



Senior Resource Association's Meals on Wheels program volunteer Melanie delivers a meal to a local senior.

Rise & Shine

WHEN A DISABILITY MAKES LIFE SEEM DARK, BE THE LIGHT



BY JEFFREY R. PICKERING

American author and educator Helen Keller, who lived from 1882 until 1968 without being able to see or hear, once said, "Walking with a friend in the dark is better than walking alone in the light." I have come to appreciate this wisdom recently, as my 50th birthday approaches and, having been diagnosed with an inherited retinal disease, have given up driving.

While it may not seem like a big deal to many, especially those who have lived in places with reliable public transportation systems, this change has taken some getting used to here in Vero Beach. To keep my spirits up and to maintain a positive outlook, I have turned to several examples from our community in which disabilities are being overcome every day with help from the kindness and generosity of

our neighbors.

In 2018, the superintendent of the School District of Indian River County introduced me to two young parents in need of a miracle. The father was a teacher at the local high school and the mother a social worker and substance abuse counselor. The couple's older daughter was healthy, attending kindergarten, and preparing for a life filled with opportunity. The other daughter was not.

In October 2018, the couple's younger daughter was born with Down Syndrome and multiple heart defects. These conditions required several heart surgeries, followed by a long road of recovery that was likely to include speech, physical, and occupational therapy. I imagined that even with good health insurance, the uncovered medical and therapy expenses would be substantial.

To care for the younger daughter, the mother stopped working, leaving the father as the sole provider for the family's financial needs. At the time, the father earned approximately \$45,000 as a teacher, which, for a family of four, meant that he earned too much to qualify for public assistance but not enough to pay for many of the out-of-pocket expenses being incurred for his daughter's medical care. In 2018 and 2019, these medical expenses equaled at least \$5,000 per year out of pocket before deductibles were met. In the long term, these expenses would likely continue, along with many others as their daughter grew.

Like many people I meet whose vocations are dedicated to serving others, these parents were reluctant to ask for help for themselves. They were a proud couple who found it difficult to accept help from family,

friends, and their place of worship, much less to ask for help from strangers.

While they did not constitute a charitable cause eligible for support from the Community Foundation or our client accounts, I agreed to connect them with others in the community who I thought might be able to help. As a result, one of the attorneys from Rossway Swan donated her time to help the couple set up a supplemental needs trust to cover expenses beyond what Medicaid and SSI would pay for. In addition, several generous members of the community offered to make financial contributions to the supplemental needs

trust. Others contributed directly to Sunshine Physical Therapy Clinic, a local charity that provides high-level therapeutic services from caring and qualified professionals regardless of a patient's ability to pay.

Over the years, I have received periodic updates from the father about his daughter's progress. In October 2020, she turned 2 years old, crossing a major milestone as a high-risk baby by moving beyond the age where infant mortality is measured.

"She is army-crawling, but not walking yet," the father told me. "She says 'Momma' and calls her sister 'La La'. She is a work in

progress." Slowly but surely, this little girl's life has been getting better and brighter, with help from a generous community.

In 2020, approximately 17 percent of Indian River County's population was living with a disability, compared to 13 percent for Florida overall. While the number of disabled children is relatively low for Indian River County, approximately 60 percent of people living with a disability were over the age of 65. More than 50 percent lived either in or barely above poverty, and 25 percent lived alone.

Over the years, I have visited several clients who fall into the category of



Meals on Wheels volunteers bring nutritious food, and a cheerful visit, to low-income seniors.

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disabled seniors who live alone or who are caring for an adult child with a disability. In these cases, however, all live in high-net-worth households with sufficient resources to hire caregivers and other services to help with activities of daily life and support independent living for as long as possible. Listening to their stories, I can see that life can still be challenging, but it is made easier because of the help they have been able to hire.

Unfortunately, there are still too many Indian River County residents living alone with disabilities and without the resources to support a decent quality of life.

One organization making life more manageable for disabled low-income residents who live alone in our community is Senior Resource Association, Indian River County's lead agency for home- and community-based services.

In addition to operating the GoLine public transportation system and senior centers throughout the county, the organization provides many of the case management services and other programs to meet the needs of older adults. With 56 percent of Indian River County seniors living more than 1 mile away from stores selling fresh produce, SRA's Meals on Wheels program ensures that hundreds of low-income seniors, many

living with disabilities, receive hot, nutritious meals and other support to remain living independently in their homes as long as possible.

When our community's disabled residents need help with home health care needs, the VNA of the Treasure Coast is there to help. Public funding from the Indian River County Hospital District and other charitable contributions make it possible for many low-income residents who are either uninsured or underinsured to receive these vital services in times of need. Other specialized support and services for residents facing conditions associated with dementia and other memory-related disabilities and their caregivers are provided by Alzheimer & Parkinson Association of Indian River County, which is funded mostly by philanthropy.

For the most severe and marked cases of community residents living with a disability, The Arc of Indian River County is there. Since 1975, this charitable organization has been serving the special needs of the community by providing services such as Adult Day Training, Supported Employment,



In April 2022, with the help of local philanthropists, The Arc opened its first home for fragile adults.

Supported Living, and Residential Group Homes.

In April 2022, with financial support from Indian River Community Foundation and other local philanthropists, The Arc opened its first group home for fragile adults with special needs. The \$1.5 million project serves people with severe cerebral palsy who cannot ambulate without a wheelchair, along with others with complicated medical needs. These special places provide a safe, dignified environment where residents and their families can overcome some of the most tenuous circumstances faced by vulnerable people in our community.

For those giving birth to a child with a severe disability or those developing a disability over time, the future can seem dark. It may even feel lonely. But we don't have to be afraid. Here in the Sunshine State, and specifically in Indian River County, there is plenty of light.

Supporting organizations that care for people in Indian River County who are living with disabilities is an investment in the future well-being of our community. Information about many of these charitable organizations can be found by searching Indian River Community Foundation's online nonprofit search at ircommunityfoundation.org.



The Arc home is designed with places for privacy and places for gathering with residents and families.



The Arc's new Vero Beach home for adults with cerebral palsy or complicated medical needs is a comfortable and dignified environment for the residents and their visiting families.