The Power of Partnerships

Pat ***Goldman***

Life is a journey. For some the road is relatively straight; for others, challenges present themselves at every turn.

In 1938, Zella and Jack Butler had an apparently normal child, Barbara, but as she developed it was clear she had severe developmental disabilities. At that time, care options were very limited, and when she was 4 years old, Barbara was placed at the Devereux School in Philadelphia where she lived until she died at age 55 in 1993.

Because Barbara did not live at home, Zella and Jack were not confronted with the day-to-day challenges that families face when a person with a disability lives with them. They led a very normal life aside from the heartache of knowing that they had a child who could not participate in their lives. They enjoyed the culture of New York, did extensive volunteer work, and spent time with all their nieces and nephews, as hard as that must have been. Jack was a man of humor and grace who had a special rapport with young people and served as their mentor and friend. He loved children and his greatest pleasure was to give all takers elevator rides on his shoes! For years, Zella read to the blind, helping countless young men and women realize their dreams and fulfill their potential in spite of their disabilities. Zella often said, "I have graduated from almost every college in New York City by osmosis." She attended the graduations of all her protégés and reveled in their accomplishments. Sabbath dinners at their home were notoriously open to any "stray" who happened to be in town. Jack's theory was, "Everyone is welcome. Just add a little more water to the soup."

To care for Barbara, Zella and Jack set up a trust to support her during her lifetime with the residual, on her death, reverting to the J. E. & Z. B. Butler Foundation, which had been established in 1968. When Zella and Jack died in 1988 and 1989, respectively, the proceeds of their estates were also added to the foundation. The foundation guidelines were very broad, and it fell to the trustees to decide how to focus its giving.

Many changes had occurred in the world of disabilities by the time of their deaths. The atrocities of Willowbrook, an institution for the developmentally disabled, had been exposed in 1972 by Geraldo Rivera, and the Willowbrook Consent Decree was signed in 1975 in which New York State committed to increasing and improving community placements for people with disabilities. In 1977, the Office of Mental Retardation and Developmental Disabilities (OMRDD) was established, and care for people with developmental disabilities was changed forever. Community residences were established to care for people who had formally been institutionalized, and many more individuals with disabilities began to live at home. Living with a person with a disability has a significant impact on a family's lifestyle—socially, emotionally, and financially. Unlike Zella and Jack, families could not come and go as they pleased. They were often isolated with

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little or no respite from their daily challenges, and they had few opportunities to participate fully in their communities.

Faced with this new reality, the board of the foundation felt that the most meaningful use of its resources would be to provide support services for individuals with disabilities and their families so that they could become better integrated into their communities. Zella and Jack had always been involved with Jewish philanthropic causes, and the trustees wanted to continue down the road they had traveled. Fortunately, we were able to identify a partner, UJA-Federation of New York, which had solid infrastructure, knowledgeable professional staff, and a network of social service and health care agencies anxious to join us on this journey. Not only did they acknowledge that there were significant unmet needs but they were also enthusiastic about partnering with the foundation to envision, plan, and then work to realize the transformation of its communal service system and its relationship to people with disabilities and their families.

In 1991, Bruce Doniger, my brother, and Beaty Doniger, Zella's sister and my mother, were asked to join the Butler Endowment Fund Committee, which oversees the fund established by Zella and Jack and administered by UJA-Federation. At the first meeting in which they participated, they met Anita Altman, who staffed the committee then and who is now the Deputy Managing Director, Department of Government Relations & External Affairs at UJA-Federation. This meeting led to discussions about how UJA-Federation and the J. E. & Z. B. Butler Foundation could work together—a most fortuitous meeting that led to an extraordinary partnership! Today the endowment fund serves as an incubator for projects, which if successful and have budgets that exceed the fund's $15,000 limit, are submitted to the foundation for consideration.

Since 1991, the J. E. & Z. B. Butler Foundation has provided more than $40,000,000 to over 250 programs at 55 UJA-Federation agencies in the New York's five boroughs, Westchester, and Long Island. Because UJA-Federation's agency system is nonsectarian, we have been able to meet our commitment to serve all people regardless of race, religion, or ethnicity. As communities have changed over time, all the agencies we support have embraced new populations and worked hard to relieve tensions that can stem from differences. Just as inclusion has become a watchword for community centers, changing populations have added to the diversity within their agencies.

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Education was key to the process. To meet our evolving goals, executive directors and their boards, families, and the foundation all had to be on the same page. The trustees met with families to understand the issues they faced and with network agencies to begin to build programming that would provide welcoming environments for people of all abilities and their families. As time passed it was clear that a more concerted effort had to be made to get everyone thinking more collaboratively.

In 1996, UJA-Federation created a Task Force on People with Special Needs, later renamed the Task Force for People with Disabilities. For the past 14 years, every six weeks, task force members and the foundation have sat around the table learning from one another. We use these meetings to explore areas of unmet need, bring in outside experts to inform us, and identify new initiatives to organize. Not only has it been an enriching, rewarding experience for everyone but it

has also fostered collaboration and mutual support. Territorial issues have broken down; agencies have become partners, not competitors.

During this time, governmental funding priorities have changed, and a focus on different disabilities, such as autism spectrum disorders, has emerged, challenging providers with new learning curves and priorities. The Task Force has met with state and local disability officials, housing specialists, and providers from distant communities to learn about innovative programs that might be applicable or replicated in UJA agencies. It has grown to include individuals in unaffiliated agencies who are also deeply committed to providing quality services for people with disabilities.

Most of the foundation's early funding focused on individuals with developmental, learning, or physical disabilities. For example, one early grant (1992) supported a social recreation group for singles with physical disabilities at a Y on Long Island. When Beaty made a site visit, she noticed that no one was drinking any beverages with their meal. When she asked why, she was informed that there was no accessible bathroom on the premises. The participants had to be driven across the street to the gas station to use a bathroom. Needless to say, our next project was a handicapped-accessible bathroom at the community center!

From our conversations with families, we learned that this question—"What will happen to my child when I am gone?"—looms as the most worrisome issue confronting aging parents of children with disabilities. Therefore another of our early efforts was to support F·E·G·S' Community Trust program, which works with network agencies to assist parents in planning for their disabled children's future when they are no longer able to care for them. As time passed, F·E·G·S became a founding partner in a three-agency initiative on Long Island, Westchester, and New York to provide families with information and referral. F·E·G·S' Family Advocacy, Information and Referral Program (FAIR) continues to provide hundreds of families on Long Island with the tools to understand new diagnoses and assistance in finding resources that help make their lives more manageable. F·E·G·S' Adopt a Family program also serves families with a disabled family member by pairing them with volunteers in the community, thereby lessening their isolation and providing much needed emotional support.

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As we worked on programming, we quickly learned that cultural differences present significant challenges and often slow down progress and inhibit participation. Some cultures fear the government and do not believe that government entitlements are available without recrimination. Others fear that admitting that a person in the family has a disability will have a negative impact on the whole family and its future opportunities. Still others are beaten down by poverty, are undereducated, and do not have access to knowledgeable, competent, cost-effective assistance. Pride and self-containment prevent others from reaching out for help, believing that it is their responsibility and no one else's. Much of our work has been focused on overcoming these stereotypes and helping families access what they need without fear of stigma.

We have endeavored to stay ahead of the curve and invested in innovative programs that address emerging issues in developmental disabilities. Today the increase in the number of individuals diagnosed with autism spectrum disorders has widened the road we are traveling and brought new challenges of creating appropriate after-school and summer programs for youth on the autism spectrum.

Severely disabled individuals on the autism spectrum have opportunities to receive services through government funding, but those who are less severely impaired are not eligible for existing government funding streams and are generally not covered by health insurance. These individuals are too "high performing" to meet OMRDD standards, yet are too disabled by significant socialization issues to be integrated into programs for neurotypical children. They need specially designed and affordable social, recreational, and educational opportunities, for which families search far and wide. Unfortunately there is a dearth of quality programming with specially trained staff. Parents may find a program they think will work and all too often are told after a few sessions that their child's needs are beyond the scope of the skills of the personnel running the program. As a result of listening to the frustration of parents, all the programs that we fund have an extensive interview process and high staffing ratios, which both prevent those problems but also make these programs very costly to run.

To help address this challenge, the foundation provided support for an innovative program, the Consortia for Learning and Service to Special Populations (CLASSP), which was formulated by members of the Task Force. Quality programs for people with disabilities require staffing ratios of 1:1 to 1:3 as compared with 1:10 or 1:15 for programs for typically developing youth and teens. Working with the Sam Field Y, Jewish Child Care Association, and Ramapo for Children, a model program was developed to provide cost-effective staffing in after-school, weekend, and summer programs and to introduce the next generation of workers to the field of disabilities. The program started at five community centers on Long Island. Participating teens aged 15–18 are required to attend five 3-hour classes on the C. W. Post campus and to work a minimum of 8 hours a month at their agencies in programs for children with disabilities under the supervision of trained professional staff. A Youth Workers' Conference in the spring of each year further enhances their experience and validates the importance of their contributions to the success of their agency's programs. Inspirational speakers present new developments in the field, and the teens participate in hands-on workshops that show them innovative ways to engage the youth with whom they work. On completion of the program the participants earn one college credit and receive a $1,000 stipend.

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CLASSP has been an overwhelming success, and there are now programs on Long Island as well as Westchester (2005) and Brooklyn (2007), and in the fall of 2010 a fourth opened in Manhattan/Bronx. In addition, there are plans to initiate a college CLASSP program that will build on participants' knowledge and enable the agencies to have more highly trained and knowledgeable staff to work in their after-school and summer camping programs. This initiative has proven to be a cost-effective way to sustain programming for disabilities during the present economic downturn. Many program graduates enter college dreaming of becoming special education teachers and lawyers, doctors, social workers, and psychologists. All participants leave the program as better informed, more tolerant, and strong advocates for people with disabilities.

We know that training is an essential component of program success and must be provided if you are asking people to develop a new area of expertise. Therefore, all foundation grants for programs serving people with disabilities provide free staff training from Ramapo for Children. Ramapo has a long history

of running summer camps for children with behavior issues and has developed an expertise in training staff at community agencies, camps, and after-school programs to manage children with difficult behaviors. Agencies have received training for new staff and coaching and supervision for more experienced staff from Ramapo's highly professional training staff.

Site visits have proven to be essential to the process. They allow the funder and the grantee to get to know one another, thereby making each more invested in the relationship. As the funder, we have the chance to meet the participants and staff and see firsthand what is being accomplished and what is needed in the future. The grant proposal does not always tell the whole story. Countless times, we have been told that most funders never see what they fund. What a missed opportunity!

Funding programs for people with disabilities is very costly and requires a long-term commitment. The typical three-year funding cycle of many foundations does not work because it takes a long time to get programs up and running. The foundation does not do "hit and run" programming, and whether we fund programs for people with disabilities or youth development programs, our other focus, we insist that agencies commit to the long-term engagement of participants.

We know that the more input parents have in the programming the more vested they will be. Creating parent advisory councils at agencies has been important to creating sustainable programming. Encouraging parents to contribute their ideas and also fundraise for the programs in whatever way they can has been a recent thrust to ensure that they take responsibility for the sustainability of the programs.

We have found disengaging from programs to be particularly difficult. As a foundation, we need to develop better exit strategies while being sure that what has been built will remain. Often our funding has served as seed money to help set the stage for changes in public policy and creation of public funding. Yet it has been difficult to extricate ourselves because these challenging times have made funding so elusive…here today, but what about tomorrow?

In the future, we hope that more community centers and synagogues will open their doors to accommodate and accept people with disabilities; that more businesses will look at individuals as differently abled, not disabled; that housing options will be developed to enable people with disabilities to live secure, dignified lives as part of a community; and that schools will worry less about test scores and more about people, creating accepting environments in which children with disabilities can reach their fullest potential. Most of all we hope more individuals, foundations, and businesses will invest in this work, which will require them to put aside their metrics and see that small numbers can provide big dividends for families and children.

The other day I was hanging a tapestry my mother had needlepointed. Every stitch was neatly done, without any mistakes, yet it would not hang straight. It reminded me that not everything can be perfect, but I love it because it reminds me of her persistence, hard work, and the beauty she saw in life. If we could all think of people as works of art, not always perfect, but unique and worthy of respect, the world would be a better place.

Thanks to our partnership with UJA-Federation and its agencies, today thousands of families, who were once stressed, tired, and isolated, now have new accepting "homes away from home."