



American Association of
Caregiving
Youth

ANNUAL REPORT

July 1, 2012 – June 30, 2013

**Including a Reflection of Seven Years of Accomplishments in
Palm Beach County**

Vision

The American Association of Caregiving Youth (AACY) is the national resource for children who sacrifice their education, health, well-being and childhood as they provide care for family members who are ill, injured, elderly or disabled. All of America's caregiving youth should be able to complete high school, know they are not alone and have the support they need to become healthy productive adults. The ultimate goal is for no child in the US to drop out of school to provide care for a family member.

Mission

The AACY mission is to raise awareness about caregiving youth, foster the replication of the Caregiving Youth Project (CYP) through an affiliate network in FL and the US, to provide direct and indirect services to caregiving youth and their families, and to establish the Caregiving Youth Institute.

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 Development

At a time when the demand for local services was increasing, the strategic goals for expansion were negatively impacted by the economic downturn. It was a stretch to provide support to an otherwise growing yet still hidden population while resource challenged. However, during this pivotal year the following has been achieved:

- ◆ Dr. Siskowski became a 2012 CNN Hero and was selected to be among the Top Ten globally, bringing national attention along with financial support;
- ◆ Diane Sawyer's team which is focused on hidden populations began working with the AACY team and came to Florida several times for filming including with morning show anchor Josh Elliott;
- ◆ WUSF filmed a CYP member for its Front Line Dropout Prevention documentary series;



- ◆ The Nashville international headquarters of the United Methodist Church produced a video, “Care for Caregiving Youth” which is archived on their website;
- ◆ The AACY Board adopted the Core Values of *Compassion, Innovation, Responsiveness, Collaboration and Empowerment*;
- ◆ AACY received organization certification from Nonprofits First;
- ◆ A newly published book by Sheri Snelling, *A Cast of Caregivers* included a chapter on youth caregiving based on the work of AACY;
- ◆ Extraordinary Charities named AACY for inclusion in its first publication;
- ◆ Dr. Siskowski was a guest speaker in a women’s national conference: Marketing to Women in Healthcare (M2W);
- ◆ The School Board of The School District of Palm Beach County presented AACY with an award for services for students;
- ◆ Affiliations agreements were signed for AZ, MD, NY, NJ and OH and are in various stages of progress, each with a slightly different model;
- ◆ The website traffic increased to > 3,000,000 hits during 2012; and
- ◆ The National Advisory Council was established, headed by Marc Watrous, RPH, PhD an executive with Genentech with goals of raising awareness and raising funds.



Major Accomplishments and Impact

AACY works locally in Palm Beach County while developing its national presence through a growing affiliate network, presentations and publications. The economic hardship of families is reflected in the increasing demand for caregiving by children. Now concluding its seventh year of the 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 one middle school in Boca Raton, FL 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 integrated in eight middle schools located in Boca Raton, Boynton Beach, Delray Beach, Lantana, Green Acres, Wellington and West Palm Beach. There are additional middle and high schools on a waiting list pending expanded funding.



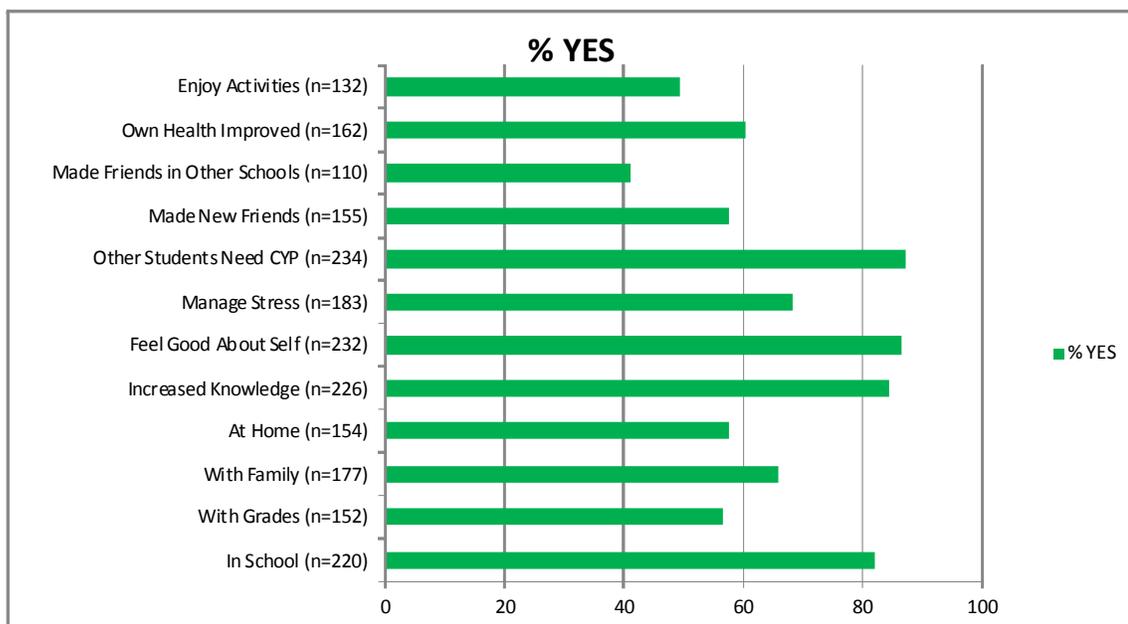
During the 2012-13 school year, the CYP directly served more than 567 youth caregivers and their families or 2,400 individuals of all ages. Additional youth and families received services but have either relocated or are no longer caregiving. There are other children, who have been identified as caregivers 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 extended

its reach to more than 12,000 students plus school staff with community resources through in-school classes and lunch and learn sessions.

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

Highlights of the CYP include:

- ◆ Conducted 250 in-home initial assessments with follow up home visits by a social worker resulting in more than 1,100 referrals for appropriate community, medical access and medical service assistance to strengthen families and reduce the burden on the child;
- ◆ Utilized collaborative relationships and resources for families to improve their safety and home environment such as clean water, grab bars, ramps to allow for accessibility, an oxygen concentrator and others;
- ◆ Provided continued process improvement through participant and family feedback from major activities (skills building group, camp, workshops) indicating the success of the activity for them personally as well as input for change and what else they want to learn;
- ◆ Regular Lunch & Learn sessions held twice/month (when school in session) provided disease specific and general resources to CYP youth and others. During these sessions, there were 1336 individual student contacts and resource distribution;
- ◆ A total of 268 students completed the feedback form during May – June 2013. Respondents were 59.3% female (n=159) and 82.5% were in middle school. Not all students responded to all questions. Some high school student respondents answered via telephone interview. Students who entered the Project during the final school quarter were not invited to complete the End of Year Feedback Form. CYP services provided are needs-driven; not all families scheduled a home visit so not all students received the same supports at home or had the same opportunities to meet caregiving youth from other schools. Qualitative results are also available.



- ◆ Sponsored > 75 various significant activities including Camp Treasures, water park picnic, fishing trip, holiday meals, wellness days, workshops, club, classes and fun for kids at the YMCA targeted to program participants for respite, education, exercise and play;
- ◆ Supported student academic success by: obtaining school supplies for 325 students in this year; continuing the distribution of laptop or refurbished computers (now totaling 143) some with internet access and printers; and provided tutoring and/or mentoring assistance for CYP participants as needed;
- ◆ Published monthly e-newsletter, “Treasure Talk” which is now directly distributed to more than 2,200 program participants and stakeholders;
- ◆ Obtained multi-media exposure regarding CYP youth and their challenges in local and national newspapers, magazines and journals as well as television, radio and internet coverage;
- ◆ Completed participation with graduate studies of a doctoral student from Brandeis, eight medical students from Florida Atlantic University (FAU) Schmidt College of Medicine as well as bachelor’s and master’s social work students from FAU;
- ◆ Expanded Continuing Care for high schools students in which there are ongoing monthly workshops at high schools that house clusters of CYP students from feeder middle schools while individually meeting with high school students attending schools in which there is no CYP cluster;
- ◆ Nominated Sephora Dubreuz who won the SunLife Financial scholarship award which also provided resources for AACY and awareness through the Miami Dolphins;
- ◆ Continued to expand the use of social media and texting to communicate with students and family members in addition to Facebook;
- ◆ Held the annual caregiving youth and family Holiday Celebration and dinner with more than 300 in attendance plus volunteers – CYP members “shopped” and wrapped gifts for others in the Holiday Shoppe organized by AACY partner Stratis Business Systems while young siblings created crafts and photographers took family portraits;
- ◆ Experienced the graduation of twenty-eight CYP high school students in 2013 of which 22 (78.6%) went on to post secondary education. There are four CYP students who no longer attend school although one, a teen mom is working on her GED;
- ◆ Held the first CYP graduation party to honor high school graduates – it was held at their request and sponsored by the Schmidt Family Foundation;
- ◆ Addressed the unique needs of bereaved CYP students with bereavement support through their time of readiness for additional children’s grief support – there were 15 deaths in 2012-13; and
- ◆ Provided a Caregiving Youth Scholarship through partnership with the George Snow Scholarship Foundation.



Building Trust during the Trust Fall at Camp Treasure



Camp Treasure students learned about “Earthing” and each received a pair of Pluggz flip flops.

The support of caregiving youth continues and grows as long as resources permit, including those of our collaborative and national partners. 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.

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

- ◆ AmeriCorps assists at Camp Treasure, with activities and tutoring;
- ◆ A to Z In Home Tutoring helps students who are unable to stay after school;
- ◆ Back to School Bash – provides school supplies, physicals and hair cuts for the return to school;
- ◆ Boca Helping Hands – provides food, relief and employment resource 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 – delivered meals at Thanksgiving to CYP families;
- ◆ Families First – assists families in which grandparents have and/or need guardianship;
- ◆ Hospice by the Sea provides services and Camp Good Grief when a child experiences death;
- ◆ Linus Project provides handmade blankets for our CYP members;
- ◆ Spirit of Giving Network helps with coordinating efforts of local nonprofits, volunteer background checks, back to school supplies and holiday gifts;
- ◆ YMCAs of Boca Raton and Boynton Beach are the sites of wellness days for fun activities and nutrition classes.

The CYP has had significant impact on student-caregivers, their families, our staff, volunteers and the schools. The evidence that AACY work is spreading appears in several ways:

- ◆ The new brochure with CNN featured student on the cover has been well received;
- ◆ Isabel Parrado, AACY Board member and Okeeheelee Middle School liaison became Middle School Guidance Counselor of the Year;
- ◆ A door to street ramp was created and donated for the Alvarado family featured on CNN to ease access for the family and care receiver;
- ◆ CYP students who are high school juniors were given the signed book by Chin Music author Lee Edelstein and selected to participate in an essay contest for monetary prizes from BOMAR Foundation;
- ◆ Funding partner, United Way featured a CYP student on their brochure;
- ◆ Hiring of staff has been intentional in recruiting multi-lingual candidates;
- ◆ The website (www.aacy.org) is having many more pages being read. For the last quarter of 2007, the total pages read were 12,652 while that same period in 2011 was 167,682 and the same period in 2012 was 290,490;



- ◆ Thirteen students received “Courage Awards” at Hearts And “Soles” the annual AACY fundraiser for sharing their stories with multi-media productions;
- ◆ Individuals and companies held fund raisers such a jeans day, Zumba event, birthday dollars and special events to benefit AACY;
- ◆ Schools in which we have a presence, welcome us back to support their students; and
- ◆ Students have remained in CYP into high school; they have stayed connected following graduation and after they have experienced the death of their care receiver.



Works in Progress

There are several activities which remain works in progress. They include:

- ♥ Improving capacity through communications proposal and network infrastructure;
- ♥ Converting client data management system to web-based Soneto which was gifted by Stratis Business Systems;
- ♥ Refining the recruitment and utilization of volunteers through the hiring of a part time Volunteer Manager in January, 2013;
- ♥ Ever present challenges with working in a large school system which are compounded because each school has 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 CYP can connect with them; and,
- ♥ Promotion of development of mental health services. CYP intersects with mental health as students have family members with mental health illnesses and a small percent of CYP members have mental health conditions. Finally, CYP members go through times of normal stress and depression because of the tough situations they are in through no fault of their own. AACY continues to work towards solutions instead of band-aids. One example is changes in school district protocols regarding the Baker Act.

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 challenge as public resources, available for adult family caregivers, are not yet available for children. United Way of Palm Beach County now has a focus on education and has again awarded AACY funds for the support of the Caregiving Youth Project. Ways to raise recurring revenue and become financially self-sufficient are development.

Additional Comments

In kind contributions continue to be very meaningful to AACY. Pro bono legal services have been valuable in reviewing our corporate documents and personnel policies. The issues challenging caregiving youth are nonpartisan. The AACY team played a pivotal role in continuing the Palm Beach County Family Caregiver Coalition in its role of advocacy on behalf of all family caregivers. Meetings have been held with elected officials to promote their understanding of

our work and assist us in seeking public funding. Finally, partnerships continue with the Spirit of Giving Network and others to mutually augment our work and to seek collaborative funding.

Selections from the Written Words of Caregiving Youth

The CYP has helped me in school and/or with grades 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.



Shayna Helping her Older Brother with Homework



Helping Each Other at Camp Treasure



Aereonna and Mom

And a message to CYP from Joyce as she was moving to another County:

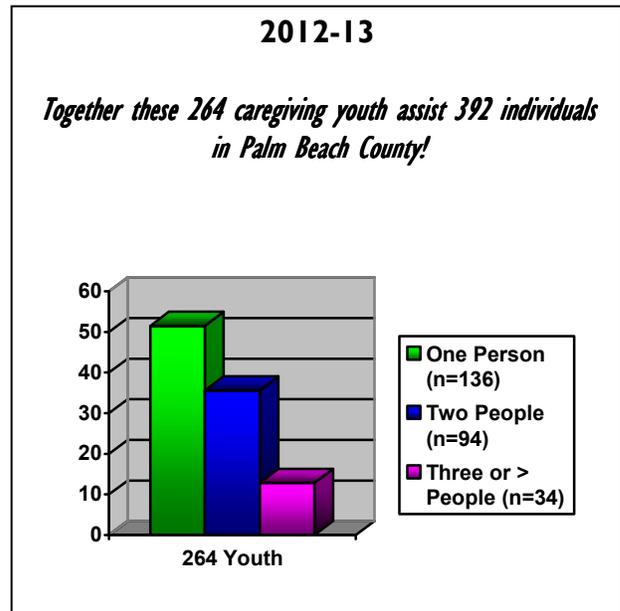
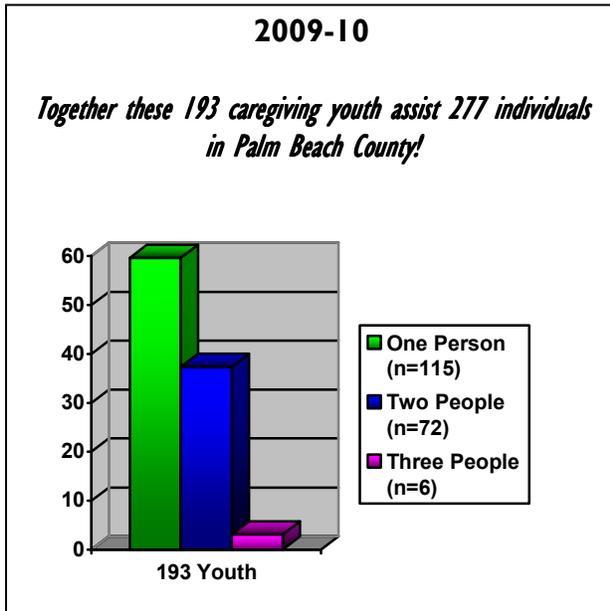
I really much appreciate all of your support and for providing a shoulder for me to lean on when tears were dripping from my eyes. THANK YOU, THANK YOU AND AGAIN THANK YOU. I use to be depressed and cried for days in my room because I was miserable and all my other friends had a fun childhood with no misery. My childhood lasted for 11 years then I was forced to become more mature and take responsibilities of an adult. I hated it because I wanted to be the one to act silly and just be a kid. I now learned that to cure depression you need love and support, and that's exactly what CYP did for me. I will be moving...I will miss you all and I promise I won't forget your faces because it's engraved on my heart forever.



2012-13 Photo Collage

The End of the Year Feedback process has documented a significant increase in the number of care receivers of caregiving youth.

This is a significant increase when in 2008 a random review of 75 records showed that 19 caregiving youth or 25% cared for more than one person. Students typically have entered the CYP from only eight of 34 Palm Beach County middle schools (23.5%).

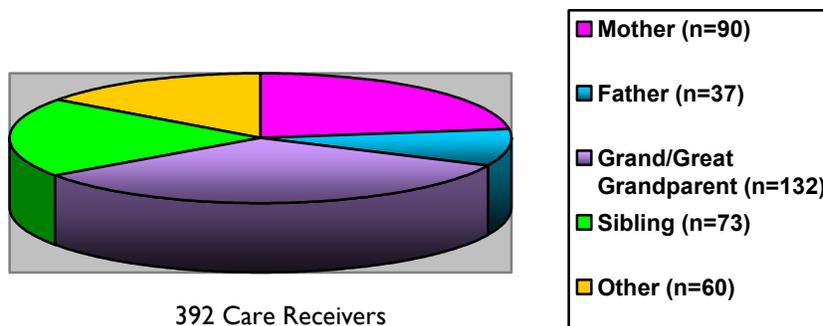


Who are the 392 recipients of care reflected above from CYP youth in 2012-13?

This year showed the percentages of categories of care receivers to be about the same as last year, except one area of significant increase is in the care of ill, injured or disabled “other relatives” such as extended family or an aunt, uncle or cousin which increased from 8.4% to 15.3%.

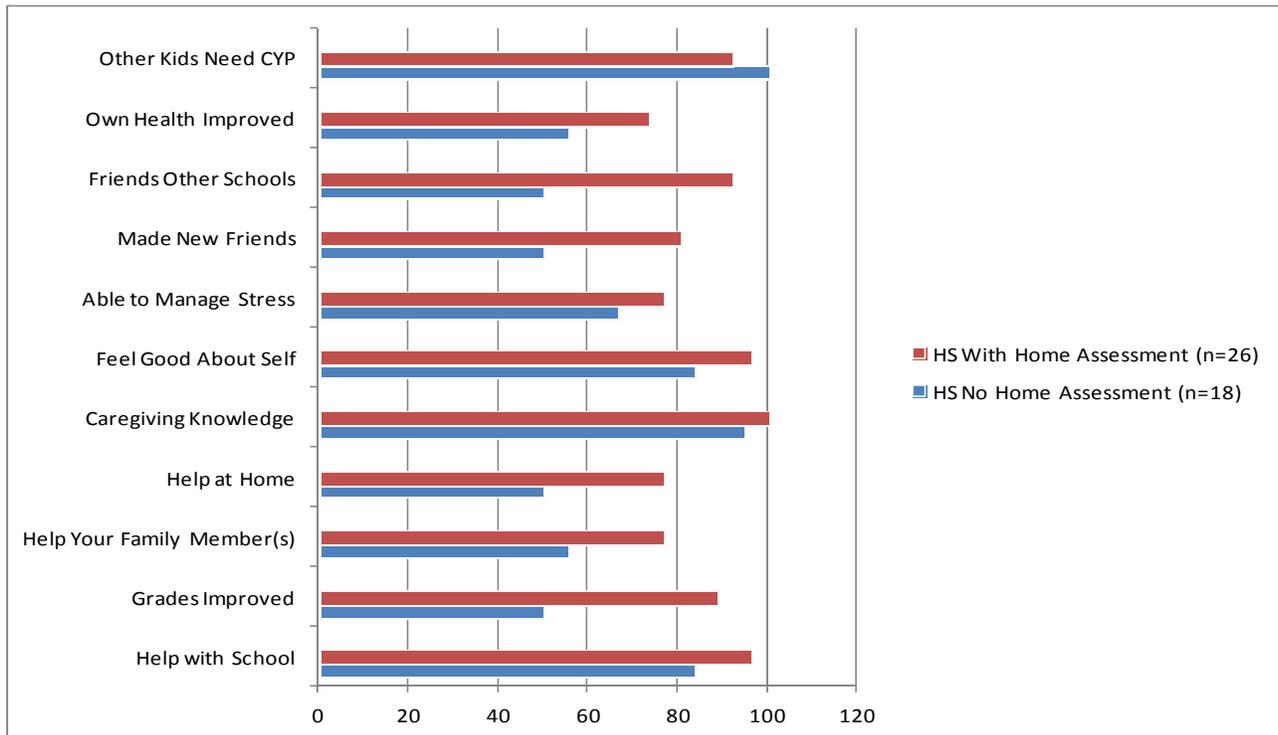
There are 16 students whose both parents have medically related needs!

2012-2013 Care Receivers Among 264 Caregiving Youth



Please note this data is from CYP youth who completed End of the Year Feedback Forms. In May/June 2013 this information was gathered from 268 middle and high school youth. There were four students who are no longer caregiving because of the death of their care receiver.

There is great documented value in the home visit as exemplified below by comparing high school student feedback from ones with home visits and those who have not.



The responses above are answers to the basic question of how the Caregiving Youth Project has helped them regarding a variety of parameters. 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. As reflected above, there is significant benefit to students and their families. There is also qualitative data available as in addition to responding “Yes” there is a space for explanations of “How”.

AACY Board Members 2012-13

- Mark Hansen – Chair
- Paula Alderson – Vice Chair
- Dr. Tom Tift – Secretary
- Scott Walters, CPA – Treasurer
- Connie Siskowski, RN, PhD – President
- Abbi Bentz, BSN,
- Charles Brown, PhD
- Gail Eagle
- Lauraleigh Gould, CPA
- Carlos Herrera, CPA
- Joseph Kraus
- Isabel Parrado
- Tammy Saltzman, JD
- Ronnette Smith
- Ronda Talley, PhD

AMERICAN ASSOCIATION OF CAREGIVING YOUTH, INC

STATEMENTS OF FINANCIAL POSITION

June 30, 2013 and 2012

ASSETS	<u>2013</u>	<u>2012</u>
Cash and Cash Equivalents	\$ 109,779	\$ 26,293
Other Receivables	6,250	
Prepaid Insurance	3,825	2,920
Property and Equipment, Net of Accumulated Depreciation of \$ 14,369 and \$ 14,329	0	40
Unconditional Promises to Give, Net of Allowance For Uncollectible of \$0 and \$0		
	<hr/>	<hr/>
TOTAL ASSETS	\$ 119,854	\$ 29,253
LIABILITIES		
Accounts Payable	<hr/> 8,115	<hr/> 10,196
TOTAL LIABILITIES	\$ 8,115	\$ 10,196
NET ASSETS		
Unrestricted	43,351	(11,331)
Temporarily Restricted	<hr/> 68,388	<hr/> 30,388
TOTAL NET ASSETS	\$ 111,739	\$ 19,057
TOTAL LIABILITIES AND NET ASSETS	\$ 119,854	\$ 29,253

AMERICAN ASSOCIATION OF CAREGIVING YOUTH, INC.

STATEMENT OF ACTIVITIES

Years Ended June 30, 2013 and June 30, 2012

REVENUES AND OTHER SUPPORT

	Unrestricted	Temporarily Restricted	2013	2012
Grants, Less Allowance for Uncollectible Promises to Give of \$0 and \$0	166,250	67,250	233,500	83,500
Other Contributions	175,319	-	175,319	121,298
Fundraising Events	47,512	-	47,512	52,787
In-Kind Contributions	171,200	-	171,200	138,525
Interest Income	-	-	-	36
Other Income	16,034	-	16,034	15,712
Grant Revenue Released From Restrictions	29,250	(29,250)	-	-
TOTAL REVENUES AND OTHER SUPPORT	605,565	38,000	643,565	411,858

EXPENSES

Program Services	505,672	-	505,672	570,976
General and Administrative	26,271	-	26,271	30,009
Fundraising	18,940	-	18,490	13,731
TOTAL EXPENSES	550,883	-	550,883	614,716

**(DECREASE) IN
NET ASSETS**

	54,682	38,000	92,682	(202,858)
Net Assets, beginning	<u>(11,331)</u>	<u>30,388</u>	<u>19,057</u>	<u>221,915</u>
Net Assets, ending	<u>\$ 43,351</u>	<u>\$ 68,388</u>	<u>\$ 111,739</u>	<u>\$ 19,057</u>