



American Association of
Caregiving
Youth

ANNUAL REPORT

July 1, 2011 – June 30, 2012

**Including a Reflection of Six 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 impacted by the economy. It has been a stretch to provide resources to an otherwise hidden population while struggling to survive. However, during this year the following has been achieved:

- ◆ Affiliations agreements have been signed in AZ, NY, NJ and OH;
- ◆ Calls for information and potential affiliations have come from other States including AR, CA, IL, LA, MD, TX, WA and others;
- ◆ AACY was the recipient of the 2011 Palm Beach County Medical Society's Heroes in Medicine Community Outreach Award;
- ◆ Awards were received by Dr. Siskowski as a Woman of Grace from Bethesda Hospital Foundation (2011) and CNN Hero 2012;
- ◆ The AACY donor base was broadened as the CNN Hero award raised awareness with contributions coming from 32 states plus the District of Columbia, the UK and Canada;



- ◆ Local and national multi-media attention to child caregiving continues including from child advocates surrounding legal issues; and
- ◆ AACY Board membership expanded to include Ronda Talley, PhD formerly of the Rosalynn Carter Institute and the CDC as well as Joe Kraus, President of Stratis Business Systems whose company has contributed to and employees have been volunteering with AACY for several years.

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 sixth 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 now integrated in eight middle schools located in Boca Raton, Boynton Beach, Delray Beach, Lantana, Green Acres, Wellington and West Palm Beach. There are additional schools on a waiting list pending expanded funding.



The CYP has directly served more than 550 youth caregivers and their families or 2,300 individuals of all ages. Additional youth and families received services but have either relocated or are no longer caregiving. There are about 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 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 assessments during the first six years 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) evaluations indicating the success of the activity for them personally as well as input for change and what else they want to learn;
- ◆ Evaluated outcomes from 242 students through an end of the year feedback process during May – June 2012 of which 55 students were in high school and 151 female. Not all students responded to all questions. Some high schools students answered using Survey Monkey and others via email. All middle school students completed the form on paper. Students who entered the Project during the final school quarter were not invited to complete the End of Year Feedback Form. Students felt that the CYP helped them:
 - Be more knowledgeable about caregiving and have new skills for both at home (92.5%) and in school (85.4%);
 - Feel good about themselves out of school (93.7%);
 - Make new friends (86.1%);
 - Be able to better manage stress (76.5%);
 - Improve their health (70.1%);
 - Have closer with family relationships (74.7%);
 - Achieve better grades (63.9%).

The overwhelming majority (95.3%) believed that the CYP needs to be available to students at other schools;

- ◆ Sponsored > 75 various significant activities including Camp Treasures, Reunion Camp, fishing trip, family holiday party, 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 130) 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 1,250 to program participants and stakeholders;
- ◆ Increased social media exposure through Facebook and Twitter;
- ◆ 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 including national TV on CNN Heroes;
- ◆ Continued participation with graduate studies of a doctoral student from Brandeis, a masters student in public health from Miller Medical in Miami and served in an advisory capacity to honors students at the University of South Florida in Tampa resulting in new and published research and journal papers in progress;



Building Trust at Camp Treasure

- ◆ Expanded Continuing Care for high schools students in which there are ongoing monthly groups at high schools with clusters of CYP students as well as at a community center in Boynton Beach;
- ◆ Established CYP group on Facebook as well as CYP graduate group;
- ◆ Experienced the graduation of twenty-five CYP high school students in 2012 of which 18 (72%) went on to post secondary education. To date there are four CYP students who no longer attend school although one, a teen mom is working on her GED;
- ◆ Addressed the unique needs of bereaved CYP students through a transition team effort so they can be supported until they are ready for alternate children's grief support – there were 11 deaths in 2011-12; and
- ◆ Obtained a landmark decision from school district officials to award CYP students community service hours for caregiving at home.



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 members assist at Camp Treasure, 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 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;
- ◆ Camelot – counseling referral resource;

- ◆ Christ Fellowship Church – delivered 410 meals at Thanksgiving to CYP families;
- ◆ Families First – assists families in which grandparents have guardianship;
- ◆ Florida Atlantic University School of Social Work - a popular site for BSW and MSW interns;
- ◆ Hospice by the Sea – referral resource for Camp Good Grief when a child experiences death;
- ◆ Linus Project – provides handmade blankets for our CYP members;
- ◆ YMCAs of Boca Raton and Boynton Beach – held wellness day for students with nutrition class through the School District of PBC.

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 term caregiving youth is being adopted in the Canadian program as opposed to the UK term of “young carers”. It is more and more common for people locally to say, “I read about that” instead of having the proverbial blank stare until the light bulb goes on;
- ◆ 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;
- ◆ Saul Becker, in his meta-analysis of child caregiving sites, “By 2006 there was only one dedicated initiative, the Caregiving Youth Project, in Boca Raton, Florida, compared with over 350 projects in the UK.” Global perspectives on children’s unpaid caregiving in the family: research and policy on young carers in the UK, Australia, the USA and Sub-Saharan Africa. Becker, S. *Global Social Policy*. 2007; 7: 23-50;
- ◆ Young carers from the UK traveled to Boca Raton to meet CYP youth and wrote to President Obama and then Boca Raton’s Mayor Whelchel;
- ◆ The School Board of The School District of Palm Beach County formally recognized the contributions of the CYP at a formal presentation in July 2011;
- ◆ 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 also wanted to remain connected for awhile after they have experienced the death of their care receiver.

Works in Progress

There are several activities which remain works in progress. This includes the organization’s certification process through NonProfits First. There are ongoing challenges with a changing School District administration 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 we can connect with them. We continue to work towards solutions instead of band-aids including changes in protocols on a district wide basis for the use of 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 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 now has a focus on education and has again awarded AACY funds for the support of the Caregiving Youth Project. With the discovery of more youth with

health concerns of their own, mirroring the adult family caregiving ramifications, sources of funding to look at this important area are being sought. Ashoka has established a hub office in Miami and has recommended AACY for an in-kind donation branding initiative through Crea7ive.com. A CYP in Broward as well as Miami-Dade would be a natural evolution of the CYP. The expansion model is to partner and affiliate with existing successful non-profits.

Additional Comments

In kind contributions continue to be very meaningful to AACY. Pro bono legal services through both the Purpose Prize and Ashoka, have been valuable in reviewing our corporate documents and personnel policies. With Board member Ronnette Smith, presentation was made at the annual American Society in Aging Conference to help bridge the gaps and gain industry recognition for the role of child caregivers of grandparents. 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, including the first County Proclamation for National Family Caregivers Month in November. Meetings were held with various elected officials to promote their understanding of our work and assist us in seeking public funding. Finally, partnerships continue such as with the Palm Beach County Mental Health Association and Knights of Pythagoras Mentoring Network 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.

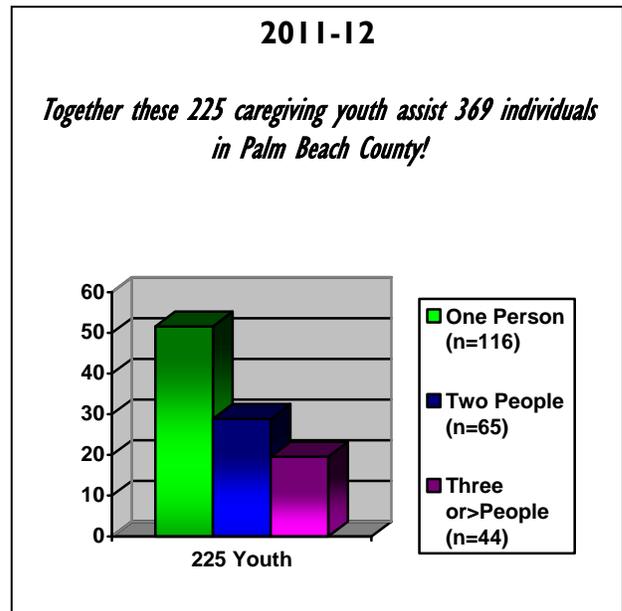
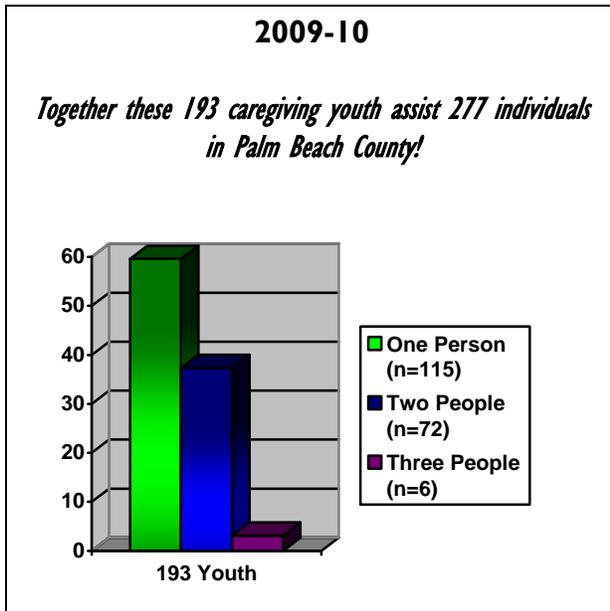


The End of the Year Feedback process has documented a significant increase in the number of care receivers of caregiving youth.

Caregiving Youth Project (CYP)

End of Year Student Written Feedback Comparisons – 2010 vs. 2012

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.

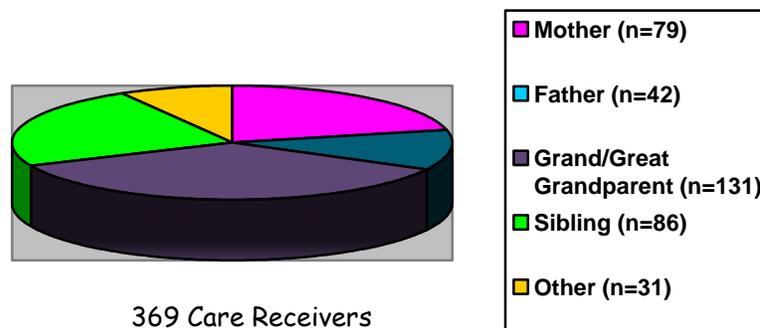


Who are the 369 recipients of care from CYP youth in 2011-12?

This year grandparents/great-grandparents are the top care receivers (35.5%) with parent care at 32.8%. Ill, injured or disabled siblings account for 23.3% of those needing care and 8.4% include other relatives such as an aunt, uncle or cousin.

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

2011-12
225 Caregiving Youth



Please note this data is from CYP youth who completed End of the Year Feedback Forms. In May/June 2012 this information was gathered from 242 middle and high school youth. Seven forms had incomplete information and 10 students are no longer caregiving – one care receiver moved and nine are deceased.