



American Association of
Caregiving
Youth

ANNUAL REPORT

July 1, 2010 – June 30, 2011

Including a Reflection of Five Years of Accomplishments

Vision

The American Association of Caregiving Youth® (AACY) is the national resource for children who sacrifice their education, physical and emotional health and childhood as they provide care for family members who are ill, injured, elderly or disabled so that all US caregiving youth are able to complete high school, know they are not alone and have the support they need to become healthy productive adults.

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 Faith in Action program funding from the Robert Wood Johnson Foundation. A subsequent grant 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). 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 project for youth caregiving. 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).

Major Accomplishments and Their Impact

Now concluding its fifth year of service, the following reflects the accomplishments of this important work during this time rather than focusing on this past year alone.

The Caregiving Youth Project (CYP), the beta program of the American Association of Caregiving Youth®, began at one middle school in Boca Raton, FL in 2006. The school was selected among 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. 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 500 youth caregivers and their families or more than 2,100 individuals of all ages. Additional youth and families received services but have either relocated or are no longer caregiving. There are about 80 other children, who have been identified as caregivers within the schools, who are in various phases of program processing. The CYP has also reached more than 10,000 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 dynamic. The work is seen by CYP members and their peers to be of value especially in light of the effects of our economy and their diminished financial resources. Thus, throughout the school year, the CYP receives referrals from school staff as well as students.

Highlights during the first five years include:

- ◆ Conducted in-home assessments by a social worker resulting in more than 900 referrals for appropriate community, medical access and medical service assistance to strengthen families and reduce the burden on the child;
- ◆ Provided families with needs-driven home safety equipment such as clean water in two homes, grab bars, three ramps to allow for accessibility, an oxygen concentrator and others by seeking special donations of supplies and labor;
- ◆ Received nearly 500 completed end-of-the-year evaluation forms during the past two years from students indicating the CYP impact on their lives, their family's life, school, for them as caregivers, what else they want to learn and why they think it is important for other schools to have a CYP. The quantitative results from the June 2011 evaluations from 234 students with a response range per question from 229-234 and an average of 232.7 per question showed that they felt the CYP helped them:
 - Be more knowledgeable about caregiving and have new skills for both at home (86.8%) and in school (82.4%);
 - Feel good about themselves out of school (82.9%) and also in school (82.4%);
 - Make new friends (79.4%);
 - Be able to better manage stress (79.2%);
 - Improve their health (70.3%);
 - Have closer with family relationships (65.4%);
 - Achieve better grades (60.9%).

The overwhelming majority (94.8%) believed that the CYP needs to be available to students at other schools;

- ◆ Sponsored > 50 various significant activities including Camp Treasures, Reunion Camp, fishing trip, family holiday party, wellness days, classes and fun for kids at the YMCA targeted to program participants for respite, education, exercise and fun;
- ◆ Supported student academic success by obtaining and distributing school supplies, including 120 laptop or refurbished computers with internet access, tutoring and/or mentoring assistance for CYP participants as needed;
- ◆ Continued well received monthly e-newsletter, "Treasure Talk", distributed >18,000 copies to date to a growing number of program participants and interested others. In addition, 1700 copies of the printed VHFC newsletter (through 12.09) containing substantial information about the CYP were distributed by mail and electronically;
- ◆ 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;
- ◆ Participated in several research projects including a nursing doctoral student from Florida Atlantic University, a doctoral student from Brandeis and a masters student in public health from Miller Medical in Miami as well as 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;

- ◆ Established a Continuing Care Division for high schools students in which there are ongoing monthly groups at high schools in which there are clusters of CYP students as well as a community center in Boynton Beach;
- ◆ Twelve CYP students were the first high school graduates as the 2011 school year ended. Of 117 students enrolled during the first two years of CYP, there are 103 who continue as caregivers and live in Palm Beach County. Of those, 98 remain in school and in CYP (95.1%);
- ◆ Established a Bereavement Transition team to meet the needs of CYP members who experience the death of their care receiver so they can be supported until they are ready for alternate children's grief support – there were 10 deaths in 2011;
- ◆ The work 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:

- ◆ Back to School Bash – provides school supplies, physicals and hair cuts for the return to school;
- ◆ Digital Divide Program and Best Buy – computers, printers and supplies;
- ◆ AmeriCorps – CYP dedicated members assists with tutoring and sponsored activities to augment the contracted services of A-Z In-home Tutoring;
- ◆ Champion Home Healthcare, CSI and Maxim provide in-home respite services;
- ◆ Boca Helping Hands – provides food, relief and employment resource for local families;
- ◆ Camelot – counseling referral resource;
- ◆ Families First – assists families in which grandparents have guardianship;
- ◆ Florida Atlantic University School of Social Work - had the help of 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;
- ◆ Lowe's partnered with the Camp Director at Gold Coast (site of Camp Treasure) to provide in-kind supplies so that a family with a totally disabled 24 y/o son could have a ramp and thus reduce the back strain on the single mom and 12 y/o who otherwise were lifting him in his wheelchair in and out of the home twice a day so he could attend medical day care;
- ◆ Soroptimist International of Boca Raton/Deerfield Beach – held a “Real Beauty” workshop with Florence Fuller Child Development Center for female caregiving youth;
- ◆ Temple B'nai Israel – created stress reliever kits for FCAT survival; and
- ◆ 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; wrote to Mrs. Obama on behalf of them and our caregiving youth requesting support;
- ◆ 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 in July 2011;
- ◆ Schools in which we have a presence, welcome us back to support their students;
- ◆ 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;
- ◆ Relationships with Florida Atlantic University School of Social Work includes the CYP as a desirable placement opportunity as evidenced by increasing demand to intern at the AACY site.

On a broader scale AACY is part of the Mental Health Alliance and has worked in the development for the Palm Beach County Family Caregiver Coalition to assist with advocacy and closing the gaps for family caregivers of all ages. It is currently the fiscal agent for the coalition.

AACY Development

During this time and with support from Dr. Siskowski’s Ashoka Fellowship, the strategic goals for expansion have been somewhat impacted by the economy and delay in building local expansion and capacity. However, with perseverance the following has been achieved:

- ◆ Calls for information and potential affiliations have come from AZ, NC, LA, IL, OH, CA, NY, NJ, AR, TX and others;
- ◆ AACY was the recipient of the 2011 Palm Beach County Medical Society’s Heroes in Medicine Community Outreach Award;
- ◆ Dr. Siskowski has received the Distinguished Alumni Award from Johns Hopkins University for this work along with the Purpose Prize and Ashoka Fellowship;
- ◆ Interviews with local and national media continue as well as from child advocates in legal issues; and
- ◆ AACY has attracted two national members (Ronnelle Smith of Walmart Corporate and Ronda Talley, PhD formerly of the Rosalynn Carter Institute and the CDC) to

the Board of Directors. The most recent addition to the Board is a middle school guidance counselor who has seen the results of the CYP with her students.

Works in Progress

There are several activities which remain works in progress. This includes the certification process through NonProfits First with whom AACY is actively working. The trailer of the yet to be filmed documentary “Grown Up Kids” may be viewed on the AACY website; however, the complete film remains on hold pending funding. The challenges of reaching students in school have accelerated this past year due to the unrest within the school district administration. This is compounded because each school has different rules regarding when CYP staff are permitted to interface with their students. Often students who are very much in need of our services are ones that are likely to have academic struggles; yet they are the ones without an elective period during which we can connect with them. As we work towards solutions instead of band-aids this is one hurdle we continue to further address.

Financial Status

The annual audit was conducted and AACY remains deficiency free. A full report is available upon request. Ongoing funding is a concern as obvious public resources such as the County have changed their focus of support. To our benefit, United Way of Palm Beach County now has a focus on education and has awarded AACY funds for the support of the Caregiving Youth Project in their focus area of education. With the discovery of more youth with health concerns of their own, mirroring the adult family caregiving ramifications, a major grant is under consideration by Allegany Franciscan Ministries to begin to address these student health issues. Ashoka is in the process of establishing a hub office in Miami. 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 local successful non-profits.

Most recently, Hands on Tzedekah, after providing funds to create the new CYP Bereavement Transition program in the past, provided funds to procure additional computers, printers, supplies and internet access for CYP students to reduce the waiting list to meet this need for academic support.

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. The issues challenging caregiving youth are nonpartisan. Meetings are 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 Communities in Schools, Palm Beach County Mental Health Association and Knights of Pythagoras to mutually augment our work and to seek collaborative funding.

The Board of Directors has spent time together in two retreats and is working synergistically on its expansion. This past year AACY Board and staff were saddened by the unanticipated death of Fred Galland. His Board Chair position was filled by its Vice Chair, Paula Alderson through his June 30th term.