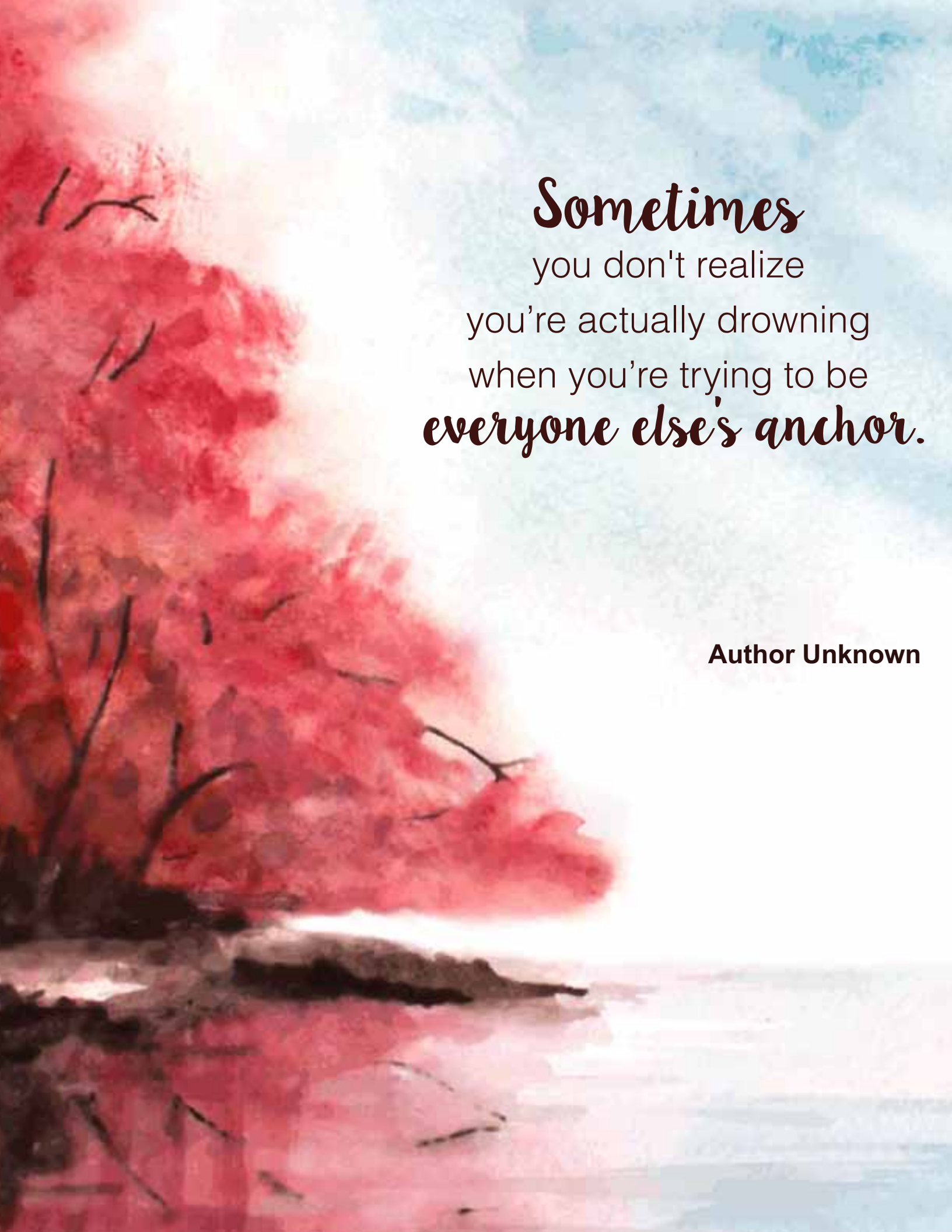




Care for the
Family Caregiver:
The Backbone of Long-Term
Care in America

A watercolor illustration of a large, vibrant red tree with dark, thin branches, growing on a dark, rocky cliff. The tree's reflection is visible in the water below. The background is a soft, light blue sky with white clouds, and the ocean is a pale blue. The overall style is soft and artistic.

Sometimes
you don't realize
you're actually drowning
when you're trying to be
everyone else's anchor.

Author Unknown

Who cares?

Well, most of us, at some point in our lives, care ... for a loved one, that is. More than 44.4 million Americans serve as informal caregivers to adults who live in the community and require help. Spouses, adult children, other family members, partners, friends and neighbors all serve as unpaid, informal caregivers. The vast majority (83%) are related to the care recipient.


For the many parents and siblings upon whom loved ones with intellectual and developmental disabilities are highly dependent, unpaid assistance is required in substantially large doses.

Family caregivers are responsible for managing a wide range of tasks, among them:

- Managing finances, buying groceries, cooking, cleaning house and doing laundry;
- Helping a disabled family member to get dressed, to shower and take medicine (on time, and in the correct dosage);
- Making medical appointments, and driving the individual to the doctor, pharmacy and other places;
- Talking with doctors, care managers and others to understand what needs to be done;
- Handling an unexpected crisis or helping a disabled loved one who is sick, and
- Performing as the designated “on-call” family member whenever problems occur.

In small amounts, these daily year-round tasks are manageable. But having to juggle competing caregiving demands with the demands of your *own* life on an ongoing basis can be an enormous challenge. It should come as no surprise, then, that many family caregivers face an agonizing dilemma.

On one hand, caring for a family member demonstrates love and commitment and can be a very rewarding personal experience. On the other hand, it's hard to take time off when you're busy caring for someone else. Exhaustion, worry, inadequate resources and continuous care demands are overwhelmingly stressful. Often, caregivers feel guilty simply taking a break.



Being a *caregiver*
for your child is part of the
job description
of being a mammal.

Mayim Bialik, PhD

(the actress who plays Amy in the CBS hit,

Family caregivers are often described as the backbone of our nation's health and long-term care system in light of the significant savings to the government, health care institutions and agencies which would otherwise be responsible for delivering care. Today, approximately 76% of the 4.3 million Americans with intellectual and developmental disabilities live at home -- a quarter of them cared for by a family member who is at least 60 years old.

Caregiving can be physically, psychologically and economically draining. If you are a family caregiver over the age of 65 and are experiencing mental or emotional strain, you have a risk of dying that is 63% higher than that of people your age who are not caregivers. The combination of prolonged stress and the physical demands of caregiving, plus the biological vulnerabilities that come with age, place you at risk for both significant health problems and an earlier death.

Consider, for instance, George and Shirley Berbaum who, in a strange twist, are elderly family caregivers sometimes thrust into the role of care recipients.



"The Big Bang Theory")



Heroes Inspire A Difference In The Lives Of Others

Married for 62 years, the octogenarians insist they couldn't even imagine life without their daughter, Kristin, sharing their East Greenville, Pa. home. George is being treated for several aging-associated ailments; but the 84-year-old retired testing machine operator describes having Krissy at home as a "blessing." Shirley, an 80-year-old retired pharmacy technician, receives physical therapy after having suffered a broken left hip and a debilitating stroke; to her, Krissy is "a part-time nurse, part-time aide and full-time best friend."

Kristin Berbaum, 52, was born with a profound hearing impairment that was discovered when she was a toddler, following an accidental fall from a swing that produced a mild concussion. She has since been diagnosed with mild-to-moderate intellectual and developmental disabilities, vision loss and hypertension. Krissy's outgoing personality, polite demeanor and ability to learn new tasks quickly make her an especially popular figure at DEC's Pottstown Training Center, where she has made many friends, voluntarily supported numerous charities and causes, and has received tailored therapies, vocational training and other innovative DEC services since 1985.

George, who struggles with his own aging-related issues, admits he devotes so much time caring for his ailing wife and daughter that he often neglects his own health needs. However, both he and Shirley adamantly reject any notion that caring for an adult daughter with special needs presents any sort of burden -- thanks largely to the help they receive from an entire team of DEC skilled professionals, a team that includes Wanda Levengood, DEC *Works* production coordinator and Supportive Living Services professional; Sally Harpold, program specialist; Brenda Engle, direct support professional, and Barbara Kennedy, Pottstown facility director.

Under the team's supervision, Krissy learns to prepare meals, set the table and develop smart eating habits; participates in an informal exercise program and other recreational activities; learns her letters and numbers, while keeping up with current events, and earns spending money (while boosting her self-esteem and independence) by engaging in DEC's contract packaging and assembly vocational program. She also enjoys weekly outings with other developmentally disabled individuals served by DEC's Pottstown Training Center -- dining out at some of her favorite restaurants, shopping, bowling, playing miniature golf -- and hitting the road with Wanda to see the latest Disney movie, go swimming or enjoy a day of sightseeing. Besides providing the parents with a much-valued respite, the DEC team helps George and Shirley with problem-solving advice, guidance and perhaps most important, strong shoulders to lean on.

"DEC is a godsend," extols Shirley. "Krissy trusts the staff, and feels comfortable bouncing her ideas or discussing her problems and frustrations with people she knows love her unconditionally and are always willing to listen. For caregivers, DEC is a lifesaver. The staff not only provides much-needed relief -- it also empowers individuals like Krissy to earn a paycheck, socialize with friends, learn so many skills and enjoy a productive, meaningful life."

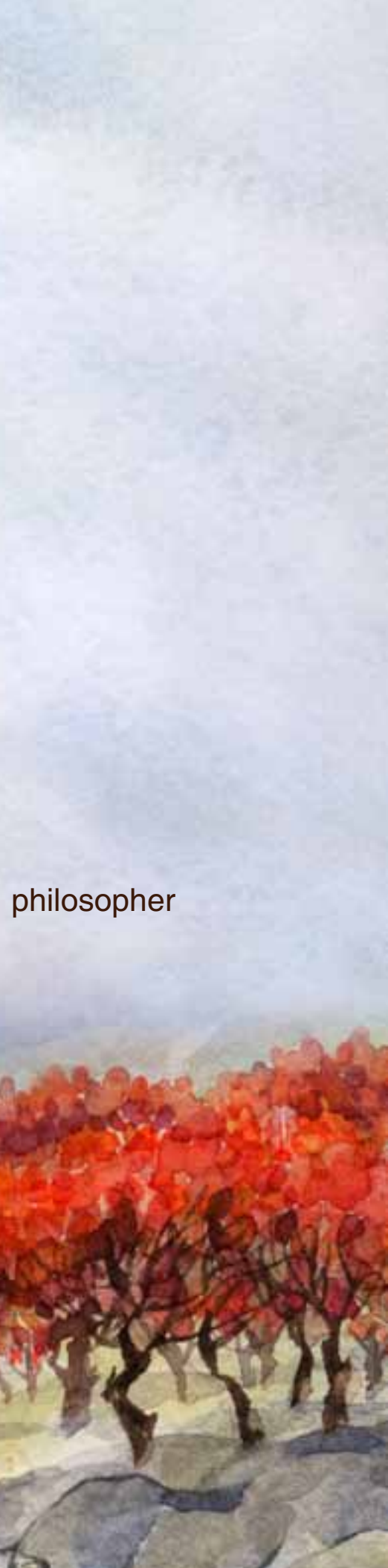
Being *deeply loved* by someone
gives you **STRENGTH,**

while *loving someone* deeply
gives you **COURAGE.**

Lao Tzu

ancient Chinese mystic





Much like their senior counterparts, younger family caregivers often put their own health and well-being at risk. If you have assumed a caregiver role for a loved one diagnosed with developmental disabilities while simultaneously juggling work and raising adolescent children, you face an increased risk for chronic illness and a possible decline in quality of life. Studies show that an estimated 46% to 59% of caregivers are clinically depressed.

Regardless of age, gender, race and ethnicity, caregivers experience very serious problems attending to their own health and well-being while managing caregiving responsibilities -- including sleep deprivation, poor eating habits, a failure to exercise, high cholesterol, high blood pressure, a tendency to be overweight and postponement of or failure to make medical appointments for themselves.

Family caregivers also face financial burdens, including substantial out-of-pocket expenses and loss in wages and other work-related benefits due to changes in work patterns.

Think for a moment about the pre-flight safety message that is delivered aboard every commercial airliner shortly before take-off. You know the drill: "Ladies and gentlemen, in the event of an emergency, an oxygen mask may automatically drop in front of you." It is absolutely critical, you are warned, that you put on your own oxygen mask before assisting your child or anyone else. Why? Because only when we first help *ourselves* can we effectively help others.

Just like their loved ones who have been diagnosed with varying degrees of intellectual and developmental disabilities, family members who serve as caretakers themselves need and deserve support. People like ... Tina Gibson -- the daughter of a most remarkable woman who is truly remarkable in her own right.

"There were times when I wondered who we'd be sharing our beds with that day," laughs Tina, looking back over the years when her mother (affectionately known throughout her Pottstown neighborhood as the beloved "Miss Millie" Ruffin) and father opened their hearts and their home to *more than two dozen* foster children -- some with special needs -- in addition to raising six biological children of their own.

Widely respected for her amazing heart, fierce determination and boundless energy, Miss Millie taught her children to see the good in *everybody*; to help others without expecting anything in return; to love your family; to keep moving forward; to always do your best, and to never tease anyone who's different -- you're no better than anyone else, and you never know what somebody else is going through. Extraordinary life lessons, passed on by an extraordinary lady.

philosopher

Love Makes A Family

Among the foster children provided a loving home was Leroy Burrell, now a 45-year-old man diagnosed with mild intellectual and developmental disabilities, sleep apnea and hypertension, who became a member of the extended Ruffin family when he was just 18-months-old. When Miss Millie passed away in 2015 following a long, heartbreaking battle with dementia, Leroy moved in with Tina and her husband, John (who Leroy lovingly calls “Spider”), and their daughter.

The transition from one family caregiver to another was seamless; not the least bit surprising, given Miss Millie’s emphasis on unconditional love, respect and family bonds. And while Tina insists she wouldn’t have it any other way, it cannot be easy assuming the role of full-time caregiver for a middle-aged man with developmental disabilities and other serious health issues while simultaneously juggling work, family and everyday challenges and responsibilities.



In addition to her husband, who she says loves taking long rides and listening to the sounds of Motown with Leroy, and her five siblings, who are always quick to pitch in whenever and however needed, Tina credits DEC for taking much of the stress and strain off her shoulders.

“Leroy *loves* coming to the Pottstown Training Center,” she explains. “There he can interact, work and socialize with others, feel comfortable being himself, learn so many important skills and enjoy freedom and independence. At the same time, I’m free to do what I need to get done, to make and keep my appointments, and to get answers to questions that enable me to help my brother at home. DEC empowers Leroy to live the life of a safe, productive citizen, which is precisely what each of us wants for ourselves. We *all* need a place where we can go.”





*Service to others is the rent you pay
for your room here on earth.*

Muhammad Ali

More than most people, Aaron M. McHugh keenly understands not only the personal sacrifices that parents, siblings and other loved ones make to care for an intellectually disabled adult living at home; but also the stress, anxiety and frustrations of navigating a complex, bureaucratic health care system.

McHugh is certified as a Qualified Developmental Disability Professional (QDDP) and is a highly-respected dual diagnosis specialist who supports local families and individuals with complicated medical issues, as well as the teams of skilled professionals who assist them in their everyday lives.

“It is imperative that family caregivers trust the system and the people within the system,” McHugh underscores, “by learning how the system works, what questions need to be asked in order to allay fears and worries, and to understand the requirements for better team communication, better treatment and, ultimately, improved outcomes.”

To those people whose elderly parents take care of an intellectually and developmentally disabled sibling living at home, McHugh offers this advice: if Mom and Dad don't ask for your help, *offer it to them anyway*. Perhaps out of pride or just plain stubbornness, he explains, people (particularly seniors) often fight tooth and nail not to receive a helping hand. But, he warns, never underestimate what stress can do to a person, physically as well as emotionally; keep the lines of communication open within the family, talk with each other, and be prepared to offer assistance -- not just for the sake of your sibling, but for your aged parent(s) as well.

*When spider webs unite,
they can tie up a lion.*

Ethiopian Proverb

It takes a large, diverse team of everyday people to provide intellectually and developmentally disabled men and women residing throughout our area with “everyday lives” – lives in which they make their own decisions, socialize with friends, enjoy community integration and contribute to society as taxpayers, consumers and responsible citizens. A team that includes families, friends and loved ones. Neighbors. Business people. Civic groups. Foundations. Government. And, of course, DEC’s passionately dedicated staff of highly skilled professionals and managers.

All of us.

“You never know when you, too, may have need for support,” notes Tina Gibson. “This world is made up of different types of people, learning at different rates. We all need help from time to time, some more than others. We all need a place to go, a place where we’re allowed to be productive and happy. Your generosity can give intellectually disabled men and women such a place -- a place where they can feel safe, secure, dignified and free ... just like you and me.”

It’s surprisingly easy to make a significant difference in someone’s life.

Visit a DEC program just to say hello and show you care ... or better yet, volunteer even a little of your time and talent. Participate in DEC’s fundraising events conducted throughout the year, such as the Martelli Games and the Phil Martelli Golf Classic. Join DEC’s growing family of corporate sponsors. Assign your business’ packaging, assembly and fulfillment requirements to the well-trained and highly motivated individuals in our *DEC Works* program. Provide a meticulously-trained, results-driven developmentally disabled individual with an employment opportunity to promote self-esteem, responsibility and independence.

Most important, please make a financial contribution to DEC, so we can continue doing what we’ve done so well since 1971: be there for individuals and their families with an array of high quality programs and innovative services whenever they need us.

Who cares? DEC cares. About our entire community.

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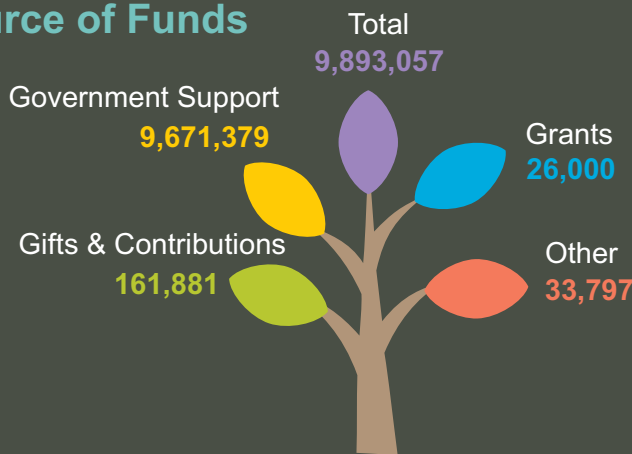
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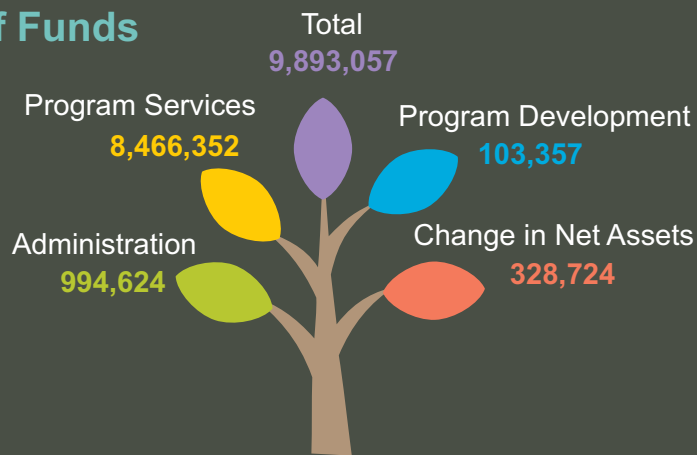


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DEC envisions persons with disabilities living healthy, meaningful, productive and safe lives that are rich in community associations and contributions and who have valued roles in their communities. DEC's services are dedicated to this vision.

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