information and connectivity with Facebook and email. Thus, CYI Connection is evolving. In partnership with The Caregiver Space, AACY has created a forum for caregiving youth as a place for conversations and peer support to take place. Ultimately there will also be an educational component to provide a means of interaction so youth caregivers learn they are part of a much larger population and know they are not alone.

Advocacy

The Mayor(s) and members of the City Council of Boca Raton have been aware and have supported the organization since its inception. Former Mayor Susan Whelchel hosted six “young carers” from the UK and wrote on behalf of all caregiving youth to Mrs. Obama with the enclosure of an unanswered letter from the UK group to President Obama. For the past several years AACY Board members and staff have identified and met with legislators and elected officials to educate them about the issues that confront caregiving youth. This includes the City Council members, county, state and federal legislators. Information was also sent to the wife of the Vice President, Dr. Jill Biden, who has a background in education. A legislative champion has yet to be identified.

With CYI, a focused educational effort is being directed to Florida legislators who sit on related committees to gain attention and raise more awareness regarding caregiving youth. With government budgetary constraints, the case will be made from an economic perspective about the cost savings and tax revenue for tomorrow by supporting caregiving youth today. Doing nothing for these children has a long range impact on them personally and then on society. The new national research data and report, when funded, will include presentations on Capitol Hill.

AACY is working to end the reverse age discrimination against caregiving youth. The omission of caregiving youth from national public caregiving program support is likely to be an error of ignorance rather than intention.

Research

The origin of the Caregiving Youth Project was research based in the What Works Survey (2002). Since its inception in 2006 a variety of research and university affiliations have developed. They include:

- ♥ Barry University - School of Social Work – internship site
- ♥ Brandeis University - Sara Elliott – Doctoral Dissertation 2011-2013
- ♥ Florida Atlantic University
 - Schmidt College of Medicine – 2012-2013
 - School of Business – 2013 - 15
 - School of Nursing
 - Doctoral Dissertation Carole Kain
 - Affiliation agreement in process as site for students
 - School of Social Work – BSW & MSW internship site
 - Student volunteer site
 - Reunion Camp with campus tours
- ♥ Fort Hayes State University, Hayes, KS – Dr. Siskowski invited to be on Advisory Board – School of Sociology
- ♥ Lynn University
 - Site of the soft launch of Caregiving Youth Institute with presentation for students in education
 - Initial Reunion Camp site
- ♥ Palm Beach Atlantic University
 - What Works Survey 2002
 - Held multidisciplinary meeting for students in Schools of Pharmacy, Nursing, Psychology & Education
- ♥ Palm Beach State College
 - Students have participated in Summer Youth College
 - Multidisciplinary meeting held with Provost Dr. B. Russell with outcome of PTK honors club to pilot mentoring relationship
- ♥ University of Freiberg, Germany
 - Graduate student – Marvi Eiland – participation in thesis on nonprofit collaborations including with government
- ♥ University of North Carolina
 - Assistant Professor Elizabeth Olsen returned to US from the UK to continue research and interest in caregiving youth
 - Multidisciplinary meeting convened in Chapel Hill resulting in the formation of the Caregiving Youth Research Collaborative (CYRC)
- ♥ University of S. Florida
 - Youth Caregivers Honors Class organized by External Evaluator – Dr. Donna Cohen and others
 - Publication of CYP data with posters at conferences and in peer-reviewed journals

- ♥ University of Miami – Miller School of Medicine – MD, MPH program
 - Grand Rounds and Broward Pediatric Society presentations with pediatrician Julia Belkowitz, MD
 - Medical students completed CYP retrospective research and presented at the annual conference of the American Academy of Pediatrics in CA., drawing national media attention and an article in the national newsletter of the AAP.

Another research component is the continued pursuit of funding to update the only national study, *Young Caregivers in the US (2005)* which is critical to the future development of AACY and the CYI. National demographics as well as healthcare systems and resources have dramatically changed since 2004 when the data was collected and showed that there are at least 1.3 million caregiving children ages 8-18 years in the US. AACY and the NAC (National Alliance of Caregiving - report author) have partnered to initiate the replication and expansion of this research. An application including a budget of \$230,000 was submitted to Genentech Foundation and verbally approved for \$100,000 pending a plan to gain the additional dollars.

Education

AACY staff members have taken and have sought opportunities to share information with both the public and professionals through service club meetings, congregations, webinars, video productions, peer reviewed journals, social and other multi-media and formal conference presentations. AACY has also created handouts that are audience specific. Examples of conference presentations have included the American Association of Pediatricians, American Psychological Association, American Society on Aging, Children's Defense Fund, National Association of School Nurses, and the National Association of School Social Workers.

The CYI will continue educational opportunities with a new focus. An asset of AACY is the intellectual property and materials it has developed since the inception of the Caregiving Youth Project in the Fall of 2006. AACY has copyrighted and will be offering its materials for sale for others to use. Additionally, conferences will generate revenue from vendor participation and sponsorship.

Thus, education of the public and professionals forms the foundation for the future support of the population of caregiving youth and their families. There are currently courses taught which include family caregiving in some sectors of related professionals however, none regarding caregiving youth. People don't know what they don't know. Credentialing of providers and inclusion of caregiving youth challenges and rewards through webinars, video productions, social and other multi-media, conferences as well as the production of media and publications for sale is the ultimate goal.

Initially the CYI will focus primarily on the issues of middle and high school youth caregiving. However, it recognizes that elementary school children may also have caregiving responsibilities. There are three phases of CYI implementation, the final phase being in the years three to five. Over time, CYI will create a learning environment that will be an invaluable resource to the greater local and state community as well as nationally. It is also

projected that the CYI will become financially self-sustaining as well as generate income for other program development and operations of AACY.

Additional Comments

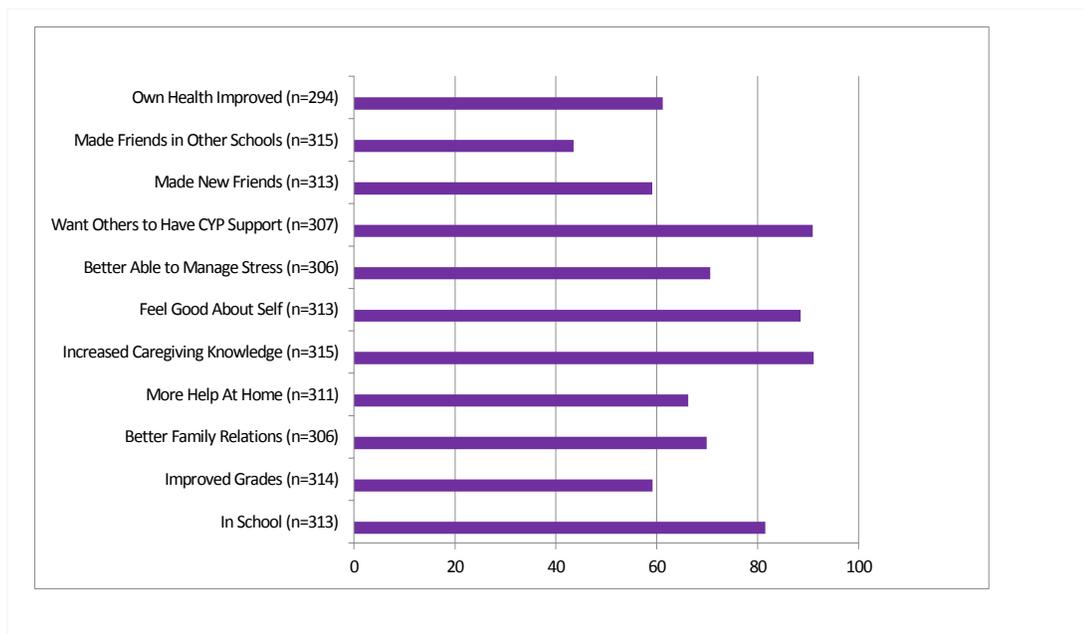
AACY has made significant progress since it became the official name of the organization on January 1, 2010. There is much work yet to be done!

The social media reach through Treasure Talk and Constant Contact is now well over 4,500 people and the “like” and “follower” numbers through Facebook, Twitter and Instagram continue to increase.

There are ongoing challenges with a changing School District administration which are compounded because most schools have new staff and different rules for CYP staff to interface with students. Often students who are greatly in need of our services are ones that have academic struggles; yet they are the ones without an elective period during which we can connect with them.

The valuable feedback obtained at the end of the school year allows us to learn how members feel that their participation in the CYP helped them. The End of the Year Feedback process collects both quantitative and qualitative information. During May-June of 2015, a total of 319 students completed this year’s form. Respondents were 64% female (n=203) and 63.9% were in middle school. Not all students responded to all questions. Some student respondents answered via telephone interview. Students who entered the CYP during the final school quarter were not invited to complete the End of Year Feedback Form.

CYP services provided are needs-driven so not all students received the same supports or had the same opportunities to meet caregiving youth from other schools. The home assessment is a trigger for respite, special projects, access to community resources and other needs-driven services to strengthen the family and thus reduce the work load on the child.

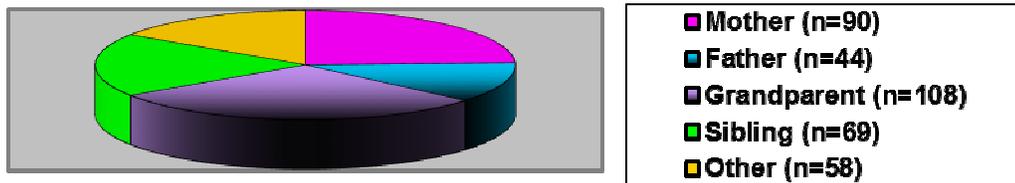


The End of the Year Feedback process also helps to document the number of persons being cared for by CYP members in Palm Beach County. During the past four years, grandparent/great-grandparent care has increased nearly 10%! Who would be providing this care if it wasn't for caregiving youth?

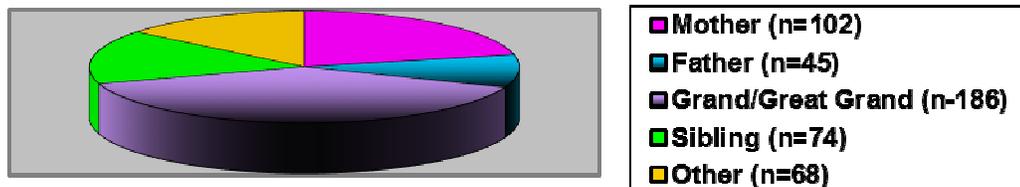
CHANGES IN CARE RECEIVERS OF CAREGIVING YOUTH 2011-12 THROUGH 2014-15

Results of End of the Year Feedback Surveys

2010-11: 226 Caregiving Youth and 369 Care Receivers
Grandparent Care 29.3%



2014-15: 309 Caregiving Youth and 475 Care Receivers
Grand/Great Grandparent Care 39.2%



Some examples of what CYP participants have written about the “how” the services have helped in school and/or with grades are *“because it helped prepare for tests, provided my computer, held programs to reduce stress and forget about worries, manage time, get community service hours, focusing ability, prioritization, attendance, tutoring, take classes online, staying on topic, new strategies, behavior and bullying, less nervous, study methods, test strategies – now I get all A’s, more energy, think more clearly, more time for homework, and to ask for help.”*

Financial Status

The annual audit was conducted and AACY remains deficiency free. A full report is available upon request. Ongoing funding both locally and nationally is a concern as obvious public resources, available for adult family caregivers is not yet available for children. To our benefit,

United Way of Palm Beach County, with a focus on education has again awarded AACY funds for the support of the CYP. The expansion model is to partner and affiliate with existing successful non-profits.

There are several initiatives in place to build sustainability:

- 1) Revenue generation through the establishment and development of the Caregiving Youth Institute with the education of professionals and the public. Two Facilitator Manuals, five workbooks and handouts are production ready.
- 2) Expansion of fundraising as already demonstrated by the increase from \$47,427 in fiscal 2013 to \$118,487 in fiscal 2014 and \$134,844 in fiscal 2015.
- 3) Follow up with Sen. Abruzzo who committed to request line item funding in the next state budget on behalf of Florida's caregiving youth.
- 4) Ongoing utilization of GiftWorks software to track and communicate with donors so that the individual donor base continues to increase.
- 5) Communicate the excellent CYP results of a graduation rate >95% yields a return on investment in terms of social responsibility of >12 times.

AACY has maintained agency certification through NonProfits First and has kept its position within the Better Business Bureau. The BBB report reflects that AACY has met its 20 Standards for Charity Accountability. Its financial review, is based on the fiscal year ending June 30, 2012 and shows that 93% of its expenses are for programs, 2% fundraising and 5% administrative.

For more information: <http://give.org/charity-reviews/national/human-services/american-association-of-caregiving-youth-in-boca-raton-fl-37773#sthash.M8bGdxaL.dpuf>

In kind contributions continue to be very meaningful to AACY. The webmaster has not only volunteered his time and talents but has also financially supported the website. Subsequent pages reflect AACY's finances through the 2014-15 fiscal year.

**AMERICAN ASSOCIATION OF
CAREGIVING YOUTH, INC.**

STATEMENTS OF FINANCIAL POSITION

June 30, 2015 and 2014

	2015	2014
ASSETS		
Cash and Cash Equivalents	\$ 81,324	\$ 108,697
Other Receivables	120,000	15,242
Prepaid Insurance	4,064	11,564
TOTAL ASSETS	\$ 205,388	\$ 135,503
LIABILITIES		
Accounts Payable	\$ 653	\$ 653
TOTAL LIABILITIES	653	653
NET ASSETS		
Unrestricted	31,097	10,462
Temporarily Restricted	173,638	124,388
TOTAL NET ASSETS	204,735	134,850
TOTAL LIABILITIES AND NET ASSETS	\$ 205,388	\$ 135,503

**AMERICAN ASSOCIATION OF
CAREGIVING YOUTH, INC.**

**STATEMENTS OF ACTIVITIES AND
CHANGE IN NET ASSETS**

For the Years Ended June 30, 2015 and 2014

	UNRESTRICTED	TEMPORARILY RESTRICTED	Totals	
			2015	2014
REVENUES AND OTHER SUPPORT:				
Grants, Less Allowance for Uncollectible Promises to Give of \$0 and \$0	\$ 297,500	\$ 172,500	\$ 470,000	\$ 311,500
Other Contributions	123,223	-	123,223	117,030
Fund-raising Events	135,348	-	135,348	119,257
In-Kind Contributions	240,660	-	240,660	237,740
Interest Income	27	-	27	2
Other Income	21,414	-	21,414	6,156
Grant Revenue Released from Restrictions	123,250	(123,250)	-	-
TOTAL REVENUES AND OTHER SUPPORT	941,422	49,250	990,672	791,685
EXPENSES:				
Program Services	829,567	-	829,567	690,397
General and Administrative	43,635	-	43,635	36,060
Fund-raising	47,585	-	47,585	49,617
TOTAL EXPENSES	920,787	-	920,787	776,074
CHANGE IN NET ASSETS	20,635	49,250	69,885	15,611
Net Assets, beginning	10,462	124,388	134,850	119,239
Prior Period Adjustment	-	-	-	-
Net Assets, ending	\$ 31,097	\$ 173,638	\$ 204,735	\$ 134,850